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Department of Health & Social Care

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NATIONAL COLLABORATING CENTRE FOR MENTAL HEALTH

Dementia 100: Pathway Assessment Tool

Summary Guidance

Introduction

The dementia challenge

In England, it is estimated that around 676,000 people have dementia[1], although recent studies from the Alzhaeimer's Society indicate this could be as high as 826,000[2]

With limited treatment options, there are multiple challenges for those living with the condition, for their immediate carers, and for their wider families. Many people play a role in caring for their friends and family, and it is recognised that for some this can be a significant commitment.

The Prime Minister's Dementia 2020 Challenge set out a vision to create a society where every person with dementia, their carers and families, receive high quality, compassionate care from diagnosis through to end of life care. The more recent Neighbourhood Health Guidelines (25/26) share a framework for systems to work in a more integrated way, towards the three shifts set out by the government for the NHS 10 year plan in 2024. This approach is critical for people living with dementia, where support, care and treatment is delivered across multiple agencies and organisations.

> **"Working in a joined-up way across sectors and organisations is key to enabling good practice."[3]**

We are working harder than ever to improve dementia care, reduce stigma, find out more about the condition and find new disease-modifying treatments. We have come a long way in improving dementia care in England, but it is imperative that we continue to build upon that and progress even further.

Sylvia's story

Thanks to Devon Carers who shared Sylvia's story and their thoughts on how the Dementia 100 can support people like Sylvia and Stan: After caring for her late husband, Stan, who had Alzheimer's and Parkinson's, Sylvia said that he reached a point where "[he] doesn't know me anymore.

"It is having a sense that both our lives have been destroyed. A sense of frustration, of desperation, often of anger. And –always – of being alone. You don't know what is going to happen; you don't understand. You have no idea why the person in front of you is changing. So - making what is going to happen much clearer, is so important."

This tool is designed to help us all to see patients as people, not just as a condition. It will help us to better understand their whole journey towards death, whilst recognising both professional care, and the incredible love and unstinting support of family members."

Names have been changed

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1 Department of Health (2015): Prime Minister's Challenge on Dementia 2020
2 Alzheimer's Society (2024): The economic impact of dementia
3 The King's Fund (2024): The role of integrated care systems in improving dementia diagnosis

Pathway Assessment Tool

The fundamental concept of the Dementia 100: Pathway Assessment Tool is to provide a mechanism for capturing and understanding the characteristics and specific requirements that are considered key to the development and delivery of service and care needs for people living with dementia and their carers.

The Dementia 100 extracts and combines pertinent information from multiple sources into a single, consolidated tool for self-assessment. Completed at Place level, it provides a holistic and integrated view of service provision. At system level it aids strategic planning and sharing best practice.

Key components of the Dementia 100

Dementia 100 is constructed in a way that presents a set of 100 criteria against which service provision can be self-assessed. These criteria are structured within six pillars which align to the main components of the Well Pathway for Dementia.

Four foundations underpin a number of building blocks upon which the criteria sit: Leadership, Carers, Holistic care, and Seamless Pathways. The foundations present essential elements that should thread throughout all criteria contained within the tool.

Whilst the Dementia 100 in its entirety provides a single point of reference for end-to-end pathways, the modular structure of the tool can facilitate a focused attention on areas of most interest and importance to a system. To support this modular approach, a priority standards list is contained in the tool, outlining a sub-set of essential criteria from across the pillars. These offer an opportunity for focused attention on a selective number of criteria considered to be of national importance and priority.

Existing regulations, guidance and policy included within the Dementia 100:

- ✓ NICE Guidelines and Quality Standards
- ✓ Neighbourhood Health Guidelines (2025/26)
- ✓ High Impact Change Models
- ✓ FRAIL strategy
- ✓ Right Care Scenario for Dementia
- ✓ Well Pathway & Dementia Care Pathway
- ✓ Universal Principles for Advance Care Planning

Benefits

There are multiple opportunities for systems to use the assessment tool, including dementia strategy development, improvement planning, and establishing a service baseline. The development of an evidence base supports interpretation, with benefits such as best practice sharing and standardisation of service and care.

With new developments and findings within the ongoing dementia research, the tool is designed for adaptability, ensuring continued usability. Collaboration and partnership working is critical to maximise the value and impact, supporting pathway suitability, and enhancing service quality.

