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NATIONAL COLLABORATING CENTRE FOR MENTAL HEALTH

Dementia 100: Pathway Assessment Tool

Full Implementation Guidance

Contents

Supporting Statements

NATIONAL COLLABORATING CENTRE FOR **MENTAL HEALTH**

NCCMH

The National Collaborating Centre for Mental Health, which is a partnership between the Royal College of Psychiatrists and University College London, is pleased to endorse the Dementia 100 Pathway Assessment Tool. As the developers of the national Dementia Care Pathway, we welcome the Dementia 100 tool as an important continuation and expansion of our work. We hope that the Dementia 100 tool is implemented widely across the country to ensure consistent care and to improve the lives of those living with dementia and their families and carers.

Tom Ayers, Director of the National Collaborating Centre for Mental Health

DementiaUK
Helping families face dementia

Dementia UK

Dementia UK is the specialist dementia nursing charity that is there for the whole family. Our nurses, known as Admiral Nurses, provide free, specialist advice, support and understanding to anyone affected by dementia, whenever it is needed.

Dementia is the defining health and social care challenge of our time and the leading cause of death in England and Wales. At Dementia UK, we believe in a world where no one faces dementia alone and where everyone gets the specialist support they need. We are therefore pleased to support the publication of the Dementia 100: Pathway assessment tool. We hope this toolkit provides a useful resource to enable local health and care systems deliver the support that people affected by dementia so desperately need. We stand ready to help.

Dr Hilda Hayo, Chief Admiral Nurse and CEO Dementia UK

Alzheimer's Society

Alzheimer's Society is the UK's leading dementia charity. We provide help and hope to everyone affected by dementia - past, present and future, via support, research, evidence and policy development. Alzheimer's Society offers people practical and friendly support through a range of virtual and in-person services, including our Dementia Support Line, our online Dementia Support Forum, and Dementia Advisers.

I am very encouraged to see the development of this improvement toolkit, particularly as it is aimed at supporting local systems to improve dementia diagnosis, care and support. I very much hope that it will be a catalyst to focus on dementia, which we know is a huge challenge in health and care and one which requires a whole system integrated approach. We particularly welcome the fact that the tool was co-produced and includes things that are important to people living with dementia and their carers. I would urge local system leaders to utilise this tool, alongside a clear and prioritised local strategy for dementia, with a focus on early diagnosis. The references, examples and evidence provided are a clear route to improvement and the tool should be used to accurately identify gaps and areas of strength and weakness. Alzheimer's Society are pleased to have supported this work and look forward to it having a positive impact on the lives of people living with dementia as well as their families and carers.

Professor Fiona Carragher, Chief Policy and Research Officer, Alzheimer's Society

Introduction

The dementia challenge

In England, it is estimated that around 676,000 people are living with dementia[1], although recent studies from the Alzheimer'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. We know that for the vast majority of people, care begins at home with their families. Many people play a role in caring for their friends and family, and we recognise that for some this can be a significant commitment. Unpaid carers play a vital role in our communities, and we all owe them a debt of gratitude.

The Prime Minister's Dementia 2020 Challenge set out a vision to create a society where every person with dementia, their carers and families, from all backgrounds, walks of life and in all parts of the country receive high quality, compassionate care from diagnosis through to end of life care. The endeavours to meet this vision require careful examination of all care settings, whether the person is living in their own home, a care home or being treated in hospital; and there is still much to do.

The Department of Health implementation plan set out a number of key commitments to ensure that dementia care, support, risk reduction, awareness and research are transformed.[3] In response to the 2020 Challenge, and through developments in knowledge, a range of resources, multiple guides and standards have been published that contribute to an improved view of how this vision can be achieved.

Largely these are dispersed, across service specific areas, or focused on isolated elements of the dementia pathway, such as diagnosis or hospital 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. Newly published King's Fund research regarding improvement to dementia diagnosis further highlights the critical role of Integrated Care Systems and collaborative working arrangements.

> **"Working in a joined-up way across sectors and organisations is key to enabling good practice."[4]**

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.

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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] Department of Health (2016); Prime Minister's Challenge on Dementia 2020 Implementation Plan

[4] The King's Fund (2024): The role of integrated care systems in improving dementia diagnosis

Sylvia’s story

“Sylvia’s first husband died many years ago and she was his carer. She then cared for her second husband, Stan, who had Alzheimer’s and Parkinsons - before finally, he went into a care home. Every day for four years, Sylvia visited him. As a volunteer, she also helped support the residents in many ways. She would do activities with them and would be there to talk to those who had no other visitors. She would help raise problems such as a resident needing dental care.

In 2021, she said: “Stan doesn’t know me anymore. This is one of the loneliest roads I’ve ever walked and I feel this, every day. It’s killing me inside. Some nights I go to bed and say, “Please God, don’t let me wake up”. 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. “We wouldn’t even have had a diagnosis, but one day he passed out and I took him to the GP.”

This tool is designed to help us all to see the patient as a person, not just as a single ‘condition’. It will help understanding of their whole journey towards death. It helps show how important the professionals are, working in their myriad different settings. And, also, the value of the incredible love and unstinting support given every day by family members.”

(Quote provided with thanks to Devon Carers: Names have been changed)

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 tool draws together existing resources that provide information, guidance and expert advice about the condition and reaches across all stages of the pathway, including prevention, diagnosis, treatment, care and end of life. Existing regulations and guidance are dispersed across a range of valuable and detailed resources such as NICE Guidelines and Quality Standards, the Neighbourhood Health Guidelines, the High Impact Change Models, the FRAIL strategy, the Universal Principles for Advance Care Planning and the Right Care Scenario. In various ways, these incorporate and address research, data analysis, medical expertise and lived experience. The Dementia 100 Pathway Assessment Tool does not seek to replace or duplicate this existing information, but rather extracts and combines the high level, pertinent information from multiple sources into a single, consolidated tool for the purposes of Place and System self-assessment.

