Bournemouth University

WAITING WELL

The Support and Information Needs of Family Carers Prior to a Dementia Diagnosis

Research Report

January 2026

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NIHR | National Institute for Health and Care Research

Executive Summary

Context

In Dorset, the average wait from GP referral to a dementia diagnosis is around eight months. However, delays often begin much earlier due to uncertainty about symptoms and barriers to seeking help. Nationally, Alzheimer's UK reports that 37% of people wait over a year before approaching their GP with concerns, and only half receive a formal diagnosis within a year of seeking help.[1]

During this period, **family carers play a pivotal but often invisible role.** They are often the first to recognise early symptoms, encourage or initiate help-seeking, and provide ongoing support while waiting for a diagnosis. Despite this, people living with undiagnosed dementia and their carers receive little or no formal support. This leaves families managing without early guidance, increasing the risk of crises, avoidable hospital admissions, and carer burnout.

The *Waiting Well* project draws directly from carers' lived experiences. It presents the key barriers families encounter when seeking help for early dementia symptoms and the information and support family carers say they need much earlier, prior to a formal diagnosis.

1. Key Barriers in the Diagnostic Journey

1.1 Recognising Symptoms

Families lack clear, accessible guidance on the early signs of dementia and when to seek help. Many are unsure how to describe subtle or fluctuating changes in a way that will be taken seriously by GPs, or how to raise concerns sensitively with a loved one who may be in denial or reluctant to seek help.

1.2 Seeking Help at the GP

Families encounter the most barriers when seeking help at the GP, delaying access to timely support. Key barriers include:

- **Patient confidentiality constraints** and lack of guidance on how carers can raise concerns within confidentiality rules or follow the outcome of help-seeking appointments.
- **Difficulty conveying the seriousness of changes,** particularly when symptoms are masked or dismissed as normal ageing.
- **Lack of guidance when a family member refuses to seek help,** leaving carers isolated and unsure how to act despite clear concerns.
- **Unclear next steps following non-referral,** including when and how to re-present concerns.
- **Poor signposting to community support**, with families often not made aware of the help available prior to diagnosis.

1. 3 Post Diagnosis Gaps

While post-diagnosis support is generally positive, carers identified two significant gaps:

- **Lack of guidance following Mild Cognitive Impairment (MCI) diagnoses,** resulting in uncertainty about monitoring changes and when to seek reassessment.
- **Inconsistent post-diagnosis referrals,** particularly where diagnoses occur privately, outside the local area, or prior to relocation.

2. Pre-Diagnosis Information Needs

Carers report feeling overwhelmed by the information provided after diagnosis. They say much of this information and support should be given much earlier and could help reduce avoidable hospital admissions, prevent carer burnout, and support earlier planning. Families want support to:

- **Plan for the future**, including legal and financial matters, service availability, and contingency planning.
- **Overcome barriers,** such as GP access, denial, refusal of care, and changes in behaviour or personality.
- **Provide good care now**, including communication, nutrition, hydration, and managing associated health complications.
- **Build resilience,** through respite options, peer support, and development of coping strategies.

Because family carers are often outside formal care pathways before diagnosis, information and support must be actively and consistently signposted across primary care, community services, and voluntary sector settings to ensure families are reached earlier.

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[1] Alzheimer's Research UK. 2025. Seeing the Unseen: Rethinking Dementia Diagnosis.

