



“A roundabout without signposts”
People’s experiences of
dementia in Suffolk

Published May 2023

66

“It’s hard emotionally, physically, and mentally. It’s changeable and relentless day and night. It’s funny, liberating, and humbling. It’s every emotion in very quick succession.

“You find unknown compassion and patience, and everyday my mum knows who I am is a good one.”

Acknowledgements

This research has benefited from the support of many people, networks and organisations working in Suffolk to improve dementia support. That includes members of the Suffolk Dementia Action Partnership, and professionals working within Suffolk County Council and the Suffolk and North East Essex Integrated Care Board.

We would particularly like to thank every single person that has taken the time to respond to this research, and to share their personal experiences of living, or supporting someone, with dementia in Suffolk.

1. Introduction

Healthwatch Suffolk has worked with the Dementia Action Partnership to develop a research project exploring the experience people with dementia, and their carers, have of accessing health and care services in Suffolk.

The Dementia Action Partnership is a local network of leaders and organisations providing information and support to those living with dementia and their carers.

The results of this research will help to inform the development of an ongoing joint NHS and Suffolk County Council strategy to support people with dementia and their carers.

This report will be shared with key NHS and Suffolk County Council decision makers, the Suffolk Dementia Forum and, nationally, with Healthwatch England to ensure that our local data can inform national work on dementia support and policy.

Dementia in Suffolk

In 2020, there were around 13,000 people with dementia living in Suffolk. Due to an ageing population, by 2040, it is likely this figure will have increased to 21,000. However, the true number of people with dementia is unknown because many people have not been formally diagnosed.

Early diagnosis is important because support and advice can ensure those diagnosed with dementia can live well, and independently, for as long as possible. In May 2021, the dementia diagnosis rate among people aged 65 and over in Suffolk was 58.4%, significantly below the national target of 66%. Ipswich had the

highest dementia diagnosis rate (64.6%), in line with the national target; diagnosis rates were significantly lower than the national target in the other four Suffolk lower tier local authorities.

In March 2021, the Suffolk Health and Wellbeing Board signed up to a shared vision (set out by the Suffolk Dementia Forum) to support and extend dementia-friendly communities in Suffolk:

“People living with dementia and their carers in Suffolk will have the best opportunities to be safe and well and continue to live an active life of their choosing, within an informed community that supports, includes and values them.”

This built on the Board’s earlier commitment (2015) to create a dementia-friendly county. The Dementia Action Partnership was subsequently established to galvanise and co-ordinate action across the system to achieve the Board’s vision.

This report looks at the individual experience of carers and those living with dementia to show how much progress is being made, where things are working well and where improvements can be made and how things can be done differently to improve the support and treatment for those living with dementia and their carers.



Rates of dementia are set to rise... By 2040, it is expected that up to 21,000 people will have a diagnosis in Suffolk. But many others may live with the condition undiagnosed.

This report aims to raise awareness of what it is like to live with dementia now, and to inform future support.



“

“I hate when people say I’m living with dementia... I live with my husband and my little dog, because I chose to. I’m not living with dementia, I’m ‘suffering’ with it. It’s taken my career, my independence, but most of all it’s taking my life. Bit by bit.”

”

2. Methodology

Engagement methods

The opportunity to participate in the project was promoted widely by Healthwatch Suffolk (estimated reach of more than 50,000 potential contacts with the project), and included:

- social media (more than 42,000 potential contacts with content)
- content on the Healthwatch Suffolk website (more than 1,000 views of pages associated with the project)
- features in newsletters and mailings (more than 5,000 contacts)
- community engagement activity by Healthwatch Suffolk Community Development Officers
- communications shared through the Dementia Action Partnership and Suffolk Dementia Forum

Collecting people's experiences

People's experiences were collected in three ways, and these are outlined below.

Feedback forms

Feedback forms were created to gain broad insights from people living with dementia, and

people caring for someone with dementia. They were made available online and in a formats accessible to people with dementia.

The forms consisted of four broad questions, with one additional question specifically for carers. People were asked to tell us about:

- Their experiences of accessing health and care services, including getting a diagnosis, and care received in hospital, at home or in a care home
- What sources of information and support they had found useful and what was missing
- What they would like people to know about living with dementia or caring for someone with dementia
- Their understanding of 'dementia friendly communities' and what is needed to make a community dementia friendly
- Carers were asked about the support they had received in their role as a carer

Interviews

Interviews were conducted to collect more detail about people's experiences. This included both people who have dementia

156 experiences shared in this report were taken from:



19
interviews

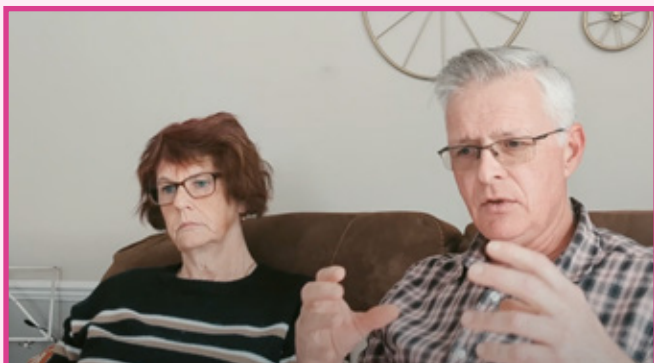
100 feedback forms



28 Feedback Centre comments

Watch our videos

Find out what **Peter, Teresa and Julia** told us about their experiences of dementia in Suffolk, including their thoughts on what could be better.



Click to play



Click to play

and people who care for someone with dementia in Suffolk.

Interviews took place by telephone, video meeting or face to face between September 2022 and February 2023. All participants gave their consent to have their interviews recorded and their experiences shared within this report.

The Healthwatch Suffolk Feedback Centre

People can visit the Feedback Centre (www.healthwatchesuffolk.co.uk/services) to find, rate, and leave reviews about local NHS and social care services in Suffolk.

Comments that included a reference about dementia care or support were extracted from the system and included in our overall assessment of people's experiences.

Participant anonymity and research ethics

To protect respondents' anonymity and confidentiality of information, all names have been removed and some information has been redacted.

The design of this research was informed by co-production with leading organisations and networks focused on dementia care and support in Suffolk. A research ethics submission was made to Suffolk County Council's Research Governance Group and was approved in July 2022.

Who we heard from

One hundred people completed a feedback form. Ninety-four were carers and six were from a person with dementia.

A total of 21 people shared their experiences with us in an interview. Of these, two people had dementia and 19 were carers of people with dementia. Some carers had experience of caring for more than one person with dementia.



Got a question? Just ask us...

More information about our methodology is available on request.

Contact:
research@healthwatchesuffolk.co.uk

3. Our findings

3.0 What has worked well?

The aim of the project has been to highlight the key issues and challenges for people with dementia, and their family carers, across the whole dementia pathway. That included finding out what had been working well for people, and where improvements could be made to local support.

What is working well?

A number of respondents shared examples of care and support that had worked well for them and their relative. However, for most, experiences of support had been inconsistent. Many reported that their needs had not been met, leading to burnout and crisis.

Though few in number, detailed examples of positive experiences are provided within each of the sections in this report. However, for ease of reference, a summary of positive experiences has been provided below.

Respondents told us that care and support had worked well when:

- Health and care professionals were supportive and willing to do things differently to accommodate the needs of the person with dementia and their family carer.

For instance, this might include when GPs had allowed extra time in appointments, or when health professionals involved people with dementia in consultations by using accessible language. In one case, a local practice had provided a separate area in the waiting room to ease any anxieties experienced by a person with dementia.

- There was consistency of care. This included examples where people told us they had been assigned a named

GP at their surgery, or that home care services had managed to ensure that people received visits from the same carers each time.

- Families felt they had been listened to, and that their concerns had been taken seriously. This was particularly important in the early stages of dementia, when families were seeking a diagnosis.
- When care and support was tailored to the individual needs of the person with dementia, and their family carers.
- Services recognised family carers for the important role they have. This included that professionals had sought their opinions and included them in discussions about their relatives care and treatment options.

In addition to these general comments, some respondents highlighted specific services or individuals who had provided good care and support. Such cases tended to note how individuals had gone 'above and beyond' their role to ensure families felt well supported.

Examples included:

- Informal help provided by families, friends and neighbours, which had been invaluable for many of our respondents. Such support had provided opportunity for much needed respite.

“GP surgery have been excellent in responding to health concerns and including the person with dementia in discussions.”

- Some respondents had benefited from regular, ongoing, one-to-one support from a health and care professional. This included in cases where people had been provided both practical advice and emotional support.
- Some respondents provided positive feedback about the support they had received from voluntary, community, faith and social enterprise (VCFSE) organisations (such as Dementia Connect, Suffolk Family Carers and Suffolk Carers Matter). However, these were often time-limited interventions focussing on specific issues rather than the ongoing, long-term help that many felt they needed.
- Two respondents mentioned the excellent advice and support they had received from the Community Memory Assessment Service (CMAS), linking them to other vital services (such as occupational therapists and the fire service). This had providing practical advice about how to access benefits.
- Three respondents had positive experiences of the care their relative had received in a residential care or nursing home. While their experiences were not entirely without issues, they highlighted the marked improvements in their relatives wellbeing since moving into the home.

“Once I’d got permission from my mum to access health services to try and get a diagnosis, the service she received was incredible. I contacted Dementia Together who advised me to contact the memory clinic. Every service involved, including Mum’s GP, were faultless. The memory service team were tenacious, my mum’s dementia is rare so it wasn’t obvious as to what it was at the beginning. We were also on the pandemic but I never felt we were left.”

“I referred my mum on September 2020, she was diagnosed in December 2021. The service she received and continues to date has been faultless.”

It is clear that, while some things are working well, there is a lack of consistency in the care and support being offered to people with dementia and their family carers. The remainder of this report focuses on different aspects of the dementia pathway, and provides more detail about what is working, what is not working and where improvements could be made.

Many of the examples of ‘what was working well’ either related to isolated incidents, or specific services and individuals. Only two respondents felt their experience had been positive across all stages and services within the dementia pathway.

3.1 Pre-diagnosis

Respondents were asked about when they first noticed changes in their relatives memory or behaviours.

For some, the signs had been present for several years. Others were aware of a history of dementia within the family, however this was not always openly acknowledged or spoken about.

Two people had been aware they could self-refer to a memory clinic 'to get their relative on the radar' and a further respondent said their GP had conducted yearly memory checks for her mother.

In many cases, symptoms were quite advanced by the time people had actively sought a formal diagnosis and some families had reached crisis point.

"I phoned up and I demanded to speak to another doctor, and I think I might have broken down and said, 'I can't do this anymore. No one believes me, I need help'." (Carer, Interview)

"I put the referral through to Community Memory Assessment Service....we were in crisis." (Carer, Interview)

Recognising the early signs of dementia can be difficult in itself. People had often dismissed them (e.g., put them down to old age), or felt others around them had dismissed their concerns. There were many other factors that had influenced when participants had sought support, or a formal diagnosis. Some of these are outlined below.

“

"Nobody else in the family could see what I was seeing... that was the worst part..."

Carer (Interview)

'Nobody would listen to me.'

"Nobody else in the family could see what I was seeing. For me, that was the worst part without a doubt. If I would say, 'Look, I can't cope with the housework,' because Mum had started to not do the housework. Again, it was only me that saw that. I felt like I was battling everybody." (Carer, Interview)

"It was hard to get help. Nobody would listen to me. I knew something was wrong with my husband. Eventually, after a considerable time, nearly two years, the nurse did the yearly health check with a dementia check as well and at last the ball started to roll. Why will the doctors not listen to wives, husbands and parents?" (Carer, Feedback form)

"I think because they had Mum for nine days in hospital, I think then people believed what we've been telling them for probably a year, what we were trying to manage... It was just all those things that we've been saying, but nobody else could see. It was a little bit of relief that somebody had acknowledged what we'd been saying." (Carer, Interview)

'We just made a joke of it.'

"She'd be scrabbling for words, or she'd not remember where she put her purse, and it would end up in the fridge or in a drawer that she never used. And it was things like that and we'd just make a little joke of it." (Carer, Interview)

'We put it down to old age – Mum's getting old.'

"My mum used to forever be forgetting to turn off the cooker. We just thought, 'Oh, she's getting old' but actually, those were the symptoms back then of forgetfulness. And then over the years, slowly, she was

66

"In some ways I think I've been denying the situation. I think I'm denying my wonderful bright, you know, at 90 she's like 'I'm 90' and punching the air. And I'm thinking 'Oh my God, that's amazing I wish I got a picture of it' 'cause that's how I see her.

"I don't want to think of her as deteriorating and not being able to cope because she's my mum."



struggling to put the keys in the door... fine movements.....that's what I noticed first. When she went to the shops, occasionally the change, she would struggle with the change in her hands, she would constantly forget where she put things. And we would all laugh because we think 'oh, Mum's getting old'." **(Carer, Interview)**

'Oh my God, that's amazing I wish I got a picture of it' 'cause that's how I see her. I don't want to think of her as deteriorating and not being able to cope because she's my mum." **(Carer, Interview)**

'It took a lot of detective work to piece things together.'

'I thought only old people get it.'

"They all think it's old people in care and to be honest, I thought very similar things until I got it in my age group." **(A person with Dementia, Interview)**

"I'm guilty of thinking that it's only old people that get it. I thought it was all those above 60, 70, and 80s. So, when it happened to me, it was the last thing I thought about." **(A person with Dementia, Interview)**

"[People kept saying] it's the dementia that causes her to not be sociable. It's the dementia that causes her to self-neglect. They had designated her as agoraphobic because she didn't want to go out whereas actually it was the fear of not remembering where she was and not remembering how to get home that gradually stopped her going now because she was frightened then but of course she wouldn't say that for quite a long time. It took a lot of detective work to piece these things together." **(Carer, Interview)**

'In our society, there isn't a diagnosis of dementia.'

"The symptoms of dementia were there much much earlier, we just didn't realise it. In our society, there isn't that diagnosis of dementia, everything is put down to old age." **(Carer, Interview)**

"She used to get confused. We just thought it was because of the language barrier." **(Carer, Interview)**

"I went up to use the bathroom and there was a layer of thick dust on the bath. I thought, perhaps, Dad just uses the en suite because he had two bathrooms. I went to check but that meant going into his bedroom and I didn't, I should have done. There were other things, but Dad was 77 and you kind of think 'Oh maybe he's just getting older'." **(Carer, Interview)**

"Dealing with the initial stages of dementia was challenging. Mum was very adept at covering up her difficulties." **(Carer Feedback form)**

'I've been denying the situation.'

"In some ways I think I've been denying the situation. I think I'm denying my wonderful bright, you know, at 90 she's like 'I'm 90' and punching the air. And I'm thinking

'He's putting it all on.'

"Even up until an hour or so before my dad died, my mum was just like 'Ohh

"Dealing with the initial stages of dementia was challenging. Mum was very adept at covering up her difficulties."

he's putting it all on' and didn't quite understand it and didn't quite grasp the fact that he was poorly." (Carer, Interview)

"[My aunt's] got a friend who comes in and says 'You do remember, of course you remember, I told you that five minutes ago' and she can't quite understand that my aunt can't help it and isn't doing it on purpose." (Carer, Interview)

'It is difficult to understand what the symptoms are.'

"I think there are so many different forms of dementia that it's very difficult to, you know, understand the symptoms in all cases." (Carer, Interview)

"I think people understand cancer. But they don't understand dementia, and I understand that to a point because it is a bit of a moving target because we're all different." (Carer, Interview)

'My mum's biggest fear in life was getting dementia.'

"In my father-in-law's case, my mother-in-law did not want to accept it, and for a long time we kept saying I think he might have dementia and she didn't want to know, but kept saying he's forgetting this and he's forgetting that. For some people it's a stigma or it's hard to just accept. So, for a long time he did go undiagnosed which was a shame." (Carer, Interview)

"My mum's biggest fear in life was getting dementia." (Carer, Interview)

Some families avoided using the word 'dementia' in front of their relative because of the distress it would cause. The example below highlights the importance of professionals being aware of, and respecting families' choices.

