

# Left to Cope Alone

The unmet support needs after a dementia diagnosis



PETER  
SOWERBY  
FOUNDATION



This report has sought the views and experience of over 2,000 people affected by dementia to understand what support they need after diagnosis. It shows that people's needs are wide-ranging and comprehensive, encompassing support for their medical, emotional and social wellbeing. Yet these needs are often not met.

We found people are regularly missing out on care that is timely and appropriate and this failure is having a negative impact on the quality of life of those affected by the condition and on the wider health and care system.

# Main recommendation

**Ensure everyone diagnosed with dementia has access to a dementia support worker or similar service, which should be commissioned as part of a ‘stepped’ model of care. These roles should include a community link worker component in areas with high ethnic minority populations.**

## National annual dementia review recommendations

- National health systems should undertake a review of the Quality and Outcomes Framework (QOF), or its equivalent funding mechanism, in collaboration with people affected by dementia. They should consider additional indicators to support a more comprehensive, high-quality annual dementia review
- National health systems in England, Wales and Northern Ireland must publish a plan for Covid-19 annual boosters to ensure that primary care need never again pause QOF, or its equivalent funding mechanism, activity as happened between 2020-22.

## Local annual dementia review recommendations

- Local health systems should support primary care to return care plan reviews to pre-pandemic levels, such as 75% in England, by April 2023.
- Local health systems should ensure that 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.
- Local health systems should 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 recommendations

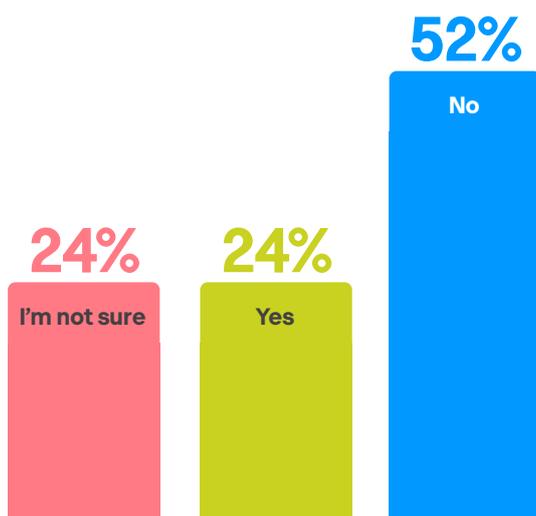
- National health systems in England, Wales and Northern Ireland should assess social prescribing provision for people with dementia, including workforce support and training. They must ensure people with dementia are offered equitable support compared with other long-term health conditions.
- NHS England must undertake a review of capacity of urgent community response services. It must also commit to a timeline to bring in the second phase of the service – providing reablement packages within two days of a crisis to prevent it reoccurring.

