

Welcome to the Councillor Network Webinar Series

March 2024



Agenda

- Welcome
- Presentation on the Alzheimer's Society report:
“Left to Cope Alone: the unmet support needs after a dementia diagnosis”
- Questions and discussion
- Close

Overview of report

- Published July 2022
- Based on the views of over 2,000 people affected by dementia.
- Addresses the needs of people living with dementia post-diagnosis and the impact of not meeting those needs.
- Includes national and regional recommendations.

“When I was diagnosed, I was just told I had dementia; I got no information. I had to look it up on the internet and it wasn’t an easy read – the internet can make things so much worse.”
- Person living with dementia

“Different parts of the system do not seem to talk to each other... It is like banging your head against a brick wall.”
- Carer of person living with dementia

“The support is exceptionally inconsistent – I had a multitude of boxes of information, but after reading the front page of one you’re totally bored out of your mind.”
- Person living with dementia

The challenge

“We have access to support through the GP and memory service, but the latter offers short-term intervention at crisis points then signs us off once a more stable position is reached.”
- Carer of person living with dementia

“What’s the point of medication to help reduce impact of cognitive decline without the social interaction and stimulation to support that medical intervention?”
- Allied health professional

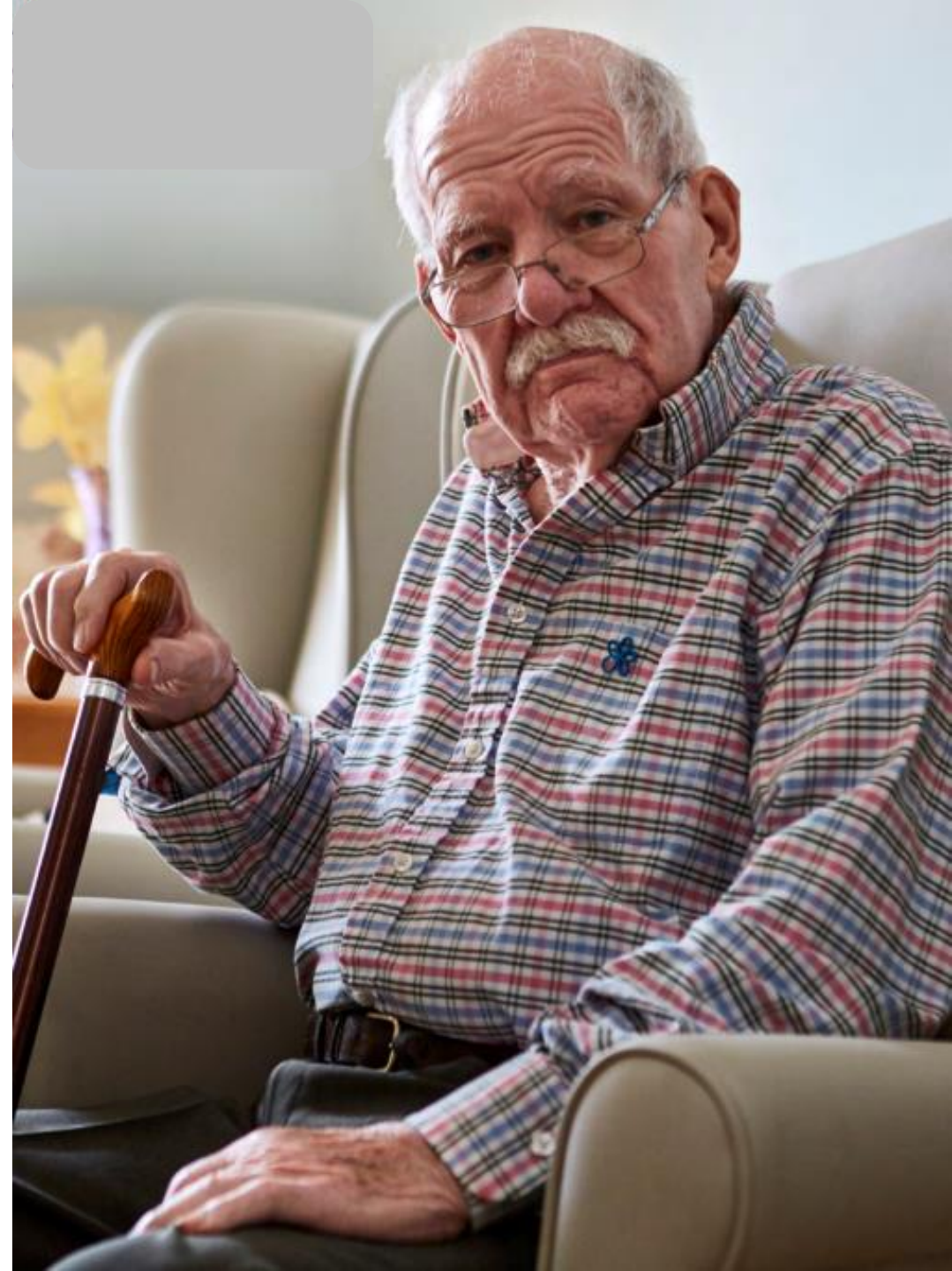
“I would have liked information about where to find out more about dementia itself. Get a handle on what my wife was going to face and what I could do to support her.”
- Carer of person who lived with dementia