'We tried not to use the dementia word'

"We tried not to use the 'dementia' word because we knew her fear. So when it did actually get to the point where she got diagnosed, we said 'Look, Mum, you've

66

"...Everything has been missing as we are unable to access how to get any care due to GP not carrying out assessment or request for memory clinic referral."

Carer (Interview)

had your stroke, your brain is not working properly, this is a gradual decline triggered by the stroke. So obviously, your brains not going to function and this will continue'. So we did everything about you've got it but we didn't keep throwing the D word at her. One day the paramedics came in, and were just blatantly saying, 'Well you've got dementia'. Mum just went into meltdown and it wasn't because we were overly protective. It was just how we were trying to broach the subject with someone who had that level of understanding. Less painful to say it that way and then she was like, 'I can't believe I've got that disease' and for quite a while she was really teary, really upset." (Carer, Interview)

While most respondents had been through the process of getting a formal diagnosis of dementia, one carer had chosen not to, as she felt the benefits (particularly in relation to treatment options and support availability) did not outweigh the inconvenience to her mother.

A further respondent reported that their GP had not supported them in their decision to seek a diagnosis, stating that it simply provides a 'label', however, the family felt that as a consequence they had missed out on accessing support.

'What's the point? There's no support, it's just a label.'

"[We haven't bothered to get a diagnosis]. She refuses and she moans about all the tablets she has to take anyway and she doesn't want to take any more.... I couldn't

see the point because if it's vascular dementia there's no treatment. And if it's Alzheimer's, it's probably a mixture, and those tablets don't always work. She's 91. What's the point?..... We used to say it at work that if you got the diagnosis it opens up all sorts of other doors, which it does. But she's 91. She's not a group person, and so she wouldn't go to groups. I mean she just, she's her own woman and she'll do what she wants to do and nothing else. And that's an issue." (Carer, Interview)

"When Mother requested a dementia assessment (for Dad) her GP declared it wouldn't be of any use, except to give

him a label... Everything has been missing as we are unable to access how to get any care due to GP not carrying out assessment or request for memory clinic referral." (Carer, Feedback form)

Others, however felt that having a diagnosis had helped them to understand what they were dealing with, to change their mindset, as well as enabling them to research more about the condition for themselves.

Key learning for systems and leaders



Information and awareness

Early signs and symptoms are not widely known. We need to help people to find information about dementia so they know what to look for.



Make it easier to find early help

People need to know what support is available if they think they or a relative has a problem with their memory, and they need to know how to access that support.



Include people without a diagnosis

Difficulties with obtaining a formal diagnosis mean people can miss out on support. People should have the same access to help whether they have a formal diagnosis or not.



Find ways to make dementia less hidden

We need to breakdown the fear and stigma people experience so that we can have open and honest discussions about dementia.



“

“We tried not to use the ‘dementia’ word because we knew her fear... One day the paramedics came in, and were just blatantly saying, ‘well you’ve got dementia’. Mum just went into meltdown and it wasn’t because we were overly protective. It was just how we were trying to broach the subject with someone who had that level of understanding.

“...She was like, ‘I can’t believe I’ve got that disease’ and for quite a while she was really teary, really upset.”

3.2 The 'process' of getting a diagnosis

Seventeen of the people interviewed shared their experience of getting a diagnosis.

Most (10) had approached a GP in the first instance, however, two people had self-referred to the Community Memory Assessment Service (CMAS), and two had been referred to CMAS after an inpatient stay at an acute hospital.

Those who were eventually diagnosed with Early onset dementia had a more complex 'route' to getting a diagnosis compared to the other cases, often involving multiple health teams across several different trusts.

Length of time to get a diagnosis

It is difficult to quantify the exact length of time it took for people to get a dementia diagnosis, as there is no consistent point from which to measure. In addition, carers often stated that this period of their life had been 'a bit of a blur' because of everything else they were dealing with. Most could only give a rough estimation of how long they had waited.

With these caveats considered, the length of time it had taken people to get a diagnosis varied considerably. Some reported that it had taken as little as a couple of months, whilst others (particularly younger people)

had waited several years.

'People don't like to put a diagnosis on people so much younger.'

"It took us three years to get a diagnosis. To begin with they said I hadn't got a form of dementia. Then a doctor somewhere looked at all my scans and said, 'This isn't right, you're saying this man hasn't got dementia but yet when we put the three scans together you can see the difference'. So, I think we went to see her and she said, 'This is what you have got because this is what the evidence says, I don't know why they say you haven't'." **(Person with dementia, Interview)**

"It took five to six years to get my auntie diagnosed, whereas it took six months to get both my parents diagnosed. People don't like to put a diagnosis on people so much younger." **(Carer, Interview)**

"I reckon it has got to be at least eight years... I reckon it has to be from the first onset of the symptoms, you know, sort of forgetfulness [to diagnosis]." **(Carer, Interview)**



Experiences of getting a diagnosis were variable.

For some, diagnosis progressed fairly quickly, whilst others said it had been months or years before they had received a diagnosis of dementia for themselves, or for the person they cared for.

There was no particular pattern or consistent reason why some people waited longer for a diagnosis than others. Respondents were, however, able to share examples of what had worked well and what had not worked well about the process.

Diagnosis: What worked well?

When the family's concerns had been listened to and acted upon

"She had to stay in hospital for something completely unrelated. I don't know how the conversation came up but we then mentioned about Mum's memory and they thought that it would be appropriate if she was to get her memory checked.... She was assessed at the memory assessment clinic near where we lived. She was also referred to have a brain scan. It didn't take long at all, it took a couple of months."
(Carer, Interview)

"The GP service understood my concerns regarding my husband and acted immediately. He was referred to the Community Memory Team." (Carer, Feedback form)

'When professionals were supportive and were willing to do things differently.'

"I had to chat to the doctor and arrange a way of getting my wife in there and really I think it was reviewing a repeat prescription of calcium tablets, or something like that... I arranged with the doctor who's a very helpful guy anyway. But when she went in for this review, I would go in with her and quite discreetly he would suddenly introduce a few sorts of tests to see whether there were signs of dementia.....and you know he actually identified what he thought was a fairly advanced dementia, fairly advanced stage... He referred me to Suffolk CMAS."
(Carer, Interview)

"So they talked to her and to me [and said] 'Normally we would do lots and lots of scans, over a period of time etc. If we do the psychological testing with you and if

66

"...I think I might have broken down and said, 'I can't do this anymore. No one believes me, I need help.' He said, 'Can you bring her in now?'"

Carer (Interview)

we did a lumbar puncture, we would know one way or the other'. And my sister chose, she said 'I just want to know why I can't remember.' So that's what we agreed and that's what they did. Lumber punctures, horrible experience. But I was really grateful to them for not prolonging it, because it would normally take probably 18 months. The head of the memory clinic was genuinely focused on... he was person-centered. 'Our procedures say we should do X, Y, and Z. However...' And that was brilliant." (Carer, Interview)

'When GPs undertook regular memory tests.'

"We'd been to the GP and she'd done a memory test and they sort of said we'll do it again in a years' time or whatever. Then the next time there was a definite difference and we ended up at the memory clinic and they did a CAT scan and that's how she was diagnosed."
(Carer, Interview)

Diagnosis: What did not work well?

'When services did not respond to requests for help.'

"I wrote to my Mum's GP three times, almost begging him really to see her. I wrote to him and the first letter, I just got nothing, no response. I let it go because I was busy [caring for my parents]. I let it go a bit longer. And then I sent another letter. By the third, I was really, really angry that

nobody, I felt, in the world was listening to me. And so, then I phoned up and I demanded to speak to another doctor, and I think I might have broken down and said, 'I can't do this anymore. No one believes me, I need help.' He said, 'Can you bring her in now?' (Carer, Interview)

"I put the referral through [to CMAS] in October, I remember having a phone call, we were in crisis in December, before Christmas. It was getting... we had a really bad point and I pleaded with them to give some support. 'We're in meltdown' and they didn't do anything. In the end, [someone] came out, I think it's was like the 23rd or 24th of March." (Carer, Interview)

'When GPs focused on medical symptoms only.'

"He'd lost a lot of weight and we'd noticed he was very forgetful. I managed to get him in to see the GP, who focused more on the medical side of why he'd lost four stone. He had arthritis and it turns out he hadn't been attending hospital appointments for that. He hadn't got his COVID jab when he should have done, he would normally manage it himself. He hadn't been taking his medication

that he should be on daily I might add. Anyway, the GP then put him forward to medically investigate why he'd lost all this weight and he had an endoscopy, a colonoscopy." (Carer, Interview)

"It was extremely difficult to get any real support at all. The doctor was useless and couldn't see further than VitD deficiency and didn't follow through." (Carer, Feedback form)

'When language barriers were not addressed.'

"It took months. I don't know, it took months and I think we also had to wait longer because they needed an interpreter. They didn't want me to do all the interpreting. They wanted an independent one. So I think we waited a little bit longer than perhaps we would have otherwise to accommodate the interpreter in." (Carer, Interview)

"She had a scan and then she had some test and they diagnosed her with dementia, but they couldn't give a specific name because assessing my mum was difficult because of the language barrier. My mum also can't read and write. She only had a minimum schooling and that

“

"After loads and loads of questions, she said to me, "He's depressed." I said, 'Yes, I know he's depressed'. She said, 'Well there you go, it's depression'. Almost like, 'What on earth have you called me out here for, for someone who's depressed?'. I said, 'He is depressed. He's depressed because of the situation, of how he is'. She was shaking her head and getting a bit irritated... and then suddenly something made me say, 'But why can't he make a sandwich anymore then?' She went, 'What?', I said 'Why does he not know how to make... He's always made his lunch, a sandwich'. I said, 'Why can't he do that now?' 'Oh, you didn't tell me that. Oh well, that's dementia then. It's not depression, is it?'. I said, 'Well, I wouldn't have thought it's depression, but he's depressed because he can't do it'."

Cultural barriers to diagnosis

Respondents highlighted how diagnosis can be delayed, or never fully completed, for those who do not speak English as their first language.



was in Bengali and then obviously, English is how they tested her. So like they couldn't do all the tests on her, but what they could test they did realise that she had a memory loss. They said that she's got dementia, but they couldn't say whether it was Alzheimer's or Parkinson's because they said that she has to have a thorough test and because of the language barrier, we weren't able to do that." (Carer, Interview)

'When families were not listened to or taken seriously.'

"We wrote to the GP and my brother was there. We voiced our concerns and she put it down to COVID and blamed Dad for being on his own." (Carer, Interview)

"I found the GP in London wasn't much help. I mean he honestly said one day to me, 'Well it's not as if she's running up the road in her nightie' and I said 'So, are we waiting for that now then Doctor?'" (Carer, Interview)

"It was only really me pestering her and saying look my dad is not right she then tried to say that dad was clinically depressed. He was put on antidepressants but come April there was no change in his mood, and by May my dad still hasn't put any weight on, and his mood hasn't improved. So, with that she referred him to the FAB clinic at the hospital and he had all the tests, had a CT scan, blood tests and they found he had a vitamin deficiency. They said he didn't have dementia, he was depressed and we'd been through this, so I wasn't happy." (Carer, Interview)

'When services failed to communicate with families or each other'

"It has been an absolute nightmare. From the very beginning when we had the memory team come out, then we didn't see them for months. Then my mum was admitted to hospital. The hospital obviously can see records or notes, and they told us she had vascular dementia, which we didn't know. Because nobody actually told us, so that came as a massive shock to us." (Carer, Interview)

"A diagnosis was given. It filtered through eventually to the GP, but it took a long time. Because every time I had to speak to the GP, because we were struggling at home with different types of things with Mum, I would have to say, well, she has been diagnosed by [the memory service] on this date, you haven't got it on your records yet, but I'm sure that'll come. I would say it took at least maybe a month or two. It wasn't instant and it definitely wasn't within a few weeks. It was quite a prolonged wait for that to hit on there." (Carer, Interview)

"I made an appointment with some lovely ladies who after a brief interview, suggested that there may be an issue with my brain. This was around 18 months ago. I had an interview with a professional at the hospital and had an MRI scan a couple of months later. They said that the results would be sent in two weeks. It is now over a year since all the investigations. I am going downhill very quickly but have not heard anything." (Person with Dementia, Feedback form)

When diagnosis was not given in a sensitive and caring way

"A woman came to the house, asked her different questions. I did sit in on it. And then at the end she just said there and then she had Alzheimer's, which my mother went berserk. [Interviewer: Was it as blunt as that?] I think she did, but I wasn't taking it in, even though I was prepared. Mum certainly didn't." (Carer, Interview)

"She said 'This is what you have got, because this is what the evidence says,

I don't know why they say you haven't'. She gave me a life expectancy of eight to 10 years and then it was 'my job is done, see you later' with one leaflet about end of life care. That was it. I do remember she wasn't very abrupt, but she was quite doctory." (A person with dementia, Interview)

"Seen by [CMAS] initially. Although they were nice, they saw Mum alone and told her she had Alzheimer's. She became quite upset and didn't understand. I feel she should have had someone with her which we would have been able to do." (Carer, Feedback form)

Key learning for systems and leaders



Listen to carers

Family carers want to be listened to and taken seriously when they ask for help – this includes health professionals doing things differently to support them or their relative in getting a diagnosis and addressing any language or cultural issues.



Improve cross-service communication

Families want services that talk and communicate with each other and with them.



Compassionate diagnosis delivery

A dementia diagnosis can be unexpected, alarming, and life-changing. Professionals must make sure that any diagnosis is communicated in a compassionate and supportive way.



66

"A diagnosis was given. It filtered through eventually to the GP, but it took a long time. Because every time I had to speak to the GP, because we were struggling at home with different types of things with Mum, I would have to say, 'Well, she has been diagnosed by [the memory service] on this date, you haven't got it on your records yet?'. I would say it took at least maybe a month or two.

"It wasn't instant and it definitely wasn't within a few weeks. It was quite a prolonged wait for that to hit on there."

3.3 Support

Respondents were asked about the support they had received following their diagnosis, or the diagnosis for their friend or relative.

Two of the people interviewed said they received good practical support from the Community Memory Assessment Service (CMAS) at the point of diagnosis, although this had been available for a short period of time only.

'CMAS did a great job....but they drop you like a stone.'

"I thought overall they were very good. They took on the role and over a period of six months or so they identified tablets for her and gradually introduced them at greater strength and checked the outcome. Measured blood pressure, that sort of thing. And well, visited me and gave me an indication of what I was going to have to expect in term of care. And also helped me in terms of all the sort of various things I could apply for like attendance allowance and reduced council tax, and things like that. Suffolk CMAS did a great job but once they were happy that they had prescribed the right drugs, they said 'Right, back to your GP now'. And they sort of drop you like a stone. And I think from that point onwards you're very much left on your own." (Carer, Interview)

Most people felt there had been a general lack of support following diagnosis that left them feeling 'abandoned'.

'You're diagnosed and then that's it, you're on your own.'

"There was nothing that came from [getting the diagnosis]. It was just, okay, you've got a diagnosis, perhaps take her to a dementia café, perhaps take her to a drop-in centre." (Carer, Interview)

"Diagnosis was relatively swift and straightforward via GP, and memory clinic. Have not had any further input from anyone since (over three years)." (Carer, Feedback form)

"Getting the diagnosis was not too bad, that was fairly easy. We've got very good GP, who has been my mum's GP for a long time so knew me, knew my mum so that really helped. So, the referral to the memory clinic and the diagnosis all went quite smoothly, but you get this diagnosis and then you're just left, what do we do now? I feel that you know at the point of diagnosis, somebody should give you all that information and where you can go locally to get that." (Carer, Interview)

"The community memory clinic staff have been very helpful and accommodating but now we have the diagnosis I feel rather lost and directionless." (Carer, Feedback form)

"Dementia Support Team in Ipswich were

66

"...the referral for the to the memory clinic and the diagnosis all went quite smoothly, but you get this diagnosis and then you're just left, what do we do now? I feel that you know at the point of diagnosis, somebody should give you all that information and where you can go locally to get that."

great in the diagnosis and drug regime along with phone contacts, but once diagnosis and drugs were sorted, just being passed back to GP, left me unaware of stages of deterring personality etc.”
(Carer, Feedback form)

“Can't fault the service. But after care is shocking. Report sent to doctor, no follow-up. Just left to get on with it. Everyone says help is available but it isn't.” (Carer, Feedback form)



“My relative was given a diagnosis and discharged in the same appointment.”