1. Leading Well

Building Blocks

- Researching well
- Integrating well
- Commissioning well
- Training well
- Monitoring well

This pillar is formed of **26** criteria

2. Preventing Well

Building Blocks

- Messaging well
- Community assets and stakeholders
- Addressing social determinants of health

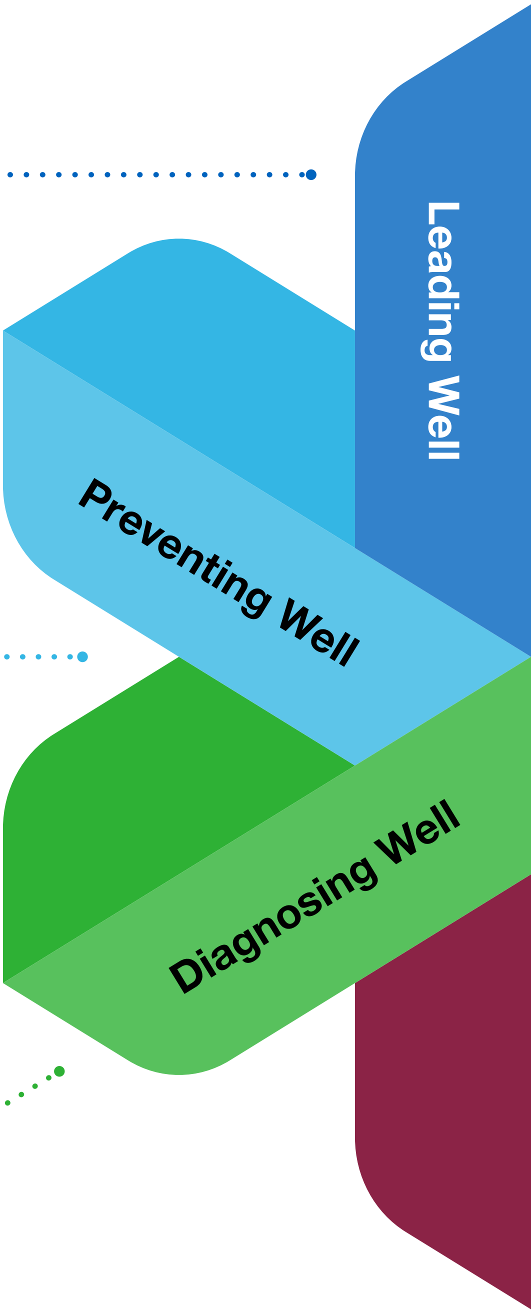
This pillar is formed of **9** criteria

3. Diagnosing Well

Building Blocks

- Equity of access to diagnostic service providers
- Joined up approach to diagnosis
- Timely and appropriate assessment and diagnosis
- Personalised approach to diagnosis