**Are peoples' support
needs being met?**



Inconsistencies

- One-third of people are not receiving **sufficient information** about dementia.
- 48% of people are not receiving support that **treats them as an individual**.
- 44% of people with dementia said their support package does not allow them to **remain independent**.



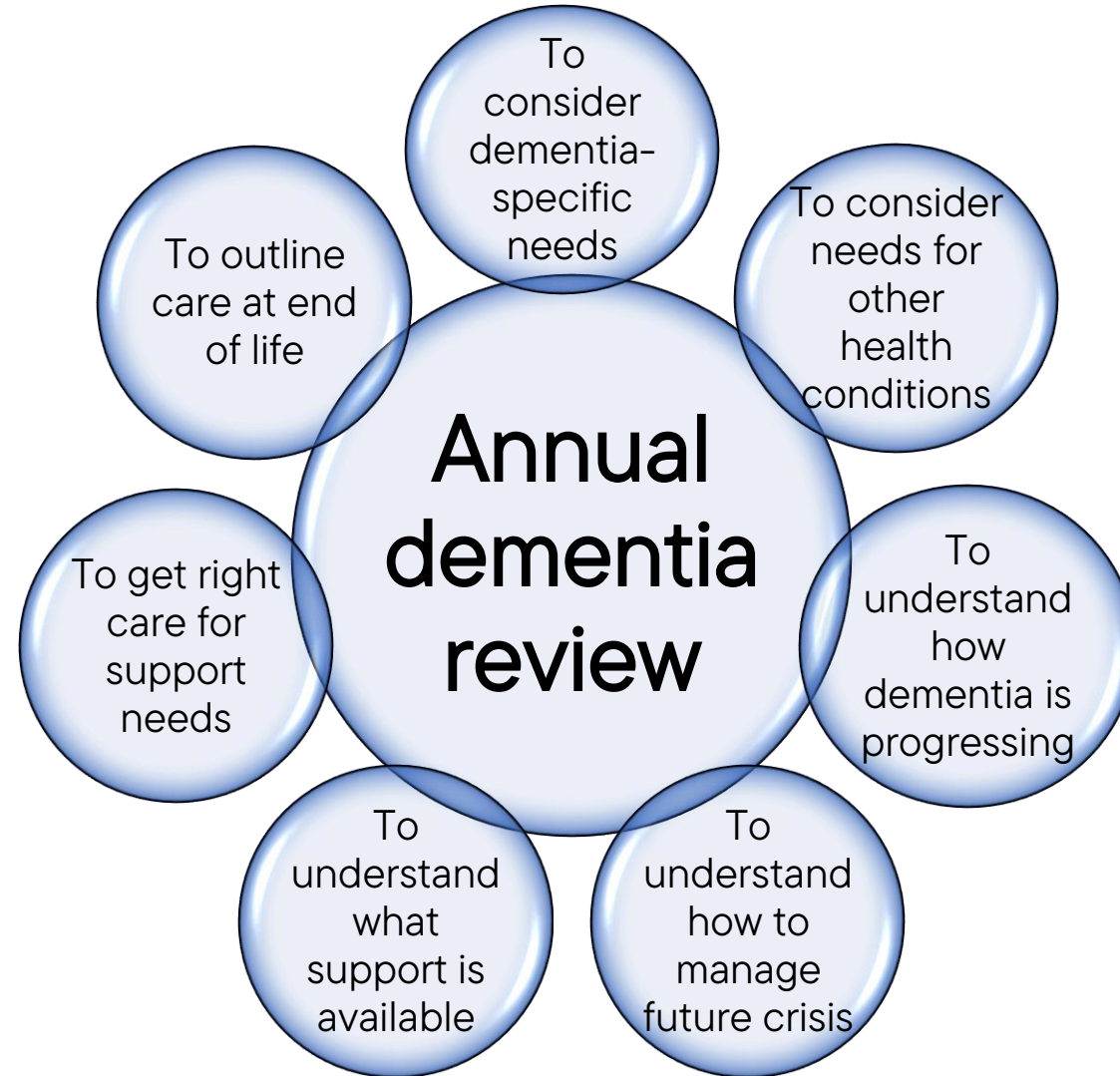
Inconsistencies cont.