Experiences of Dementia Connect/Dementia Together

Since 2017, Suffolk County Council and the local NHS have commissioned a countywide pre-and-post diagnostic Dementia Support Service. Originally provided by Sue Ryder (and named ‘Dementia Together’), the contract was awarded to the Alzheimer’s Society in April 2021 and is now named ‘Dementia Connect’.

To ensure continuity of support, existing users of the Dementia Together service were automatically transferred to Dementia Connect without need for re-referral.

The service (whether as Dementia Together or Dementia Connect) offers support to people who are concerned about their memory, as well as those with dementia and their carers. It provides information on all aspects of dementia, expert practical guidance on how to navigate services, and supports people to manage and live well with dementia.

The service is embedded within the local health and care system with an aim of ensuring people are linked to support and advice at the earliest opportunity. This means that the service works alongside (and can take referrals from) GPs and practice staff, Integrated Neighbourhood Teams, alliances, acute hospitals, specialist dementia services inc CMAS and DIST), ACS Customer First and Voluntary, Community and Social Enterprise organisations including dementia groups across Suffolk. People can also self-refer directly into the service.

Despite its unique position as the ‘go-to’ support service for people with dementia and

their family carers, only nine of the people interviewed had heard of either Dementia Together or Dementia Connect and only five had some form of contact with the service.

- Two had been directly referred (either through CMAS or their GP)
- Two had found out about the service from friends or relatives
- One did not specify how they came into contact with the service



Only nine (42%) of the 21 people we interviewed knew of Dementia Together or Dementia Connect, and just five had contacted the service.

Opinions of the service(s) varied.

Two people had found the support provided to be very helpful, however one had lost contact when it changed to Dementia Connect.

Two people said they had been provided with information but that it wasn't particularly helpful, especially as, for one carer, she had 'already done' all the things they suggested. The remaining respondent did not offer an opinion but simply stated that they had received some support from Dementia Together.

'The most help I'd had from anybody.'

"Dementia Together came to visit us, [this was two years after the diagnosis]. Very pleasant young woman. She came to the house but she was going to leave at the end of March because Dementia Together was being reorganised, or was going to merge with the Alzheimer's Society or something? But she recommended that we apply for Attendance Allowance, that we set up a family carers emergency plan and suggested two places for day care and this was the most help I'd had from anybody at all, and also organised the carers eligibility assessment and a carers support plan for me." (Carer, Interview)

'They changed to the Alzheimer's.... I don't hear from them anymore.'

"[My daughter] said have you tried Sue Ryder and I said 'No' and then... because they changed to the Alzheimer's... But I don't hear from the lady anymore. I know I could probably ring her up.... nobody gets in touch with me anymore... [The lady from Sue Ryder] used to ring me up and see if everything was alright or I could email her. And then she said that they were changing over and I don't know what happened then." (Carer, Interview)

'Not particularly helpful.'

"When Mum first was diagnosed with dementia, the community dementia team directed us to Dementia Together. I had

a phone call with one of the ladies and she just sent me a load of information via email, which wasn't particularly helpful. It wasn't hands on support." (Carer, Interview)

'I've already done that.'

"Someone I worked for from another GP surgery gave me Dementia Connects number but if I didn't do the job I do, I wouldn't know.... I did phone them and basically sort of the information that they'd given me of like next steps I needed to do so.... Looking at getting carers in, obviously I've done that. Power of attorney, I've done that. What else did they suggest? Ohh about dementia cafés which there are several, but the problem was my brother and I work. So how could we take Dad?" (Carer, Interview)

Of the four people who had heard of Dementia Together or Dementia Connect, but had not used the service:

- One felt that the support on offer did not meet her needs
- One had been signposted to the service by the receptionist at her GP practice but had not followed up the suggestion
- One was made aware of Dementia Together after meeting someone from the service at an event they were attending
- One simply stated that they had heard of the service but did not offer any further information.

'The emotional support is missing.'

"With Suffolk Family Carers or Dementia Together, it's informing you about where you can go for help and support and what they might be entitled to. I knew all that but the actual emotional support I suppose and psychological support for carers, isn't there. That does not exist in Suffolk at all. And for me, that's one of the biggest gaps because of the toll that it takes on you." (Carer, Interview)

“

“Once I’d got permission from my mum to access health services to try and get a diagnosis, the service she received was incredible. I contacted Dementia Together who advised me to contact the memory clinic.

“Every service involved including my mum’s GP were faultless. The memory service team were tenacious, my mum’s dementia is rare so it wasn’t obvious as to what it was at the beginning. We were also on the pandemic but I never felt we were left.”

'He came to a meeting and handed out some leaflets.'

"I think it was [name redacted] wasn't it from Sue Ryder. They come to one of the meetings, but that was it. I think once again, perhaps it was lockdown or funding I don't know. But we had only seen them once, they gave out some leaflets and disappeared after that." **(A person with dementia, Interview)**

'I was told to contact Sue Ryder, but I was too emotionally upset.'

"I rang up my surgery, I said 'Look, I'm

worried. I think I might need to consider long term care with my mum's dementia. She's physically deteriorating as well. Can I speak to somebody with regard to her mental health?' And the lady said to me, because my mum's got dementia, they can't give any advice. I should contact Sue Ryder. So they will give me that number, the receptionist, and I wasn't put through to anybody else and I think I put the phone down. I was very upset emotional." **(Carer, Interview)**

Support from family and friends

Respondents highlighted the significant role family and friends made in helping them to continue in their caring role – not least because they provided much-needed opportunities for respite, which were not available anywhere else.

“

"I'm really lucky... My children and my partner to open up their home and their lives... because we all take turns in supporting [my sister] as well. They've been really great. They are my main source of support - but in terms of other things being available, it's just not there."

"We've gone over before and stayed the night so that my dad can have a sleep. The idea being is, when my daughter moves out, they can just have a little bit of respite with us. You know, put a bed downstairs so they can sleep. And if my mum goes to bed early, my dad has some

company. Because it's not just about my mum." **(Carer, Interview)**

"My support is my siblings over the phone. Whenever I can't take it anymore or it's really hard. I just ring up my siblings, I have a good cry, they will then rally around me and then I get some temporary relief for a day. Or something. Or, my sister she takes my mum for a couple of days, so that I get a bit of a break." **(Carer, Interview)**

"We were members of a walking group. And some of those members of the walking group formed a rota. They would come in pairs Wednesday afternoons, obviously outside the COVID lockdowns. But they were done in pairs, and I would go off and play nine holes of golf in the afternoon. That was very precious. And I had a guy who is a great friend of mine... he made sure he set aside Wednesday afternoon to play a round of golf. And it was like gold dust. It was something I really looked forward to." **(Carer, Interview)**

"I have a friend who picks my husband up from the daycare, because they have to be to be picked up about 2:30 and I [do my volunteering work then], so she picks him up and keeps him and takes him to her house for about an hour so that I can

finish my shift there, but I don't get any other support." (Carer, Interview)

Other sources of support

Many respondents had undertaken self research, (predominantly using the internet), to find information, advice and services, with varying levels of success.

Support - what did not work?

While people recognised that there was a lot of useful information available, this could be overwhelming making it difficult to find the right advice for their specific situation. It was also clear from respondents that being handed a list of phone numbers, or a wadge of leaflets was not enough.

'It's a strange combination of too much choice and not knowing where to start.'

"It is very hard to find the right information and to navigate what support is out there." (Carer, Feedback form)

"I did do some looking on the internet.online, you can get a very good amount of information from the Alzheimer's Society. They do cover everything. They're very good and there's a lot of resources out there. But it's overwhelming." (Carer, Interview)

"I've had some emails sent over, that's about it. It was so overwhelming. We had a list of maybe 20 or 30 different things. I had no idea even where to start." (Carer, Interview)

"I've been trying to research myself with no success." (Carer, Interview)

'They sent me loads of leaflets... I just couldn't cope.'

"I remember phoning them [SFC] up once, and I was just distraught because I just couldn't cope. And then they sent me loads of leaflets. I just sat with these leaflets and I did nothing, and then just put them away. These will be handy, I'll put them in a folder, and I just plodded on." (Carer, Interview)

"All along its easy to find information on the internet. What's impossible is human connection and practical support."

“

"... I remember phoning them [SFC] up once, and I was just distraught because I just couldn't cope. And then they sent me loads of leaflets. I just sat with these leaflets and I did nothing, and then just put them away..."



Leaflet fatigue does not help

Respondents often felt that they had been overwhelmed by leaflets with information that often went to waste. People viewed this type of response from services as dismissive, simply not meeting their need in moments of stress.

Charities in early stages and social services just sent leaflets, which just went in the bin.” (Carer, Feedback form)

“Giving somebody a list of numbers is not enough.” (Carer, Interview)

“All I seem to be offered is leaflets to read.” (Carer, Feedback form)

“I got the diagnosis was given a big sheet of all the organisations you could contact. Off you go yeah and feeling so overwhelmed and not knowing what each of those organisations might offer them or do for them. My wife wanted somebody to take it and say, right, OK, let’s just take some of this away from you and just some reassurance that she didn’t get.” (A person with dementia, Interview)

Where people had tried accessing support, it did not always meet their needs.

For example, respondents were able to share some positive experiences of accessing support through organisations such as Suffolk Family Carers, Suffolk Carers Matter, Pear Tree Fund, Admiral Nurses, Alzheimer’s Society, but these tended to be one-off exchanges of information or advice or time-limited interventions (e.g workshops run by Suffolk Family Carers or the provision of counselling through Suffolk Carers Matter). They did not provide the ongoing support that most respondents seemed to want.

‘They are very good at first, but they just all drop off.’

“Like the Sue Ryder, they were very good at first. Family Carers were very good at first. And social service is very good at first and they just all drop off. You don’t get them again.” (Carer, Interview)

Those with early onset Dementia highlighted that a lot of support is aimed at older people and did not meet their specific needs.

‘Everything was tailored for older people.’

“We did go to a few dementia meetings as you would call them, but they were all tailored to people who were further down the journey for me and it was very depressing to see and see what will inevitably happen to me at some point.” (A person with dementia, Interview)

“

“Nobody’s there to help us. My wife tried to access services, but everything was tailored for people older.”

A person with dementia, Interview

"The other bit that's missing for me is there isn't anything for people with dementia who want to live an independent life... She wouldn't go to a group where, I don't know they did a quiz in the afternoon or where they played old music. So, in terms of what's on offer in Suffolk for her there isn't anything.....if you've got somebody who still wants to go out and do things, but when you look at the list of what's on offered to be able to do things, they're all old." (Carer, Interview)

Carers, hoping for some much needed respite, found that accessing support groups or dementia cafés etc. only added to their list of things to do, rather than offering a meaningful break for them.

'It's not respite for me.'

"I have to take her there and I have to sit with her the whole time. So I stopped there thinking 'Oh, God. I have got tons of washing to be doing at home'." (Carer, Interview)

"I did mention like about support groups. I know that Ipswich Town do one on a Thursday or last Thursday of every month or something, but it's like then I have to take her. It's just another catch-22 situation because you want them to have that, but I'd be the one who takes her. And then I don't get that break. I'm still doing the... and I work full time. I have a house. I have a puppy and I have an 11-year-old and a husband." (Carer, Interview)

"I did get in touch with the person at Suffolk Family Matters because I wanted to find out what the possibilities were of paying somebody to come and take him to an activity, there are some singing activities in Bury and if I go that's another half-day out of my life when I can't do things that I need to do, and I thought it would be nice and I thought probably he'd accept somebody else taking him if I worked it right, if I said it right. So I asked them if they could you know, give me any help with that and they just sent me a directory of carers. And that was not, that's not what I wanted." (Carer, Interview)

Other example of what did not work well with existing support services included:

- Dementia Café's, or support groups that open during the day when carers are working and there are no other options for transport
- Community groups where there are no advisors on hand to answer questions
- Day services where activities are 'kiddish' and patronising
- Online Information that was not always up to date or accurate
- Support is often one off or time-limited



"...it's just another catch-22 situation because you want them to have that, but I'd be the one who takes her. And then I don't get that break."

Carer, Interview

'I work, so how can I take Dad to a Dementia Café?'

"Dementia cafés which there are several, but the problem was my brother and I work. So how could we take Dad? We couldn't, because they have to go with a carer. So and I have still, as far as I know, got my dad's name on a waiting list with several care providers and charities where they provide like companions to take them to these dementia cafés. But Dad's been on a wait list now for over six months." (Carer, Interview)

"I work so support groups are not an option as I struggle to fit everything in as it is." (Carer, Feedback form)

Watch Peter talk about the support people with dementia, and their families, need in our short film...

“We had come to a roundabout with no signposts, there were many exits from that roundabout and we didn’t know which one was the best one – or even which one was the right one to take... so we just went nowhere.”

[Click to watch now](#)

‘They were singing Old MacDonal had a Farm.’

“My dad did go somewhere twice. I remember the second time I picked him up and they were singing, Old MacDonal Had a Farm.... He got back in the car and went, ‘I am not going back there again’. Fine. That was it.” (Carer, Interview)

“My wife tried the local day centre but stopped after four weeks because she found it boring and the activities childish. The transport was not reliable to get her there.” (Carer, Feedback form)

‘The dates and times were incorrect.’

“We are east Suffolk and the support groups either shut down or don’t run as they say they will [with offered] times or days.” (Carer, Feedback form)

‘It was only ever one off support.’

“I wouldn’t have the energy to go through leaflet and figure out, well, who should I phone? I did make a few phone calls, but they only ever were one-offs, because

nothing happened. ‘Phone us again, if you’re feeling down’. It’s like... ‘I’m asking for help right now’, but no one seemed to grasp that.” (Carer, Interview)

Support – what people say they need

It was clear from the feedback received that what people wanted was individualised support.

People expressed their need for support with the flexibility to be delivered both in person and through remote methods (telephone or online video calls). This included support that:

- is proactive in contacting families at regular intervals
- could offer objective advice and signposting (specific to their particular situation)
- offers ongoing emotional support and a ‘listening ear’
- helps people to prepare for the future

'Someone knowledgeable on health and welfare issues who will walk with them through the maze.'

"I do not mean the endless signposting which passes for support these days. It is no help to be signposted to another agency which usually advises to look up whatever the problem is on the internet. Carers themselves need someone knowledgeable on health and welfare issues who will walk with them through the maze. Whilst it can be good to have someone just listen, it is more helpful to have someone stay with you and guide one through the health, welfare and care systems." (Carer, Feedback form)

'Face to face support.'

"My mother would like face to face support. She struggles with always having to go on the computer or the phone." (Carer, Feedback form)

'Somebody actually looking at your situation.'

"It's nice when somebody informs you or whatever, but that's not the same

as somebody actually looking at [your situation] and that's the bit I feel was missing." (Carer, Interview)

'A key worker.'

"If you could have like a key person who helps you navigate the system. Somebody who could just be your key worker, your dementia key worker who you know was there to help you navigate the system, help you find the care that you need, and know what you're entitled to." (Carer, Interview)

'Just someone to talk to.'

"Sometimes it's just talking to somebody you don't have to ask for information or you don't something you just want to talk to them and sort of have a bit of ... 'I had a bit of an awful night' or something... just a bit of sympathy really." (Carer, Interview)



Someone to be a guide

"Carers need someone knowledgeable on health and welfare issues who will walk with them through the maze. Whilst it can be good to have someone just listen, it is more helpful to have someone stay with you and guide one through the health, welfare and care systems."

“I don’t want people to talk to me generally about things.... I want specific help.’