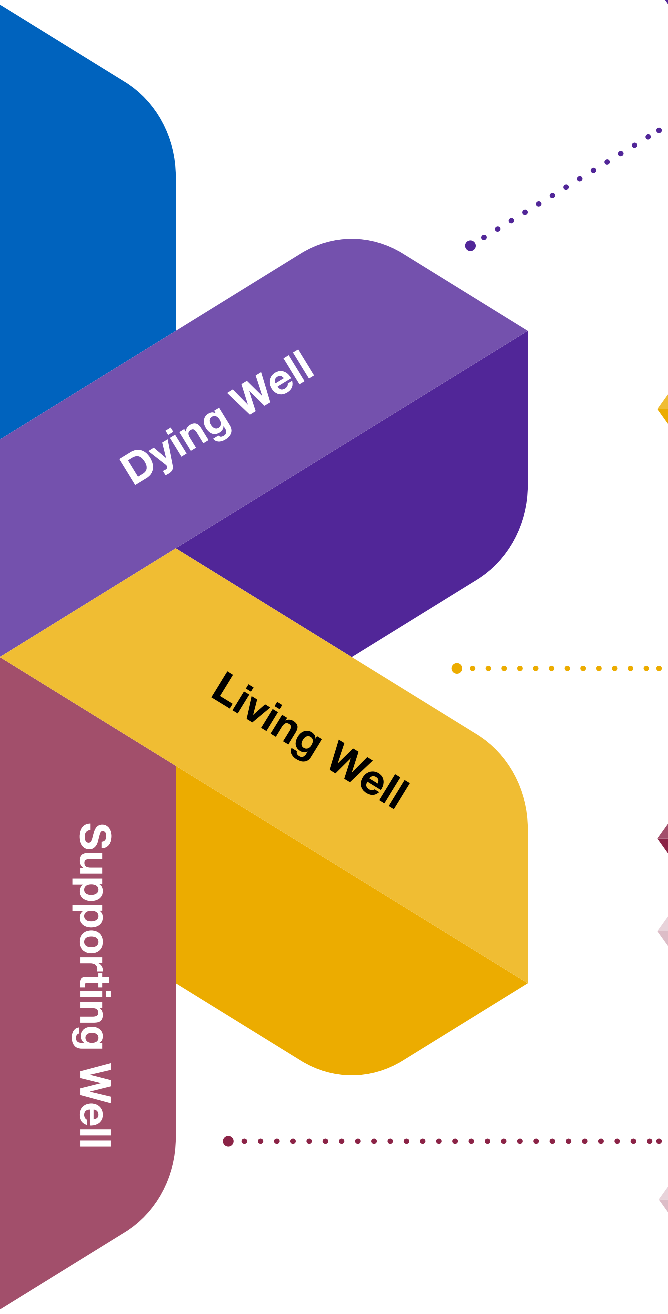
This pillar is formed of **19** criteria



Foundations of the Dementia

Leadership

Carers



6. Dying Well

Building Blocks

- Personalised care and support planning
- Joined up care
- Knowledge and skills

This pillar is formed of **8** criteria

5. Living Well

Building Blocks

- Inclusive neighbourhoods
- Urgent neighbourhood services
- Supporting carers

This pillar is formed of **8** criteria

4. Supporting Well

4a – Supporting Well in the community

Building Blocks

- Post-diagnostic continuity of care
- Supportive care
- Communication

This pillar is formed of **11** criteria

4b – Supporting Well in hospitals

Building Blocks

- Emergency Department
- Admission
- Inpatient stay
- Communication
- Mental capacity and safeguarding
- Discharge

This pillar is formed of **19** criteria

100 Pathway Assessment Tool

Holistic care

Seamless pathways

Foundations

The pathway assessment tool is built on four foundations, woven throughout the Dementia 100 criteria.

The foundations give special attention to those who devote a significant portion of their time to helping those living with dementia, including health professionals, unpaid carers, and community dementia supporters.

Leadership

Effective dementia care relies on an integrated approach, working together with services like Frailty and Older Adult Services. Strong leadership and governance enables multi-agencies, to assess the needs of a system against the Dementia 100, and ensures well-planned, data-driven services tailored to community needs.

Carers

Dementia care is provided by loved ones, professionals, and communities. Supporting unpaid carers is vital, helping both them and those with dementia live well at home for longer. Carer roles vary and as such, it is key to acknowledge that the needs and expectations also vary widely against the underpinning principles and values.

> **"I want people to know that they are more than a disease or diagnosis. You still have creativity and can experience new things and take on new challenges."**
>
> *Vesna's Story, Alzheimer's Society*[1]

Holistic Care

In complex healthcare settings, dementia care requires a holistic approach. This means treating the person, not just symptoms, by addressing physical, mental, emotional, and social well-being. Tailored interventions enhance quality of life, meeting medical, psychological, social, and spiritual needs.

Seamless pathways

Pathways of diagnosis can feel complex and disconnected. Collaboration and partnership are key to creating smooth pathways across services. Integrated care systems should work together to improve flow, timelines to diagnosis and treatment and reduce avoidable hospital admissions.

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4 Vesna's story, Alzheimer's Society

#1

Pillar One: Leading Well

There is a coordinated approach to the leadership, planning, and monitoring of dementia services across a system

Building Blocks

Researching Well:

The active presence of research studies, links with Research Delivery Networks, and Research Champions all support the promotion of research across the system.

Integrating Well:

Strong integration across services includes data sharing, collaborative work arrangements, and the robust upkeep of the Primary Care dementia register.