Contents

Key Findings

Introduction

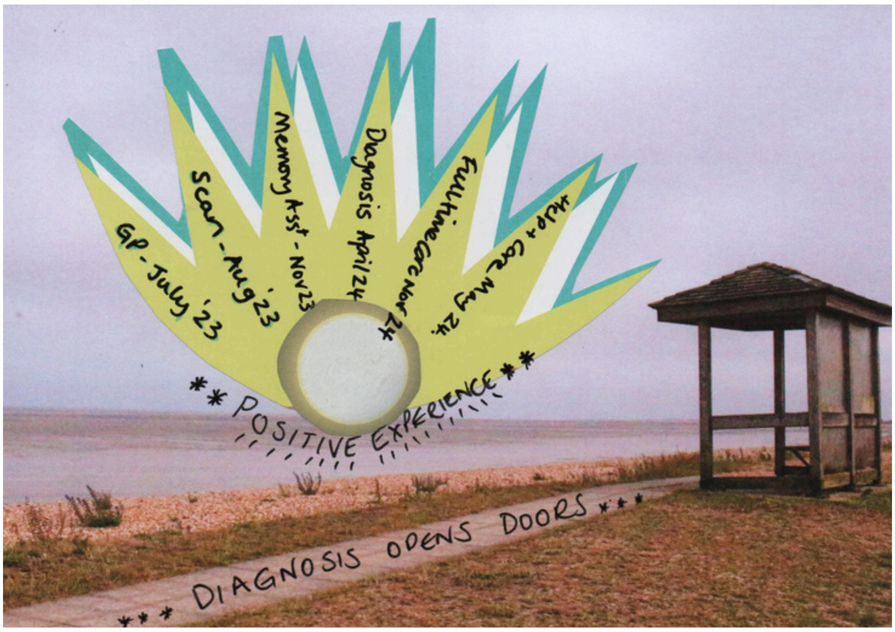
In Dorset, the wait from GP referral to memory assessment and diagnosis is typically around eight months but varies depending on how cognitive issues present and the pathways people follow. This is consistent with national experiences. In 2025, Alzheimer's UK reported that only 51% of people received a diagnosis within a year of seeking help, with 22% waiting more than two years. Notably, 37% had waited over a year from first having concerns before approaching their GP, and although most were referred immediately, some faced a further six-month delay before referral.[2]

For many, the journey from initial concern to receiving a diagnosis is not straightforward. Delays, barriers, and bottlenecks can leave families without the information or support they need. Timely diagnosis remains critical to helping families understand the specific type of dementia involved and what to expect, to plan for care, and access support and treatments that may slow progression. But while efforts to improve diagnostic timelines continue, there remains an immediate need to provide support and information for those waiting for a diagnosis.

The Waiting Well research project was developed by Help & Care and Bournemouth University as part of the NIHR ARC Wessex Capacity Building in Social Care Research initiative. Help & Care operate Dorset's Dementia Coordinator Service. Working with NHS colleagues as part of the Dementia Pathway Review, they identified a gap in pre-diagnosis support and as a result launched a pilot in April 2025 within their existing service, to provide continuous support before, during and after a dementia diagnosis.

The Waiting Well project ran in parallel to this new service to explore carer experiences of the diagnostic pathway and identify what support they needed earlier. The research focused on carers because they are often invisible but play a central role in recognising symptoms, seeking help, and coordinating care.

This report highlights the key barriers carers experience during the pre-diagnosis stage and the information and support carers tell us they need much earlier when supporting a loved one waiting for a diagnosis.



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[2] Alzheimer's Research UK. 2025. Seeing the Unseen: Rethinking Dementia Diagnosis.

Methodology

Seeking a diagnosis is a shared experience. While symptoms affect one person, their impact is felt across family and friends. Recognising this, we adopted an inclusive approach that allowed for participation from anyone waiting for an assessment themselves or already diagnosed, family carers and wider informal networks, including adult grandchildren and friends who may support someone but do not identify as carers.

A Multi-Sited Community Approach

This study mapped the carer's experience of supporting someone from initial concerns through to eventual diagnosis. We identified key stages in the journey and where carers encountered barriers and delays. Data was gathered directly from carers to understand the process from their point of view.

Pre-diagnosis research with carers is challenging because few carers have accessed support at this stage and may not yet identify as a carer. To address this, we used a multi-sited approach that included 'listening posts' held at community events and carer groups; pop-up postcard making sessions; and two in-depth focus groups. We worked closely with local charities PramaLife and In Jolly Good Company to reach participants across a range of activities and locations in Dorset. Data collection ran over 7 months from May to November 2025.

Arts-Based Engagement

Arts-based activities can help participants express experiences that are hard to verbalise, allowing participants time to reflect and process strong emotions. Working with community artist Casey Brett, we invited participants to create A5 collage postcards expressing their pre-diagnosis experience, caring roles, and what they need to stay physically, emotionally, or mentally well. Participants were encouraged to write reflections and/or suggestions for improvements on the reverse. These postcards were later displayed locally as part of a community art exhibition.

