

## From diagnosis to end of life: the lived experiences of dementia care and support

### Overview

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This [report](#) looks at four stages of NHS England's 'Well Pathway for Dementia' – Diagnosing Well, Supporting Well, Living Well and Dying Well.

It explores in detail what NICE and the Government say people in England should be receiving at each stage of the dementia pathway, and benchmarks it against the experiences of people affected by dementia.

We spoke with 75 people affected by dementia to better understand their experiences of care and support from pre-diagnosis to end of life. We also spoke with a range of health and care professionals to identify the barriers to providing effective care.

Our research revealed that people aren't consistently receiving high quality, integrated care and support that enables them to live well. While there is good practice happening in parts of the country, and significant progress has been made on improving dementia care and support over the years, there is still work to be done.

This report considers current provision of dementia care, but it was mostly researched and written before the COVID-19 crisis. From diagnosis to end of life, people affected by dementia have been disproportionately affected by the COVID-19 pandemic. The evidence in this report must be used to inform future thinking about how we can improve the dementia pathway – both as we continue to respond to the pandemic but also as we emerge from it.

This short briefing focusses on what local systems can do to transform the experience of someone with dementia. The report identifies actions to improve care and support. It also highlights many examples of good practice from across the country, so that these can be learned from and adapted to local contexts.

### Key findings

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A recurring theme at each stage of the pathway is the sense of disjointed, fragmented care. We heard many accounts of where care is failing to provide what's needed. Some of the main issues we identified across the pathway are:

- People struggle to access a timely and high-quality diagnosis, as well as get a subtype diagnosis.
- Access to post-diagnostic care, dementia advisers and care coordinators is variable, leaving people unsupported or unable to manage symptoms effectively.
- There is a lack of integration between care plans and a lack of ownership of advance care planning.
- People receive limited access to coordinated, proactive and ongoing care and support. Follow-up care is variable, and care plan reviews are inconsistent or not meaningful.
- Informal carers are left without support due to inconsistent assessments of their needs, or the quality of formal care acts as a deterrent to them seeking help.
- Within hospitals and care homes, people struggle to access the appropriate care for their level of need.
- People with dementia struggle to access appropriate palliative and end of life support and face unnecessary hospital admissions.

### Recommendations

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The detailed recommendations set out in the report provide a roadmap for action to improve dementia care, from pre-diagnosis to end of life. They offer insights from people affected by dementia about what makes a good pathway, and how meaningful change can be implemented.

Local decision-makers, services and professionals are best-placed to take ownership of developing dementia pathways. But these must be underpinned by clear roles and responsibilities at each stage. We suggest that Integrated Care Systems, where they're already in place, have oversight of the whole dementia pathway to better integrate health and social care elements.

In this briefing we include a selection of our key recommendations. Please refer to the main report for the full list and for details of the good practice examples we found:

### **Diagnosing Well**

- To facilitate dementia diagnosis, particularly complex cases, there must be formalised arrangements that enable multidisciplinary team meetings between memory service clinicians, neurology and neuroradiology.
- Memory services should have clear referral pathways to enable access to psychiatrists, psychologists, occupational therapists, social workers, dementia advisers, as well as linguists and interpreters during the diagnostic process.
- Memory services should all include dementia adviser services, with people automatically referred to the service unless they opt out. There must also be integration of dementia adviser services within primary care.
- People diagnosed with dementia should have access to follow-up opportunities to discuss their diagnosis and this should be embedded within the local pathway.

### **Supporting well**

- All people with a dementia diagnosis should have a named care coordinator to support them to navigate the complexity of the health and care system and access the right professionals at the right time.
- Each Clinical Commissioning Group (CCG) should have a dedicated dementia lead with dedicated time to fulfil this role – this should ensure the roll-out of training to GPs on referral criteria and diagnosis, as well as personalised care and support planning
- Evidence-based, post-diagnostic support interventions should be provided for people with dementia and their carers. These must be appropriate and tailored, considering age, ethnicity, religion, gender and sexual orientation and should consider projected future population trends and needs.

### **Living Well**

- High quality support for carers should be provided, which includes straightforward methods of booking overnight care in advance, and accessible lists of recommended local respite care services identified by local authorities.
- Care homes should have enhanced access to professionals through local multidisciplinary teams, and all professionals should be trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework.
- Memory services should consider accepting referrals from sources other than primary care, including social services and patients and carers themselves. This would support access to timely specialist input, especially in urgent or crisis situations.
- There should be ongoing opportunities for people with dementia and carers to access support interventions following diagnosis.

### **End of Life**

- Access to end of life care should be ensured by reviewing capacity and access to palliative care in care home settings, including an audit of training for care home staff as well as access to out-of-hours support.

For more information please contact: [Local@alzheimers.org.uk](mailto:Local@alzheimers.org.uk) and one of the team will be in touch.