Dementia UK
Helping families face dementia

Delivering better dementia care
Policy briefing



Dementia UK's new research, **'Crisis before care'**, shows how gaps in dementia care leave people fighting for support and holding a fragmented system together. A diagnosis must mark the start of ongoing care, with access to specialist help as needs increase for both the person living with dementia and those who care for them. Families should not have to reach breaking point before services respond.

The forthcoming Frailty and Dementia Modern Service Framework (MSF) is a critical opportunity to reduce unwarranted variation in dementia care and address the gaps in ongoing support, as exposed by our research.

This briefing sets out the national action needed.

Recommendation

The Government must use the Frailty and Dementia MSF to close the gap between recommended dementia care and what people receive by:

Specifying the ongoing support services will provide, including timely specialist help and practical and emotional support for unpaid carers.

Introducing an access standard setting a maximum wait from diagnosis to an initial follow-up, with a named professional responsible for coordinating care.

Setting out clear responsibilities, sufficient capacity and a delivery timetable, with public reporting and action where services fall short.



What the evidence shows

Dementia presents a growing challenge across health and social care. Nearly one million people were estimated to be living with dementia in the UK in 2024, projected to rise to 1.4 million by 2040[i]. An estimated **70%** of older care home residents in England have dementia or severe memory problems[ii]. Most people with dementia also live with other health conditions, requiring care that works across services and adapts as needs become more complex.

Yet Dementia UK's research, **'Crisis before care'**, surveyed more than 1,000 people affected by dementia about their experiences of dementia care in the community and found:

Support is not dependable after diagnosis.



Around half of respondents struggled to access support after diagnosis. Only **36%** knew who to contact when needs changed, and 'a named person to coordinate support' was the most frequently selected change that would have helped (**51%**).

Care does not anticipate need.



Only **9%** said professional support was typically provided early, before problems became more serious. **41%** experienced delays in getting help and **37%** received no additional support.

Families are left to organise support.



65% of respondents said families were mostly or entirely responsible for organising professional support, and **49%** reported carer exhaustion or breakdown.

Participants valued a continuing relationship with someone who understood their circumstances, support that adapted as needs changed, and practical and emotional help for carers. These are also reasonable public expectations: in a separate survey of adults in England without firsthand experience of dementia, **70%** would expect there to be a named professional overseeing care.

Taken together, these findings reinforce why improving dementia care requires more than a single appointment or referral. People need ongoing professional involvement, support that adapts as needs become more complex, and practical help for carers.

i Carnall Farrar (2024) The economic impact of dementia: Module 1: Annual costs of dementia. Alzheimer's Society. Available at: alzheimers.org.uk/sites/default/files/2024-05/the-annual-costs-of-dementia.pdf (Accessed: 9th November 2026).

ii Alzheimer's Society (2024) Facts for the media about dementia. Available at: alzheimers.org.uk/what-we-do/news-and-media/facts-media (Accessed: 9th November 2026).

An opportunity for a new approach

There is a substantial gap between the support people need and the support they can depend on receiving. Many of the underpinning interventions we are recommending already exist in NICE guidance, but across the country these are either not accessible, not proactively offered, or are insufficient.

The Government's 10-year plan for the NHS sets a clear mandate for MSFs to identify the best evidenced interventions and set standards for how interventions should be used alongside a clear strategy to support and oversee uptake by clinicians and providers.

A national minimum support offer would set out what people should be able to depend on, while giving flexibility around the type and intensity of support so that it is responsive to individual needs and preferences. Managed entry into this pathway is key to avoiding support falling away.

The MSF is an opportunity to close the gap between recommended care and what people currently receive, through defining NHS responsibilities and measurable delivery. It will need to align with local authority social care responsibilities and be backed by workforce, service capacity and resource capabilities.

What people should be able to depend on through the MSF

Ongoing support with clear responsibility

Each person should be connected to a named health or social care professional who is responsible for coordinating care. The professional should get to know the person and their circumstances, coordinate assessment and personalised care planning, and have oversight of agreed actions and their follow-up. People should know who to contact and how to get help. The offer must also work for people living alone or without an unpaid carer.