### Regionally, dementia pathways should be commissioned to:

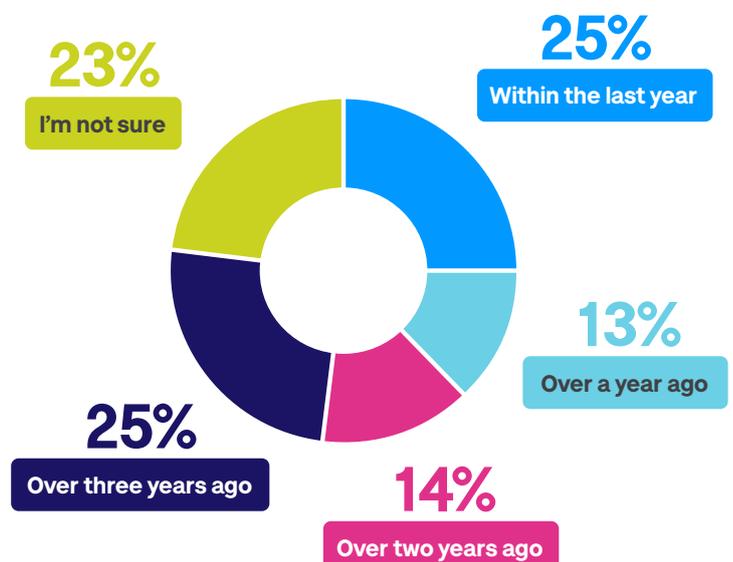
- Achieve the Memory Services National Accreditation Programme standard, which states everyone diagnosed with dementia should be offered a face-to-face post-diagnostic meeting.
- Provide post-diagnostic information and education support in relevant community languages other than English, as well as in non-written resources, to reduce health disparities.
- Offer equitable access to non-pharmacological interventions as per national guidance, such as cognitive stimulation therapy (CST), and ensure all memory services have access to CST by April 2024.
- Ensure occupational therapists, psychologists and other allied health professionals have protected time to carry out post-diagnostic support at memory service level alongside their diagnostic responsibilities
- Ensure all memory assessment services are designed to provide an equal offer of support for all subtypes of dementia, and that the needs of ethnic minorities are catered for.
- Ensure that all carers are offered a psychoeducation course as per national guidance to support them in their caring role and that carer information and support groups are available locally.
- Ensure services under the Improving Access to Psychological Therapies (IAPT) programme do not reject referrals based on a diagnosis of a cognitive disorder and accommodate the needs and symptoms of people with dementia and their carers.

## Getting the most from an annual dementia review

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



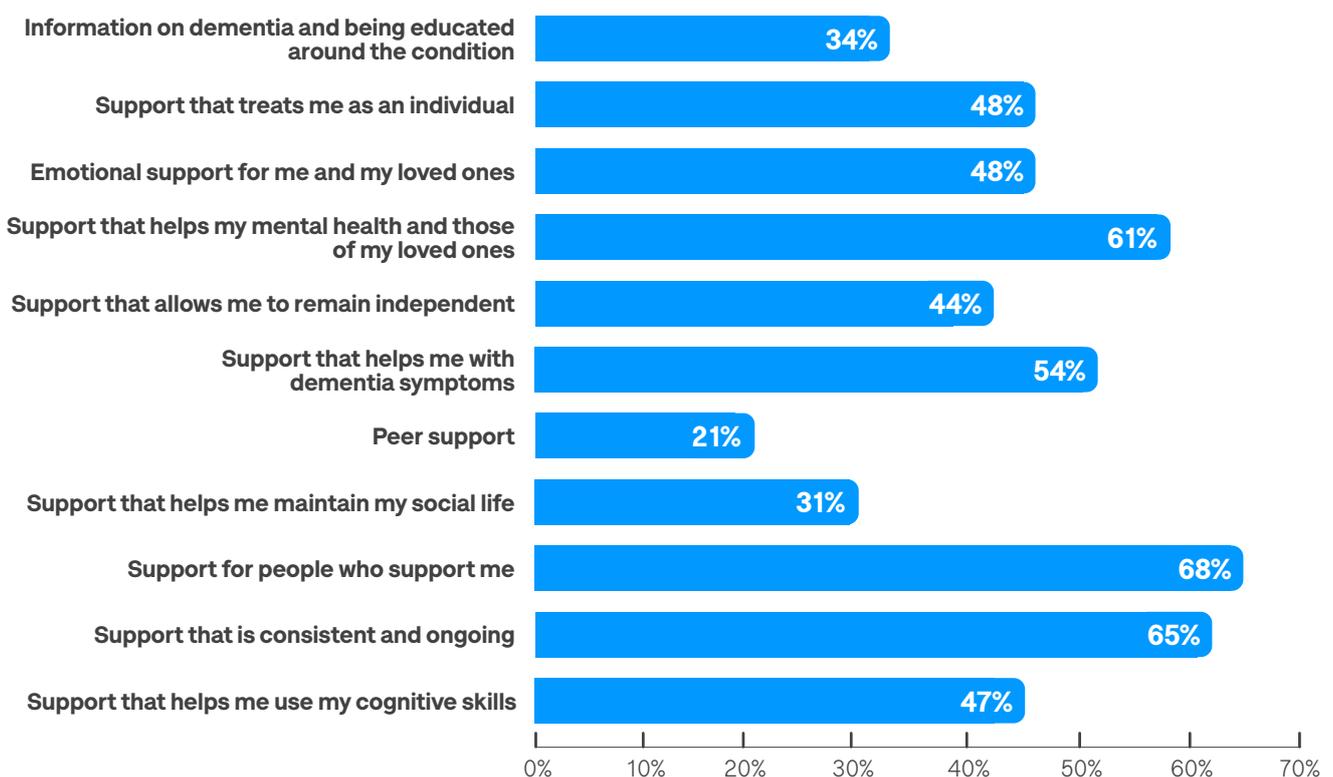
When was the last you have, or the person you care for, had an annual dementia review?