Community Research Engagement

We used a multi-sited approach to reach carers in the community.

47 Carers

Spoken with in the community

2 Focus groups

Indepth discussions with 9 carers

7 pop-up postcard making sessions

9 community 'listening posts'

43 hours

in the community

112

postcards collected

Key Findings

1. Key Barriers in the Diagnostic Journey

The journey from experiencing initial symptoms to receiving a dementia diagnosis is not always straightforward. Individuals and the families that support them can encounter many barriers along the way that prevent them from getting a timely diagnosis.

We identified 4 key stages of the diagnostic journey where carers said they wanted further support and information: 1. Recognising symptoms prior to seeking help; 2. seeking help at the GP; 3. waiting for a Memory Assessment; and 4. diagnosis.

1.1 Recognising symptoms

The journey towards diagnosis begins well before raising concerns with a doctor. Alzheimer's UK suggest 1 in 3 people will wait over a year before seeking help. In our research, family carers identified 4 key barriers that stopped them seeking help sooner:

- **Difficulties recognising symptoms.** Participants were unsure of which changes in memory or behaviour could be considered early signs of dementia, and which were part of 'normal ageing' or other factors such as stress or bereavement.
- **Uncertainty on *when* to seek help.** Participants did not know at what point they should seek help, leading to delays in approaching healthcare professionals.
- **Uncertainty on how to communicate effectively.** Participants worried over how to describe observed changes in a way that would be taken seriously by GPs, particularly when symptoms might seem inconsistent or trivial.
- **Uncertainty over how to encourage someone to seek help.** Carers wanted guidance on how to raise the subject sensitively with the person they had concerns over, particularly when they refused to seek help or were in denial about symptoms.

Although checklists and online resources do exist, carers said they rarely encounter this information early in their journey — often searching online only when symptoms or behaviour have escalated significantly.

> *"What are the first signs we need to look out for? How do we know what to look for? Where is that information? It is not something you come across easily."*
>
> Couple seeking information on symptoms

> "*It's hard to get a Doctor's appointment and I don't want to waste the Doctor's time. How do you know it isn't just normal ageing? I'm in my 80s, and you've got to expect things to decline."*
>
> Person experiencing memory symptoms

1.2 Seeking Help at the GP

The GP is usually the first point of contact for memory or cognitive concerns. Initial assessments typically include blood tests and other investigations before referral to the Memory Assessment Service (MAS). Carers report encountering the greatest barriers at the GP stage. Those who were turned away at this stage often delayed seeking any further help until symptoms had significantly worsened or reached a crisis point.

Key barriers included:

- **Patient Confidentiality and GDPR.** Families were frustrated by being unable to share concerns with GPs due to confidentiality restrictions and being turned away by reception staff. No guidance was offered on how to raise concerns appropriately, leaving carers unsure of how to seek help or flag symptoms.
- **Denial or Refusal to Attend Appointments**. Carers struggled when the person experiencing symptoms refused to seek help or denied there was a problem. No practical advice or signposting to further support was given, with one carer recounting their GPs simply said, “everyone has free will”.
- **Dismissal or Masking of Symptoms.** Carers struggled to communicate the gravity of the situation. Concerns were not always taken seriously and symptoms were dismissed as ‘normal ageing’. In some cases, the person being supported masked symptoms during appointments, leading GPs to discount carers’ observations. As one carer sumarised, “It’s about being believed — this dismissive attitude really needs to change.”
- **Lack of Guidance on Next Steps.** When MAS referrals were not made, carers were rarely advised on what to do next, when to return, or whether a second opinion was possible.
- **Misdiagnosis.** Families supporting someone with young-onset dementia reported additional barriers, with symptoms frequently misattributed to stress or mental health issues. This is consistent with the existing literature.
- **Uncoordinated support.** While carers were struggling to raise concerns with the GP, other professionals encountered (e.g. paramedics, nurses, occupational therapists) sometimes recognised carers’ concerns but did not signpost them to relevant support or information, or share concerns with GPs. This contributed to feelings of isolation and fragmented care.