- 54% of people **lack support** needed to help them manage their or their loved one's dementia.
- 25% of memory services are **unable to provide**, or refer onto, **cognitive stimulation therapy** that helps people with dementia maintain their cognitive skills.

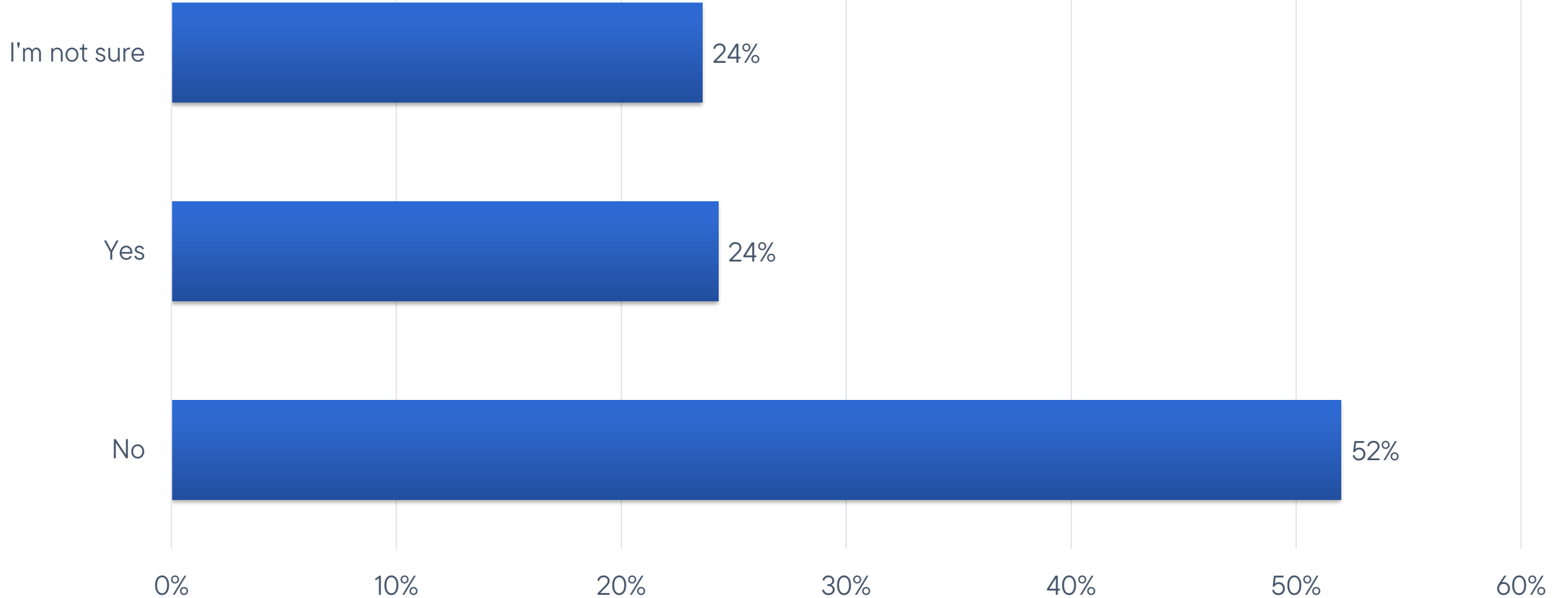


