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

Report being considered by: Health and Wellbeing Board

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Item for: Discussion

1. Purpose of the Report

- 1.1 The report, from Alzheimer's Society, aims to shine a light on the inconsistent provision of high-quality, integrated care and support for people affected by dementia across England, from diagnosis to end of life.
- 1.2 It also has the objective to provide a roadmap for action to improve dementia care from pre-diagnosis to end of life, offering insight from people affected by dementia about what makes a good pathway and how meaningful change can be implemented by local decision-makers.

2. Recommendations

- 2.1 Alzheimer's Society recommends that the Health and Wellbeing Board notes the findings of the report and implements its recommendations to address the current care and support needs of people living with dementia and their carers in West Berkshire;
- 2.2 Alzheimer's Society also recommends that the Board considers how the Council can work with care homes and the NHS to improve care for people with dementia, including making provision for meaningful visits by key family and friends carers for patients in care homes.

3. How the Health and Wellbeing Board can help

In line with the current Joint Health and Wellbeing Strategy's priority aimed at ensuring early assessment of and good provision of care for those with dementia, the Health and Wellbeing Board can help address the issues raised by committing in its new Joint Health and Wellbeing Strategy to develop a dementia strategy that includes the recommendations for dementia care and support set out in the report.

Will the recommendation require the matter to be referred to the Executive for final determination?	Yes: <input type="checkbox"/>	No: <input checked="" type="checkbox"/>
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4. Introduction/Background

The report looks at the four stages of NHS England's Well Pathway for Dementia. It explores in detail what NICE and the Government say people in England should be receiving at each stage and benchmarks it against the experiences of people affected by dementia. The four stages of the NHS England's Well Pathway were used as a framework for structuring the report – Diagnosing Well, Supporting Well, Living Well and Dying Well. The aim was to show the discrepancy between what people living

with dementia are entitled to in terms of care and support at each stage of the pathway, and what people are actually receiving based on their own experiences.

5. Supporting Information

The report has highlighted that:

- People are struggling to access a timely and high-quality diagnosis, as well as get a subtype diagnosis.
- Access to post-diagnostic care and support, as well as access to dementia advisers and care coordinators is variable across the country.
- Access to coordinated, proactive and ongoing care and support is limited. There is variation in the provision of follow-up care and people with dementia reported inconsistent care plan reviews, which were not meaningful.
- Many people with dementia receive most of their support from their primary informal carer, but carers are struggling to access support services for their own wellbeing. This is a result of inconsistent needs assessments, as well as the quality of formal care acting as a deterrent to them seeking help.
- Many people living with dementia are struggling to access the appropriate care for their level of need within hospitals and care homes.
- Many people living with the condition struggle to access appropriate palliative and end of life support, which often exacerbates unnecessary hospital admissions.

6. Options for Consideration

The Health and Wellbeing Board can choose to implement the Alzheimer's Society report's recommendations in full or in part, or it can choose to continue with current provision of services. Alzheimer's Society's preferred option is to implement the recommendations in full as per the proposal below.

7. Proposals

7.1 Alzheimer's Society proposes that the Health and Wellbeing Board implements the following recommendations as set out in the report:

- To facilitate dementia diagnosis, formalise 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.

- 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.
- 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.
- 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.

8. Conclusion

Alzheimer's Society research concludes that people aren't consistently receiving support that enables them to live well. A recurring theme across all stages of the pathway is a sense of disjointed and fragmented care. This means that people are falling off the pathway after diagnosis, are unable to receive appropriate, proactive and ongoing post-diagnostic support, and they struggle to access early and effective palliative and end of life care.

9. Consultation and Engagement

9.1 The Health and Wellbeing Steering Group has been consulted on the report.

9.2 Alzheimer's Society gathered evidence for this report by:

- identifying and analysing national guidance and legislation relevant to the dementia pathway and using this as a benchmark against what people affected by dementia had told Alzheimer's Society about their own pathway.
- undertaking a thorough literature review of existing pathways, standards and datasets for people with dementia.
- running a series of focus groups with people affected by dementia from November 2018 to April 2019 to explore their experiences of care and support in England. In total, Alzheimer's Society engaged with nine focus groups, and spoke to over 75 people with dementia and carers of people with dementia.

- contacting a range of health and care professionals, including General Practitioners, geriatricians, nurse practitioners, occupational therapists, neurologists, psychiatrists and dementia advisers.

10. Appendices

Appendix A:

From diagnosis to end of life: The lived experiences of dementia care and support (Executive Summary) (The full version of the report is available online at:

https://www.alzheimers.org.uk/sites/default/files/2020-10/pathway_report_full_final.pdf)

Background Papers:

None

Health and Wellbeing Priorities 2019/20 Supported:

- ☐ Give every child the best start in life
- ☐ Primary Care Networks

Health and Wellbeing Strategic Aims Supported:

The proposals will help achieve the following Health and Wellbeing Strategy aim(s):

- ☐ Give every child the best start in life
- ☒ Support mental health and wellbeing throughout life
- ☐ Reduce premature mortality by helping people lead healthier lives
- ☐ Build a thriving and sustainable environment in which communities can flourish
- ☒ Help older people maintain a healthy, independent life for as long as possible

The proposals contained in this report will help to achieve the above Health and Wellbeing Strategy aim by ensuring an early assessment of and good provision of care for those with dementia.

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