Key components of the Dementia 100

The Dementia 100 is constructed in a way that facilitates a review of all relevant information, capturing the maturity of best practice and regulated processes, services, and models of care as a series of self-assessment scores against a range of criteria.

Four foundations underpin the building blocks upon which the criteria sit. The foundations present the essential elements required to establish a strong basis from which to create a high quality pathway. These ground dementia service provision in the key principles for best practice and adherence to legal regulation. Leadership, Carers, Holistic care, and Seamless pathways are the foundations that underpin the building blocks and criteria at the core of the six pillars outlined here. These six pillars follow the main components of the Well Pathway for Dementia.

The tool has been mapped against the key points in the optimal pathway within the RightCare Scenario for dementia. RightCare Scenarios draw on the insights of people living with dementia and their carers and reveal the key factors that influence both optimal and suboptimal experiences. From the optimal pathway, the RightCare Scenario demonstrates what high-quality care looks like when all of the pillars are achieved.

Purpose

The Dementia 100: Pathway Assessment Tool is a set of 100 criteria across six pillars which collectively describe best practice standards for dementia services, from commissioning through to delivery of high-quality care at all stages of condition progression.

The tool provides Places and Systems a way to better understand how to create communities and services where people like Sylvia and Stan have the best possible care and support available to them. This self-assessment tool has been mapped to the key themes of the Well Pathway for Dementia; Preventing Well, Diagnosing Well, Supporting Well, Living Well and Dying Well. 'Leading Well' does not feature in the Well Pathway, however within the Dementia 100, this pillar brings together a number of foundational elements of the Well Pathway – specifically Researching Well, Integrating Well, Commissioning Well, Monitoring Well and Training Well.

Use of the tool

This full implementation guidance provides detailed direction to support the use of the tool, augmenting the benefit that health and social care systems can derive from it. It is important to note that the tool is designed to be completed at Place, and is "provider agnostic" in its approach. This Place-based assessment method means that, once the tool is completed, Places have clear direction for the development of their local plans and strategies, while Integrated Care Systems can get a bird's eye view of areas of the pathway that are going particularly well and areas that require improvement. Integrated Care Boards may wish to benchmark scores across the System in order to facilitate and enable cooperation and collaboration opportunities in improvement, service development, and local policies and strategies. Place-based and System-level governance groups may utilise the findings of the assessment to create task and finish groups to create collaborative spaces for shared learning and reporting mechanisms for the monitoring of progress. The tool can then be revisited on a regular basis to monitor elements of the pathway working well as well as measure progress in areas requiring improvement. Over time, this maturity matrix allows organisations to self-assess their progress on the governance of each domain, indicating whether they are making early progress, substantial progress, or are mature in the provision of their services.

Benefits

There are multiple scenarios providing opportunities for Systems to utilise the assessment tool, including supporting the development of dementia strategy, improvement planning, assessing change and improvement priorities, and establishment of a baseline position for service development. The development of an evidence base provides additonal reassurance in interpretation of findings. Ensuing benefits and impact may include the identification and sharing of best practices, standardisation of service and care provision, and an understanding of gaps and opportunities for service improvement.

The role of integrated and collaborative partnership working in the use of the tool is critical. This maximises the value and impact of the assessment's utilisation, to ensure pathway suitability, and therefore ultimately the quality of service and care provision.

The Pathway Assessment Tool Structure

The Dementia 100 Pathway Assessment Tool comprises of the following:

Foundations:

Four foundations of **Leadership, Carers, Holistic care** and **Seamless pathways**, run through the dementia pathway. All Systems should consider the strength of these foundations within their own services and how they ensure they act as a base for high quality care.

Leadership

Carers

Holistic care

Seamless pathways

Pillars:

The Dementia 100 Pathway Assessment Tool is structured under six pillars:

1. **Leading Well**
2. **Preventing Well**
3. **Diagnosing Well**
4. **Supporting Well**
5. **Living Well**
6. **Dying Well**

Whilst these pillars largely cover key stages of a dementia pathway, they are not designed to be service specific and should be reviewed and assessed as a collaborative exercise, across a Place or a System.

Within each pillar in this guidance, the following contributing information can be found:

What we already know:

This section includes some key points from existing literature, published documents and policies.

What we have learnt:

Through the rigorous testing and engagement that has taken place in the development of the Dementia 100 Pathway Assessment Tool, this section includes some of the key learning that has been achieved.

The building blocks necessary to realise the pillar:

See separate definition of Building Blocks.

How the pillar links to the RightCare Scenario optimal pathway:

This section shows the alignment between the pillar and the key areas of focus for Systems within the RightCare Scenario, drawing on key sections of the optimum pathway to demonstrate what good looks like when this pillar is achieved in a person's care.

Building Blocks:

Each pillar is broken down into two or more building blocks, which focus on the contributing themes within each pillar. Further guidance is given on practical translation into full achievement of each building block in practice.

Criteria:

The Dementia 100 Pathway Assessment Tool is comprised of a total of 100 criteria. These are individual statements against which a Place is able to assess themselves, using an evidence-based approach. Collectively these support the achievement of the building blocks, pillars and overall vision for high quality dementia care.

Priority criteria:

Each pillar has one or more priority criteria, which allows an opportunity for focus on a small subsection of 14 criteria across the pillars. Addressing these core priorities will help to ensure that dementia care is comprehensive, person-centred, and sustainable. Each element contributes to better care outcomes and support people living with dementia and their families. These priorities aim to create a more supportive, responsive, and equitable care system for people with dementia and their families. Where resource is constrained, these priority areas offer a focus set of criteria that give a view across the full pathway.