Annual Dementia Reviews

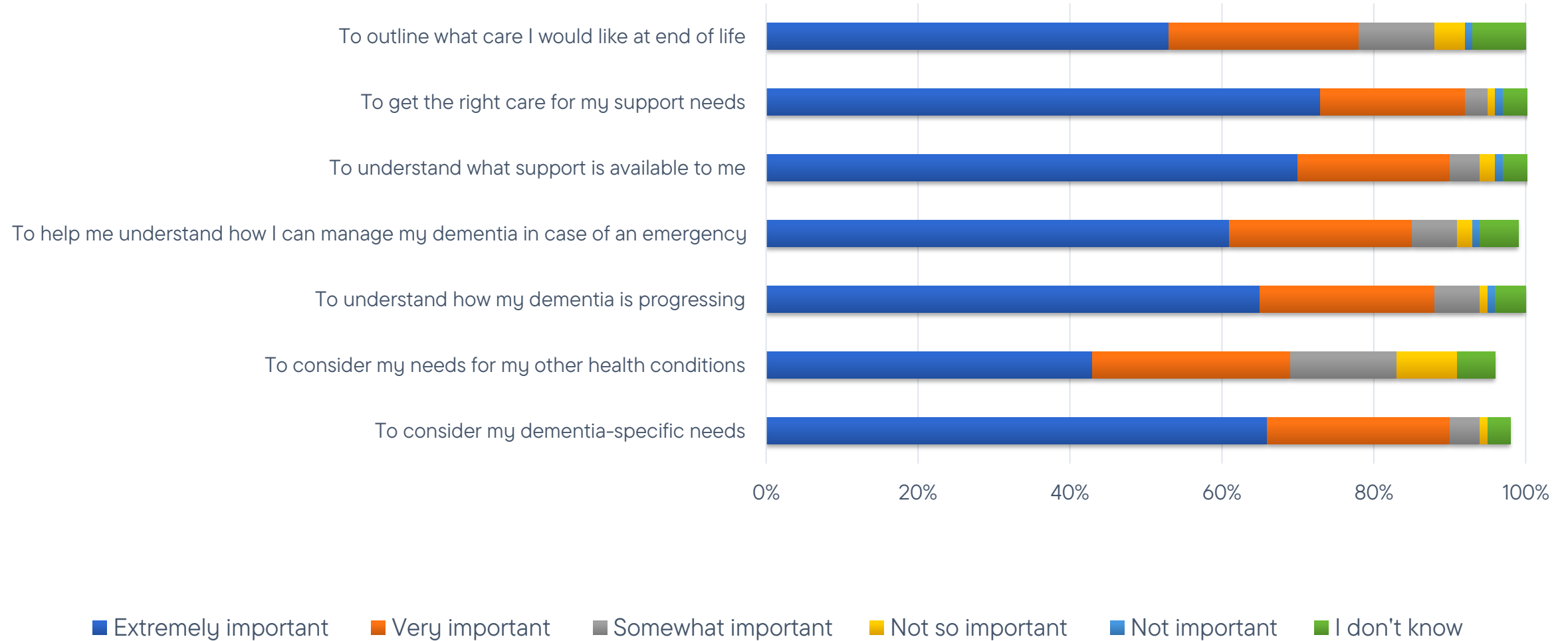
- 25% of people reported they or their loved one had had their dementia review within the past year.
- 39% said it was at least two years ago.



If you or the person you care for has had an annual dementia review, did you feel it helped manage the condition?