Commissioning Well:

Dementia service commissioning can benefit from co-production and should consider population needs. It is especially important that services are designed in a way that minimises health inequalities and are tailored to their diverse communities.

Training Well:

Training delivery and needs assessments should be tiered and include unpaid carers as well as professionals, and providers should ensure training compliance is recorded.

Monitoring Well:

Dementia governance at system level can provide assurance and direction. It is a priority focus within the Dementia 100 to ensure robust system level oversight of performance metrics, which support a multi-agency vision, strategy and improvement plan for dementia care.

Priority criteria:

- Commissioned services undertake dementia-focused equality impact assessments to evaluate the effect of service changes on the local populations and communities
- Health, social care and relevant third sector organisations apply a tiered dementia training programme, which is monitored and reported
- Education and training for unpaid carers is available, monitored and tailored to their needs
- The ICB has a co-ordinated dementia strategy and improvement plan in place
- Dementia performance metrics are reviewed at ICB level and overseen by a co-ordinated, multi-agency group.

#2

Pillar Two: Preventing Well

There is a coordinated approach to prevention and awareness.

Building Blocks

Messaging well:

Public Health messaging for dementia should including individual risk management and focused messaging for rarer types of dementia, such as young onset dementia.

Community events are critical to addressing loneliness or social isolation and should be tailored to the unique needs of the population they serve, taking into consideration what is required to increase accessibility.

Community assets and stakeholders:

Systems should scope and work with a range of community assets, which may include community and faith groups, the voluntary sector, charitable groups, and businesses. Opportunities should be maximised wherever possible.

Addressing social determinants of health:

To fully achieve this pillar, systems should act boldly in addressing the social determinants most linked to dementia; and those that are localised to their population, making this a priority within the Dementia Pathway Assessment Tool.

> **“I was given information about reducing my personal risk of getting dementia”**

Priority criteria:

- ✓ Strategies addressing the wider and social determinants of health reference their impact on dementia risk.

#3 Pillar Three: Diagnosing Well

Diagnosis and post-diagnosis support is in place (mental health and primary care).

Building Blocks

Equity of access to diagnostic service providers:

To achieve this pillar, potential common causes of patient inequity in terms of the availability of, and access to, diagnostic services for dementia must be identified. This should include people being referred for diagnosis of young onset dementia, and those in high risk groups.

Joined up approach to diagnosis:

It is a critical priority that people living with dementia benefit from a single named health or social care professional in the community who is responsible for coordinating their care from assessment to end of life.

Timely and appropriate assessment and diagnosis:

Services and systems should be working to increase the number of people with suspected dementia who receive an assessment within six weeks of referral, and this should be monitored at both provider and system level.

Personalised approach to diagnosis and post-diagnostic support:

Taking a personalised approach to diagnosis involves considerations around appropriate post-diagnostic advice and guidance, personalised care and support planning, advance care planning, and suitable onward referral options.

'I am treated with dignity and respect'

'I get treatment and support which are best for my dementia and my life'

Priority criteria:

- ✓ People living with dementia are provided with a single named health or social care professional who is responsible for coordinating their care from assessment to end of life
- ✓ People with suspected dementia have an initial assessment within 6 weeks of referral and, where possible, receive a diagnosis and start treatment
- ✓ People with a dementia diagnosis have had their care and support plan reviewed in the preceding 12 months
- ✓ Pharmacological interventions are delivered in line with the NICE dementia guideline

#4a

Pillar Four : Supporting well in the community

There is access to safe high quality health and social care for people living with dementia and their carers.

Building Blocks

Post-diagnostic continuity of care:

Continuity of care aids avoidance of unnecessary escalation and interventions. Services should be based on the principle of aiming to optimise a person’s functioning which in turn supports well-being; and should be delivered with dignity and respect.

Supportive care:

Whether people with dementia are living at home or in care homes, access to a range of suitable activities and services that are available for them, and their carers, should be identified and facilitated. Access to care packages should be equitable and should consider a standardised, multi-disciplinary assessment and regular review of suitability.

Personalised care and support plans are paramount for every person living with dementia. Audits should be carried out by the care provider to ensure these are being undertaken by relevant staff, they are appropriate to the current needs of the person and are updated annually as a minimum.