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

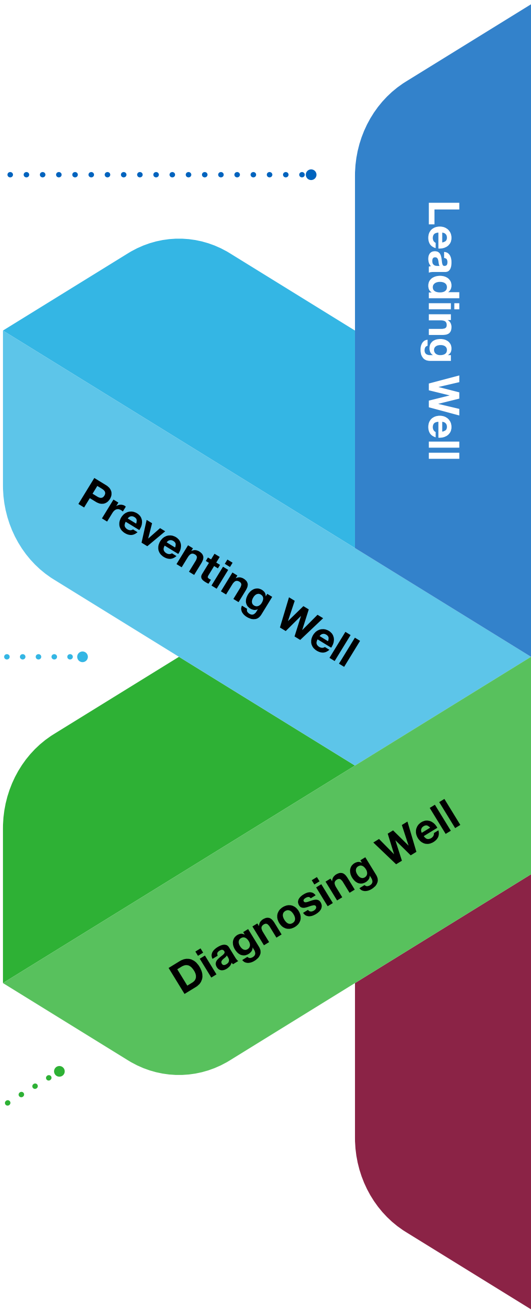
This pillar is formed of **9** criteria

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

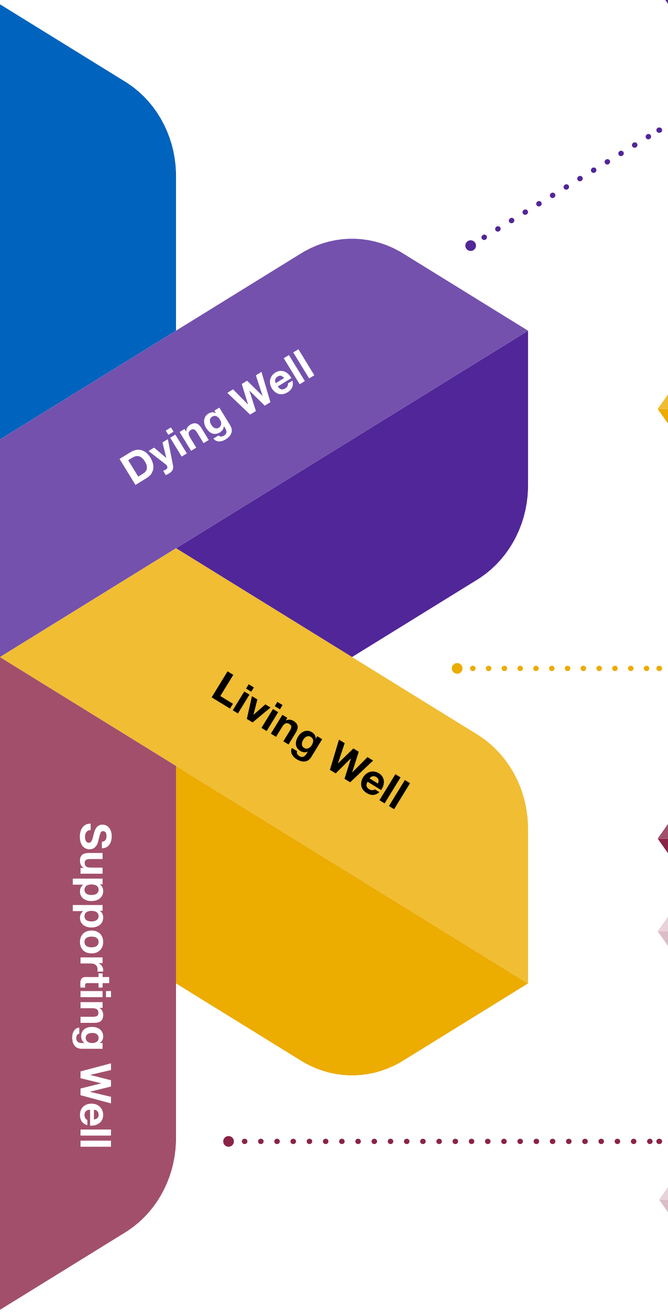
This pillar is formed of **19** criteria



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 following four foundations embody the core requirements of the Dementia 100 Pathway Assessment Tool. These foundations weave through all stages from dementia awareness, diagnosis, living with dementia and the provision of high-quality end of life care. They provide a basis for Systems to review and consider how well **Leadership, Carers, Holistic care,** and **Seamless pathways** work towards excellence in dementia care, for their communities and populations. The foundations – which should provide deeper understanding of the principles upon which dementia diagnosis, treatment, and care are based – also take into consideration and give special attention to those who devote a significant portion of their time to helping those living with dementia; for example, health and social care professionals, unpaid carers and community dementia supporters.

