

Primary Health Network Dementia Support Pathways Initiative

Briefing paper for people living with dementia, carers, and former carers.

Thank you for expressing interest to participate in this consultation.

This document provides important information that can help you prepare to contribute to the Primary Health Network Dementia Support Pathways initiative.

If you have any questions or are unsure about anything in this paper, please contact **Jackie Hayes (Team Leader Consumer Engagement)** on 0490 427 779 or jackie.hayes@dementia.org.au.

Introduction

The Aged Care Royal Commission reported that people living with dementia experience challenges accessing an appropriate diagnosis and early support tools or resources. To improve this, Dementia Australia is supporting Primary Health Networks across Australia to understand the early support and diagnosis needs of people living with dementia, their family and carers.

The aim of this project is to inform the development of better local dementia diagnosis and support pathways.

Primary Health Networks (PHNs) work closely with GPs, hospitals, allied health professionals and aged care providers in local regions. They connect health services to ensure that people have access to high-quality services in their communities.

Ideally, PHNs should support people living with dementia to:

- understand their condition and current care needs;
- navigate appropriate service and care options in their community;
- cover the support needs areas of the dementia journey;
- build knowledge so people living with dementia can remain in the community as long as possible; and
- build the knowledge of Health Professionals about dementia and how they can best support their patients.

This project is about PHNs understanding an 'ideal pathway' for someone living with dementia to gain a diagnosis and the early supports people need for quality care.

This is why we need to hear from you. We want you to share with us what the early support and diagnosis needs are for people living with dementia, their family and carers.

Ways People Living with Dementia, Carers and Former Carers can participate:

There are a few ways that you can participate in providing feedback through this consultation.

You may participate in an:

- Online focus group (individual or group);
- In-person focus group (for eligible locations*); or
- Complete a short online form (5 mins)

Dementia Australia's Consumer Engagement Coordinators will work with you to understand which option might suit you and your circumstance best.

*For some participants, Consumer Engagement Coordinators will reach out to you specifically if you reside in an eligible location for an in-person focus group. If you are unable to attend in person at the specific time or would prefer an online session, an online alternative may be arranged via Zoom or Microsoft Teams.

For each contribution option, you will be provided the opportunity to share responses to the following prompts:

- What tools and resources for diagnosis and early support are currently available to people living with dementia? (Do you know of any specific resources that are particularly valuable?)
- What are the challenges for people living with dementia in gaining a diagnosis through their GP?
- What are the challenges for people living with dementia in accessing the supports they need through their GP or other health care professional?
- Thinking about the 'ideal pathway' for someone living with dementia to gain a diagnosis and early supports for their care, what should be included?
- What resources would help a person living with dementia early in their diagnosis journey?
- What phone call help lines are you aware of that can help people living with Dementia access a diagnosis or early support? Please list the helplines you are familiar with / that you use?
- Are these help lines valuable? What could be changed / improved?
- What were some of the thoughts and feelings you had during the diagnosis process? How could the diagnosis experience have been made easier for a person living with dementia or a carer?

What will happen following your contribution to the initiative?

Following the focus group:

1. Members of the Consumer Engagement team will be available to answer any questions you might have
2. Your responses will be used to develop recommendations to Primary Health Networks that will inform enhancements to their dementia support pathways
3. Your responses may be used to support Dementia Australia submissions
4. Your information will be kept confidential and your name or contact information will not be shared further
5. You will be invited to join any further conversations on this topic should future consultation be required
6. If you require any extra support following this consultation, please contact the National Dementia Helpline on 1800 100 500. This is a free telephone service.

Contact person

If, following the focus group you have any questions that were not raised, please contact **Jackie Hayes - Team Leader Consumer Engagement** on 0490 427 779 or jackie.hayes@dementia.org.au.

Thank you for your time and participation in this project. We value your feedback and views.