

WAITING WELL:

What support do families need while waiting for a dementia diagnosis?

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Introduction

In Dorset, the **average wait from GP referral to dementia diagnosis is around eight months**. This is longer than the national average and reflects the county's coastal location and older population, as higher numbers of people retire to the area, increasing pressure on diagnostic services.

During the pre-diagnosis stage, **family and informal carers play a pivotal but often invisible role**. They are frequently the first to recognise early symptoms, encourage or initiate help-seeking, and provide essential support while awaiting diagnosis.

Despite this, **information and support is focused on the post-diagnosis stage, leaving families with little guidance and support during the long waiting period**.

Objective

The *Waiting Well* project focused on the pre-diagnosis experiences of families and informal carers. It sought to identify:

- What barriers families/informal carers encounter when seeking help for someone experiencing early dementia symptoms?
- What information and support families/informal carers say they needed much earlier?

Methodology

A multi-sited approach was used to reach families in the community, including those who may not identify as 'carers'. Participation was open to anyone supporting someone with dementia symptoms with or without a diagnosis.

- 9 'listening posts' at community events and carer groups.
- 7 pop-up creative postcard making sessions.
- 2 focus groups.

 Conversations with 47 carers.

112 postcards collected.



What support do families need while waiting for a dementia diagnosis?

Help to overcome barriers when raising concerns:

Families faced the most barriers when contacting GP surgeries and wanted clear guidance on:

- Raising concerns within patient confidentiality rules.
- Ensuring concerns are taken seriously, particularly when the supported person masks symptoms.
- Accessing support/information when someone refuses help or does not acknowledge their symptoms.
- Next steps after non-referral or a Mild Cognitive Impairment (MCI) diagnosis (i.e when to return and signposting to available support).

Key information and support needed earlier:

- Practical information on financial and legal planning, available services, and safety planning (i.e if carer gets sick).
- Guidance on managing health and complications (nutrition, hydration, UTIs, managing coexisting health conditions).
- Responding to behaviour changes (i.e aggression, accusations, wandering) and when/how to seek further help.
- Respite options, healthy coping strategies, and peer support.

Impact- what if it works?

Proactive, targeted support and information for families in the pre-diagnosis stage has the potential to:

- **reduce the barriers that prevent access to a timely diagnosis.**
- **reduce avoidable hospital admissions (i.e for UTIs, and at crisis point).**
- **prevent carer burnout and ill health.**
- **empower and support families to provide the best care that they can at home.**

This can be achieved by providing families and informal carers with the information they need earlier and reducing the barriers encountered when seeking help from GPs.

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