# The postcode lottery of post-diagnostic support

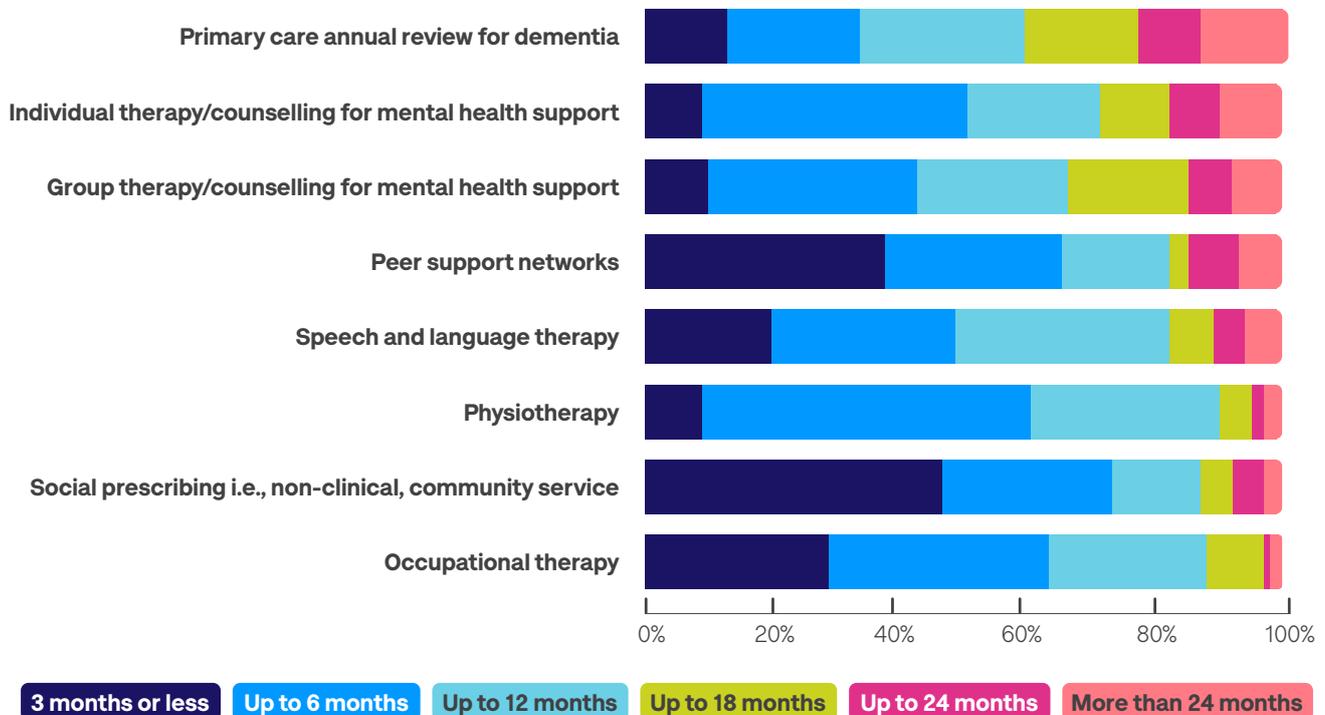
- Around one-third of people are not receiving sufficient information about dementia.
- 48% of people are not receiving support that treats them as an individual.
- Around 60% of people aren't receiving sufficient emotional and mental health support; just 0.2% of all referrals to IAPT services in 2018 were for people with dementia.<sup>1</sup>
- 44% of people with dementia said their support package does not allow them to remain independent.
- 54% said they lack the support needed to help them manage their or their loved one's dementia.
- One in five (21%) and almost one in three (31%) people do not receive peer support and provision that helps maintain their social life, respectively.
- One-quarter of memory services (25%) are unable to provide, or refer onto, cognitive stimulation therapy that helps people with dementia maintain their cognitive skills.