Communication:

Communication considerations should include multiple language, accessibility for those with visual or hearing impairment and the use of communication aids, as a minimum.

> **“I get treatment and support, which are best for my dementia and my life”**

Priority criteria:

- ✓ Non-pharmacological interventions are delivered in line with the NICE dementia guideline

#4b Pillar Four : Supporting well in hospital

There is access to safe high quality health and social care for people living with dementia and their carers.

Building Blocks

Emergency Department:

Adaptations should be made within the Emergency Department to meet the needs of people with dementia. Consideration also needs to be given for those who are undiagnosed and the identification of frailty within the Emergency Department.

Admission:

Access to a dementia specialist to provide advice or patient review, where required, can facilitate good communication with patients, carers and ongoing community care providers.

Inpatient stay:

The criteria under this building block seek to ensure that people living with dementia experience safe and high-quality inpatient stays and their dignity and respect is taken into consideration throughout. The role of the unpaid carer is also given emphasis in this section of the toolkit.

People living with dementia are at higher risk of delirium; and as such it is important that screening should take place reliably, using a structured screening tool, such as the 4AT. Use of this tool also supports a wider frailty assessment, where appropriate, as indicated within the Frail Strategy.

Communication:

Communication considerations should include multiple languages, accessibility for those with visual or hearing impairment and the use of communication aids, as a minimum.

Mental Capacity & Safeguarding:

Where there is a reason to believe a person may lack the capacity to make a specific decision, existing legal duties outlined in the Mental Capacity Act (2005) and inspected by the Care Quality Commission (CQC) must be followed.

Discharge:

The involvement of the multi-disciplinary team in early discharge planning and the inclusion of the carer in plans, can support people with dementia to get back to their home or place of care in a more coordinated and timely way.

Direct referrals from secondary care settings to dementia specialist diagnostic services help to ensure that assessment and diagnosis happen in a timely and accurate way through a standardised referral to treatment pathway.

> **“I get treatment and support, which are best for my dementia and my life”**

#5

Pillar Five: Living Well

People with dementia can live well in safe and accepting communities.

Building Blocks

Inclusive neighbourhoods:

This building block focuses on ensuring adequate infrastructures are in place to facilitate safe and welcoming neighbourhoods for people living with dementia. This can include accessibility of the physical environment, as well as wellbeing activities and community peer groups.

Urgent neighbourhood services:

Urgent community provision should aim to keep people with dementia at home for as long as possible. These criteria address crisis prevention, urgent and intensive support teams, as well as access to specialist advice out of hours. Advice should be available to emergency services to help ensure appropriate conveyance to hospital.

Supporting carers:

Systems and providers need to ensure provision is available to support families and unpaid carers to stay healthy and safe including needs assessments that consider the unpaid carer and the availability of respite services. Interventions on offer should be co-designed, tailored to the individual and the local population.

> **“I know that those around me and looking after me are supported”**

Priority criteria:

- ✓ A range of suitable urgent community-based services are commissioned, including crisis prevention, urgent, and intensive support services
- ✓ Advice is given to carers about their right to carer assessment, and accessibility to respite care, breaks, and support groups

#6 Pillar Six: Dying Well

People living with dementia die well (End of Life & Palliative Care)

Building Blocks

Personalised care and support planning

Enabling frequent discussions for people living with dementia to discuss their futures and make advance care plans while they are well Includes ensuring health and social care professionals are equipped with the knowledge, skills and confidence to identify when a person with dementia is likely to be within the last 12 months of life.

Joined up care

It is a priority to ensure that the delivery of palliative care and end of life care is delivered using collaborative working approaches and that organisations function in an integrated way.

Partnership working is key to joined up care and the kind of joined up thinking that will be required by individuals and by organisations.

Knowledge and skills

Health and social care professionals responsible for caring for people living with dementia should be trained in starting and holding difficult and emotionally challenging conversations to support Advance Care Planning, and to help ensure the person living with dementia and their family are central to decision making.

"I am confident my end of life wishes will be respected"

"I can expect a good death"

Priority criteria:

- ✓ Integrated multidisciplinary approaches are taken to the delivery of palliative care and end of life care for people living with dementia

Copies of this Dementia 100: Pathway Assessment Tool may be made for non-commercial purposes to aid strategy and service development.