“For somebody, well I think, for somebody, after about a couple of months after the diagnosis, somebody to just talk to, so I could say look, is there an order that I should do things in for example. Yes, if somebody just to, and I think that’s what I still need; somebody that I can say to look this happened, I did that. Is there something I should have done differently? If I treat it this way will it help him or is it going to make things worse? What can I do to keep things, to make the progress of the disease as slow as possible really. Do you see what I mean? I mean what I need is when I want help, I know what help I want, if you see what I mean. I don’t just want people to talk to me generally about things if I want something specific I want them to be able to help me on that.” (Carer, Interview)

‘Emotional support for Carers does not exist within Suffolk.’

“Actual emotional support I suppose and

“

“The mental health nurse that comes out see to see mum, she’s here for an hour, she spends about 20 minutes or half an hour with mum, then she comes and chats with me about how I’m coping with things and what they can do to help if there’s anything. So, she’s been really, really supportive.”

Carer (Interview)

psychological support for carers, isn’t there. That does not exist in Suffolk at all. And for me, that’s one of the biggest gaps because of the toll that it takes on you.” (Carer, Interview)

‘Someone to help you work things out for yourself.’

“That’s where that emotional support sometimes can come in and help you kind of work through some of those things for yourself to work out what it is that would help or might not help.” (Carer, Feedback form)

Some respondents had already benefited from support of this kind, however it felt like this was more by chance than design.

‘She chats with me about how I am coping.’

“The mental health nurse that comes out see to see mum, she’s here for an hour, she spends about 20 minutes or half an hour with mum, then she comes and chats with me about how I’m coping with things and what they can do to help if there’s anything. So, she’s been really, really supportive.” (Carer, Interview)

‘It was the best support I’ve ever had.’

“The psychologist who was seeing my sister before lockdown agreed that we would have the telephone calls. So, she wouldn’t phone my sister, she would phone me. And actually that six or so months that I spoke to her, once a fortnight, was probably the best support I’ve ever had, because.... we were able to talk about my sister, we were able to talk about what happened, but also how I was feeling and what I needed to do. So, in terms of making sure I was looking after myself, but also in terms of how I needed to support my sister. Now none of that would’ve been possible if it was face to face because we couldn’t have those conversations in front of my sister and that’s not usual.” (Carer, Interview)



“

“Even just to phone up in tears and say ‘I don’t know what to do next’ and they’re giving you a sympathetic ear and saying ‘You’re doing all that you can, you’re doing really well, but keep trying, keep persevering, you’re doing the right thing for your mum’.

“Just to know that at least someone gets it, gets what you’ve been through.”



Support

"At the beginning they thought more MND. So, they threw everything at me physiotherapy and speech therapy. I had a neurological nurse who became a friend because she knew what I was going through and how frightened I was. They came round and put a handrail and stall in the bathroom. It was all sorted.

"Then... all of a sudden, she said they're pulling the funding. Because the MND wasn't diagnosed as the main problem, everything was withdrawn. But they're both neurological conditions...

"Dementia is like the poor relation. Dementia is the biggest killer and it seems like the poor relation."

'She has been consistent, she has been a voice of reason.'

"[The community Nurse] has been our mainstay. What's been brilliant is she has been consistent and that's what my dad has needed, because now he trusts her. And my mum.... she likes and she trusts her. Mum thinks she's my friend, not a professional, but we go with that, She books, she comes. She comes when she's supposed to and if she can't, she's got another person who'll come up and see my mum. If it wasn't for her, I think my dad

would have probably have gone under by now. She can be a voice of reason. She's got that medical training, and just be able to put him... 'That's fine, it's to be expected', or 'Actually, you know what, maybe I just need to check up'. I mean she's been very informative all the way through.... she found us carer's numbers. She told us about the Pear Tree Fund."
(Carer, Interview)

Others had experience of one-to-one individualised support being provided for other long-term life-limiting conditions (e.g., cancer or motor neurone disease), or had experience from other settings (e.g., family support workers).

'There isn't the support there, like there is for cancer.'

"Watching my mum die from cancer was awful. This is a different type of awful, but what is more scary is that there isn't the support that was there for my mum. Like with Macmillan and all that type of thing, all the nurses going in. Dad is ill and there isn't... he's not been looked after." **(Carer, Interview)**

'Dementia is like the poor relation.'

"At the beginning they thought more MND. So, they threw everything at me physiotherapy and speech therapy. I had a neurological nurse who became a friend because she knew what I was going through and how frightened I was. They came round and put a handrail and stall in the bathroom. It was all sorted. Then all of a sudden she said they're pulling the funding. Because the MND wasn't diagnosed as the main problem, everything was withdrawn. But they're both neurological conditions, so MND gets everything thrown at it. Dementia is like the poor relation. Dementia is the biggest killer and it seems like the poor relation."
(A person with dementia, Interview)

'Similar to family support workers.'

"...And that person just to contact, just to say we are here. When you get to that

point where you need this advice and support, you phone us we are here. Just so people know, and we haven't had that... When somebody has a diagnosis to go and do a home visit, if there's any initial stuff that needs to be done around that, to be supported with that. I mean, I work with family support workers in Suffolk. It needs to be a similar type of service, but in as much as you can go in and actually do like an assessment of any needs there. Actually, the family might be functioning okay, which we were at the start, we were doing fine. But as it escalated, having been able to touch base and say, "Hi, it's me. I met you six months ago, things have changed. I wonder if we could touch base again." And having that would be, I think a lifesaver for carers. Because actually the cost of putting a person into care is massive." (Carer, Interview)

Other types of support respondents said they would like included:

- More 'hands-on' help to understand what technological solutions are available to help support someone live independently at home.

"[Talking about assistive tech] More hands-on help to talk through what each alarm does. You get GPS trackers and things, your Fitbit, or your Apple phone. You can track people, where they are or what

they're doing. You can get alarms on your doors but how you get them set up or which ones are better than others.... Confusing." (Carer, Interview)

"I've been trying to research myself with no success, but I really need something that I can put on him so I know where he is because he sometimes... Oh, like when he goes to the barbers or something, it would be really good if there was some sort of device that he could use, or I could use for him so that I could track him on my mobile phone, like you could track children, but the thing is you track children through their mobile phones but he doesn't use the mobile phone so that doesn't work. But I've tried several things so far that don't work." (Carer, Interview)

- Peer support or buddying systems, both for themselves as family carers and for their relatives with dementia.

"If we could buddy her up, for example, with a couple of other people with similar interests then that sort of thing might work. But that doesn't exist." (Carer, Interview)

"I've asked if we can have a buddy-up system in the home because



Guide people to find and use assistive technology or digital services

Some respondents had struggled to find digital solutions to support their caring role. They felt more advice or guidance on what to choose, and where to source it, would be helpful.

66

“They have a project called the Cassius Project, which is supposedly about the use of technology to support people like me but they don’t know anything about what I want.

“They just say no, we’ve got no idea all they want to offer are things like fall alerts.”

Carer (Interview)

complete more forms to delay the payment or eat into more of Dad’s funds. I need to work out what I’m going to do for that. You need some kind of financial adviser or advice or more information about these kinds of things would be really helpful.” (Carer, Interview)

now there’s somebody that’s like, Mum I’d like to meet her daughter or her son, whoever it is so that perhaps we can take them out together.” (Carer, Interview)

“So, having learnt an awful lot from caring for my mum, I feel that I’m able to support my cousin because she’s had some struggles and challenges with her mum.” (Carer, Interview)

- More advice about paying for care and one to one financial support.

“There needs to be more information out there for applying for funding from the council. Its just not user-friendly and some understanding around invoices rather than just being sent them... I was led to believe that they were getting these carers in and that was being funded by the council and it wasn’t. I ended up having to pay, dad had to pay for that.” (Carer, Interview)

“We are given 12 weeks to sell Dad’s house. That’s not going to happen in 12 weeks. So, we’ll have to

Key learning for systems and leaders – Dementia Connect



Communicate about the service consistently

People need to be consistently referred to the dementia support service (Dementia Connect) at the earliest opportunity – at time of diagnosis, if not before.



Help people to know how to access support

People need to know that they can self-refer for help and support. Many people were unclear about how to access the service.



Be clear with people about the service offer

People need to be consistently informed about what the service provides, and that it is not only available to those with a diagnosis.

Key learning for systems and leaders – other support



Aim for services to be a guide

People want individualised support, that is proactive in contacting families and offers emotional and practical support.



Support people to find digital solutions that help

People want advice on technological solutions that can help them live independently with dementia.



Clarify and differentiate support for those with early onset dementia

There needs to be a different approach to providing support for people with Early onset dementia. The issues or challenges they face are very different to those for older people.

3.4 Support from GPs and other health professionals

People often commented about their experience of contact with health professionals, including their GP practice.

Annual reviews

The Alzheimer's Society website states that:

"Annual reviews are a key part of a person with dementia's care. In an annual review the GP will ask questions, do a medication review, check for new symptoms or changes in behaviour, and discuss planning ahead and support for carers."

Furthermore, the [NHS Quality and Outcome Framework \(QoF\)](#) requires GPs to report on 'the percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months'.

Despite this, only four of the people interviewed mentioned having had a post-diagnosis annual review with their GP. Of these, one felt positive about the experience, whilst the others were left feeling 'disappointed' at the lack of advice and support offered.

'It's a lovely, friendly consultation memory meeting.'

"We see the consultant every year to show him the MRI. The last MRI we showed was last year, but we have only just got the results reviewed a few weeks ago and he has asked for another MRI straight away. We've talked to people in the various groups we've been to and a lot of them get their diagnosis, and that's it. They don't get this back-up, you know?... Our consultant is a lovely fella.... It's a lovely, friendly consultation memory meeting." (A person with dementia, Interview)

'There's no advice on how to deal with anything.'

"On two occasions, we've gone into the practice.....where Mum was assessed that

was an annual review. To just see where she is. And other than that... I had a phone call assessment, I think this year... So yeah, just basically, how my mum was doing or had done the last year so. How we were and where we were now. Now it was just a conversation. For me, I think the first two I found interesting. This one, at the end of it, I was irritated by it, because what was the point? I felt the last few years I struggled with my mum and I thought what was the point of you ringing me just to ask me how I am because you're not really interested? There's no advice on how to deal with anything. They just basically want to know how my mum was, is she still taking the medication and there was a care package that they've sent me through my email." (Carer, Interview)

"So anyway we got an appointment at the doctors. And I went and we sat down and he said to [my husband], 'How are you?' and [my husband] said 'I'm tired' and then the GP looked at me and said 'is he getting worse?' I said 'yes his memory is getting really, you know, really bad and he said 'Oh, OK, then that's it then, right bye'. And that was it. That was a few months ago this year, so since he was diagnosed five years ago, this is the first time that [our GP had] spoken to us about his Alzheimer's." (Carer, Interview)

'Very disappointed.'

"I think they were once a year, but then I don't think they're anything much. I think my wife was all very disappointed in them, weren't she? I think that's just a nurse person who says, right, your blood pressure is OK. This is all right. How are you getting on? And that's it. See you next year." (A person with dementia, Interview)

Comments made by respondents, both in interviews and on the feedback forms, indicate that people had expectations of there

being some form of regular health review.

"If we just had a yearly call, at least now I know. If we could have that, it'd be something. [Interviewer: Does anybody do a yearly review of their medication or not from the doctor surgery, nothing like that?] No, nothing like that." (Carer, Interview)

"I cannot believe that with what is a terminal condition patients are not routinely offered a review with a doctor. I have finally booked one for Mum this month but not without a fight." (Carer Feedback form)

"I would expect the GP to regularly review my father's condition and behaviour but all contact has had to originate from my mother." (Carer Feedback form)

"We finally had contact from her GP surgery who carried out an annual dementia assessment a couple of months ago. Four years after diagnosis." (Carer Feedback form)

"She goes for an annual cardiovascular check each year but they blatantly ignore the fact that she has dementia." (Carer, Feedback form)

"Diagnosis was good, however, after that there has been an unbelievable lack of support. My mum has had no real input from and HCP since diagnosis." (Carer, Feedback form)

"I had thought in my naivety that there would be more care from outside for her. That somebody who knew what they were looking for would come and see her, or we'd have appointments to go somewhere. But I now realise that doesn't happen with dementia. It's more than two years ago [since we got the diagnosis] and she's not seen anybody about dementia since. I just thought that there would have been something. There's been nothing." (Carer, Interview)

“

"I cannot believe that with what is a terminal condition patients are not routinely offered a review with a doctor.

"I have finally booked one for Mum this month, but not without a fight."

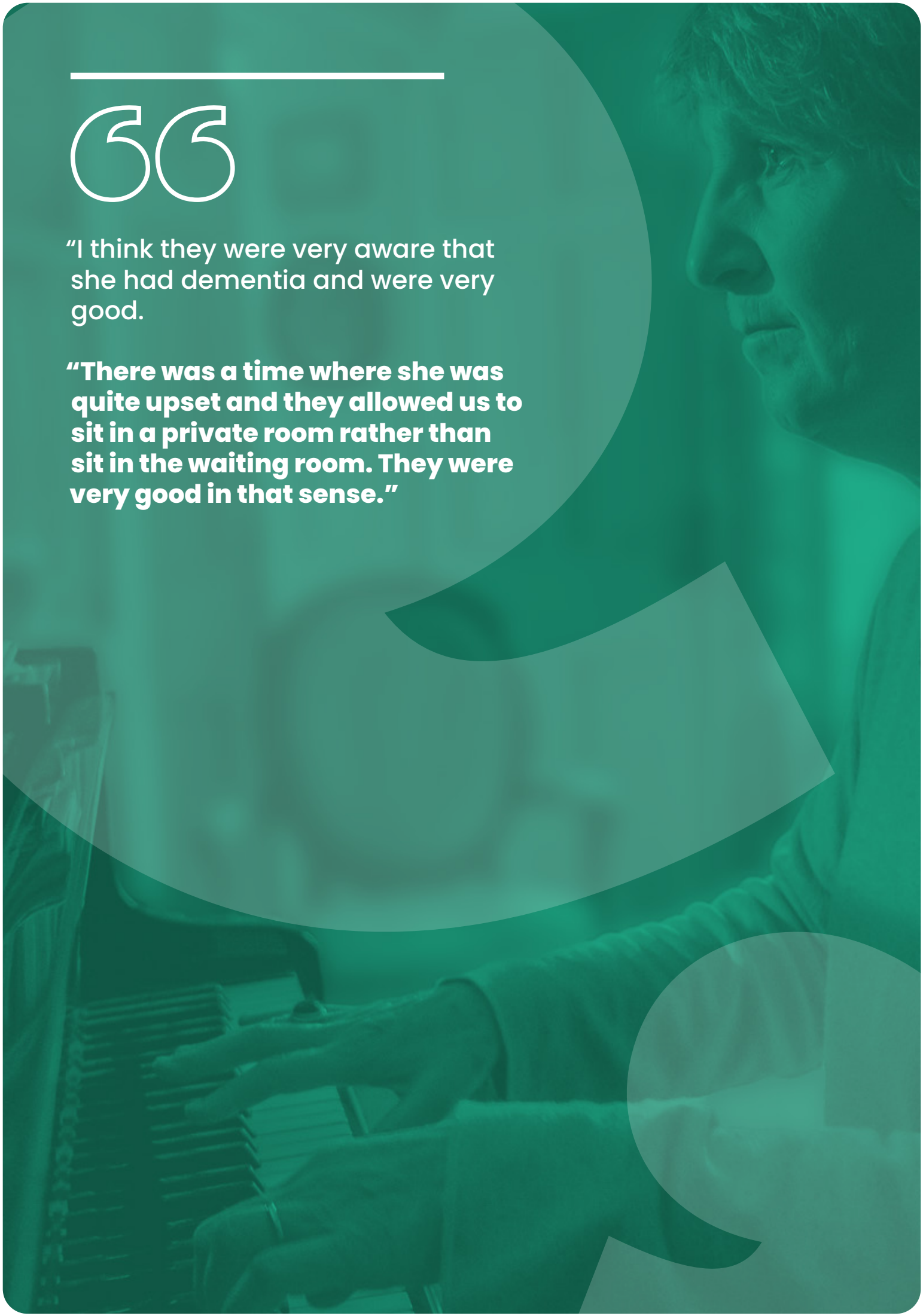
(Carer Feedback form)

”

“

“I think they were very aware that she had dementia and were very good.

