

Dementia Survey Feedback

Service User Experience Evaluation

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Contents	Page
Introduction	1
Methodology	1
Qualitative Feedback	2
Feedback from People who are Living with Dementia or Who are Seeking a Diagnosis	2
Knowledge of the Condition	2
What to do in a Crisis	2
Virtual Ward	2
Assistive Technology	2
Regular Review	2
What Could Help Post Diagnosis	2
Dementia Buddy	3
Opt Out with Alzheimer's Society	3
Additional Comments	3
Feedback from Carers or Family Members of Someone Living with, or Seeking a Diagnosis of Dementia	3
<i>Pre-Diagnosis</i>	3
What prompted a GP Appointment?	3
How Knowledgeable was the GP?	3
How Long did you Wait?	3
Encouraging People to Come for a Diagnosis	3
Opt Out with Alzheimer's Society	3
Attending Dementia Café's	3
Using Technology	4
<i>Memory Assessment Service</i>	4
Feeling Informed About the Appointment	4
How Did the Appointment Go?	4
Attending the Appointment with a Loved One	5
Waiting Time	5
Travel	5
Appropriateness of the Assessment	6
Talking Alone with the Consultant	6
Delivery of Diagnosis	7
Information Upon Diagnosis	7
Improving the Memory Assessment Service	8
Receiving Information about Research	9
Additional Comments	9
<i>Post-Diagnosis</i>	9
Knowledge of Dementia	9
Information Given at Diagnosis	10
Care Plan	11
What Would you do in a Crisis?	11
Personal Experiences of Crisis	12
Having a Regular Review	12

Help for the Carer	13
Opt Out with Alzheimer's Society	14
Knowledge of Alzheimer's Society	14
Deciding on a Care Home	15
Assistive Technology	15
General Thoughts on Technology	16
Additional Information, Comments and Experiences	16
Conclusion	16
Recommendations	19
	20

Introduction

The Cambridgeshire and Peterborough Integrated Care Board (CPICB or ICB) are working on a project to transform the Dementia Pathway that is currently in service in Cambridgeshire and Peterborough NHS Foundation Trust (CPFT). There is a necessity to increase the Dementia Diagnosis Rate (DDR) in line with national ambition, which presents an important opportunity to change and improve the wrap around care and support that people receive when pursuing a dementia diagnosis. Specifically, what support people have pre-diagnostically, from the moment they may attend a General Practitioner's (GP) surgery with concerns about their memory, or other dementia symptoms – all the way through to diagnosis, to living well with, and dying well with dementia.

The SUN Network are an organisation whose objective is to hear the voices of individuals with lived experience of mental health and/or drug and alcohol challenges across Cambridgeshire and Peterborough and ensure that those voices are influencing and shaping service provision, locally. The SUN Network's role within the Dementia Transformation work, is to ensure that the lived experience perspective is acknowledged throughout any changes, and to ensure where possible, that elements of the pathway are co-produced and meeting the needs of those who are accessing the care and support.

Methodology

The SUN Network co-ordinated a co-production workshop where a set of surveys were designed. The workshop included people with lived experience of dementia, carers, the ICB, Alzheimers Society, Cambridgeshire Libraries, a CPFT Researcher, a CPFT Dementia Nurse, a Local Care Home representative and Voluntary Sector Influence and Participation Manager. Six surveys were constructed to gather people's experiences in the following three areas; pre-diagnostic care, memory assessment, and post-diagnostic care. Three surveys were for the person living with dementia/suspected dementia, and three surveys were for the carers/family members of someone living with dementia/suspected dementia.

A link to the online surveys was shared throughout both the statutory healthcare system and voluntary sector. Alongside being accessible online and via a QR code, paper copies were available on request and there was the opportunity for The SUN Network to meet people face to face and ask questions in a conversational way. The latter was by far the most effective way of attaining responses and feedback.

People were able to submit responses between 7th October 2024 and 18th November 2024, and during this time 85 responses were acquired. Fourteen responses were recorded online, and these responses are recorded verbatim. Other responses have been paraphrased and edited to maintain anonymity but accurately reflect conversations and sentiment.

It is important to note that not every person filled in a survey, some of the feedback was gained from general conversation surrounding the questions, therefore not all the tables in this report will represent the entirety of the participants' feedback. The 'Additional Information, Comments and Experiences' are comments from people that The SUN Network have spoken to during this time frame, however, it was not appropriate to complete a questionnaire with them therefore contains feedback from conversational research.

A software named Linktree was used to house all the surveys, which can be accessed [here](#).

Qualitative Feedback

Feedback from People who are Living with Dementia or Who are Seeking a Diagnosis

No online feedback was received from this group of people. However, two people did give feedback about their experiences after diagnosis.

How Much Do You Feel That You Know About the Condition You Have Been Diagnosed With? Can You Tell Us About the Information You Were Given at The Point of Diagnosis (Leaflets, Signposting, Information to Read)?

‘For the person with dementia, they are not given enough information or communicated with during the process, we didn’t know what dementia was, we hadn’t heard of it until the diagnosis. But even now we are not given information about what it is and why we may do things the way we do.’

‘No one asks us how we feel - a piece of paper wouldn’t help – it needs to be a face-to-face conversation so we can have things explained to us.’

‘My husband (carer) went on the CrISP1 (Carer Information and Support Programme) course after my diagnosis. Although we (people with a dementia diagnosis) don’t get anything like that, I think we would benefit from something like that type of course.’

‘The practitioners do not talk to the patients. A leaflet means nothing to a person with dementia, it would be better to be spoken to.’

‘Because we got diagnosed at the Dementia Resource Centre (DRC), it was really good as automatically referred to Alzheimer’s Society (AS).’