## What support do you feel you need now to help you manage your dementia that you are not currently receiving?



A further survey of an additional 1,000 people affected by dementia was carried out in May 2022. We asked about the impact of Covid-19 in 2020/21, including how it affected their access to services. This is what we found out:

### Average time person affected by dementia has spent waiting for post-diagnostic support service after being signposted to it



## Living with dementia

**84%**

report a decline in their loved one's health and wellbeing over the past year.

**53%**

report their loved ones experienced a worsening of their memory over the past year.

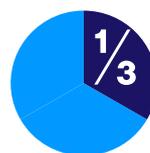
**22%**

of carers report their loved one had to be admitted to A&E with a crisis in their health care.

## Caring for someone with dementia

**54%**

of carers report reaching a crisis point over the last year due to a lack of necessary support – with 13% needing emergency social care intervention.



of carers say they feel “constantly exhausted”, while 38% feel anxious.

# Providing timely post diagnostic support is cost-effective

Over 85% of dementia patients with a hip fracture stay for up to 14 days and 34% for over a month, despite the national average length of stay being 7 days. The extra cost is estimated as £5,950 per patient.<sup>2</sup> Proactive occupational therapy can help reduce falls, which accounted for 17% of all admissions of people with dementia in 2021.<sup>3</sup>

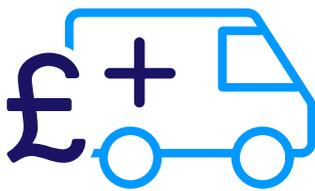


**Dementia support workers are cost-effective – every £1 invested in dementia support worker roles results in almost £4 worth of benefits.**

Research shows a £14,000 reduction in costs of residential care if psychosocial care is given to carers through enabling a 200-day delay in need for residential care.<sup>5</sup>

## The cost of unmet support needs

Over one third of all hospital admissions (32%) in 2020/21 were between zero and one day, suggesting the need for better community care to reduce unnecessary, adverse admissions. If these short stays were eliminated the NHS could have saved around £326m between 2015 and 2020.



In the same period, almost **336,000 admissions costing almost £1bn to the NHS were for chest infections, delirium, falls and UTIs all of which can be prevented or managed well in the community.** One system case study projected it could save £2 million through improved community support for people affected by dementia.

You can access the full report and recommendations on our website [alzheimers.org.uk](https://www.alzheimers.org.uk)

1. **ADAPT Lab.** (2022). The MODIFY Project. Available: <https://www.adaptlab.net/modify> Last accessed 05/05/22
2. **Alzheimer's Society** (2009). Counting the cost: Caring for people with dementia on hospital wards. London. Retrieved from: [www.alzheimers.org.uk/countingthecost](http://www.alzheimers.org.uk/countingthecost)
3. **NHS England.** (2022). 2018/19 to 2020/21 Hospital Episode Statistics. Data relating to dementia and provided by Office for Health Improvement and Disparities
4. **Alzheimer's Society.** (2016). Dementia advisers: A cost-effective approach to delivering integrated dementia care. London
5. **The Health Foundation.** (2011). Spotlight on Dementia Care: A Health Foundation Improvement Report. London

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

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Alzheimer's Society operates in  
England, Wales and Northern Ireland.  
Registered charity number 296645.

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