“There was a time where she was quite upset and they allowed us to sit in a private room rather than sit in the waiting room. They were very good in that sense.”



Day-to-day support

The All-Party Parliamentary Group report from 2016 ('Dementia rarely travels alone: Living with Dementia and other conditions') suggested that almost seven in 10 people with dementia also have one or more other health conditions – conditions for which they require access to, and support from, GP services.

The reality however, is that dementia can often make everyday tasks like booking and attending GP appointments, as well as monitoring and managing conditions, more difficult.

Respondents were asked about the day-to-day support they received from GPs. Their responses highlight that people wanted GPs (practice staff and other health professionals) to show understanding, empathy and a willingness to make reasonable adjustments to accommodate their needs as a carer, as well as the needs of the person with dementia.

Respondents highlighted how even small adjustments could make a huge difference to their experience of accessing GP services.

Examples included:

'She gives us a double appointment.'

"We have a good GP. He books an appointment to see her instead of a 20-minute appointment. She gives her a double booking of 40 minutes and the receptionist knows that so they have to give you 40 minutes. It makes it harder to book it in a working day." (A person with dementia, Interview)

'She has a named GP.'

"She's kind, she's empathetic. And she has put on my sister's notes that if there is to be an appointment, it is with her. So, she has a named GP in the practice, which I know is really unusual." (Carer, Interview)

'We see a care co-ordinator regularly.'

"The care coordinator. We see on a monthly basis, which is a new thing that

started a couple of months ago. She can get us an appointment because she's got access to the list, so it saves that.... From our point of view, it's like we know we're seeing her in a few weeks' time so we're going to jot this down and you know ask this and that. And she is keen to get this group going which is lovely." (A person with dementia, Interview)

'My GP practice recognises me as a carer with authorisation to speak on my sister behalf.'

"My GP practice are great for that because it's on her records. Because my sister very early on when we first registered her wrote a letter giving me authorisation. But no, because she did that, that's really easy. It's on her record. So, I don't have an issue with that at all. It's great." (Carer, Interview)

'GP has included the person with dementia in discussions.'

"GP surgery have been excellent in responding to health concerns and including the person with dementia in discussions." (Carer, Feedback form)

In contrast, there were several examples where respondents felt their GP practice had shown a lack of consideration and empathy to their specific needs or situation. Several respondents mentioned the difficulty they had faced getting their GP to recognise their need for home visits.

'We've had to register Mum as housebound.. but now they think we'll be in at whatever time they call.'

"We've had to register Mum as housebound even though she can go out. We've had some appointments at the GP practice where Mum isn't ready, or she's just stuck and doesn't want to go out. Then the appointment is cancelled, and you have to wait five to six weeks again.... Now we've got the problem that because they've said she's registered as housebound, they take it that we'll be in at whatever time they call. That's not why she's housebound, they

know the reasons why she's housebound. They're making it difficult for us. They're just making the situation more difficult. Just support us." (Carer, Interview)

'No-one phoned to tell me the outcome of the home visit.'

"I said 'When my dad has home visits, as he has dementia, can you phone me up and tell me the outcome and no-one phoned. And this was on a Friday, so I had to wait until Monday to do an 'AskMyGP' and insist that someone called me to tell me what was happening with my dad. I've also emailed the GP to say that they can speak to the carers at the very sheltered complex, but they don't always speak to them. So, I've had the carers phone me to ask me what was going on, what the outcome of the home visit was.'" (Carer, Interview)

'My mum is not going to remember to turn up for an appointment.'

"The GP would come out after a push because it got to the point where I was like, 'Well, I can make an appointment for Mum to come to you, but she's not going to turn up she won't remember', and she wouldn't want me to go with her. So we got the GP to come out." (Carer, Interview)

'It's not about us being difficult'

"To get a home visit... it's not about us being difficult. I mean my mum can't walk any distance now, she's very fragile. But also getting her up and dressed, especially when she's having a muddled day." (Carer, Interview)

Other areas where respondent felt that GPs and other health services had not been responsive to their needs included the following.

'There's no continuity [of care] whatsoever.'

"While she's in [the care home], you see she's registered with a different GP surgery. The GPs at [her usual practice] didn't

really know her that well anyway. I must have seen about six GPs over the period. There's no continuity whatsoever." (Carer, Interview)

"I don't think they've really had consistent GP service." (Carer, Interview)

'The psychiatrist used formal, medical and complicated language.'

"The psychiatrist who carried out a home assessment of my relative's condition used formal, medical and complicated language during the consultation which my relative simply did not understand, such that they simply gave up trying to respond." (Carer, Feedback form)

"[At Mum's annual cardiovascular review], the questions asked are clearly being read from a script and ignore her diagnosis. E.g., 'How is your memory these days?', to which she replies 'Not too bad, we all get forgetful don't we?'" (Carer, Feedback form)

'She's still a person that needs respect.'

"When I've spoken with the GP about Mum, she says, well, your mum's very difficult because she's a complicated lady. It's not her that's complicated, it's the illnesses that are complicated. She's still a person that needs respect and needs the help if things aren't going well. So, we haven't found them helpful." (Carer, Interview)

'Unless there's something serious, they don't want to know.'

"I can't get into the GP unless there's something serious. Like I've had to cope with all aspects of her care. Like for medication to whatever handling unless there's an emergency I can't get through and so you know what you were saying about how to cope with her changing behavior. That seems like a luxury from the past, that somebody would ask me. Now it's a case of is she having a heart attack, then we want to know, otherwise we don't." (Carer, Interview)

“Listen to the carers because they know that person...”

Watch Julia talk about her experiences of support from health professionals...

[Click to play](#)

‘What is it that you need to know that we can't tell you over the phone?’

“[Talking to continence service] ‘You're asking me to diagnose stuff when I haven't seen her.’ And I went, ‘I'm quite happy to bring her in. She'll get me to answer all the questions, but I'm quite happy to bring her in. But what is it that you need to know that we can't tell you over the phone?’ She wants to know the history. ‘I need to know how long it's been going on for. I need to know how frequent it is’. I went, ‘Well, she's not going to be able to tell you any of that.’ And she said, ‘Why not?’ I went, ‘Because she hasn't got a memory’.” (Carer, Interview)

GPs' connection to the rest of the health and care system as well as their base in the community, also makes them well placed to take a leading role in care planning and care co-ordination for people with dementia (APPG report).

Given the lack of support people felt they received at diagnosis, it is not surprising to find several respondents had turned to their GP for help and advice on non-medical issues.



“...in the end, I took my own whiteboard marker and filled it in, so that they knew... because it sounds simple, but some of those things (people's preferences in hospital) are so vital.”

[Click here to watch more in our video with Julia.](#)

66

“One of the things I find is my GP surgery, when you ring them, it’s not because there’s this desire to make contact with your GP, it’s because you’re stuck and you’ve exhausted all your other options and I know and you genuinely need advice to go further with that whatever problems you are having. When you ring them, and when you don’t get anywhere, it gets a bit frustrating.”

Carer (Interview)

Comments from respondents, however, highlight how difficult they found it to ask for help, that approaching their GP was often done as a ‘last resort’ action and how disheartened they felt when requests for support went unanswered or were responded to with a lack of kindness or empathy.

‘My role is really to prescribe medicines.... I have little information to help you.’

“He said sadly.... because I asked for advice about care in the local community and things like that...he said, ‘Sadly my role is really to prescribe medicines these days, I have little information to help you.’”
(Carer, Interview)

‘You’ve done everything possible not to contact them’

“The problem is that when you want them, they don’t understand that you know you’ve done everything possible not to be in the surgery or not to contact them that you want some kindness and compassion and understanding and you don’t get any of that.” **(Carer, Interview)**

‘Going through the door is the hardest’

“When you reach out...at that moment... whatever you reach out for, whether it be

GP or whoever..... it’s just going through the door is the hardest.” **(Carer, Interview)**

‘Just be nice and respectful’

“When someone phones up and you know that they’re a carer, it comes up on their screen that they’re a registered carer, just to be nice and respectful and not to give you a hard time because you’re phoning up and asking to speak to a GP.” **(Carer, Interview)**

Key learning for systems and leaders – Support from healthcare professionals



Make sure people receive an annual review

People need to be able to access their annual review after a diagnosis of dementia.



Compassion and empathic responses are important

People need, and should expect, compassionate responses from their health and care professionals.



Make reasonable adjustments

People want health professionals to make reasonable adjustments to accommodate the needs of the person with dementia and their family carers.



Help people to access support

People need GPs, practice staff and other professionals to help them to access other support by proactively referring, as appropriate.

3.5 Social care support

Dementia is a progressive condition. As symptoms increase over time, people become more dependent on others for assistance in managing daily life and everyday tasks. In this section, we explore people's experiences when they have needed to rely on social care support to live at home, or within other community settings (such as residential care and nursing homes).

As a person's condition begins to deteriorate, family carers often take on the responsibility of supporting their loved ones to live independently, but this is not always possible (particularly for long-distance carers) or sustainable over time.

Support, in the form of either homecare or a care home placement, is an option when things become too difficult, however, respondents were not always clear about how to access social care support or what they would be eligible for.

'Mum needs supervision, not physical care, so we won't qualify for support.'

"That's one of the reasons why I've not gone to them, because for me, I need help but not with Mum's physical care. If that makes sense. My mum is more supervision than [the physical] side. So I'm not going to, like knowing what their criteria's are, I'm

not going to qualify because if there's any help to be given it's for me. It's not for Mum and so I can't see me qualifying." (Carer, Interview)

'It was a case of googling care services locally.'

"No, it was a case of googling care services locally." (Carer, Interview)

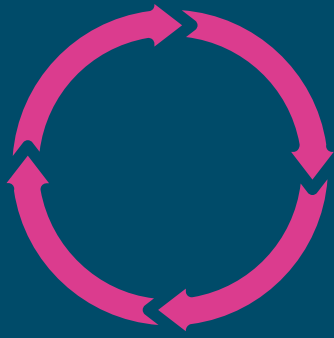
"I went online and just put in care companies in Ipswich or carers in Ipswich. I phoned a few others, but they were the ones that came out." (Carer, Interview)

Those who were financially secure felt they were particularly disadvantaged when it came to support with finding care, often feeling like they were left to just get on with it by themselves.

“

“[The Doctor said] maybe he does need some help. So, then I went online and got in touch with [a homecare company] to get carers in to cook for him because he wasn't cooking any meals. He wasn't getting himself any drink or food. So, I had to then go on a waiting list for carers and we had to wait a month. My dad obviously lived in his own house and had some savings, it was kinda like left to me to sort....”

Carer (Interview)



Continuity of care is crucial

People who had experience of accessing homecare support stressed the importance of continuity of care staff.

People reported mixed experiences of homecare. Some had very positive experiences, whilst others lost trust in the staff supporting their loved ones. In those cases, it was clear that the loss of trust had negatively impacted their personal wellbeing.

'You've got funding yourself, you just need to get care.'

"We are self-funders as Mum owns her own home. And that also I think was a huge block with getting support about what we needed to do because it seemed to be.... 'Oh you're self-funded. Well, you've got funding yourself, you just need to get care'. What type of care? What's she going to do next?" (Carer, Interview)

'We didn't really get any help from them.'

"Social services... well no... she's not high enough and you're personal funders or private funders.... So we didn't really get any help from them." (Carer, Interview)

"Social services weren't involved because we found we couldn't get any help from them.... we weren't given information. I think because Mum and Dad's financial earnings or what they've accrued over the years goes above the limit of what social services will provide." (Carer, Interview)

Homecare

Thirteen of the people interviewed shared their experience of using homecare. Ten had been long-term recipients of home care, and three had received a package of support on discharge from hospital.

Building and maintaining trust with home care staff was a key theme that emerged out of the feedback from those who received long-term homecare support. For those who had a positive experience, continuity of care was crucial in establishing trusted relationships between carer, cared for and their families.

'It's always the same carers.'

"Mum has two carers, one covers if the other one available isn't available. They're both trained in caring for people with dementia. So, it's always the same one or the other. Mum likes them both....If they can't come for whatever reason, we always get a phone call to say, 'Would you still like it today but it won't be whoever'. They've been really good. The manager's come out every couple of months to make sure that the care Mum's receiving is still what we're looking for, and if there's extra needs that

they need to help with, as well. So, we're quite happy." (Carer, Interview)

"Eventually, we settled on one care agency and she had two main carers, well one main carer and then other was a bit of a standby when that carer was on holiday or whatever. My mum developed a brilliant relationship with her carer and was able to trust her and was comfortable with her. She was able to allow her to do those private, personal things." (Carer, Interview)

Issues relating to care quality could quickly affect the relationship families had with home carers, resulting in a loss of trust.

'I started to lose trust.'

"I just said to them, keep the fridge, make sure things are in date and get rid of anything else. But apparently she used to go back down the bin and get stuff out that she'd seen them throw out and put it back in the fridge. So THEY said. I was like I'm not sure I believe that they actually did the fridge part because I'd go in there and empty the fridge out and talk to her about it and say, this is the date on here, this is the date today.... so I don't know if they did it. I started to lose trust, I think." (Carer, Interview)



"We had a couple of worrying incidents with carers that proved that they breached the trust that you know, you'd put in them.... and it just made us realise how vulnerable she was."

Carer (Interview)

In situations where trust had been broken, some families had resorted to using digital technology to monitor carers. One respondent highlighted how, feeling that she needed to continually 'watch' the carers in this way, had impacted on her own emotional wellbeing.

'I had a camera.... but bit by bit it took over my life completely.'

"I had a camera in [Mum's house] but bit by bit it took over my life completely, and that's not healthy. That is not healthy for me, and not really in Mum's best interest because you start to lose the relationship being a mother and daughter. The impact of watching those things on the camera, it was very negative for me. It's good to have the cameras because then it means the local authorities don't have to pay any more money but then who makes allowances for the impact of the person that's watching the cameras. I have had to have some counselling just to talk it all through, to be honest." (Carer, Interview)

"We've got cameras in the house. The cameras were there before the carers. My sister, she'd be doing the looking. She sent me a text one day and said, 'You do know that the carer only stays about four minutes, don't you?'. Like what? I then got it on my phone and it's like 'Oh my God, yes'. They rush in and rush out, and we couldn't figure out what on earth they were doing.



“The social worker always said to me, ‘Keep quiet, don’t make a fuss.’ Because I would complain to her about things that weren’t happening. She said, ‘Please don’t make a fuss.’ And that’s always been, don’t make a fuss, they’ll tell you to find someone else, and there isn’t anyone else....”

Carer (Interview)

We then decided to get to the camera in the living room, and we could see that all they did was empty his catheter bag and go. It was then, it's like, ‘Right, I have to look at the cameras a bit more often’. Now I do that in the afternoons. My sister mostly does the evening one. I get stressed doing the afternoon one.” (Carer, Interview)

When families had concerns about the quality of care being provided to their relative they either did not know what to do, or they were too worried about losing the care, to complain. One carer said that she had been advised by her social worker not to ‘make a fuss’.

‘Keep quiet, don’t make a fuss.’

“The social worker always said to me, ‘Keep quiet, don’t make a fuss.’ Because I would complain to her about things that weren’t happening. She said, ‘Please don’t make a fuss.’ And that’s always been, don’t make a fuss, they’ll tell you to find someone else, and there isn’t anyone else.... We don’t have [that social worker] now, we’re taken off the books because I guess we’re okay.... [Interviewer: If there was a problem now with the care agency and you were really unhappy with what they were doing, would you know what to do?] No. I’d just keep quiet and have a lot of stress and scream to myself.” (Carer, Interview)

In three instances, homecare had been provided to patients on discharge from hospital. However, families found that the inconveniences (and cost) outweighed the

benefits of the service and they had therefore chosen to cancel the support. Those who received long-term homecare packages also reported having similar difficulties with the service.