Leadership

> **"I know that services are designed around me, my needs and my carer's needs."**
>
> *Prime Minister's Challenge on Dementia 2020*[5]

The experience of living with dementia is unique for every individual, and many find themselves navigating a range of services, health and social care settings, and professional disciplines over the course of living with the condition. It is critical that health and social care provision is well-led, so that providers understand the population need, with the determination to address delivery challenges and a passion to identify opportunities for improvement.

Strong leadership and governance across an Integrated Care Partnership involves taking a collaborative approach to assessing the needs of a System against the Dementia 100, creating a route for positive change and purposeful action. System leadership should be facilitated by named lead roles for dementia, sound governance structures, and clear lines of accountability across geographical and organisational boundaries.

This leadership forms a core foundation for successful dementia pathways that are planned and well-commissioned, using population health data to understand how best to shape their services to the communities it serves. Furthermore, the continued use of data and intelligence ensures the monitoring of process and outcomes, enabling dementia strategies and improvement plans to focus attention on closing gaps where they may exist.

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[5] Department of Health (2015): Prime Minister's Challenge on Dementia 2020

Carers

> **“It’s important to feel that you’re not on your own and that there’s help out there”**
>
> *Clare, Carer of someone living with dementia [quote provided with thanks to Dementia UK]*

Caring for, and supporting, a loved one with dementia can be physically, mentally, and emotionally challenging. To achieve high quality dementia care, the focus must extend beyond the person living with dementia to provide support for unpaid carers and wider families and friends, taking a holistic approach to the person and their support networks. It is important to recognise that carer arrangements vary widely. Whilst the term ‘carer’ is frequently used in this document, arrangements often involve multiple family members or friends providing some form of unpaid support, whether or not professional carers are involved. Therefore, carers’ needs and expectations also vary widely. Carers assessments, clear and timely information, and access to respite care, are all some of the possible interventions that can ensure the most appropriate support for carers is identified and delivered. A recent King’s Fund study[6] highlighted how access to emotional and therapeutic support for unpaid carers is important both to the carer as an individual, and to the person with dementia for whom they care.

People with dementia are more able to live well in their homes and in their communities when those who care for them feel safe and supported. Practical training for unpaid carers, as well as awareness training for extended friends and family, builds an understanding of how dementia can affect the individual and the wider family, and provides advice on how best to support each other and work together. Training and ongoing support mechanisms can help unpaid carers and family members to find strategies and ways of overcoming difficulties and importantly, ways to enjoy life together with their loved ones. It is critical to ensure there are mechanisms in place to support unpaid carers and family members to be involved, alongside the person living with dementia, in decision making in all care settings, including at home, in the community, in care homes and during hospital admissions.

Providers must create robust mechanisms to enable them to listen to people living with dementia, carers and relatives as well as take action based upon constructive feedback gathered. It is fundamentally important that there is collaboration with people with lived experience in the design of service provision, and this is based on the principles of co-production so that the needs of the population are fully reflected in service delivery.

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[6] King’s Fund: Caring in a complex world (2023)

Holistic care

> **"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."[7]**
>
> *Vesna's Story, Alzheimer's Society*

In the complex settings of our healthcare services, addressing the challenges of dementia requires a holistic approach. Holistic dementia care should acknowledge the seamless interconnection of physical, mental, emotional, and social well-being, embodying those living with dementia as a whole person rather than just their symptoms. It maximises quality of life by tailoring interventions to meet not only medical needs but also psychological, social, and spiritual needs. Holistic approaches that take a broad, whole-person view of health and wellness enable a deeper understanding of the person and what they are experiencing so that the support they receive is tailored to their specific needs.

Whilst a dementia diagnosis can be daunting for some individuals and families, it is vitally important that there continue to be many opportunities for hope, joy, sharing and fulfilment.

A holistic person-centred approach to dementia care and support can empower individuals and families to navigate the disease's challenges with a sense of positivity. People living with dementia need to feel that they have purpose and that they still have an active part to play in life as much as they did before their diagnosis.

It is important not to reduce people living with dementia to their diagnosis alone. There is a need for more interconnected solutions, particularly in dementia diagnosis and care, where many people living with dementia have at least one other long-term condition. Holistic dementia care as a foundation to dementia care aims to enhance the well-being and dignity of all affected by dementia, advocating for comprehensive approaches in hospital and community settings that acknowledge the interconnectedness of mind, body, and spirit in promoting health and wellness.

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[7] Vesna's story, Alzheimer's Society

Seamless pathways

> **“Care Coordination [is] a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings.”[8]**
>
> *World Health Organisation (2018)*

Pathways for those living with dementia can be complicated, over-whelming and disconnected. Achieving a seamless pathway across boundaries can be achieved through collaboration and partnership working. Integrated Care Systems can work together to improve flow and the timeliness of diagnosis and treatment, as well as reduce hospital admissions, by connecting services and information along the pathway.

Forming collaborative working partnerships across provider organisations and establishing the processes to enable sharing and viewing of patient level data is fundamental to creating a pathway that is not hindered by delayed or missing information. Dementia coordinators are not yet commonplace, but where this provision has been tested, it is shown to support individuals to access services in an appropriate and timely way, acting as advocates and reducing unnecessary distress or delay. These roles need to stretch beyond diagnostic settings or hospitals, providing continuity of care from assessment to end of life.