GPs consider multiple factors when deciding on whether to refer a patient to MAS. However, clearer guidance is needed on how carers can effectively communicate their concerns so their observations are taken into account.

Although strategies exist — such as registering as a carer or using symptom diaries — carers emphasise that this information needs to be proactively given at GP surgeries to help them overcome these barriers, as it is not something they come across on their own.

> *“If you’ve lived with someone for 50 years, you have a good idea when things are changing. We need to be listened to more”.*
>
> Carer for husband, post-diagnosis.

> *“You have to push it with your doctor. To keep going back to say ‘something is not right’”.*
>
> Carer for husband, post-diagnosis.

> *“Nan doesn’t want to seek help, forgets Doctors' appointments, doesn’t want carers coming in. How do you deal with this pre-diagnosis? Because officially, before diagnosis, they are still classed as ‘having capacity’”.*
>
> Supporting grandmother, pre-diagnosis.

1.3 Getting a Memory Assessment

Patients are referred to the Memory Assessment Service (MAS) for an initial assessment. They may then be referred on to a consultant and undergo further tests and scans before a diagnosis is made. In Dorset, the current waiting time from referral to MAS to receiving a dementia diagnosis is approximately eight months. People under 65 are fast-tracked through the system, but others face long periods of uncertainty.

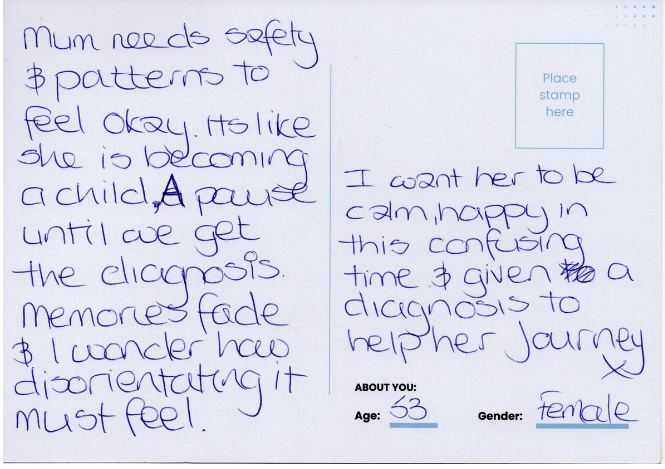
Although few barriers were reported at this stage, carers consistently described feeling unsupported during the lengthy waiting period.

- **Long waiting times.** Families find the uncertainty of waiting difficult to manage and sometimes fear that the referral has been lost or forgotten. They worry about how much the person they support may decline during this time and whether there is more they could be doing while waiting for assessment or diagnosis.
- **Language barriers.** Carers supporting someone whose first language is not English worry that language misunderstanding or poor translations could affect the accuracy of assessments. In one case, a carer sought a second opinion after recieving a non-specific dementia diagnosis abroad but was told by the GP that her mother would not be referred to MAS because she only spoke Spanish and was already on suitable medication.
- **Denial or refusal to attend.** Carers were not always aware that they could be included in MAS communications or that MAS teams have experience working with people who are in denial or reluctant to seek help. Many carers find it difficult to speak openly in front of the person they support and worry that MAS assessments do not capture a full or accurate picture as a result.
- **Lack of guidance following MCI diagnosis.** Families reported feeling unsupported following a Mild Cognitive Impairment (MCI) diagnosis. There are no treatment options and often no onward referrals. Carers want clearer guidance on next steps, including how to monitor symptoms, when to request a reassessment, and how best to support the person they care for.

> *"I feel very alone in this waiting period. It was 6 months to the Memory Assessment and now we have to wait 5 or 6 months to go back for the diagnosis"*
>
> Carer for parent, pre-diagnosis.

> *"When you get that diagnosis of MCI, you feel like the door has just closed a bit."*
>
> Carer for husband, MCI diagnosis.

> *"It took 18 months from first MAS assessment to a dementia diagnosis because the first time was MCI, but no one told us when to go back again. It was only when the physio, following a second fall, said we needed to go back that we did, and by then we'd lost the window for medical treatment."*
>
> Carer for husband, post-diagnosis.