‘The carers chop and change constantly.’

“The carers chop and change constantly. There are times when we’ve had 14 carers in a week.” (Carer, Interview)

“We did go through two care agencies because what was really important for my mum was consistency and being able to build up that relationship, and some care agencies you’ll have a different person every time and that made my mum more confused. My mum was quite a private lady, so to have someone washing her or anything like that wasn’t easy and so, she needed to be able to build up a relationship.” (Carer, Interview)

“... there are times when we’ve had 14 carers in a week..”



'Don't really fit the hours that the carers come.'

"Every time she's come out of hospital, we've had carers. It's been very difficult because they come in to get her dressed at 10 o'clock in the morning but she's been up since 6[AM]. So, she's already dressed. The one who helps her go to bed, she's been in bed for three hours by that time. It's been difficult. It's mostly because Mother-in-Law's hours don't really fit the hours that the carers come. They've always been very

nice, but they've not really been a lot of help with anything." (Carer, Interview)

"They came in at night when he was asleep in bed and all I did was sign the book." (Carer, Interview)

“

“When she was discharged from hospital last time, she had care put in, but they kept sending male carers for my mum. My mum's of a generation, she doesn't want men looking after her, and that was very difficult. I mean, we kept saying, but they just kept turning up. In the end, my dad just said, 'I can't... Just no.'”

“She doesn't want male carers, because she still has dignity.”

(Carer, Interview)

”



“

“I had a camera in [Mum’s house] but bit by bit it took over my life completely, and that’s not healthy.

“That is not healthy for me, and not really in Mum’s best interest because you start to lose the relationship being a mother and daughter. The impact of watching those things on the camera, it was very negative for me...”

Residential care and nursing homes

Five of the people interviewed had relatives who were residents in care homes. In two instances, the person with dementia had moved from one home to another, meaning a total of seven experiences were shared with us.

Three respondents were generally positive, two were negative and two were 'mixed' in sentiment. Two carers had raised safeguarding concerns. Issues raised in conversations about care homes included that:

- families sometimes felt pressured to find and accept a home quickly
- families found the transition of moving their relative into a care home difficult to manage
- people with dementia found it hard to adjust to living in a care home

'It took two or three weeks to find a home.'

"They wanted to discharge her after a week, but we said 'Well, she can't go home. We need to put something in place'. My

mum's flat was just a one bedroom so having overnight carers was not going to be possible, so me and my brother had the process of finding somewhere. They kept her in hospital until we were able to find a care home that we liked and we thought would be appropriate for Mum and then they had to visit and assess Mum. It was probably two or three weeks before she was eventually discharged." (Carer, Interview)

'I didn't want her to know what was going on.'

"The actual process of moving my wife into care was quite difficult. I didn't want my wife to learn what was going on.....My son went down and prepared the room (in the care home). And then I said, that I was going out to get the car cleaned while she went for a drive with our son. And he did take her for a drive, but it was down to the care home. He walked in without any fuss at all. I mean they were obviously prepared to meet and greet her and everything and move her to her room. And my son stayed with her for a couple of hours. But we did it without any emotion. We had to treat it as a routine process. But when he came back afterwards, we were in floods of tears as you can imagine." (Carer, Interview)

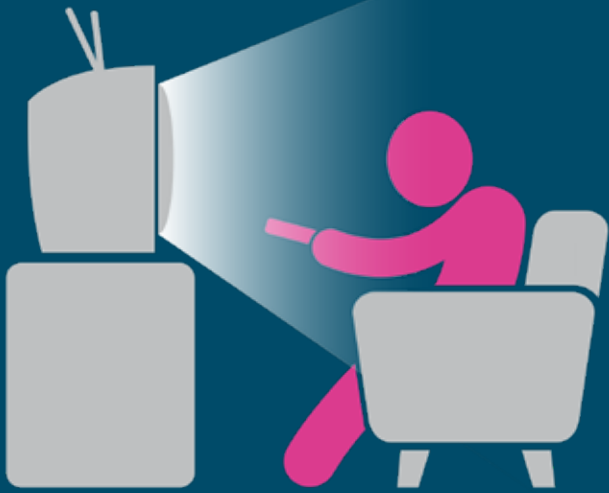
'She couldn't remember how she got there.'

"We told her we were going to afternoon tea and that's how we got her in. And we had all her bags in the back and we had it all packed. They said to her 'Would you like to stay here overnight?' And first of all, she was 'Oh, yeah, I'll stay overnight'. She thought it was a hotel. The manager said for us not to go back and say good bye because she wouldn't understand. And we agreed with that. And then they suggested that we didn't go in to visit her for at least eight to 10 days to give her a chance to get over that. But she was so angry and difficult to manage, which really wasn't like her. I went back in after five days... She said she couldn't remember how she got there and she was really angry." (Carer, Interview)

66

"There was pressure on me to accept the [care home placement] when the out-of-county local authority had said 'Yes, this is all right' based on the cost and the fact they had a good rating. They didn't mind if it was an hour away from me."

Carer (Interview)



“She’d just be watching telly all day, sitting in her chair.”

Stimulating and engaging activities were seen as important for people’s wellbeing, but this was missing from the experience of some people with dementia living within local residential care or nursing homes.

‘Need advice on moving loved one into a care home.’

“There’s a need to have advice for carers after the process of moving their loved one into a care home. That was lacking as well.”
(Carer, Interview)

‘Mum found it really hard to cope.’

“It was a lovely home and they were lovely there but it just wasn’t Mum’s surrounding and she found it really hard to cope with the other residents. There were other residents that were quite loud and vocal, but mum lived quite a quiet peaceful life in her little flat playing the piano and she just never really recovered.” **(Carer, Interview)**

Quality of care in homes varied, and some respondents referred to some areas of particular concern.

Support with food and drink

“One of the main criteria was that she was forgetting to eat and drink at home. She needed the prompting, the reminding, and a degree of supervision. She didn’t need someone to feed her, but just five minutes of their time to be in the room to make sure that the two rounds of sandwiches were eaten and wasn’t just in the bin, because she used to wrap up little things and hide them.” **(Carer, Interview)**

Lack of stimulation

“She was not engaging, she didn’t come out of her room, she’d just given up and their attitude was, ‘Oh, well, she doesn’t want to come out of her room we’ll leave her in there’. And that’s not in someone with dementia’s best interest....Just because they don’t want to come out, there are ways. You take the mountain to Mohammed, don’t you? You go in to them, you chat with them.” **(Carer, Interview)**

Communication

“I would go in and I would read the daily note and it would say, drank 200ml and ate a sandwich and I’d go in and it was still sitting there from 9:00. And they weren’t monitoring accurately. They weren’t testing output because then they’d say she hadn’t been [to the toilet], and then they’d give her some medication to make her go, and then she’d go too much and they weren’t recording that. So the communication was really poor.” **(Carer, Interview)**

“[The psychiatrist] prescribed her some medication to calm her down. It basically took all her personality away, there was nothing to her. I went back and saw the manager and I complained about it and the information didn’t get through to the staff nurse working that night, who then gave her another one that night and

another tablet in the morning. So she was even further out of it when I went back in.”
(Carer, Interview)

Sometimes, families had felt powerless, or lacked confidence, to raise issues when they had concerns about the quality of care provided to their relative.

‘I had no power to do anything.’

“I just was uneasy for some time but I couldn’t.... I had no power to do anything.”
(Carer, Interview)

‘The DIST nurse added her weight to what I was saying.’

“I felt invisible half of the time because it was almost as if ‘Your mum’s in [the care home] now, you don’t have to worry’. Whereas actually I felt I had to worry more..... You need to be very thick skinned because when they’re saying ‘No, no, no, that’s all right’, you need to be able to say, ‘But I know my mum and this is not right’. If the DIST nurse hadn’t added her weight to what I’d been saying, I think my mum would still.... honestly, I don’t think she would have survived much longer.” **(Carer, Interview)**

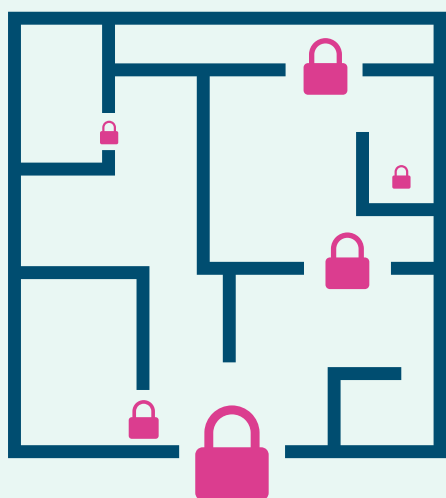
‘I was trying to preserve the relationship with the home.’

“I think I was still trying to preserve the relationship [with the care home] whereas my daughter was much more black and white and said ‘This is not acceptable’ and took the next steps. And so sometimes because you’re so emotionally involved, you can’t always advocate in a black or white way because you think of the impact to your mum, the disruption, whereas actually staying somewhere that they’re not giving her the care she needs is a worse impact overall, but you don’t always see objectively when you’re so emotionally in it.” **(Carer, Interview)**

Three respondents had positive experiences of care provided by care homes. Two reported seeing a significant improvement in their relative, who were now settled, actively engaging in activities and making friends.

‘She’s now full of confidence.’

“She’s participating in activities and I’ve got this mother now full of confidence and able to join in. She’s got a lot of empathy now, you know, she’s always saying ‘dear would you like me to get you a drink?’ and things like that to other people. So that bit has really improved and now there’s another lady that just gone in that she’s made friends.” **(Carer, Interview)**



Confinement

“She was completely locked up with no access to outside and she could only get through the doors to the living area or back to her room if they allowed her, everything was keypad...”

“[It was like a] part time prison, it was horrible, I hated it.”

(Carer, Interview)



66

"She's participating in activities and I've got this mother now full of confidence and able to join in. She's got a lot of empathy now, you know, she's always saying 'Dear, would you like me to get you a drink?' and things like that to other people.

"So that bit has really improved and now there's another lady that just gone in that she's made friends."

66

“She is a different person, she’s happy, she’s settled, she’s cared for and blessed. There is still things that are not perfect but just the level of care and it’s like they really treat her like they want her there and she’s cherished.

“When I go and see her now, she’s had an active part in having a wash. She’s had an active part in choosing her outfit. She’s had an active part in walking down to the cafeteria to go to breakfast, to get her food so she can do it when it’s put to her in the right way and when she feels wanted to be part of it and, you know, the whole package, she’s willing and able to do and happy to do it, which I never thought I’d see.”

(Carer, Interview)

99

‘I am spending more quality time with my mum.’

“I am spending more quality time with my mum too. I pick her up on a Sunday and I take her swimming and then we come back here and have a Sunday roast and then I take her back. So we spend the day, but it’s doing something different for her, something normal because she loved swimming. We have lots of good stuff. More good stuff than bad stuff, isn’t it?” (Carer, Interview)

Key learning for systems and leaders – Support from social care



Help people to know how social care can help

People need more information about how social care can help them, what support they might be eligible for and how to access social care – they need this information earlier.



People who can fund care still need help to find social care support

Self funders need as much support in finding social care support as those who are funded through the local authority.



Trust and continuity really matters

Homecare providers need to work with families to build trusted relationships. Continuity of care is crucial to the success of homecare for people with dementia.



Make sure people know how to raise concerns

People need to understand what they can do if they have concerns about the care being provided to their relative (either homecare or care home). Providers must make this information clear, and be prepared to engage with people if they have a concern.



Help people with the transition to care

There needs to be more support for people with dementia and their families to manage the transition into care homes.



Make sure staff are trained to care for people with dementia

Care quality issues could be addressed by ensuring that homecare and care home staff are adequately trained in understanding the needs of people with dementia and most importantly in how to communicate.

3.6 Long-distance caring and cross boundary issues

Four of the people interviewed had been, or were, caring for a relative who lived in a different county. Long-distance caring presents some specific challenges and issues, and these are described by our participants below.

The additional physical and emotional impact it has on carers from 'being so remote.'

"She would come back from London exhausted. I would make sure the house was clean and have a nice dinner on a Sunday, but it was almost like she wasn't here. She was so tired and exhausted."
(Carer, Interview)

"We had a couple of worrying incidents with homecarers....The suggestions were obviously that IT could help. You have the Ring camera, you have the security camera inside. But with all those there is a degree of time delay, because by the time you see what's actually happened, you can't affect the outcome because your remote. especially as we were in Suffolk and Mum was in London."
(Carer, Interview)

Carers are not always clear 'where to go for information or support.'

"So I live in Norfolk and she lives in Suffolk and yeah, and that's our biggest problem, not only in terms of time and getting to her, but also I don't know where to go for

information in Suffolk." (Carer, Interview)

"I think that was the problem with the carers assessment, was did I have one in Norfolk or did I have one in Suffolk." (Carer, Interview)

'Different rules and policies' apply in different areas.'

"Later with Dad, I was trying to get the dementia intensive care team to come out, but... in Ipswich you have to get a GP referral but, in the West, the family can ask for the referral so in different parts of the county. Different rules and policies, but all under one trust."
(Carer, Interview)

"I don't know whether it's different... I mean here, I know what to do, but in Suffolk I don't know if it's different." (Carer, Interview)

There often comes a point where carers are unable to continue to support their relative 'at distance' and a decision is made to move them 'in-county'. However, families did not feel well supported, or that services worked together seamlessly, to help smooth that transition.

66

"I had some misgivings [about the care home] so I tried to get hold of the London social worker and she was just overloaded. And in her mind 'I've done what you ask, you know, your mum is in Suffolk, you do it'."

Carer (Interview)

'It was disjointed....there was no real interface.'

"The MH nurse in London sent all the details and made a referral to Suffolk and Suffolk didn't pick it up initially. It came in later."
(Carer, Interview)

"The out-of-county local authority went... So, what should have been a six-week review was extended out to nearly three months. And then, I think she only came because Mum had been in hospital and she was covering herself to make sure that she was seen to have done what she needed to, which of course she hadn't. And because it was a different authority to the authority that the home is responsible to, it was extra disjointed because one side are only taking care of their part and the other, there was no real interface as such." (Carer, Interview)

Sometimes the move across a boundary was minimal in geographical terms, but massive in administrative and bureaucratic terms. One respondent shared her experience of moving her father into supported housing – a move of less than six miles – but which has

meant having to change his whole network of support.

'It's all fragmented.'

"This was one of the big problems because it's all fragmented. Dad lived like five minutes down the road. You'd think we were trying to move him the other side of the country, how hard it was. That caused me a lot of problems and he will have to change teams and caregivers with the DIST and social services. I did have to email the previous social worker though, and she did actually reply to me. That was really helpful, but in [the new area] he hasn't been allocated a new social worker yet.... I've also had to move his GP." (Carer, Interview)

Key learning for systems and leaders – Long-distance support



Improve support for long-distance carers

There needs to be better identification of and support for people who are long distance carers.



Improve coordination of care when people move between areas

There needs to be more co-ordinated support for families who are moving their relative into Suffolk. Improved information what people should expect could help people to know how to find care and support if they need it.

3.7 Dementia care in hospitals

In this section, find out what people told us about their experiences of dementia care if they, or the person they were caring for, needed to visit a hospital.

The [2019 National Audit of Dementia: Care in General Hospitals](#) estimated that, at any one time, one in four hospital beds are occupied by people living with dementia. Moreover, they concluded that people with dementia often experience longer hospital stays, delays in leaving hospital and reduced independent living as a consequence.

Ten of the people interviewed provided feedback about hospital care, some respondents shared more than one experience.

- Five spoke about their experience in A&E
- Four had been admitted to a general ward within an acute hospital
- Three people had experience of in-patient stays on a specialist dementia ward
- Two people did not specify what type of ward their relative had visited
- One respondent talked about her experience when her mother was admitted to a specialist mental health hospital

What did not work well?

Regardless of the type of hospital or ward, some common themes emerged from the

feedback, and these are illustrated by the following quotes from our respondents.

Hospitals are a difficult environment for people with dementia to be in

'It was just the whole confusion of hospital'

"She went into hospital and obviously the environment just wasn't, she didn't understand where she was, what was happening, and she started to deteriorate very quickly. She just deteriorated so quickly, and it was just the whole confusion of hospital and she stopped eating and deteriorated very quickly." (Carer, Interview)

'They just weren't geared up.'

"Previously, she's been on the main ward and her dementia behavior has been... I don't mean challenging as in bad behavior. It's just been difficult. My mum would go up and wander around thinking she was at home or something like that and I mean they just weren't geared up for it." (Carer, Interview)



"I found the lack of knowledge of dementia from the doctors and nurses, I was amazed..."

It was common for people to feel that staff in hospitals lacked knowledge or training related to care for dementia patients. At times this had added to people's stress at difficult times, and put people at risk.

“I went with my granddaughter to pick him up and I said ‘Well, I gotta go in and get him in the wheelchair’. She said ‘Grandma, there he is sitting outside in a wheelchair’. So I was not happy. I was so cross I actually wrote to PALS... He could have walked into the road, you know, he could have done anything...”



‘She was on a trolley in the corridor in A&E for ages.’

“He was on a trolley in the corridor in A&E for ages, not knowing what was going on and very confused, and disorientated. It just took forever, all night we were in A&E, and she had X-rays and eventually was admitted.” (Carer, Interview)

Staff do not always have the time, skills or knowledge to deal with the specific issues of patients with dementia

‘There weren't enough staff and there wasn't enough time.’

“I think that generally we found that everybody we spoke to was very helpful and very kind, but there weren't enough of them and there wasn't enough time.” (Carer, Interview)

‘Tell her to use her phone.’

“[At the start of COVID, Mum went into hospital] we'd try and make contact, but it was absolutely impossible. We're just told if someone did want to speak, they'd say, ‘Tell her to use her phone.’ What? Dementia? Use her phone. She wouldn't have a clue on how to use her phone.” (Carer, Interview)

‘He could have walked into the road.’

“The only time I got really cross - he had a very bad hypo. Took him to the hospital, yeah. And then in the evening I had a

phone call saying ‘Can you come and pick him up?’. So I said ‘OK, yeah, of course I will’. They said ‘He's in casualty.’ I said fine, I'll come and fetch him. I went with my granddaughter to pick him up and I said ‘Well, I gotta go in and get him in the wheelchair’. She said ‘Grandma, there he is sitting outside in a wheelchair’. So I was not happy. I was so cross I actually wrote to PALS. And then I had a Sister ring up from casualty and I said ‘I'm sorry, I don't like complaining because you're very good and I know you have a lot of, you know, plates and you know but that is not on. You can't leave someone... he could have walked into the road, you know, he could have done anything. I was absolutely worried to death that... don't you think that your staff and the doctors need, even if they're not trained about dementia, to have a bit more information, a bit more training’. She said ‘I think you are right’.” (Carer, Interview)

‘I found the lack of knowledge of dementia from the doctors and nurses amazing.’

“I found the lack of knowledge of dementia from the doctors and nurses, I was amazed really because they must do it as part of their training. (Carer, Interview)

Discharge planning often felt disorganised and rushed. Families did not always feel fully engaged in the process

'Before I knew where I was they had done an assessment and she was placed in 24/7 care.'

"I said, I want a full package before she comes out because I just can't carry on doing it. It really opened my eyes to if I wasn't available, how like it's like a house of cards, it all fell down. And so I asked for a package and before I knew where I was... they'd done one and she was in 24-hour care in London." (Carer, Interview)

'All that they said was going to happen, didn't happen.'

"The doctor's sort of promise you the world and say 'We'll take care of her and make sure she mobilises gradually, then she can go to convalescent in Felixstowe. After a week, they wanted to discharge her and so all that they said was going to happen, didn't happen. They wanted to discharge her, she could barely walk and so, my brother and I said, 'Well she can't go home. There's no way she can go home'." (Carer, Interview)

'They couldn't get the care package sorted.'

"He got a UTI, and it all went wrong. He ended up in hospital for four weeks, Because, what was happening, they couldn't get the care package sorted. Social worker hadn't done this. Someone else hadn't done that. The physio hadn't been. We'll try next week. Oh, it was a nightmare. Talk about bed blocking." (Carer, Interview)

Families did not always feel they were listened to, or that their knowledge of the person with dementia was recognised

'As her carer, her main carer and her daughter I know her so well.'

"Another time, she wasn't eating, and I think a lot of that was because she was on really strong painkillers, she was on morphine. I think the hospital needs to learn that as her carer, her main carer and her daughter I know her so well, all those little nuances, so I knew that the medication was making her feel sick. I could just tell that's what it was and I kept saying, could she have an anti-sickness tablet? Because I knew you could have that and they'd give it to her one day and then not the next, there was no consistency." (Carer, Interview)

'They were determined I didn't need to be there but then they realised that I did.'

"I had to fight my case to stay with my mum. Basically, they said I can't stay. I said, 'Well, how are you going to communicate with her?'. They said 'Oh, I'm sorry, it is hospital policy'. When they took my mum in, obviously, they were telling my mum, but she couldn't understand could she. So, she was sitting there, and then wanting her to transfer from chair to the couch and then obviously, they could see that my Mum wasn't understanding. So, she was trying to do as they say, but there was an issue, and then they said 'OK, I could stay'. So, I stayed with my mum for that consultation, and a really lovely young junior doctor came in and did the test and she was really, really nice but the nurses were very determined that I don't need to be there. But then, after trying to communicate with my Mum, they realised that I did." (Carer, Interview)

'I could see Mum had delirium, but the ward thought this was usual for her.'

"When Mum had knee surgery visiting was not allowed because of COVID. I arranged the video calls, which was helpful. I could see she had delirium, but the ward seemed to think this was usual for her. I had to talk to the ward sister and doctor to explain how different she was." (Carer, Feedback form)

“

“The doctors sort of promise you the world and say ‘We’ll take care of her and make sure she mobilises gradually, then she can go to convalescent in Felixstowe’. After a week, they wanted to discharge her and so, all that they said was going to happen, didn’t happen.

“They wanted to discharge her, she could barely walk and so, my brother and I said, ‘Well she can’t go home. There’s no way she can go home’.”

Other aspects that were highlighted as not working well

Three respondents reported there had been a lack of support for their relative to maintain or regain mobility. In two cases this had resulted in falls that required re-admission.

'They had to permanently sit.'

"When he did come out, he couldn't do a thing. He couldn't do anything whatsoever. He went in walking, eating himself, everything, and he couldn't do anything... First, we thought it was marvellous, because they had two nurses, young nurses at the doorway. They were a bit like 'God, I suppose'. We were like, 'This will be fabulous, he's totally looked after'. And then slowly but surely, we realised he was going downhill, and he was starting to talk about the guards and the prison. And then we realized none of them in the ward were allowed to stand up. They had to permanently sit, and that's why they were standing there. 'Sit down, sit down'. My Dad is like, "I need to stand." "Sit down." And so, his mind deteriorated rapidly. He really, really thought he was in prison. What we thought was marvellous, was anything but really." (Carer, Interview)

'They just wheelchaired her everywhere.'

"By this time we established that her mobility since that admission, I don't know what they've done but they hadn't been doing, potentially, what they said. She was walking independent with a frame with supervision and she was weak, fatigued, and her legs weren't doing as well as they could have done. So we weren't very happy. Because, for ease, from what I can gather they just wheelchaired her everywhere. Convenience. It's all we witnessed." (Carer, Interview)

One respondent commented that tools to help communicate patients' needs (e.g. whiteboards above patients beds) were not being actively used by ward staff.



"...in the end, I took my own whiteboard marker and filled it in, so that they knew... because it sounds simple, but some of those things (people's preferences in hospital) are so vital."

[Click here to watch more in our video with Julia.](#)

'They've got these systems in place, but they don't use them.'

"In the hospital, even on the dementia ward, one of the things I found was they've got these systems in place, but they don't use them. So, behind the bed they have a whiteboard and it's got a little thing where you can tick to say somebody has got dementia and it was never ticked. Another thing, my mum was struggling to eat and drink, and she takes tea with one sugar. If you give her a cup of tea without sugar, she wouldn't drink it. So, I kept writing it on this board and then it would get wiped off... It's those fundamental things that are going to make a huge difference and aren't being noted or cared for." (Carer, Interview)

Hospital staff were not always aware when someone had dementia

'They just thought she was an older person.'

"I got a phone call about 9:00[AM] to say that she was in hospital A&E and she'd cut her head. But they didn't recognise she had dementia, they just thought she was an older person they couldn't see it, you know. [Interviewer: It wasn't on her record?] It doesn't seem to move from place to place." (Carer, Interview)

'I had to tell them my wife had dementia.'

"I think, you know, I was there to explain the situation which helped. I think they had the knowledge to deal with it. But I had to tell them you know... that [my wife] was a dementia sufferer." (Carer, Interview)

What worked well?

One feedback form respondent highlighted that hospital staff working in an assessment clinic were aware of the need to engage with the person with dementia.

'The staff aware of the need to talk to the person with dementia.'

"...The assessment clinic at Ipswich Hospital is thoughtfully designed and the staff aware of the need to talk to the person with dementia. The local health care team have been sensitive and patient as the physical problems associated with dementia developed and prompt with equipment and advice to help. We felt supported and that we could contact them at any time." (Carer, Feedback form)

One respondent highlighted that being on a specialist dementia ward had worked well for her relative.

A further respondent commented that she felt her husband would have received better care if he had been on a dementia ward.

'She was a round peg in a round hole.'

"The good thing about this is that, on the dementia ward she was a round peg in a round hole.....Previously, she's been on the main ward and her dementia behavior has been difficult.....they just weren't geared up for it." (Carer, Interview)

'He would have been better with nurses that know what they are doing.'

"I think it would have been better if he was put on the dementia ward. I'm not being funny, but with the nurses that know what they're doing. It's like having a teacher that is trained in special needs. Teachers, although they do try, but special needs teachers know what they're doing so." (Carer, Interview)

Key learning for systems and leaders – Hospital care and support



Admission avoidance and step down support

Hospitals are a difficult environment for people with dementia, there needs to be more access to admission prevention (to prevent people going into hospital in the first place) and step down services (to help patients transition back home).



Improve dementia knowledge in hospitals

Care quality issues could be addressed by ensuring that hospital staff are adequately trained in understanding the needs of people with dementia, and most importantly in how to communicate with patients and families.



Prevent rapid deterioration by providing the right care environment

There needs to be more help to prevent people losing vital skills whilst they are in hospital.



Improve discharge planning with families

Families need to be engaged in hospital discharge planning. Poor hospital discharge has negative consequences for both patients, and carers.



Listen to carers

Family carers experience and knowledge about the person with dementia should be recognised and used by health professionals. People sometimes felt dismissed by staff, and that this had affected the quality of care provided to the person with dementia.

“

“By this time we established that her mobility since that admission, I don't know what they've done but they hadn't been doing, potentially, what they said. She was walking independent with a frame with supervision and then she was weak, fatigued, and her legs weren't doing as well as they could have done. So we weren't very happy. Because, for ease, from what I can gather they just wheelchaired her everywhere.

“Convenience. It's all we witnessed.”

3.8 – Services working together – integrated health and care for people who have dementia

In this section we explore people's experiences of how well health and social care services have provided integrated care to support those who have a higher complexity of need.

"What matters to me is that all the different parts of my local health and care system are genuinely 'Working Together' for me and my family." – SNEE ICS Integrated Care Strategy

In 2022, the Suffolk and North East Essex Integrated Care Partnership (ICP), working in co-production with members of the public and professionals, developed an Integrated Care strategy.

Responding to feedback about what mattered most to people about their local health and care services, this document sets out how the NHS and local authorities, working with providers and other partners, can deliver more

joined-up, preventative, and person-centred care for their whole population.

One of the key messages the ICP heard from people was that they wanted better co-ordinated services that work well together to support them when they have health and care needs – a message which has also been highlighted by participants in this project.

Several respondents highlighted the sense of frustration they had at being 'bounced' between services who simply blamed each other for a lack of action and left them having to jump through hoops to get support.



Being passed between services

"DIST actually said '[It's the mental health hospital's] problem' and [The hospital] were of course 'it's not our problem. She's in the community now'. I said 'I know that but we're now getting desperate again'. So they both blamed each other and they all wanted to blame health and I started on the social worker saying 'Come on, this is looking like we're going to need urgent respite or something. This is not going to be manageable. 'Well, we need to rule out there's not...'

"...And so we kept going."

'Bounced between services.'

*"I got the distinct impression I was bounced between the clinical nurse and the GP."
(Carer, Interview)*

'There is no accountability.'

"I finally got in touch with DIST and said 'Look, something's got to give here. We're in meltdown'. He then said we can't get involved unless an organic cause is ruled out. It always feels like health blame social care, social care want health to take it up, and there's no accountability. Luckily I had a good rapport with one of the doctors at her surgery and I said, 'Can you just do this to placate the DIST team to get involved?'. So they went out and they did an assessment. They felt there was no underlying cause, like a urine infection. I think she even had a CT head at this point. Because they would not get involved unless everything had been ruled out. So I jumped the hoops, cut the corners, I went through the tick boxes, and got everything done and finally DIST came in...." (Carer, Interview)

'It's not our problem.'

"My mum is registered blind. She can't do her medication herself. We were told that she could have a phone call or alarm clock come on to say 'this is the time that you need to take your medication'. But to do that, she needs to be able to see where the blister packs are and what to take. Health we're saying it's not their problem, social care were saying we understand, but as she can still wash and dress herself, it's not their problem either. So my brother was doing evenings and I was going in every morning, even before a 14-hour shift I'd be going in to do her medications."

One respondent felt that services did not work together enough to call on each other's expertise, knowledge and skills to provide a personalised and person-centred approach to her sister's health and care needs.

"I said 'I'm not going to complain that you've transferred her to the later life team."

What I am going to say is you need to take the expertise from the early intervention and psychosis team...', because again, I found out they've got no trauma informed training [in the later life team]. 'You know nothing about the trauma that she's experienced as in the effects that has on her. You purely deal with dementia, right? So, you are going to need the expertise from this team' and I was basically told that I was asking for the Earth." (Carer, Interview)

While there were occasions when services did meet to discuss a particular case, families either felt excluded or were not supported enough to help them fully engage in the discussions. One respondent also reported how difficult it was for families to initiate a multi-disciplinary meeting.

'Still having professional only meetings.'

"NSFT said 'I think what needs to happen then is we'll have a conversation with our psychology team and then maybe you can have a meeting with us and the psychology team'. I just went back and said 'Great but we could just do it all in one hit'. So, the reply comes back 'So, we'll speak to our psychology team first and then we will arrange a meeting with you'. Okay, great... so we're still having professional only meetings." (Carer, Interview)

'I couldn't really see what was going on.'

"So I had at least, I think it was three maybe four MDT meetings in that four-week period. Care was discussed. I've gone to all these meetings and couldn't really see what was going on, to be honest." (Carer, Interview)

'I wanted a meeting with everybody.'

"I emailed to say we wanted an urgent meeting with mental health, social... with everybody... so we could discuss the implications of Mum going [into the Mental



"I said 'I'm not going to complain that you've transferred her to the later life team. What I am going to say is you need to take the expertise from the early intervention and psychosis team...', because again, I found out they've got no trauma informed training [in the later life team]. 'You know nothing about the trauma that she's experienced as in the effects that has on her. You purely deal with dementia, right? So, you are going to need the expertise from this team'...

"...and I was basically told that I was asking for the Earth."

(Carer, Interview)

Health Hospital] and we did not wish to lose the bed at the [care home]. But basically her remit is CHC and the place with the care home. She can't get involved with mental health. I can't imagine for the life of me trying to get people around a table. The care home have suggested it. We just need to have some support so we can make a best interest decision, on behalf of Mum, as a family."

Lack of communication between services had sometimes led to delays in treatment or care provision. This was particularly important when people with dementia were admitted to hospital but the hospital staff were unaware of their diagnosis.

'No shared care agreement in place.'

"I had to ask Addenbrookes to send copies of the [diagnosis] letters to NSFT, because even though NSFT did the referral, they don't automatically send them, because there isn't a shared care agreement in place. I'm going 'Aren't you supposed to talk to the original referrer?'"

'The diagnosis filtered through eventually.'

"[The diagnosis] filtered through eventually to the GP, but it took a long time. Because every time I had to speak to the GP because we were struggling at home with different types of things with Mum. I would have to say, well, she has been diagnosed on this date, you haven't got it on your records yet, but I'm sure that'll come... I would say at least maybe a month or two. It wasn't instant and it definitely wasn't within a few weeks. It was quite a prolonged wait for that to hit on there."

Finally one respondent shared her experience of trying to arrange support for her dad at end of life and the difficulties she had in getting a co-ordinated response from the services she needed to support her father and the family.

'I needed someone to say 'I'm going to take over'... but they just said 'it's not my problem.'

"The last 24 hours of his life I was just pulling at... I was phoning left right and centre saying 'can you just do this? Can you just do that? Can you just?'..... And I'm like... I needed somebody to just say 'right

I'm gonna take over' but nobody did and I was phoning social care for... I said... I think I had a phone call at 10 o'clock to say it's not our problem and I said 'Well, whose problem is it?'

'I don't care who's role it is, I just need help.'

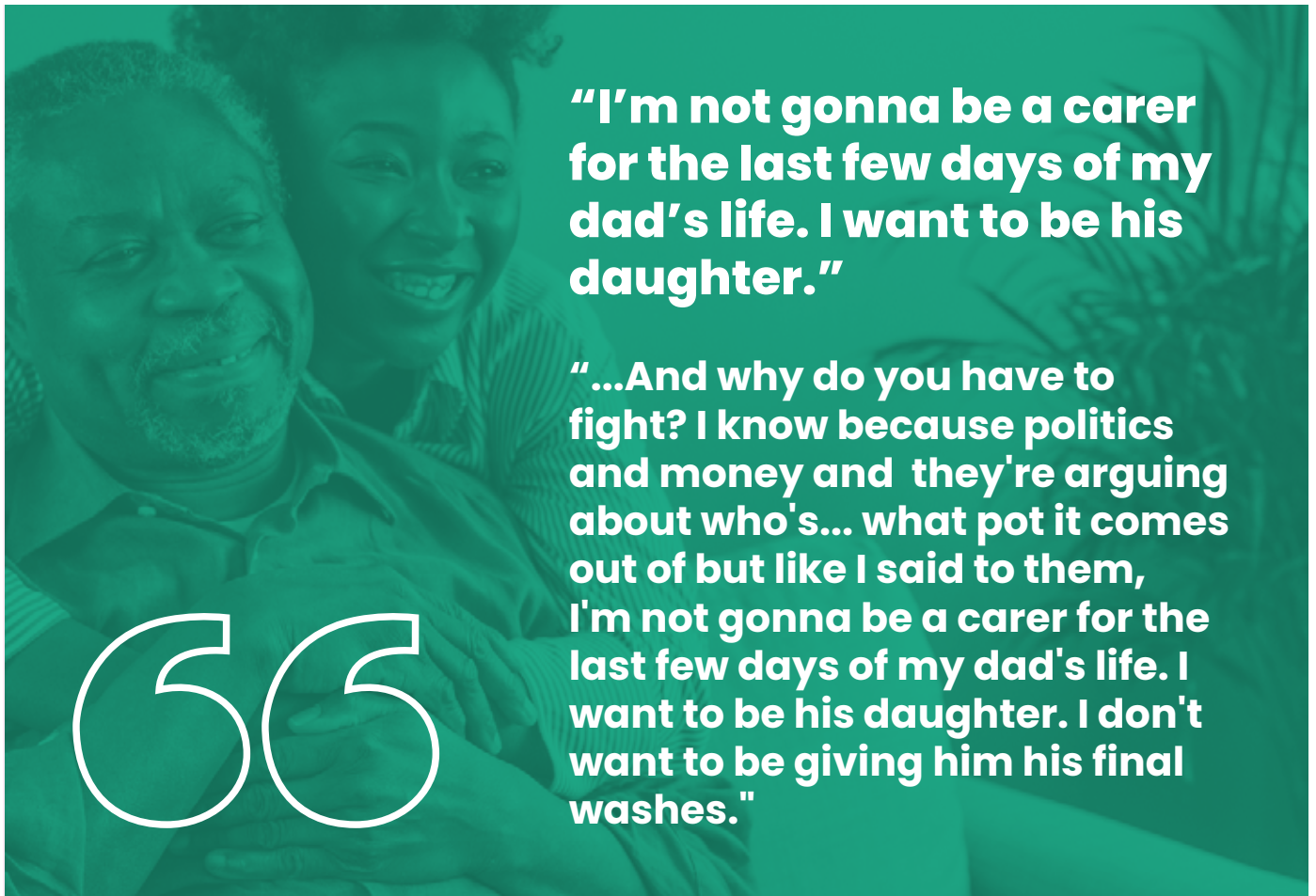
"They needed a hospital bed and I needed him to be in that hospital bed and I needed double-up carers four times a day for my dad to be comfortable and it wasn't... And I said 'I don't care who's role it is, whose job it is. I just want them in place..."

'We can't take it as urgent from you because you are a family member.'

"I managed to get hold of the Community team where all the OT and physio all sit and I said 'It's urgent...' And they said, 'We can't take it as urgent from you because you're a family member, but if you get a professional to phone up' I said 'But I

need it now. I need an OT to come out and assess. I need this help. Social care have told me that I need to go to you'. It's not clear cut who you go to...'I'm not gonna be a carer for the last few days of my dad's life. I want to be his daughter."

"I was with the carers, so he was still on one carer three times a day and they were struggling so I was helping them do a double up by giving my dad strip washes, turning him, because I knew what to do but if I didn't know what to do then the carers would be doing it all themselves. It's just that break in the system that... You have to fight for everything. And why do you have to fight? I know because politics and money and they're arguing about who's... what pot it comes out of but like I said to them, I'm not gonna be a carer for the last few days of my dad's life. I want to be his daughter. I don't want to be giving him his final washes."



"I'm not gonna be a carer for the last few days of my dad's life. I want to be his daughter."

"...And why do you have to fight? I know because politics and money and they're arguing about who's... what pot it comes out of but like I said to them, I'm not gonna be a carer for the last few days of my dad's life. I want to be his daughter. I don't want to be giving him his final washes."

66

Key learning for systems and leaders – integrated care



Improve integrated care

Services need to work well together to support people when they have health and care needs.



Coordinate resources

Services should draw upon the expertise, knowledge and skills that other teams/professionals offer in order to provide person-centred care and support.



Support families to participate

Families should be invited and supported to participate in multi-disciplinary meetings. They should also be informed about how they can initiate a Multi-disciplinary meeting.



Improve communication between services

There needs to be better basic communication between services to ensure key information is made available to everyone involved in the care and support of someone with dementia.



Prevent people from being passed between services at the end of life

There needs to be better co-ordinated support for people with dementia and their families at end of life.



“

The last 24 hours of his life I was just pulling at... I was phoning left right and centre saying 'Can you just do this? Can you just do that? Can you just?' And I'm like...

“I needed somebody to just say 'Right I'm gonna take over' but nobody did.”

3.8 Dementia-friendly Communities

A dementia-friendly community is a city, town, or village where people with dementia are understood, respected and supported. These communities are considered vital in helping people live well with dementia and remain part of their community. – Alzheimer’s Society, 2023.

The feedback form asked people what a dementia-friendly community means to them, and what would help them to live well at home, and within their wider community. In total, 73 comments were provided (68 comments from carers and five from people with dementia).

What does it mean?

Six respondents highlighted they had never heard of the term and would not know what is meant by, or what is needed to create, a dementia-friendly community. This included one respondent with dementia who stated they had “absolutely no idea” what would help them live well with dementia at home, and within their wider community.

Overall, responses demonstrated that ‘dementia-friendly communities’ are difficult to summarise. However, some common ideas were evident within the responses.

Respondents felt that a dementia-friendly community is an environment that has a level of understanding and awareness of dementia. An environment that increases people’s acceptance of dementia-related behaviours, as well as being a community that is empathic, kind, patient and safe.

The table below shows all responses to what makes a dementia friendly community.

Dementia-friendly communities...	Count
Never heard of or didn’t know	6
Are empathetic “That people have empathy and some understanding.”	1
Show understanding, and work on increasing awareness “People who understand dementia more. More activities for people with dementia to go to and take part in. People who do not shy away from people with dementia but are supported to understand it and stay in touch.” “People being educated in shops, hairdressers, public transport, etc. about dementia and to be aware of some of the symptoms. People with dementia don’t always have family around them. We should all be looking out for each other.”	14

<p>Treat people with respect</p> <p>“People who treat people as people. A dementia person is still a person.”</p>	3
<p>Kind and friendly</p> <p>“A dementia-friendly community is one where the community recognises that people are different and take care of and are kind to those who appear to be confused or lost.”</p> <p>“People with dementia just need other people to be kind and helpful.”</p>	3
<p>Safe environments</p> <p>“Safe environment imperative with kind, friendly staff. What a breath of fresh air that would be.”</p> <p>“Somewhere we can live safety.”</p>	3
<p>Make sure people feel accepted, and like they belong</p> <p>“Somewhere where people don’t treat him as if he’s daft....[somewhere] we feel we belong, in a friendly community.”</p>	6
<p>Encourage patience</p> <p>“People in supermarkets not shouting for people being slow or hesitant or forgetting the PIN number.”</p> <p>“Patience is one of the key attitudes those of us close and anyone else must nurture.”</p>	2
<p>Sheltered housing or supported living</p> <p>“A supported living community designed for people to live with as much or as little tailored care as they need - with shops, social space and activities all catering for dementia.”</p>	2

3.9 What should people know about caring for someone with dementia?

Respondents were asked what they would like other people to know about caring for someone with dementia.

A total of 54 comments focused on the negative impact's dementia has had for them. This included 30 comments that expressed how hard and exhausting it is caring for someone with dementia, how difficult it is to cope with the level of care they needed to provide, the relentless nature of the disease, and the struggle of watching a loved one deteriorate.

"It is very difficult. More support for carers is needed. Carers are pushed to breaking point."

"It becomes very hard as you slowly watch that person become a different person and start to lose the ability to do things for themselves and become very upset as they do not understand reality."

"That it is unrelenting. That a day will arrive when I cannot cope. That I cannot make plans for future events. That I am not equipped or educated to deal with his decline, but I am doing my best on a daily basis."

A further nine comments highlighted how isolating being a carer of someone with dementia becomes as other aspects of their life often stop, including loss of contact with friends, and the lack of support available to them.

"How hard and alone you are - there is no support, and no one cares. There is no treatment and there is little hope."

Further comments focused on the lack of support available for people with dementia and carers (14), the guilt carers felt when making difficult decisions (3), the challenge of managing two households (2), and the frustration felt due to the nature of the disease (5).

Examples of these comments, showing how

hard it is caring for someone with dementia. Are given below.

"So hard, 24/7 care while grieving for your loved one who you are losing before your eyes, with little to no support."

"The feeling of not being able to cope and support loved one is unbearable. Putting loved one into residential care owing to lack of support available at home is a guilt that is hard to live with. I will never forgive myself even though I know it was the only decision."

"That's its 24 hours a day. It is hard for carers, even though I don't live with my mum to manage. I must manage my own home and at weekends manage their home."

"It's very difficult and frustrating for the sufferer and the carer. I feel you need to be calm and remember that the sufferer can't help repeating themselves as they don't know they have said it already."

Eight respondents, however, gave a mixed response to what it is like caring for someone with dementia. These responses highlighted that it is often a rollercoaster of feelings, both positive and negative. So, whilst it is extremely difficult, it is also rewarding.

"It's hard work but rewarding when you see that smile on their face".

"It is hard work, but it is also so rewarding. I have learnt so much about dementia from caring for my mum, about what works and what doesn't. You need lots of patience, but you also need to just go with it. Once you realise that this person can't help what they are doing and you stop trying to correct them and just go with it, it is much easier."

66

“So hard, 24/7 care while grieving for your loved one who you are losing before your eyes, with little to no support.”

99

“It’s hard emotionally, physically, and mentally. It’s changeable and relentless day and night. It’s funny, liberating, humbling, its every emotion in very quick succession. You find unknown compassion and patients and every day my mum knows who I am is a good one.”

Advice for others in the same position

Some respondents took the opportunity to provided meaningful advice to other carers who may find themselves in a similar position.

Advice suggested included seek supporting from specialists like Alzheimer’s society, educating yourself on dementia and the behaviours loved ones are likely to exhibit and the best way to manage those.

“Talk to other people in a similar position, share experiences and tips. Be patient and keep smiling”.

“Focus on the person and not the dementia. Sometimes enter into the persons world with dementia.”

“Treat the person like you would normally and don’t take anything to heart.”

“Try and arrange some time out to leave the situation and get some fresh air.”

“Be calm and remember that the sufferer can’t help repeating themselves.”

“Try to separate the person’s behaviour which is caused by the disease from the person inside who is still there sometimes.”

“You need lots of patience, but you also need to just go with it. Once you realise that this person can’t help what they are doing and you stop trying to correct them and just go with it, it is much easier”.

“Don’t rush, keep things simple, be kind, and keep a sense of humour. You get a bit sad sometimes thinking of the good times you’ve shared, and what’s to come. But it’s easier when you accept you can’t change the situation and that you can still have good times together. Life is full of shocks and surprises, and this is just one of them!.”

healthwatch
Suffolk

“A roundabout with no signposts.”

What people told us
could help people to
live with dementia in
Suffolk.



Download
as a poster...

A summary of key le

1. Pre-diagnosis

- Provide information so people know what to look for.
- Make it easier to find early help, and include people without a diagnosis.

2. Diagn

- Listen for he
- Be res individ
- Improv comm
- Ensure comm comp

5. Social care support

- Tell people how social care can help.
- Ensure people who can fund care also feel supported.
- Trust and continuity of care really matters.
- Make sure people know how to raise concerns.
- Help people with the transition into care.
- Make sure staff are trained to care for people with dementia.

6. Hosp

- Enhanc avoid down
- Train so the how to comm people
- Prevent losing hospit
- Improv plann
- Listen

“Carers need someone kn

Please refer to each of our repo

Learning for systems and leaders

Diagnosis

when carers ask for help.
Responsive to individual needs.
Have cross-service communication.
The diagnosis is communicated with compassion.

Hospital care

Prevent admission and step support.
Staff in hospitals that they know to care for, and communicate with, people with dementia.
Prevent people from losing vital skills whilst in hospital.
Have discharge planning with families.
Support carers.

3. Post-diagnosis support

- Guide people through health and care systems.
- Provide emotional and practical support.
- Support people to find digital solutions that help.
- Customise support for those with early onset dementia.
- Make referral to dementia support services easier.
- Help people to know how to access support.
- Be clear about what services offer.

4. Support from health professionals

- Carry out annual dementia reviews.
- Make adjustments to meet people's needs.
- Direct people to further support.

7. Services working together

- Prevent 'bouncing between services'.
- Support families to participate in meetings.
- Improve communication between services.



Watch Peter & Teresa talk about their experiences.

Knowledgeable who will walk them through the maze..."

Support sections for more detail (some are not included in this summary)

Get in touch

www.healthwatchsuffolk.co.uk

t: 0800 448 8234

e: info@healthwatchsuffolk.co.uk

Find us on:

 @HWSuffolk

 /HealthwatchSuffolk

 /healthwatchsuffolk

 Healthwatch Suffolk C.I.C

Image credit:

Some images included in this report are from the Centre for Ageing Better free image library. It includes 'positive and realistic' images of older people in a bid to challenge negative and stereotypical views of later life. The experiences featured are not those of the people in the images.

Explore the image library on:

<https://ageingbetter.resourcespace.com/pages/home.php>