> **“Continuity and care coordination [create] the conditions and relationships to support seamless interactions among multiple providers within interdisciplinary teams or across care settings or sectors.”[9]**
>
> *World Health Organisation (2018)*

Seamless pathways include access to professionals and services out of hours, with 24/7 care for people with dementia and their families. This access extends to dementia specific advice and guidance, to prevent escalation of care or conveyance to hospital out of hours, where that is not required. Where a hospital stay is required, improving flow between services, starting discharge planning and communications at the point of admission, or before elective procedures, and keeping onward services and existing home care providers informed and prepared, all contribute to getting people home as early as possible.

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[8] World Health Organisation (2018) - Continuity and coordination of care

[9] World Health Organisation (2018) - Continuity and coordination of care

#1

Pillar One: Leading Well

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

The Well Pathway is underpinned by five critical elements which together build a strong basis for service design and delivery: Researching Well, Integrating Well, Commissioning Well, Training Well and Monitoring Well.

These five elements have been combined within Pillar One ‘Leading Well’.

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 have a tiered training programme in place, which is monitored and reported
- Education and training for unpaid carers is delivered, 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.

What we already know

- People's experience of living with dementia is significantly determined by individual characteristics, which may include ethnicity, age, co-morbidities or whether they have a carer living with them.[10]
- Social and economic factors such as where we live, or whether we experience discrimination, may influence our health more than our own lifestyle choices[11]
- Structured training should be available for all staff working with people with dementia and for unpaid carers[12]
- The Dementia Training Standards Framework is available online and provides a tiered approach to assuring appropriate education meets the needs of the unpaid carer or professional[13]
- During the most recent national audit, not all care providers were able to provide training records or evidence training competencies.[14]

> **"Being able to identify someone who has or may have a dementia condition as they are admitted allows the multidisciplinary team to plan and provide the right inputs, care and discharge planning during their admission. Without such knowledge, the hospital also lacks information needed for planning care provision and resource allocation."[15]**
>
> *Healthcare Quality Improvement Partnership (2023)*

What we have learnt

- Integrated Care Systems health and care partnerships are still in the early stages of establishing routine and robust oversight of dementia provision and not all have a clear, documented strategy
- Where leadership and oversight are present at System level, this enables a more accurate and robust review of current performance
- Sharing intelligence of achievements across Places within a System presents opportunities for sharing best practice
- Training for unpaid carers should extend more systematically to wider family members; and should include a greater focus on emotional and psychological well being
- There is more to do to ensure GPs are able to maintain their dementia registers in an accurate manner. Timely coding and registration on local GP registers provides a route for data sharing and increases the visibility of a persons needs when presenting to other health care settings.

> **"Local commissioners and providers need to continue to improve their understanding of the best ways to tailor post-diagnosis support services to diverse needs."[16]**
>
> *Department of Health, Prime Ministers Challenge on Dementia 2020*

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[10] Department of Health (2015): Prime Minister's Challenge on Dementia 2020
[11] Alzheimer's Research UK (2023): Towards Brain Health Equity
[12] Skills for Health, HEE and Skills for Care (2018): Dementia Training Standards Framework
[13] Skills for Health, HEE and Skills for Care (2018): Dementia Training Standards Framework
[14] Healthcare Quality Improvement Partnership (2022): National Audit of Dementia Memory Assessment Services
[15] Healthcare Quality Improvement Partnership (2022): National Audit of Dementia Memory Assessment Services
[16] Department of Health (2015): Prime Minister's Challenge on Dementia 2020

The building blocks necessary to realise Pillar 1

Researching well

Research studies and trials drive best practice and should hold a prominent position across all Providers, with identified opportunities and processes to ensure learning and sharing across the System.

Strong relationships should be established with the Research Delivery Networks, ensuring a clear link from the Network to the staff that are able to recruit and advocate for active research trials.

Having Research Champions in place gives opportunity for service users, carers and members of the public to promote the value of research, increase uptake and ensure people's views and experiences are factored into the planning.

Integrating Well

The Neighbourhood Health Guidelines[17] identify the existence of neighbourhood multidisciplinary teams as a best practice component of an effective neighbourhood service. These teams are able to coordinate care for population cohorts with complex health and care or social needs who require support from multiple services and organisations. These cohorts include those with dementia, frailty and palliative care needs.

Data sharing and collaborative work arrangements across partner organisations within Integrated Care Systems are fundamental to a successful and integrated model of service provision and delivery. This includes capability for multiple agencies to share electronic records.

Maintenance and assurance of a robust dementia diagnosis register is fundamental to support the collection and analysis of the national dementia diagnosis rates. It is known that people who get an early and timely dementia diagnosis have a better quality of life and more access to support.

Appropriate data sharing agreements between organisations and robust System level governance, management and audit arrangements for data access and sharing will aid in achieving this building block.

Commissioning well

Commissioners should seek a lived experience perspective on service suitability and needs, extending to coproduction when designing and developing services. Population needs, based on forecast case numbers and trends, should be factored into service plans, along with consideration of the needs of under-served groups and diverse communities.

It is especially important that providers design services in a way that minimises health inequalities and are tailored to their diverse communities. As such, a priority area within the tool encourages the completion of Equality Impact Assessments. Along with improvement plans, these are a good way to address identified inequalities. Joint Strategic Needs Assessments and an up-to-date health equity assessment should also be considered within the commissioning planning process.

Training well

To provide the highest quality care for those with dementia, it is vital that every Place and every profession has a framework for workforce education, training and continuing professional development. Training should be tiered, multi-agency and include appropriate training for unpaid carers and family members.