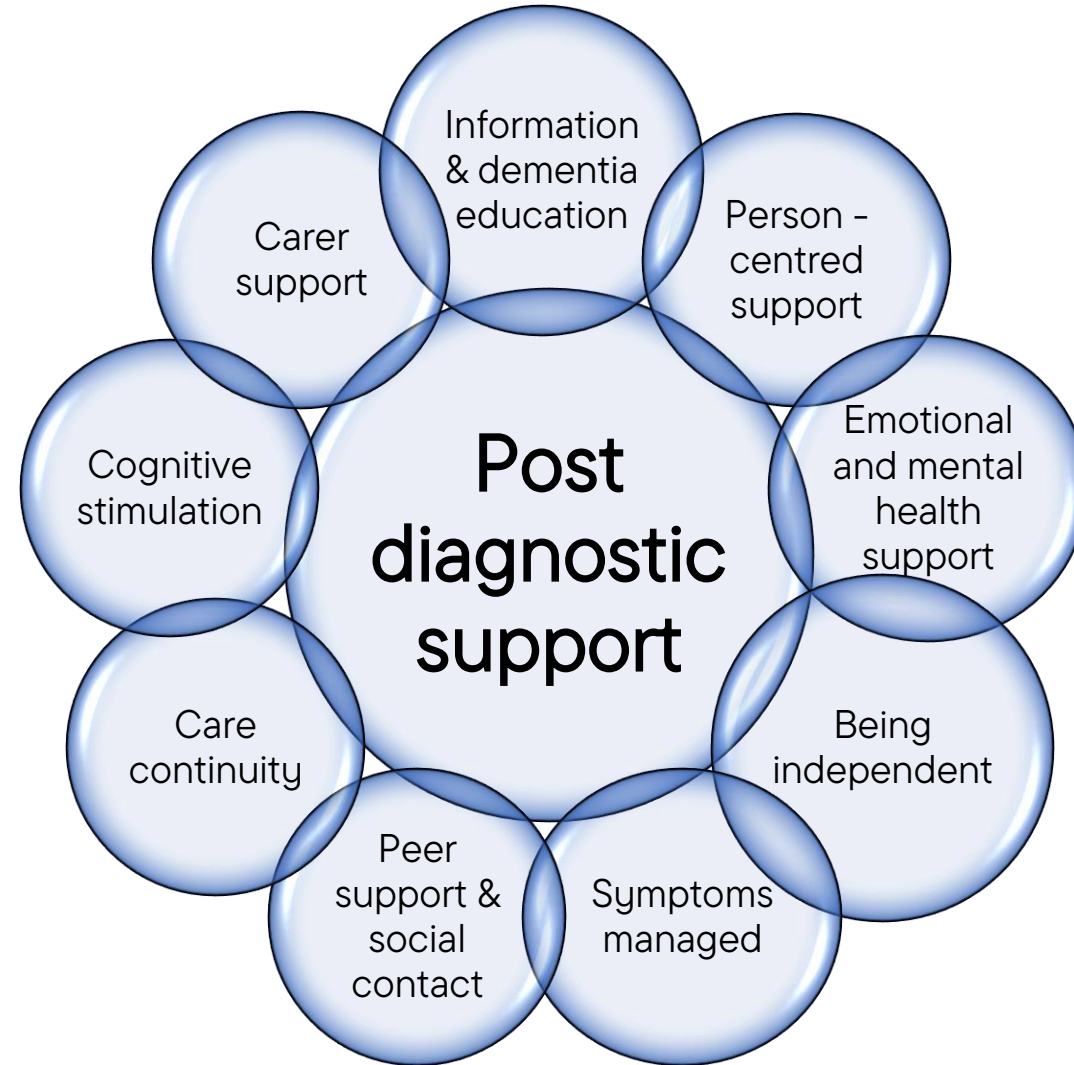


Thinking about the annual dementia review, how important are the following to you?

