

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

Laura Vicinanza

Regional Public Affairs and
Campaigns Officer



From diagnosis to end of life

West Berkshire Joint Health and Wellbeing Strategy

2

- Supporting people living with dementia and their carers as a group of people at high risk of bad health outcomes to live healthy lives is a priority across West Berkshire, Reading and Wokingham
- Commitment to introduce an integrated programme in partnership with other sectors for the early diagnosis, rehabilitation and support for people affected by dementia

Alzheimer's Society

Where did it start?

How we structured the report:

- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well

How we gathered the evidence:

- Used national guidance and legislation as a benchmark
- Literature review of existing pathways, standards and datasets
- Focus groups and interviews with people affected by dementia
- Interviewed and surveyed professionals

Key theme: a sense of disjointed and fragmented care

‘For us, there was no dementia pathway. Everywhere I turned for help, I felt like I was walking through candy floss – everywhere I turned I met a sticky end.’

Carer for a person with dementia

‘The only support my husband and I had were things I had to discover and instigate myself. We were given a life-changing diagnosis, then left to our own devices to navigate the complexity of the health and social care system.’

Wife of a person living with dementia

‘In the 13 months from December 2017, when [mum] was first identified for palliative needs, right up until her death, absolutely nothing was done to provide mum with the palliative care and support she required.’

From diagnosis to end of life

DIAGNOSING WELL

KEY FINDINGS
AND
RECOMMENDATIONS

From diagnosis to end of life

Summary of key findings

- People are being misdiagnosed or opportunities are being missed
- Referral processes can be confusing
- Service improvements can be challenging due to variation between memory services and limited performance data
- Delivery of a diagnosis, including a subtype and tailored information, is variable



From diagnosis to end of life

Local recommendations

- CCGs to have a dedicated dementia lead to train GPs on referral criteria and diagnosis
- Multidisciplinary team meetings between memory service clinicians, neurology and neuroradiology
- Clear referral pathways to enable access to Allied Health Professionals
- Memory services to include dementia adviser services, with people automatically referred to the service unless they opt out
- Access to follow-up opportunities to discuss diagnosis

Diagnosis rates during Covid-19

- Dementia diagnosis rates have declined since lockdown
- Referrals from primary care to memory services have decreased
- There is a backlog of assessments which will worsen waiting times
- Need to ensure people can access their GP, face-to-face, to discuss concerns with cognitive impairment or memory
- Secondary care specialist diagnostic services need sufficient workforce and resources to cope with current and expected backlog of appointments

From diagnosis to end of life

SUPPORTING WELL

KEY FINDINGS
AND
RECOMMENDATIONS

Summary of key findings

- Information provided at point of diagnosis is not being delivered in the right way, if at all
- People are struggling to access a care coordinator
- Care planning, including advance care planning, if undertaken, can be insufficient and dementia-specific needs are not considered
- The provision of post-diagnostic support interventions can be variable and inappropriate

From diagnosis to end of life

Local recommendations

- All people should have a named care coordinator
- Appropriate and tailored post-diagnostic support interventions for people with dementia and their carers
- Integration of dementia adviser services within primary care
- Clear local responsibility for advance care planning

From diagnosis to end of life

LIVING WELL

KEY FINDINGS
AND
RECOMMENDATIONS

From diagnosis to end of life

Summary of key findings

- Limited access to coordinated, proactive, ongoing care and support
- Follow-up care is not the same for everyone
- Carers are struggling to access support services
- Hospital and care homes need to identify and accommodate dementia specific needs



Local commendations

- Straightforward methods of booking day care and overnight care in advance
- Accessible lists of recommended local respite care services
- Care homes to have enhanced access to professionals through local multidisciplinary teams
- All professionals trained to at least Tier 2 of the Dementia Training Standards Framework

From diagnosis to end of life

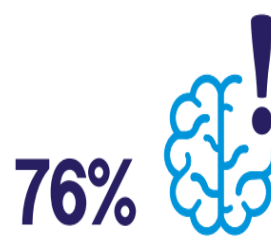
Cognitive decline and the need for rehabilitation

- Deterioration of people's mental health and significant cognitive decline
- Worsening of dementia symptoms, including memory loss, agitation and depression
- Decrease in the numbers of people receiving care plans or care plan reviews over the last year
- Need to bring forward care plan reviews to proactively identify rehabilitation needs and offer rehabilitation services

ne carers' xperience during oronavirus



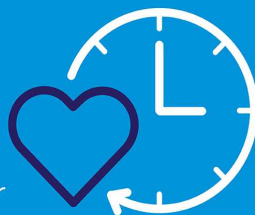
of carers reported that their caring responsibilities have increased during lockdown.



reported their caring responsibilities had increased because of worsening dementia symptoms of the person they care for.

92 million

extra hours have been spent by family and friends caring for loved ones with dementia.



95%

of carers of people living with dementia reported a negative impact on their mental or physical health.



From diagnosis to end of life

DYING WELL

KEY FINDINGS
AND
RECOMMENDATIONS

From diagnosis to end of life

Summary of key findings

- People often struggle to access palliative care, including end of life care
- Advanced decisions are sometimes ignored, meaning the interests of people and their wishes at end of life are not being fulfilled

Local recommendations

- Manage hospitalisations through integrating services, upskilling care home staff and increasing access to out-of-hours specialist support
- Local multidisciplinary teams should be formed to assist local care homes, and include palliative care teams
- Local services should be set up to ensure that professionals involved in end of life care can easily and quickly access advance care plans

To conclude...

- From diagnosis to end of life, people with dementia face challenges in accessing effective care and support
- A recurring theme at each stage of the pathway is the sense of disjointed, fragmented care
- Government and national bodies must make further progress on dementia care quality and outcomes
- But local decision-makers, services and professionals are best-placed to take ownership of developing dementia pathways, to promote streamlined and consistent support.