Listening to the needs and preferences of those caring for people living with dementia is crucial to be able to provide what they require and not take a one-size-fits-all approach. People with young onset dementia may have

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[17] NHSE: Neighbourhood Health Guidelines (2025)

specific needs, and training should cover psychosocial impacts, including employment, financial planning, and parenting. Due to their age and stage of life, they may for example be working, have dependent children and greater financial commitments.

Dementia training is fundamental to ensuring there is standardisation in the care provided as well as making sure that unpaid carers feel equipped to embrace their roles. It is essential that training records are robust and regularly monitored.

Monitoring well

System level dementia vision, strategy and plans need to be deployed to provide consistency and alignment between all key stakeholders, including robust cross-organisational governance arrangements with clear designation of roles and responsibilities of partner organisations. This should be a priority focus for the System and includes oversight of performance metrics, with a particular focus on:

- ✓ Population data to address the known or likely sources of inequalities
- ✓ Quality and appropriateness of referrals from General Practice to dementia diagnostic services
- ✓ Waiting times to assessment and diagnosis
- ✓ Assurance of the accuracy of registers held within General Practice
- ✓ Annual review of prescription rates for dementia treatment, including anti-psychotic medications
- ✓ Diagnosis rates in care homes.
- ✓ Measures of experience for people living with dementia, their families and unpaid carers

Further consideration may be given to:

- ✓ Delayed discharges and progression of onward pathway for patients with delirium and dementia
- ✓ General Practice Dementia Annual Reviews
- ✓ Outcomes of patients diagnosed with delirium and dementia

The National Audit for Dementia Care in General Hospitals 2022-2023[18] found that there were significant gaps in identification of patients with dementia within secondary care settings. Performance oversight needs to include assurance that patients can be easily identified in order to receive the right care at the time that they need it.

Identification and diagnosis of dementia within care homes remains relatively low. The DiADeM (Diagnosing Advanced Dementia Mandate) tool offers one approach to creating an alternative pathway for diagnosing dementia in care homes.

> **"For those with advanced dementia, a referral to memory services may not be feasible or desirable and is likely to be distressing for the individual. However, they can still benefit from a formal diagnosis. A diagnosis may enable access to appropriate care to meet individual needs and prompts staff to consider mental capacity and deprivation of liberty issues where appropriate."[19]**
>
> *NHSE Dementia Programme Update (February 2024)*

Ensuring all services are demonstrating dignity and respect is important across all care settings. Those caring for people with dementia should recognise uniqueness and adapt care and support accordingly, whilst considering communication, privacy and creating a respectful environment.

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[18] Healthcare Quality Improvement Partnership (2022): National Audit of Dementia Memory Assessment Services

[19] NHSE Dementia Programme Update (February 2024)

How this links to the RightCare Scenario optimal pathway

Areas of the RightCare Scenario optimal pathway covered within this Pillar include:

- Training for carers
- Data review
- Needs analysis
- Joint Strategic Needs Assessment.

Maria also makes Tom aware of dementia research that is taking place at the local hospital. It includes a trial on a new drug that could slow down the progression of Alzheimer's disease, which Tom joins.

Best practice case study: Integrated Care Records

- Living Well in the community
- Inclusive environments
- Admission avoidance

Staffordshire and Stoke-on-Trent ICS have maximised their collaboration efforts to ensure their populations are advantaged by the sharing of appropriate information and data across organisations

'One Health and Care' is a confidential digital shared care record, bringing data together from the different organisations involved in health and social care across the System. It allows doctors, nurses and other registered health and social care professionals directly involved in the care of individuals to view relevant information to provide better and safer care.

Patients can access their own data and care plans can be uploaded and managed by multiple organisations involved in the provision of health and social care.

The ICS are able to gain additional benefits from the analytics function within the System, informing service transformation and population health intelligence.

Across Staffordshire and Stoke-on-Trent, the One Health and Care System users include four hospital Trusts, 142 GP practices, the ambulance services and two councils, as well as care homes, hospices and the Multi Agency Safeguarding Hub.

The use of this collaborative system has allowed a more holistic view of the patient record to inform decision making, it has empowered people to have access to their own information and it has reduced duplication with single care plans and less time repeating or seeking information.

#2

Pillar Two: Preventing Well

There is a coordinated approach to prevention and awareness.

> **“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

What we already know

- Research suggests that up to 40% of cases of dementia are linked to modifiable factors[20]
- Poor recognition and understanding of symptoms, particularly in groups where dementia remains misunderstood and stigmatised, or in atypical presentations, such as young-onset dementia or dementia associated with learning disabilities, can lead to late presentation to services
- NHS Health Checks can aid with the identification of early signs of dementia and discuss modifiable risk factors.[21]
- Information on dementia diagnosis should include advice on how to maintain a high quality of life with the condition.

> **"Health and care professionals should provide support and advice on dementia risk reduction as part of their daily contact with individuals. Every contact counts as a chance to educate and empower people to make positive choices about their own health."[22]**
>
> *Office for Health Improvement and Disparities, Feb 2022*

What we have learnt

- NHS Health Checks can provide information on early signs of dementia and discuss modifiable risk factors
- Health Checks should comprehensively cover Physical, Emotional, Mental, Cognitive and Social Health. Social interaction is a protective factor to dementia but can often be missed
- Traditional delivery models for general health assessments, comprising of an initial assessment followed by an 'as and when required' approach can miss or delay required support or treatment changes for people living with dementia. As such, it is beneficial to schedule these as routine practice.
- In addition to identification of individual modifiable risk factors, structural factors should be addressed within System policies, such as air quality, noise levels and deprivation

The building blocks necessary to realise Pillar 2

Messaging well

Public Health messaging for dementia should include a range of content areas, not least the individual's own behaviour modifications that can affect the risk of developing Alzheimer's Disease and vascular dementia. These include reducing caffeine and alcohol intake, maintaining good levels of sleep and physical activity, avoiding tobacco and drug use, and ensuring good nutrition. Specific messaging around Young Onset Dementia is also critical to support early identification of presenting symptoms.