Mum needs safety
& patterns to
feel okay. Its like
she is becoming
a child, A pause
until we get
the diagnosis.
Memories fade
& I wonder how
disorientating it
must feel.

I want her to be
calm, happy in
this confusing
time & given a
diagnosis to
help her Journey
x

ABOUT YOU:
Age: 53
Gender: Female

1.4 Diagnosis

There are over 400 types of dementia, with the four most common being vascular dementia, dementia with Lewy bodies, frontotemporal dementia and Alzheimer's. A diagnosis helps carers and the person they support understand how symptoms and disease progression are likely to manifest. This knowledge is essential for planning ahead and ensuring the best possible care. Although few barriers were reported at diagnosis, carers identified several areas where improvements could be made.

- **Diagnosis can feel overwhelming.** Carers describe feeling like "a rabbit in the headlights". There is a lot of information to take in at once. They are given a lot of leaflets and weblinks and expected to navigate the information themselves.
- **The information carers want is missing.** Carers describe spending hours searching online for answers to practical questions. The main thing they want to know is what they should do next. But even elements of the diagnosis sometimes need better explanation: "What does Stage 4 actually mean?" "What do the scan results show in practical terms?"
- **Inconsistent referral to post-diagnosis support.** Although a diagnosis should trigger a referral to the Dementia Coordination Service, some people slip through the gaps. This can happen when the diagnosis is made privately, in another county or country, or when someone moves to a new area and is unaware of local support.

"All of a sudden when you do get that diagnosis, it's so overwhelming with information that you're like 'where do I go from here?'"

Carer for parent, post-diagnosis.

"There was no support after diagnosis if you didn't want medication. We asked, 'so what can be done?' and were just told 'self-educate'...The information you're given is sporadic. We need a list of what do you do right now."

Carer for husband, post-diagnosis.

"There was a single point of failure. If you don't get picked up at diagnosis there's no one. It was only one year later, after diagnosis, when I approached the GP again that we were given the information about local carer groups."

Carer for husband, post-diagnosis.

2. Pre-Diagnosis Information Needs

Family carers feel overwhelmed with information and signposting following a diagnosis. They stress that this **information is needed much earlier, during the pre-diagnosis stage.** Early information and signposting could help reduce avoidable hospital admissions, prevent carer burnout, and support care planning. Carers want information to help them:

1. Plan for the future
2. Overcome barriers
3. Give good care now
4. Build resilience

Because family carers are often outside formal care pathways prior to diagnosis, **information and available support must be actively signposted at multiple points across the community** to maximise opportunities to reach families early.

> *"You don't know what you don't know–and nobody tells you."*
>
> Carer for parent, post-diagnosis.

> **"***Why doesn't the incontinence nurse tell you about bill reductions?"*
>
> Carer for parent, post-diagnosis.

2.1 Planing for the Future

Planning for future caring responsibilities is complex and often begins before a diagnosis is confirmed. Early planning is particularly important for legal and financial matters, yet many carers feel unprepared for this. This can be particularly challenging for spouses or partners who have not previously handled tasks such as banking, utilities, or legal arrangements. Some carers also face additional difficulties due to limited digital skills, making it harder to find information or manage online services.

Information and signposting that carers say would be helpful pre-diagnosis include:

- **What to prioritise as immediate next steps,** including what can be done before a diagnosis is confirmed.
- **Financial and legal advice,** including information on Wills, Trusts, Power of Attorney, managing joint and individual accounts, and overseeing utilities and bill payments.
- **Available services,** including when they become accessible, and how to access them.
- **Available benefits and financial support,** and guidance on how and when to apply.
- **How to set up safety nets,** including planning for the carer becoming unwell or managing risks such as wandering.

> *"The main thing that needs to change is how people and services respond when you're seeking information before diagnosis. There needs to be more information, to prepare, to know what to expect and what services are going to be available. But people look at you as if you are crazy by talking about dementia and seeking information before a diagnosis. This needs to change."*
>
> Carer for parent, pre-diagnosis.