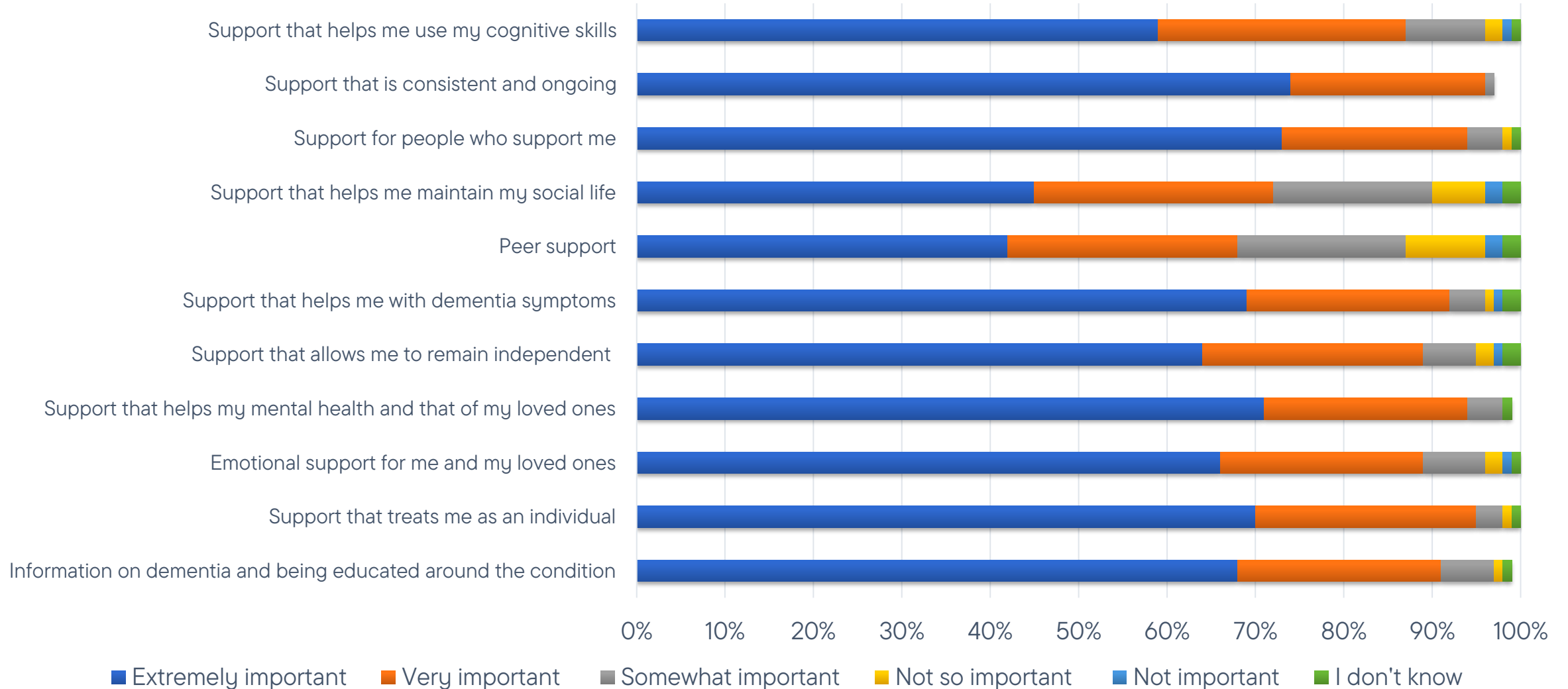


Overview of support

- 60% of people are not receiving sufficient emotional and mental health support.
- 21% of people said they currently lack receiving peer support and 31% lack receiving support to maintain their social life.



Thinking about support after diagnosis, how important are the following to you?



Report Recommendations



Main Recommendation

Ensure everyone diagnosed with dementia has access to a dementia support worker or similar service.

- These roles should be the first point of contact in every primary care network, with automatic referral from memory services.
- To reduce crises, the service should be delivered as part of an overall, integrated 'stepped' model of care
- These roles should include a community link worker component in areas with a high ethnic minority population.

Annual Dementia Reviews

- Ensure a system is in place to identify those with dementia who are most vulnerable and at risk of crisis, who can then be offered more frequent care plan reviews if needed.
- Undertake a multidisciplinary team approach to annual reviews and stagger reviews throughout the year to improve quality and increase primary care capacity.

Wider Post-diagnostic support:

- Everyone diagnosed with dementia should be offered a post-diagnostic meeting.
- Post-diagnostic information and education support should be provided in relevant community languages other than English.
- Non-pharmacological interventions such as cognitive stimulation therapy should be offered.
- All carers should be offered a psychoeducation course and make carer information and support groups available locally.

Main takeaways

- Support needs are not regularly being met (medical, emotional and social wellbeing) and **people are not accessing timely and appropriate care.**
- This leads to increased risk of crisis – deterioration, carer breakdown and hospitalisation.
- This also has an impact on the wider health and care system.
- National and regional recommendations have been set out to address this challenge.

Best Practice Examples

- **Camden Memory Service** – 6 monthly home-based reviews by a named practitioner.
- **Hertfordshire Memory Service** – co-produced a document to help people navigate support services
- **Bristol Dementia Wellbeing Service** – named Dementia Navigator and Dementia practitioner linked to each GP practice.
- **Mid and South Essex Young Onset Service** – peer support buddy scheme.

Support from Alzheimer's Society

Your local officer can:

- Attend local Health and Wellbeing Board meetings to discuss the report
- Provide support to develop local based dementia strategies and action plans.
- Share best practice from other local authority areas/Integrated Care Systems.
- Share access to the latest policy reports and briefings.

Alzheimer's Society resources

- Dementia Strategy Toolkit
- Briefing for local Councillors
- Dementia information for councillors and elected representatives
- Local dementia statistics
- Dementia Experience toolkit

Questions and discussion



Thank you for joining us.

For more information, please
contact us via:

Local@alzheimers.org.uk