Community events are critical to addressing loneliness or social isolation and might include workshops, seminars, informational sessions, support groups, memory cafes, fundraising events, art exhibits, film screenings, and educational talks.

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[20] The Lancet Commission (2020)
[21] NHS Health Checks
[22] Office for Health Improvement and Disparities (Feb 2022): Dementia - applying All Our Health

Messaging and events need to be tailored to the unique needs and cultural diversities of communities; and efforts need to include communicating in languages and through means that increase accessibility, such as for those with hearing or sight loss. These events serve to educate the public, provide support to caregivers, and foster understanding and and inclusivity of individuals living with dementia.

Community assets and stakeholders

Systems should scope and work with the range of community assets that are available to them, which may include community and faith groups, voluntary sector and charitable groups, or commercial organisations wishing to support their local residents. Maximising the opportunities posed through these assets for the purposes of messaging of risks, and encouraging the establishment of supportive environments, can provide significant benefit for people living with dementia and for their families.

Raising awareness at scale across communities can begin by working closely with academic institutes to reach young audiences. This process could involve implementing educational programs, workshops, guest lectures, and interactive sessions tailored to young people. These initiatives aim to educate students about dementia, its impact on individuals and society, risk factors and prevention strategies. Additionally, it may involve promoting volunteer opportunities or projects related to dementia care and research, encouraging students to engage actively in raising awareness and supporting initiatives in their communities.

Addressing social determinants of health

It is well documented that the social determinants of health present profound variables on a person's risk factors in the development of dementia[23]; and on their ability to access diagnosis and treatment in an equitable way, as such this is a priority criteria within the assessment tool.

To fully achieve the pillar to Prevent Well requires Systems to identify and act boldly in addressing the social determinants most linked to dementia; and those that are localised to their population. Through addressing structural factors within wider health policies and plans, such as air quality, noise levels, social isolation, active travel policies, deprivation, and access to lifelong education systems are able to tailor services to benefit the diverse nature of their unique communities.

For achievement of this, Systems should consider how dementia, frailty and healthy ageing is considered and noted in health policies around social determinants of health.

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[23] Alzheimer's Research UK (2023): Towards Brain Health Equity

How this links to the RightCare Scenario optimal pathway

This Pillar directly links to Information Point 6 within the RightCare Scenario:

Preventing Well - Risk of people developing dementia is minimised

There is limited awareness among both the public and practitioners that the risk of developing some types of dementia can be reduced, or the onset or progression delayed, through lifestyle changes. Making this clear in interventions and programmes that promote behaviour change, such as NHS Health Checks and stop smoking services, should encourage changes in behaviour in mid-life, which could lead to fewer people developing dementia in later life.

Areas of the RightCare Scenario optimal pathway covered within this Pillar include:

- ✓ Assessment before treatment
- ✓ Needs analysis.

The Nurse advises John that he can reduce his risk of dementia by eating a healthy diet, maintaining a healthy weight, exercising regularly, reducing his alcohol intake, not smoking and keeping his blood pressure at a healthy level.

Best practice case study: Healthy Ageing Champions and 'Making Every Contact Count' Fact Sheets

- Messaging Well
- Community Assets and Stakeholders.

Dudley Public Health Team have established a volunteer programme running from their Healthy Ageing team. Adults of any age, who wants to support people to age well and make Dudley more age friendly, are invited to become Healthy Ageing Champions. Champions can be from organisations, businesses, or communities and they provide help by promoting healthy ageing in their workplace, place of worship, social group, friends and neighbourhoods. An initial training session for Champions includes advice and guidance on how to age well; as well as nine key focus areas specifically focussed on reducing the risk of dementia, pointing to further online resources that are available. Regular informal meetings are run as optional for healthy ageing updates on relevant topics, providing a strong route for two way communication to inform the Public Health Team on what is happening on the ground. The Champions are able to signpost to community activities and events, maximising on people's awareness of the support on offer. These include a 'Befriending' and 'Pleased to Meet You' services, reducing the risks associated with social isolation.

'Make Every Contact Count' fact sheets are available, focusing on Loneliness and Social Isolation and Physical Activity. These include wider key messages as well as Dementia specific advice, such as symptoms to watch out for and ways to prevent risks, where to get help and support, how to self-help, how to get involved with your community and a list of helpful contacts and local services.

Become a
Healthy Ageing Champion
Help support people to age well in Dudley

#3

Pillar Three: Diagnosing Well

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

'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

What we already know

- Having a single named health or social care professional, responsible for co-ordinating care, has been shown to create positive outcomes, such as a reduction in carer pressure and improved quality of life.[26]
- 65.4% of people aged 65 or over, who are estimated to have dementia, had a recorded diagnosis of dementia (as of February 2025) enabling them access to post-diagnostic support[27]
- The average time to diagnosis is 4.4 years in younger people compared to 2.2 years for people aged over 65[28]
- Resource, skills and knowledge of health and social care professionals in managing a diagnosis are key factors in achieving a high-quality diagnostic experience[29]
- It is critical that all services are designed to provide an equal offer of support for all types of dementia[30]

> **"Prompt diagnosis of dementia enables the person and their family and/or carer to plan for the future while the person still has the capacity to make decisions. Having a care plan and access to evidence-based treatment at the earliest opportunity can improve the long-term outcomes of people living with dementia."[24]**

What we have learnt

- The inclusion of Place and System level monitoring of performance against a six-week assessment target can help to facilitate an integrated approach to improvement planning.
- Plans are in place across various Systems to make improvements against waiting times, but many still have a significant gap to achieve this target
- NHS Talking Therapies should be promoted as a potential avenue for treatment following a dementia diagnosis.

