Waiting Well

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

Key Findings, Jan 2026

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 frequently the first to recognise early symptoms, encourage or initiate help-seeking, and provide ongoing support while waiting for a diagnosis. Despite this, most information and support services focus on the post-diagnosis stage, leaving families with little guidance before this.

What Were the Aims of the Research?

The Waiting Well project explored the pre-diagnosis experience from family carers' perspectives. Its aim was to identify where earlier information, guidance, and support could help people obtain a timelier diagnosis, overcome common barriers, and improve the health and well-being of both carers and those they support.

Grounded in Carer Experiences

Our research findings are based directly on what family carers told us they need, the barriers they face, and the information gaps they encountered.

A multi-sited community approach was used to reach family carers who may not yet identify as 'carers' and those not yet given a referral. This included:

- 9 Listening posts at community and carer events.
- 7 Postcard making sessions encouraging carers to creatively reflect on their
- experiences.
- 2 Focus groups with carers at different stages of the diagnosis pathway.
- Conversations with 47 carers from the pre- and post-diagnosis stage.

This inclusive design provided insight into the lived experience of families waiting for a diagnosis and allowed us to map key barriers and opportunities for early intervention.

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

This document shares the key findings from the Waiting Well research project. It outlines the key barriers families tell us they encounter when seeking help for dementia symptoms, and the information and support family carers say they need much earlier, before a formal diagnosis.

1. Key Barriers in the Diagnostic Journey

1.1 Recognising Symptoms and Encouraging Help-Seeking

Families lack clear guidance on the early signs of dementia and when to seek help. They worried over how to describe changes in a way that would be taken seriously by GPs, especially when symptoms seemed subtle, inconsistent, or easily dismissed. They also wanted support on how to raise concerns sensitively with the person they cared for, particularly when they were in denial or reluctant to seek help. Although checklists and online resources exist, carers rarely encounter this information early in their journey — often searching online only when symptoms or behaviour have escalated.

“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.

1.2 Seeking Help at the GP

Families encounter the most barriers when first seeking help at the GP. This prevents them from getting timely help for a loved one. Key barriers included:

- **Patient confidentiality barriers.** There was often a lack of guidance on how to raise concerns within confidentiality rules. As a result, family members struggled to pass their concerns to a GP or follow the outcome of help-seeking appointments.
- **Difficulty conveying the seriousness of changes**. Family carers struggled to communicate the significance of observed changes and felt their concerns were not believed or were dismissed as “normal ageing,” particularly when loved ones masked symptoms.
- **Lack of guidance when a family member refuses to seek help.** Despite observing clear symptoms, carers felt unheard, isolated, and unsure of how to raise concerns when the person they were supporting refused to seek help.
- **Unclear next steps after a non-referral.** When referrals to the Memory Assessment Service (MAS) were not made, carers were left without guidance on what to do next or when to return for further support.
- **Poor signposting to available community support.** Although community support does exist, families were not made aware of these by GPs and other healthcare professionals prior to a diagnosis.

“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.

“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.

While post-diagnosis support and information were generally good, two significant gaps were noted by carers:

- **Lack of guidance following Mild Cognitive Impairment (MCI) diagnoses.** Some carers reported no clear guidance on how to monitor changes or when to return for further assessment after an MCI diagnosis, leading to delays in seeking further help.
- **Gaps in post-diagnosis referrals.** Some families were not referred to post-diagnosis support services, particularly where diagnoses were made privately, outside the county or country, or when families had recently moved into the area.

“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.

2. Pre-Diagnosis Information Needs

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

- **Plan for the future**: Legal/financial advice; the availability of services and how to access them now or in the future; and how to set up safety nets (i.e for carer sickness or wandering).
- **Overcome barriers:** Guidance on how to navigate barriers at the GP, deal with challenges such as denial and refusal of care, and address changes in personality and behaviour.
- **Provide good care now:** Practical advice on how to live well day to day, including how to communicate effectively; ensure good hydration and nutrition; recognise and prevent common complications (such as UTIs); and manage comorbidities.
- **Build resilience:** Guidance on how to access respite options; develop healthy coping strategies; and signposting to peer support.

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

“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

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.

“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.

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.** 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.

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.

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.

This study is funded by the National Institute for Health and Care Research ARC Wessex. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care.

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