What Would You Do If You Felt You Were in Crisis?

‘If there was a crisis, we would call the DRC.’

A Virtual Ward Is When Someone Is Able to Stay at Home Allow the Person to Have Hospital Level Care A Home. Is This Something That You Would Be Interested in Engaging With?

‘We would very much like a virtual ward and would like more information about this and what it actually means – but be aware, that is not a dementia friendly term.’

Are You Aware of How Assisted Technology Could Help You? How Do You Feel About Technology and What Do You Use It For?

‘It would be good to get technology support and be shown how to use technology. We wouldn’t really use the assisted support; it would be better if someone was there face to face.’

How Do You Feel About Having a Regular Review with a Consultant or Dementia Specialist, Regarding the Dementia Progression? Can You Explain a Bit About Why This May Be Helpful to You?

‘Having an annual review with a specialist would be really helpful, and not just a medicine review with a GP or a nurse ‘who doesn’t really understand dementia’. It would be helpful to compare previous years and see where you are and know what to expect in the next few months/year. The GP is not a specialist.’

What Else Could Be Done to Help You, After Your Diagnosis and Living with Dementia?

‘Without the DRC we would be isolated and would not have coped. When you are having a bad day, you can come here and talk to other people, and it helps with your mental health not just

dementia support. It is nice to have someone that knows you. We have the DRC and Dementia Advisor, so I think we have been supported that way, we probably don't need counselling as we feel supported by the team. Stacey is amazing. However, training would be so beneficial so we can know what to expect and understand the disease. '

Do You Think Having A 'Dementia Buddy' Would Help You? A Dementia Buddy Would Be Someone Who Has Lived Experience of Dementia Who Is There for You.

'A dementia buddy for the carer yes. Maybe not for the person who is living with dementia.'

Would You Be Happy to Be Part of An Opt-Out System with Alzheimer's Society?

'Absolutely. Yes.'

Is There Anything Else You'd Like to Tell Us About Your Experiences?

'Peer support for us is really helpful (groups to chat) and to get out the house. The DRC is a safe space, and without it we would be lost and very isolated. Sometimes to ask for help you have to swallow your pride, and it takes a lot for people to do that.'

Feedback from Carers or Family Members of Someone Living with, or Seeking a Diagnosis of Dementia

There is a mix of online and face to face feedback within this category.

Pre-Diagnosis

What Prompted You or Your Family to Go to The GP Because Of Concerns with Memory or Any Other Signs of Dementia for Your Loved One?

'My mum has memory loss that we have all noticed. We know that medication can be prescribed to slow this. We would like this if necessary.'

How Knowledgeable Did You Find the GP in the Subject? For Example, Were They Forthcoming and Understanding?

'Yes, they were forthcoming and understanding.'

How Long Was the Wait for The Memory Assessment Service Appointment, After the GP Appointment?

'We are still waiting and were not told how long we would wait.'

Support Whilst Waiting

'I'm unsure/don't know'

'We got no help whilst waiting, I researched everything myself. Age UK came and helped, and they were brilliant.'

How Could More People Be Encouraged to Come Forward for A Potential Early Diagnosis?

'Routine memory tests.'

Would You Be Happy to Be Part of An Opt-Out System with Alzheimer's Society?

'Yes.'

Would You Attend Dementia Cafés to Access Help and Support, Prior To Your Loved One Receiving a Diagnosis of Dementia?

'Probably not.'

Do You and Your Loved One-Use Technology (I.E. Phone And/or Laptop)? If Yes, What Do You Usually Use It For?

'Emails, WhatsApp, internet.'

Memory Assessment Service

Did You Feel Informed About What Was Going to Happen at The Memory Assessment Appointment?

Key Themes:

- There were no conclusive themes
- Some felt informed, others did not

Qualitative Data:

'No. We had no idea of what to expect. We were not happy receiving a video consultation. It is confusing for people who have limited computer skills.'

'No, we didn't really get much information before or afterwards.'

'No, I didn't feel informed about what was going to happen at the appointment.'

'No, I didn't feel informed about what was going to happen at the appointment.'

'Yes, I felt informed about what was going to happen at the appointment.'

'No details of what to expect but I had an idea from reading up about it.'

'Yes, I felt informed.'

'I have a professional knowledge, so I knew sort of what was going to happen for my relative.'

How Do You Feel the Appointment at The Memory Assessment Service Went?

Key Themes:

- Lack of detailed information available for some, resulting in inconsistent care

Qualitative Data:

'It was brief. Diagnosis was given. Did not know what to expect.' (Assuming this person means that they didn't know what to expect when going into the appointment)

'It was ok but not a lot of information given at the assessment.'

'Poor.'

'My aunt would only go in by herself, she didn't understand anything and reported back to the family a story she had made up. We had no idea what was going on!'

'It went well.'

'The appointment was good and helpful.'

'Good, immediate diagnosis.'

'We had several appointments. The professional was very pleasant and helpful but again I had a professional background.'

Was There the Opportunity for You to Attend the Appointment with Your Loved One?

Key Themes:

- Yes, people could attend with a loved one

Qualitative Data:

'Yes – someone was able to attend the appointment.'

'Yes, because my family member wouldn't have attended without full support.'

'Yes, someone was able to attend the appointment.'

'Yes, someone could attend, but my aunt didn't want anyone with her.'

'Yes, we could attend.'

'Yes, we could attend.'

'Yes, we could attend.'

'Yes, and no barrier was made to attendance. The only time we left my relative was when the assessment happened.'

How Long Did You Wait for The Memory Assessment Service Appointment?

Key Themes:

- There was no thematic data
- Very dependent on when people went through the MAS service (before, during or after covid)

Qualitative Data:

'12 months for the online assessment. Several more weeks before the diagnosis at the memory clinic.'

'It seemed like forever was probably about 18 months or more and by then family member had deteriorated quite a bit.'

'Eight months.'

'I don't know, about 3 months.'

'Nearly 2 years.'

'Ten months from the time of receiving the appointment date but it was a number of months from GP to getting the appointment letter.'

'Over a year - but that was due to Covid.'

'It could have been a lot worse. I think that it was about a year.'

Was The Appointment Easy to Travel To?

Key Themes:

- Yes, easy to access

Qualitative Data:

‘Yes - it was easy to travel to.’

‘If you’re a car driver, it’s easy to get to yes.’

‘Yes, easy to travel to.’

‘Yes, easy to travel to.’

‘Our appointment was conducted at home.’

‘Yes as on the ring road in Huntingdon.’

‘I drove to Cambridge, so yes.’

‘Yes, easy to travel to.’

Do You Think the Tests and Questions That Were Used in The Assessment Were Appropriate?

Key Themes:

- There were no thematic responses
- Appropriateness of the assessment depends on the person (where they are with their illness, their cultural background and other factors)

Qualitative Data:

‘It would have been easier if the patient could have had a face-to-face appointment. She would have felt more at ease instead of trying to concentrate on images on a computer screen that were not very clear.’

‘Some where ok but often with the general knowledge questions not everyone knows them in general so can be difficult to understand if they just didn’t know the answer or had genuinely forgotten.’

‘No. One size fits all, not fit for purpose. The questions were relatively simple, and not directed to her memory loss.’

‘No, the tests and assessments weren’t appropriate.’

‘Yes, it was appropriate.’

‘Yes, it was appropriate.’

‘Yes, it was appropriate.’

‘For my relative, yes, it was appropriate.’

Were You Able to Talk Alone with The Consultant at Any Stage?

Key Themes:

- Generally, people were not offered a chance to speak alone with the consultant

Qualitative Data:

‘No, we weren’t able to chat alone with the consultant at all.’

‘No. In actual fact the consultant told me not to interrupt when I needed to clarify my mother’s answers, as the family knows her best. She gets lost, can’t remember where she put things, and doesn’t remember to take her tablets, amongst other issues. This was not taken into consideration, and the consultant passed my mother’s memory as fine, with absolutely no follow up!!’

‘My mum could eventually speak to the GP after supplying a permission letter from my aunt (who wasn’t agreeing to anything) but had to supply another letter to CPFT as they were another department! My mum gave up by this point.’

‘No, we were not able to chat alone with the consultant at all.’

‘No, we were not able to chat alone with the consultant at all.’

‘Yes, we were.’

‘We did not see a consultant, we saw a nurse specialist.’

How Did You Feel About the Delivery of The Diagnosis, Or Non-Diagnosis?

Key Themes:

- Delivering the diagnosis seems fine, it’s what does or does not happen subsequently to that

Qualitative Data:

‘It was just told to us at the appointment.’

‘It was ok, just not enough information going forward on how to support them, and what facilities and support available.’

‘I’m very disappointed and very angry. There was no meaningful assessment, and consequently no help.’

‘My aunt was hospitalised by the time a diagnosis was given to her. She had struggled for a year up to the point of crisis.’

‘It was delivered respectfully.’

‘It was matter of fact but that was ok. It is hard to understand timescales but that is the nature of the diagnosis.’

‘It was fine.’

‘It was not a surprise to us, so I’d have been more concerned if my relative had not had a diagnosis.’

Do You Think More Information Should Have Been Available at The Point of Diagnosis?

Key Themes:

- Information given should be personalised to the need at that time
- Potentially more information on what dementia is and how it affects people

Qualitative Data

‘We weren’t really given enough information, as it was a shock to get the diagnosis.’

'Yes, most definitely more information should be available upon diagnosis.'

'Yes, more information should have been available.'

'We found our own information on the internet.'

'Yes, more information should have been available.'

'Yes. It would be good to have a leaflet from DVLA about dementia and driving. Especially for the patient to have because it is a challenging area. The letter post (MAS) appointment is very detailed. Maybe an explanation of (MAS) scores would be good if it would be helpful.'

'I would have liked more information on just how bad it was going to get. My father has Lewy Body Dementia. Most of my info has been gained off Facebook.'

'No. More information could have been overwhelming, and if I had any questions I could search on the internet.'

Can You Tell Us Something That Would Have Improved Your Experience of Using the Memory Assessment Service?

Key Themes:

- More family member involvement throughout the assessment
- More information on what the diagnosis means is needed, immediately and long term (proactive help, a 'what happens next')

Qualitative Data

'A consultation with the family member beforehand would help to enable them to think of questions before the main consultation.'

'A follow up appointment or phone call after the family and individual have had time to process the diagnosis.'

'A proper and meaningful assessment, along with consultation with family members to get a true and accurate picture of my mother's condition.'

'Better communication.'

'Knowing what can and can't be done after assessment.'

'Because it then falls back to the GP after diagnosis and medication start/settling in, and because GPs don't have any idea, it feels then you are left on your own with it.'

'A plain fact sheet or timeline of what would happen (*specifically in relation to dementia with Lewy bodies*). It would have helped. The literature we got did not show how bad it would get. Well, unless I chose to ignore that bit. Things like the Lewy lean (*a posture issue that can occur in people with dementia with Lewy bodies*), eyes closed and Lewy string (*a hallucination where a person sees or feels strings in their fingers*) being mentioned in a timeline would have made it easier to deal with. Instead, we have come across these things and then found out via a Facebook group that these characteristics are normal for Lewy. I know it's very difficult with Lewy body, but it would have given a realistic appraisal. We have had complete personality changes, complete paranoia, fixation, anger, falls, incontinence, temperature regulation problems, irregular breathing,

hallucinations, being 100% dependent on daily activities, eyes shut and now end of life for over 6 months. What a rollercoaster!! We have had calls to say he's at the end - only for him to be sitting up and drinking a cup of tea the next day. He has had no quality of life for three years now. He had to be near the end to get continuing health care.'

When Would Be Best for You to Receive Information About Memory and Dementia Research, So You Would Know How to Take Part If You Wanted To?

Key Themes:

- After diagnosis

Qualitative Data

'A couple of weeks after diagnosis so things can be put in place to support the individual and family.'

'After diagnosis. I received some and have taken part in one lot of research already'

'N/A'

'I'd still like it! I did a relative impact one and that was (to me) stating the obvious so not sure how worthwhile the study was.'

'Yes. I tried subsequently to sign up for research and the link for CPFT was diabolical. Highly delayed response from the service and still to this day I'm not signed up.'

Is There Anything Else You'd Like Us to Know About Your Experiences?

Key Themes:

- People feel left on their own to manage
- More long-term support is needed

Qualitative Data

'There were no follow ups or any input after diagnosis. It's an awful illness and feel like we have been left in the dark with it all. Very upsetting.'

'Once again someone has to reach crisis point before they are listened to. Taking care of my aunt has put a strain on the whole family because we had to make do with what we had.'

'The wait was far too long. By the time he was assessed there were very few options available for treatment.'

'It becomes very lonely for the patient after diagnosis. Perhaps drop in/ groups for after diagnosis would be helpful.'

'The fact sheets we read at the time were too general. They did not show us the severity of what was to come.'

'Great to have it at the PoW (??). Would have been good to have closer input about drug reactions. Also, the service is only for diagnosis, and the long-term support from CPFT needs improvement.'

Post Diagnosis

How Much Do You Feel That You, Your Family and Your Loved One Know About the Condition That Your Loved One Has Been Diagnosed With?

Key Themes:

- People mostly do their own research
- There is an inequity of information / no standardised process for all

Qualitative Data

‘As a family, we are very educated in mum's diagnosis. My mum lacks capacity therefore understands very little. My dad, who is mum's main carer, has little insight into the diagnosis and best interest decisions for my mum. This continues to make caring for my mum extremely difficult.’

‘Not as much as I would like to know. Reading leaflets is time consuming and not all the information is relevant.’

‘Not very much. The onus is on the family to look up or read literature about the condition. Not everyone retains information by reading.’

‘I have researched a lot on dementia and Alzheimer's disease on my own once I started caring for my mum in law.’

A Group of 24 Carers and People Living with Dementia

‘We received nothing at diagnosis, no phone numbers to call – nothing.’

Can You Tell Us About the Information You Were Given at The Point of Diagnosis (Leaflets, Signposting, Information to Read)?

Key Themes:

- A lot of people learn by themselves
- It depends on if you have been through the MAS and what the diagnosis process was
- Is information being given in a timely way?
- Information is not personalised

Qualitative Data

‘My mum was diagnosed in Lowestoft where we received positive support from a Community Memory Nurse. We were signposted to The Alzheimer's Society who provided us with lots of useful information verbally and via leaflets etc. Since my parents moving to this area, we were unable to access an equivalent to a Community Memory Nurse and unfortunately it took us 15 months to be referred to the Elderly Mental Health Team.’

‘Nothing at the diagnosis. A letter was received two weeks later. A dementia nurse visited and left two booklets.’

‘Two booklets - one for the family, one for the patient.’

‘Absolutely nothing.’

‘I was given information on the disease. My wife (with dementia) wasn't, and the time wasn't taken to speak with her to explain things. When we got the diagnosis, the consultant was in the DRC and it was a really good flow through of information. We got signposted to Alzheimer's Society straight away and given loads of information - so we have had Alzheimer's Society support from the off and they have been invaluable. I (carer) did the CrISP 1 course and that has massively helped, although my wife had nothing, and we feel that she would benefit from something like that. The practitioners do not talk to the patients, and a leaflet means nothing to the person with dementia. It's good to talk.’

‘I was bombarded with information that can help me but at the time I didn't want to call the suggested support, however, when I did need them – they really didn't help me. They either didn't call back or

just couldn't help or were a bit useless. I feel they were all a bit of a letdown and now I manage on my own.'

A Group of 24 Carers and People Living with Dementia

'We didn't know much about the disease at all, we have learned from each other and researched on our own and found online support groups too. A Dementia Navigator would be good, to guide you through (*a reference to how people get this navigational support if they have cancer*).'

Group of 11 Carers

Not everyone was seen by the Memory Assessment Service, so it was difficult to judge the level of information that people had been armed with, however, people stated that 'We go along with what we learn by ourselves.'

If You Were Offered a Care Plan, How Was This Created?

Key Themes:

- Not everyone is offered a care plan, people do not know what they are

Qualitative Data

'Our care plan was created in Lowestoft between the social worker and me over the phone.'

'Literally left to care on our own. Received help from crisis care and contacted Alzheimer's society and age UK for help and guidance.'

'We haven't had a care plan yet, but it's on the Alzheimer's Society's radar.'

A Group of 24 Carers and People Living with Dementia

Some people have been offered a care plan, however, mainly people were not offered a care plan

Group of 11 Carers

No one in the group had been offered a care plan. If they had been, they would have liked it to happen without their loved one being present

If You Felt That You or Your Loved One Were in A Crisis, What Would You Do?

Key Themes:

- People know of 111 option 2, but this service cannot provide dementia crisis support
- No specialist dementia knowledge within any crisis care service

Qualitative Data

'Depending on the crisis, we would contact our Mental Health Support Worker, our Social Worker, 999 or call 111 option 2.'

'Don't know'

'Phone 111 ??'

'Contact crisis care'

'There absolutely needs to be a dedicated dementia crisis care and a team of people who understand, that we can talk to and who can reassure us.'

'I would call the DRC.'

'There is no one to call when things get tough. I just feel so lost.'

A Group of 24 Carers and People Living with Dementia

Did not know who they would call in a crisis. Guessed at Caring Together.

Group of 11 Carers

This was split in terms of who knew what to do in a crisis. Some would call 999. Others would call Alzheimer's Society.

If You Have Called Support in A Crisis, Can You Tell Us a Bit About That?

- There is no immediate physical, in person support for a carer when there is a dementia crisis
- No emergency respite for carers

Qualitative Data

'To date, most of our crisis have been due to falls so paramedics have been called.

At times when it has been difficult to cope, I have contacted the GP, Mental Health Team, and more recently our Social Worker which has now been assigned to us. Although we feel more supported now, it has been very overwhelming and difficult to source this support.'

'Sought support after 9pm by calling 111 for help and received a JET (Joint Emergency Team) team member and crisis care at my home the following morning. We struggled through the night frightened for safety - stayed awake all night and the following day had still got to be alert for our loved one.'

'I was at crisis point and went to the local library who were pretty useless but did point me in the direction the St Ives (*Dementia Friendly Community*) groups.'

A Group of 24 Carers and People Living with Dementia

It is very lonely when you feel you cannot cope especially. When you *need* respite what do you do? There are no respite services. It depends on the care home, and how do you find them?

How Do You Feel About Having a Regular Review with A Consultant or Dementia Specialist, Regarding the Dementia Progression? Can You Explain a Bit About Why This May Be Helpful to You?

Key Themes:

- Regular reviews are very important
- The purpose would be to talk to a specialist (not necessarily a consultant, could be a Dementia Advisor) – someone who understands
- It needs to be a Dementia review *not* a medication review
- People do not have faith in GP knowledge
- Peace of mind and reassurance for the carer that they're doing the right things

Qualitative Data

'I feel this would be useful. It would provide a professional opinion and provide confidence and support in our caring roles. It would be good for dad especially to have a review from a specialist as he would be more likely to accept information from them.'

'It would be beneficial to have support from someone experienced on a regular basis. It is down to the family to have to contact someone or look online for answers or to check that something that is happening is part of the condition.'

'It would be reassuring to have a specialist's support.'

‘We have a psychiatrist allocated as well as a psychiatric nurse to help us with mum in law. It feels we are not alone as her condition worsens.’

‘My husband was diagnosed, and his condition is deteriorating rapidly. I don’t get a regular review to know what is normal, and we get told by the GP that there is nothing they can do to help. Even the GP review has been reduced down to the healthcare assistant now. There is no Admiral Nurse either.’

‘Having an annual review with a specialist would be really helpful, not just a medication review with a GP or a nurse who does not really understand dementia. It would help to compare previous years and see where you are and know what to expect in the next few months/year. GP is not a specialist.’

‘There is no review to understand where the dementia is going and if everything is ok, whether things are dementia related or not. There needs to be a dementia team that understand dementia properly.’

A Group of 24 Carers and People Living with Dementia

We just feel stranded... there is zero contact. To have a regular review would be good so we know where we are and if we are progressing properly and to help identify issues, we may not be aware of.

Group of 11 Carers

An annual visit or check-up is very important. It helps to revisit the diagnosis, to reassess what it currently going on and to help prepare and plan for the future. If you are known to Older People’s Mental Health services (OPMH) then you get a regular check-up – and these nurses seem to be dementia informed. The GP would not be helpful for dementia reviews as they do not seem to know what dementia is.

What Can Be Done to Help You as A Carer?

Qualitative Data

‘I have sought out help so far through my own recognition that help is needed.’

‘What happens when the carer absolutely NEEDS a rest? Just even overnight? There are not very many options. Yes, you can have a carer come in, but I am still in the house. If I don’t sleep. I can’t cope. I am up multiple times in the night with confusion and incontinence issues and it’s never ending.’

‘Without the DRC we would be isolated and would not have coped. When you are having a bad day, you can come here and talk to other people, and it helps with mental health not just dementia support. It is nice to have someone that knows you. Because we have had the DRC and direct Dementia Advisor, we don’t really feel like we would need counselling as we feel support by the team, however, training would be so beneficial.’

‘There is no time to engage in anything for me, I was really resentful about what has happened and how it’s affected my life, but I have gotten over that of my own accord.’

A Group of 24 Carers and People Living with Dementia

The group mentioned however support is so important, saying ‘if we didn’t have the group we would be absolutely lost.’ They believe dementia training would be really good, equipping them to know what to expect and maybe how to deal with it. There should be more information on the different

dementia types. Some of the people in the group would absolutely access counselling and training. More help on how to deal with challenging behaviour should be available and would be very helpful.

Group of 11 Carers

Counselling could be good, and counselling for the family could be good. Some of the group had already accessed counselling and found it helpful.

Some of the group would have liked training about dementia, but some thought that the disease happens so differently for everyone so people could not have been told what to expect – they have learned to understand and manage by looking after their loved one.

Would You Be Happy to Be Part of An Opt-Out System with Alzheimer's Society?

Key Themes:

- Yes!

Qualitative Data

I'm not sure that I understand the implications of this.

Do not know what this is

Don't know what this is

'I'm not sure what this entails'

'Yes!'

A Group of 24 Carers and People Living with Dementia

Yes. We need proactive care and support.'

Group of 11 Carers

The premise of an opt-out scheme was explained in terms of how people were referred for support and people were extremely receptive to the idea.

Do You Know What the Alzheimer's Society Offer?

Key Themes:

- Generally, people who have used the AS, did know what they offer

Qualitative Data

'Yes... they are amazing.'

'Someone to talk to on the phone.'

'Support at the end of the phone.'

'I know who they are, but they are all telephone based, we want someone to proactively care and help. We just get left.'

'Yes, I have been in touch with them, and they have really helped.'

Group of 11 Carers

Everyone was already affiliated with the Alzheimer's Society so were aware of the support they offer.

A Group of 24 Carers and People Living with Dementia

This created a mixed response, some people did and others did not

What Help Would You Need When Deciding on A Care Home, If the Time Arises?

Key Themes:

- Raises a lot of questions
- Reliability of care home
- Cultural customs

Qualitative Data

'We are going through this season at the moment! I feel quite well informed and do feel that I am supported with this by my social worker and other people having gone through the process themselves.'

'Every bit of help possible. I would want a care home to have a proven track record of dementia support. Proof of support & doing everything possible to make the person's life a good one.'

'Firsthand experience from someone who has lived there and benefitted from being there.'

'I have promised my loved one I will not put her in a home. As and when I feel cannot look after her needs myself, I would prefer home help, but only if I cannot manage by myself due to health reasons. So, she can still see us each day to avoid any anxiety.'

'We find out about care homes via word of mouth, but Age UK have a fantastic booklet about what to look out for and which questions to ask.'

Group of 11 Carers

This was heavily debated. People absolutely wanted help choosing a care home, and expressed the following concerns:

- Queries raised about what does CQC (Care Quality Commission) actually mean? What does it actually do and regulate? It isn't a regular thing, so the group did not necessarily trust the ratings or see the value
- How do we know if the care home is a dementia specialist?
- How do we know if the care home offers respite?
- How do we know they will do what they say they do?

For this group, cultural differences were highlighted, and there were concerns that care homes may not adhere to cultural customs, such as specific dietary requirements - which would ensure the person living in the home would be comfortable.

There was a concern in needing to know that the care home was right for their loved one, and they could trust the home to do what was in the person's care plan and best interests not just from a medical and social care perspective, but from pastoral cultural perspectives too.

Are You Aware of How Assisted Technology Could Help You?

Key Themes:

- Inconsistency of awareness

Qualitative Data

'Yes.'

'No.'

'No.'

'No.'

'Yes, I know how that works.'

'Yes, I know how it could help. There was a flat set up at a support housing place that showcased all the things that assisted technology can do.'

How Do You Feel About Technology and What Do You Use It For?

Key Themes:

- Use of technology would be dependent on the person

Qualitative Data

'It is a great support. We have a Reminder Clock for mum and an Alexa. There are other ideas for mum, but the cost is a barrier.'

'I have limited knowledge. Technology scares me.'

'Not confident.'

'I need to learn more to understand the help it can provide.'

'I do use technology. My wife with dementia would prefer face to face'

Additional Information, Comments and Experiences

Key Themes:

- There is a lack of professional support
- People feel 'lost' – left to their own devices and feel there is no proactive support or a place they can turn to
- Stigma in the community, people are fearful of a diagnosis as there is not a particularly positive message that comes with dementia
- Importance of peer support
- Though peer support is invaluable, people still value medical and professional input in to care
- There are pathway inconsistencies and general confusion around what happens when you go for a diagnosis, and what happens afterwards
- There is a lack of faith in GP knowledge
- It's a very tough place to be and people feel left without support

Qualitative Data

'The most difficult thing on our journey is my dad's inability to understand mum's needs. The best support we could have is an "influencer" for my dad...providing he would allow one through the door! But a weekly visit from such a person could make all the difference. If this could be achieved, mum could potentially stay living at home. Instead, we are having to source residential care which as a family, is not our choice.'

'The waiting time for diagnosis is too long. The support prior to diagnosis is limited. The family are just left to get on with it.'

'It has been a struggle, a real struggle not knowing where to get help from but I have researched a lot on my own to understand and critically help mum in law. I am on this journey, a tough journey

that I would like to get help for others who may be struggling too, especially in our community (*Asian, Hindu*) where help is much needed.'

'I think I have memory issues but have been told by my GP years ago that it is anxiety so it must be that.'

'So many people don't want a diagnosis as there is fear around it, I do not want to get to a stage where I can't control my mind and have someone look after me 24/7. I am going for a diagnosis as I know I have memory issues, but as soon as I have that diagnosis I am going to Switzerland (*where assisted dying is legal*).'

'My husband has recently died, and he had dementia. The GP had no idea what to do and openly said so. They provided no help at all.'

'We are really well connected as we have Brampton, and the Love to Move group has a WhatsApp group so I can contact them when I am having a bad time. We feel quite lonely, but we are happy with the support we are getting.'

'My wife has been put on the waitlist and her appointment is in April 2025. They thought she had Hydrocephalus and had a lumbar puncture which confirmed it wasn't that, and she has been referred for dementia. I was not given any form of support or signposted to anything.'

'The group we come to in our community is amazing and I don't know what I would do without it, but it's not medical or professional support when we need it. We can share notes and talk to each other, but it doesn't go any further than that.'

'There needs to be more sympathy from GPs.'

'I have been diagnosed with long term memory loss but am waiting for a diagnosis of dementia. I come to the DRC but cannot access the groups as I don't have a diagnosis. But I come and chat to people and talk to the dementia advisors. I have been told I have long term memory loss by a care co-ordinator at the mental health place in Peterborough and she referred me here. I don't feel very informed about the condition at all, only the information that I can pick up at the DRC. If I was in crisis I would call my support worker. Regular checks are really important., I feel lost without the contact. I only leave the house twice a week and I have a Personality Disorder too. I don't tell anyone that. I am not sure if I would use a dementia buddy system. I am very aware of how assisted technology can help me. I use the internet and technology a fair amount. I feel very forgotten by the council, why are they cutting the service in Peterborough?'

'The DRC is a safe space and without it we would be lost and very isolated. It's a really good hub as other organisations can come in and talk to us about things.'

My wife has been told by the GP that she has dementia, but they said don't bother going through the MAS because it'll take you two years to find out which one. Because I do not know which type of dementia she has, I cannot research and investigate or prepare any support. I struggle to cope day to day, and I have not been given any support. I just struggles how to manage with my wife, and I try not to lose my patience. My wife doesn't know she has dementia, and I am very much caring for her. I am happy to talk about dementia talk to people about it but I realise there is a stigma. My GP did not tell me about any support and I am not in regular contact with any services.'

‘I went to the GP for my memory issues, and I waited ten months for a brain scan which I have at the end of November. The waitlist didn't bother me as I knew if it was urgent then I would have been rushed through. ‘

‘The waitlist is FAR too long.’

A lady that we spoke with had a lot of questions about dementia, and questions surrounding how do you know if you have it, and it isn't just age related memory concerns? Assumed that medication was just tranquilizers and was not aware that medications were available that slowed the disease (in some cases). Had very 'old school' views of what dementia is but also was very intrigued to understand more. A lack of understanding and knowledge.

A Group of 15 People

What is the difference between all the dementias? How do you know when you have it, who do you speak to? What's the point in calling the GP?? There's still so much stigma around it. Also, around mental health too.

A Group of 11 Carers

What could improve support is more culturally informed care in the system. For example, more South Asian or Indian people in the workforce. People who can speak differing languages properly (i.e. Gujarati is not one language, it is full of multiple dialects). It has been difficult when there have been translators involved as they have not translated properly or used the correct language – the family member should be allowed to help. There needs to be an acknowledgement of differing cultures. There is an Asian menu in the hospital, but no one seems to make you aware. People need to take the time to ask the family members how to care for their elders in a sensitive way. It isn't just a different culture that is the problem, the nature of dementia means the patient is experiencing confusion and these cultural awarenesses can really help to soothe them.

Their experience of hospitals is that the staff do not do personal care if you (the family member) are present. Also, the hospital is not dementia informed, several people's family members had been in hospital and had not had the service of a dementia champion to help.

The idea of peer support, dementia buddies, and/or dementia champions were all very well received. Everyone stated that it was very important to learn and share experiences with other people who are going through or have been through the same as you. Family are not always supportive or understanding.

People had not been told or educated about power of attorney and lasting power of attorney (a power of attorney (POA) is a legal document that gives someone the right to manage another person's affairs, while a lasting power of attorney is a type of POA that can take effect when the donor loses mental capacity). It was vitally important that people are informed about what this is and what happens if you don't have it in place.

The most important things and key takeaways are:

- Culturally informed care
- Care homes
- Peer support/dementia buddies/dementia champions
- Power of attorney
- Understanding and knowing which benefits and other social care you are entitled to

Notes from the Dementia Advisory Group.

The Dementia Advisory Group are a group of people living with dementia and carers who work alongside The SUN Network and the ICB to help inform the dementia pathway from a lived experience perspective.

Dementia vs. Cancer

If someone has a suspected cancer, they are fast-tracked through the system and given an appointment in weeks. Dementia is the biggest killer in the UK, so why is it not treated with the urgency of cancer and other diseases? If someone goes to the GP they are then put on a 14 month wait list with no access to treatment (medication) or other support. It is so important to get medication in some instances, and also not to give wrong medications (anti-psychotics for certain types i.e. Lewy-body with dementia, that can kill). People's treatment is being delayed because of a waitlist when actually a diagnosis can improve quality of life where medication can be given. There was an acknowledgement that it yes you can die from cancer, but dementia is a slow death. However timely diagnosis can improve quality of life QoL in people's last years. In most circumstances, the diagnosis is given to late. The velocity and impact on people's livelihoods doesn't seem to be loud enough in the system.

Make Sure the Public Know What a Diagnosis Means

Some people have not had a formal diagnosis, and some people are told by GPs they have dementia but don't go through the waitlist as it' will take too long (fundamentally that isn't right, it is a person's right to choose whether they go through the diagnosis process or not). It is so important to get a correct diagnosis, so you know how to manage and treat. We discussed doing a 'What does diagnosis mean to you?' video that can be shared county wide.

Diagnosis Process

What even is it? Why is it different depending on which type of practitioner you see? When do you get a brain scan? When do you not? Why? How can a paper questionnaire diagnose a brain disease? Does this create a misdiagnosis?

GP Education

There are concerns that GPs are not specialist enough to be able to diagnose any dementia.

Conclusion

Thank you to every person who took the time to speak with The SUN Network or fill in an online survey, it has been very humbling to hear people's stories and experiences, and to learn of the incredible resilience that people living with and caring for people with dementia have.

There is an overwhelming sense of an inequity in the access to, and experience of the dementia pathway – depending on where a person lives. This ranges from pre-diagnostic care all the way through to post diagnostic – living well and dying well with dementia. It also depends on if a person is known to services, whether they have a social worker, a care coordinator, or are known to mental health services. The latter group tend to get more support and access to knowledge than others. To provide some examples and context to this:

- If you live in Peterborough, you have/had access to the Dementia Resource Centre, a place where people could receive a diagnosis, be instantly referred to the Alzheimer's Society, and have a hub where they can go and access groups and invaluable peer support. Also, near unlimited access to a dementia advisor

- Conversely, if you live outside of Peterborough, and possibly didn't get diagnosed through MAS or even if you did, you may **not**
 - Receive a diagnosis as the GP may not have the appropriate knowledge or understanding (though this can still happen in Peterborough)
 - Be referred to the Alzheimer's Society (highly likely) and thus not have information on local groups, additional information, timely information, proactive care and support, crisis support, a listening ear, information about what dementia is
 - Be known to the system and support services as someone living with or caring for someone with dementia
 - Feel like you have any form of support network around you – and have to do a lot of research yourself in a very tumultuous time

This difference in levels of support outside of Peterborough is also highlighted through people's feedback. For example – St Ives have a wonderful peer support network and multiple groups, somewhere like Doddington – far, far less so.

Overall, there is a feeling that people quite often felt lost and do not know where to turn in the system for help. There is a lack of personalised care, and it is not a one size fits all – it is a challenge to provide one service that will suit everyone, therefore providing options is key i.e. timing of contact, mode of contact, digital access, counselling and training offerings.

People don't have faith in GPs to be able to support or advise on what to do when people are in need, and the majority of people do not know who to turn to in a crisis. The carers are severely burnt out and there seems to very much be an 'if you know, you know' lottery of where to turn for help and support. And even if people do have excellent peer support, they are lacking in professional support. How do we, as a system, replicate the feel of the DRC in the community? Where people have access to peers and dementia advisors, amongst other professionals.

There are positives to the care people are receiving. Generally, people who have used and are using the Alzheimer's Society find that support invaluable. People who are accessing peer support also say they would be at crisis point without that help. If people are known to people in the system who are knowledgeable, then they seem to feel calmer and more supported.

Recommendations

- **Crisis Care**
 - Currently there is no specialist dementia crisis care pathway – there is an opportunity to co-produce what this looks like. Mainly for carers
 - Emergency carer support is needed
 - Physical support needed; can the JET function be adapted?
- **Streamlining of the Diagnosis Process**
 - Create a standardised route to care, where everyone is given the same route to an assessment. This will ensure that everyone is entitled to a diagnosis, and when they have had this – they have access to AS proactive support (this may not apply to people being diagnosed in care homes, due to existing support and progression of the disease)
 - This should include the right to a care plan, information about lasting power of attorney and wills.
- **Care Homes**
 - We could lean on existing resources (i.e. Age UK) to help people look for a care home.

- Create a frequently asked questions document that people can refer to regarding care homes i.e. how do I know if they're dementia informed? How do I know if they have respite services? It may be too much to create a central point where people can upload this information to
- Have Lived Experience conversations about what it is that people need, and work out how this can be facilitated
- **Alzheimer's Society**
 - Introduce an opt-out system. This could reduce feelings of isolation, feeling lost, not having access to correct information, and create equity in access to care resulting in people feeling they have agency within their/their loved one's care
 - The Alzheimer's Society have researched the best time for people to be contacted after a diagnosis, and this sat at 12 weeks post diagnosis. Please contact Wendy Dunn for further detailed information
 - Co-produce what the post diagnosis offering from AS looks like (thinking about level of information, time of information, personalised information, care plans, etc.)
- **Dementia Buddy/Champions**
 - Co-produce what the role of a dementia buddy is, and discuss how a dementia community could be created
 - Peer Support is invaluable to a lot of people, how could we replicate the St Ives model in multiple places? Dementia advisors could visit groups, alongside champions, buddies, and multiple other organisations – this could resolve the issue of people feeling 'lost and left' and provide people with that all important feel of a proactive route into their care
 - Consideration in to how the above could weave in with Dementia Advisors in local GP surgeries (it gives the option of meeting people where they are at)
- **Carer Support**
 - Provide a counselling service for carers
 - Provide the option to have training about what dementia is and how it may affect someone, how to deal with unhelpful or challenging behaviours. Opportunity to co-produce this so it really meets the needs of the carer
 - Create some form of emergency respite
- **Proactive Care and Regular Reviews**
 - People want to be contacted at a time that is right for them and also to not have to look for the information themselves. 'Opt out' with Alzheimer's Society will help with this
 - Having a regular review with a specialist is really crucial for people. Co-producing what this could look like will give people the ability to decide what they need, in context of other changes within this pathway
- **Information Pre-Diagnosis**
 - Co-produce an initiative that enables people to access help and care whilst waiting for a diagnosis (Alzheimer's opt out?). Arm people with information to have agency over their care and research things like Lasting Power of Attorney and the Alzheimer's Society, early on
- **Practitioner and Professional Education**
 - From GPs to library workers – mandatory training for some staff in what dementia is and how it affects people – depending on their job role
 - Creating a Dementia Champion within a workplace can inform other staff on management and support of people living with dementia

- Frontline workers to have access to a central point of information to signpost people to local groups and support (HAY?)
- **Personalised Care**
 - Not a one size fits all and people would like to be asked how they would like to be contacted, treated, communicated with, and spoken to – with cultural needs being met
 - Amendment of the MAS appointment to cater to differing needs
 - Dementia Passport for use within healthcare and when people are going to hospital
- **Appreciation of the Severity of the Disease**
 - Someone to call, when people are in burnout – who understand, a Dementia Specialist Team, an Admiral Nurse, a Dementia Navigator?
 - Reduce waitlists and ensure people are seen in a way that matches the seriousness of the disease
 - Provide support earlier
- **Raise Awareness in the Community**
 - Dementia Champions and buddies to go to any local groups and help reduce stigma
 - Make a 'what diagnosis means to me' video
- **Post Diagnostic Care**
 - A what happens next document
 - A what to expect document
 - People to be asked what information they want, and when