> **"A timely diagnosis of dementia is an important step in receiving the tailored support and treatment that enables people to lead full lives, engaged with their families and communities, for as long as possible."[25]**
>
> *Dementia Care Pathway 2018*

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[24] Dementia Care Pathway 2018
[25] Dementia Care Pathway 2018
[26] NICE guideline [NG97]
[27] NHS Digital (2025): Primary Care Dementia Data
[28] Vliet et al (2012): Time to diagnosis in young onset dementia as compared with late onset dementia
[29] Alzheimer's Research UK (2022): Improving dementia diagnosis: What could change in primary care?
[30] Alzheimer's Society (2022): Left to Cope Alone: The unmet support needs after a dementia diagnosis

The building blocks necessary to realise Pillar 3

Equity of access to diagnostic service providers

Potential common causes of inequity in terms of the availability of, and access to, diagnostic services for dementia must be identified and addressed. This includes consideration of factors such as religious and cultural diversity and underserved communities, and equal support being offered for all types of dementia diagnosis.

There needs to be rigorous and robust strategies in place, with accompanying implementation plans to strive for equity of access, targeting any known or potential inequalities based on the local population, and ensuring the regular review of referral pathways.

Getting an accurate and timely diagnosis of dementia is important, no matter the type of dementia being assessed. As atypical, rarer types of dementia can present differently from Alzheimer's Disease and symptoms may be harder to recognise (changes may not be in memory but in behaviour, language, vision, or personality), it is crucial that service providers have in place robust assessments and processes to ensure that there is equity of access to a diagnosis.

Dementia UK's extensive work on a new pathway framework for young onset dementia emphasises the importance of dedicated specialists to address some of the existing inequalities in diagnosis. These include the common misdiagnosis of young onset dementia and the increased number of consultations before a diagnosis is made. They also point out the significant variation in diagnostic and support services for young onset dementia across Systems and the fact that memory services often exclude those under 65 or lack specialised expertise.

Rapid access to a specialist service with expertise in diagnosing young-onset dementia and those in high-risk groups, such as people with Down's syndrome, is vital to expedite timely referral for diagnosis and ongoing support.

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 who is responsible for coordinating their care from assessment to end of life, with formalised arrangements to ensure multidisciplinary input from appropriate specialisms. Coordinators of care can also ensure unpaid carers are gaining the emotional and physical support they require, to keep them healthy and safe.

Timely and appropriate assessment and diagnosis

It is a priority criteria within the Dementia 100 pathway assessment tool that people with suspected dementia are assessed within six weeks of referral, and receive a diagnosis and start treatment, where appropriate. Monitoring of this at Provider, Place and System level can review performance and track progress against improvement initiatives.

Systems should ensure advice and guidance is available to GPs on carrying out dementia assessment and diagnosis and all service pathways need to be well documented and audited, with the correct performance analysis information available and regularly reviewed.

In urgent or crisis situations, there should be clear protocols and pathways in place for urgent community teams to be able to draw on expertise from across Place to ensure timely assessment, triage and onward referrals.

Personalised approach to diagnosis

Consent should be routinely sought to involve families and unpaid carers in the diagnostic process and decisions around care and treatment, including clear and documented communication about disease progression and management.

Health and Social Care professionals working with people who have received a dementia diagnosis should give attention to the development of a holistic personalised care and support plan. A person-centred approach will ensure a focus on what is important to the individual. Personalised care and support plans should be outcomes-focused, reviewed and updated regularly, and mechanisms should be in place to allow them to travel with the person across all care settings.

People diagnosed with dementia are encouraged to plan ahead and should have had their care and support plan reviewed in the preceding 12 months. Taking the time to carry out comprehensive reviews of care plans is important to ensure that people living with dementia are still receiving the best possible care and support throughout the pathway.[31]

Appropriate advice and guidance must be provided following diagnosis, including the potential use of Lasting Power of Attorneys, the availability of NHS Talking Therapies as an avenue for treatment, and the offer of appropriate pharmacological interventions. Clear onward referral pathways at the point of diagnosis will help to ensure those diagnosed with dementia continue on a treatment path that best suits their needs.

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[31] NICE Guidance [NG97]

How this links to the RightCare Scenario optimal pathway

This Pillar directly links to three of the seven Information Points within the RightCare Scenario.

i. **Information Point 2: Referral to a specialist dementia diagnostic service**
Referral to dementia specialist diagnostic services ensures that diagnosis is timely and accurate, and dementia subtypes, such as Alzheimer's disease and dementia with Lewy bodies, can be identified. It also means that people can access support and treatment sooner. The benefits of a timely diagnosis include the person and their family and carers knowing what to expect so that they can consider future mental capacity and make plans early (advance care planning).

Tom agrees to be referred to the local memory clinic and Dr Turner makes him and Barbara aware of the Next Steps website to provide them with an idea of what to expect next.

ii. **Information Point 3: People with dementia have a single named practitioner to coordinate their care**
Dementia is a progressive condition with symptoms and care and support needs that change over time. People with dementia often have other long-term conditions and many different practitioners might be involved in supporting their health and social care needs. To ensure that people with dementia experience person-centred care, it is important that there is a person responsible for supporting them through the disease course. The type of support needed will depend on the stage of dementia. During the earlier stages, this might be signposting to different services and support, whereas later it might be coordinating all aspects of their health and social care. The person with dementia can also develop and review a care and support plan with their named person.

Dr Fisher introduces Tom and Barbara to their Dementia Adviser, