



Preparing the National Dementia Action Plan

Workshops for people with lived experience of dementia

16 November 2022

In August and September 2022, the Department of Health and Aged Care held workshops with people with lived experience of dementia, including carers, people with younger onset dementia and First Nations peoples living with dementia or caring for people with dementia.

The workshops were an opportunity to hear first-hand from a range of people about their experiences and challenges and what has or has not worked well in terms of dementia support.

What we heard

Key themes we heard across all workshops included:

- the stigma surrounding dementia
- the sense of devastation, isolation, grief, despair and loneliness many people felt on being diagnosed with dementia
- the lack of a clear pathway, roadmap or management plan immediately following a diagnosis
- challenges in getting a diagnosis
- the need for coordinated and integrated supports
- the impact on families and carers and the need for more responsive and appropriate support for carers.

In terms of the National Dementia Action Plan (Action Plan), participants highlighted that:

- it was important to have a clear vision in the Action Plan
- the language should not be bureaucratic
- the Action Plan should be communicated with clear, 'punchy' and meaningful language and using audio visual formats
- national objectives and actions need to be outcomes-focused and measurable
- highlighting key things that are going to really make a difference is important.