2.2. Overcoming Barriers

Carers encounter a range of barriers in the pre-diagnosis stage. There are also common challenges associated with dementia that can emerge while waiting for a diagnosis. Carers want information to help them address these issues much earlier. Priorities include:

- **How to navigate the system and communicate effectively,** including how to ensure services listen to their concerns and how to respond to barriers encountered at primary care.
- **How to manage behavioural challenges,** including strategies for dealing with denial and refusal of care, violence and aggression, accusations of theft and paranoia, personality changes, and signposting to services that can help with these challenges prior to diagnosis.
- **How to support independence safely,** including practical guidance on driving, personal finance, and consent-based monitoring.

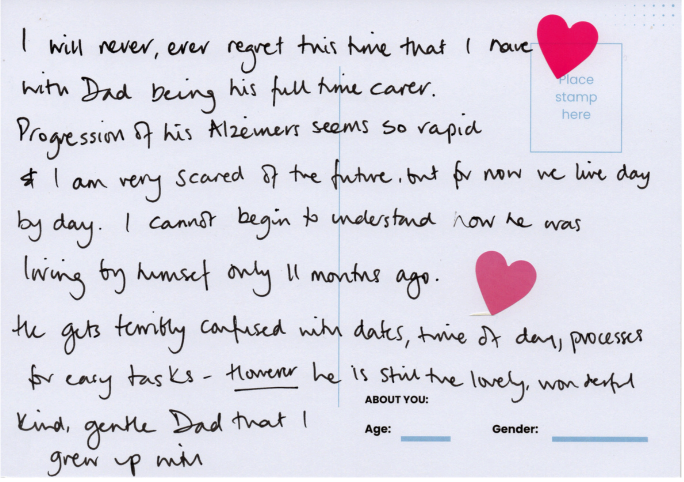
2.3. Giving Good Care Now

Carers want to provide the best possible care for the person they support. This requires information and advice on managing symptoms and physical needs, but also recognises the importance of maintaining relationships and emotional wellbeing. Carers identified five types of information they wanted while waiting for a diagnosis:

- **Explanation of MCI, dementia, and how it presents,** including how these conditions may progress, how to monitor change, and when to seek further assessment or support.
- **How to live well with dementia as a family,** including practical advice on how to communicate effectively, maintain shared activities, provide emotional support, and help the person they support live a happy and fulfilling life.
- **How to maintain good nutrition and hydration,** including practical strategies to encourage adequate intake, and how to recognise symptoms of dehydration or malnutrition.
- **Raising awareness of possible health complications,** and how to recognise symptoms**.** For example, carers reported frustration that they were not informed earlier about the increased risk of urinary tract infections (UTIs), which resulted in potentially avoidable hospital admissions.
- **How to manage comorbidities,** such as hypertension or diabetes and other long-term conditions alongside dementia. Carers reported that information often focused on the condition considered more serious, without explaining how dementia may complicate condition management or offering practical strategies to address this.

> *"Show us, the carers, the best way to make them feel a person. I'd like an expert to give me some ideas on how to make him happy, fulfilled and have a purpose. I don't want him to feel empty and [think] what's the point anymore?... And somebody to tell me how to talk to him, so we can have a conversation and it's not me telling him how to do things all the time."*
>
> Carer for husband, pre-diagnosis.

> *"It is 16 months since I raised my concerns with my GP, who I found unhelpful. Maybe a second opinion would be good. Also more information would be good — [husband] was hospitalised with a urinary infection recently. I now know to encourage him to drink more."*
>
> Carer for hisband, pre-diagnosis.



I will never, ever regret this time that I have
with Dad being his full time carer.
Progression of his Alzeimers seems so rapid
& I am very scared of the future. but for now we live day
by day. I cannot begin to understand how he was
living by himself only 11 months ago.
He gets terribly confused with dates, time of day, processes
for easy tasks - However he is still the lovely, wonderful
Kind, gentle Dad that I
grew up with

Place stamp here

ABOUT YOU:

Age:

Gender:

2.4 Building Resilience

Carers experience profound emotional strain, likening dementia to “losing someone who is still there.” Role reversal and personality changes amplify feelings of grief and guilt. These emotions often coexist with practical challenges, creating daily pressure.

Carers say they need support and information to help them deal with these challenges before they are overwhelmed.