The professional must have appropriate dementia knowledge to recognise changing needs, with arrangements to secure timely responses across services. Responsibility for care coordination must remain clear through hospital discharge and transitions between services or care settings.

Support that anticipates change and increases with need

Care reviews should look ahead as well as assessing current needs, covering health, symptoms, daily life, preferences and carers' circumstances. They must result in action, with additional assessment and support available when circumstances change between reviews.

As complexity or risk increases, people must have timely access to specialist dementia assessment, advice and clinical case management, including specialist nursing such as Admiral Nursing and multidisciplinary care. This must connect with appropriate healthcare and practical help with daily living.

Planning for future care and access to palliative and end of life support must form part of continuing care, with opportunities to revisit decisions as needs and preferences change.

Help for carers that recognises their needs and choices

Carers should be identified early and offered assessment of their own needs, followed by an agreed response. Practical and emotional support should include appropriate breaks, advice, training relevant to the care being provided, and contingency arrangements if they become unwell or can no longer provide care.

Services must review support as circumstances change, recognising carers' health, wider responsibilities, and willingness and ability to continue caring. Care for the person living with dementia must not depend on a relative being available to provide or organise it.

These arrangements must reflect individual needs and preferences, including those of people with young onset dementia (where symptoms develop before the age of 65), people living alone and those without an unpaid carer.



The national action required

The MSF is an opportunity to improve care after diagnosis. Its impact will depend on clear commitments, alignment with social care reform, and a credible plan for delivery. Dementia UK is calling for three connected actions.

1. Make ongoing care a priority

A new access standard: getting a timely diagnosis alone is not enough. The MSF should introduce a time-bound access standard that sets a maximum wait from diagnosis to an initial follow-up with a named professional responsible for coordinating care.

The follow-up must address immediate needs, agree next steps for care planning, and arrange continuing contact. The MSF should define the professional's responsibilities and competencies. Recording a name, sending contact details or providing signposting alone must not count as meeting the standard. The NHS should publish the proportion of people who receive their initial follow-up within the standard and the number who are still waiting beyond it.

Clear and measurable expectations for support: alongside the access standard, the MSF must set clear expectations for ongoing care.

- **Reviews and action:** people receive regular reviews and additional assessment when needs change. Identified needs have agreed actions, timescales and a professional responsible for following them through, including securing specialist support where required
- **Support for carers:** carers are identified and offered assessment of their own needs. NHS services provide appropriate support or arrange onward referral, with responsibility for checking whether help was received
- **Transfers of care:** before responsibility transfers, the receiving professional or team is identified, relevant information and care plans are shared, and follow-up arrangements are confirmed with the person and their carer, where appropriate
- **Palliative and end of life care:** people's palliative needs are recognised and assessed; they are offered opportunities to discuss and revisit future care preferences; and services respond to symptom management needs with specialist advice where required

2. Align health and social care responsibilities

The Government should set out how NHS bodies and local authorities will coordinate assessments, arrange support and resolve disagreements about responsibility without leaving people waiting.

The Casey Commission should recommend how social care access, funding and carer support can underpin the national offer, including for people with complex or advanced dementia and those who need residential care. Better coordination cannot make unavailable or unaffordable care accessible, so improvements should begin alongside longer-term reform.

3. Publish a delivery plan with clear national leadership and accountability

The MSF must be published with a phased and accountable implementation plan setting out what changes on publication, what must be delivered in the first two to three years, and what requires longer-term development. The Government and national NHS leaders must explain how commitments will be embedded in planning, commissioning and oversight, including for people already living with dementia who lack continuing support.

National dementia leadership, including the Dementia Tsar role, should bring NHS and social care leaders together to oversee progress, address barriers and escalate issues requiring Government action. Its remit must explicitly include care and support after diagnosis.

Ministers, commissioners and service leaders must remain accountable for delivery. Measurement of success should establish whether people receive timely follow-up and agreed support, alongside changes in their experiences and outcomes. It should build on existing NICE quality measures and NHS reporting, with a timetable for filling gaps. People living with dementia and unpaid carers should help shape the standard and how its impact is assessed.



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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm

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