This should include:

- **Signposting to available respite options,** including how to access funded options, make use of community social groups, and build opportunities for carers to take a break.
- **Developing healthy coping strategies,** including support to manage emotions such as grief, establish healthy boundaries, build resilience, and take time for themselves or ask for help without guilt.
- **Signposting to peer support.** Carers say the best support for carers is often other carers. This support can take the form of community groups, online support, or phone calls from befrienders, to reduce isolation and offer emotional support.
- **Positive stories.** Facing a future as a carer for someone with dementia can be daunting. Families starting out on this journey ask for a more balanced representation that show positive times are still possible in the future.

> *“I know it’s going to be hard but it would be good to hear something positive, to think that there might be positives to what is coming, that there might be more than it just going to be bad and downhill from here on.”*
>
> Carer for parent, pre-diagnosis.

> *“There's just so many things you have to be thinking about all the time. It's a bit like being in the stocks and people keep throwing mud pies at you. You can't move. You can't run away. And somehow you've got to either duck or cope with it.”*
>
> Carer for husband, pre-diagnosis.

> *“It’s hard asking if you want a break. As a carer you feel you’re not entitled to it. Charities do help, providing respite care, but you shouldn’t have to rely on charities, you can only stretch these services so far”.*
>
> Carer for husband, post-diagnosis.

3. Support Needs Identified by Carers

Carers consistently described the need for support that is timely, accessible, and adaptable to changing circumstances. This should include:

- **Right information at the right time:** Carers need clear, timely, practical guidance to confidently make informed decisions throughout the pre-diagnosis phase.
- **Single point of contact:** Carers often feel overwhelmed. A single point of contact can support carers to identify immediate priorities and navigate complex systems — especially when time or digital confidence is limited.
- **Adaptable support:** Dementia is progressive, so carers need services that provide evolving advice, resources and reassurance as their own needs and the needs of the person they support change.
- **Inclusive communities:** Dementia-friendly groups, activities and communities that do not require a diagnosis can help carers and the people they support stay active, socially connected, and access opportunities for respite and support. This is particularly important for families without a diagnosis — whether due to reluctance to seek help or long referral waiting times — who often feel unsupported and isolated.

4. Implications: Why Does Pre-Diagnosis Support Matter?

The Alzheimer's Society estimates that 1 in 3 people living with dementia do not have a diagnosis.[3] Our research shows this can be due to reluctance to seek help, uncertainty about symptoms, barriers when raising concerns, and long waiting times for diagnosis.

Because the current system is structured around diagnosis, **undiagnosed individuals and their carers are often overlooked.** This leaves families supporting loved ones without guidance, increasing the risk of crises, avoidable hospital admissions, and carer burnout. Reaching families earlier has the potential to prevent these outcomes and improve well-being throughout the dementia journey.

Achieving this requires a coordinated, community-wide approach to ensure that the right people receive the right information at the right time. This must include proactive signposting, to reach families who may not yet identify as 'carers' and "don't know what they don't know".

Recommendations

For Commissioners & System Leads:

- Make pre-diagnosis support a core element of the dementia pathway.
- Strengthen integration between primary care, Memory Assessment Services (MAS), local charities and community groups.

For Primary Care:

- Develop carer-centred guidance for raising concerns and overcoming barriers.
- Provide clear "next step" pathways when a referral is not made.
- Improve recognition of carers' insights and the risk of symptom masking.

For Community & Charity Organisations:

- Expand inclusive, dementia-friendly activities that offer support and advice without requiring a diagnosis.
- Increase proactive signposting, recognising that carers often "don't know what they don't know."

For All Professionals:

- Support earlier conversations about planning, safety, and resilience.
- Recognise and validate carers' emotional and practical needs.

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[3] Alzheimer's Society. 2024. https://www.alzheimers.org.uk/get-involved/our-campaigns/improve-dementia-diagnosis

The *Waiting Well* research project was developed by Help & Care and Bournemouth University as part of the Researcher In Residence programme in the NIHR ARC Wessex Capacity Building in Social Care Research project. It was supported by project partners PramaLife and In Jolly Good Company, and community artist Casey Brett.

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Contact

For further information, please contact the author of this report, Dr Natalie Djohari, **ndjohari@bournemouth.ac.uk**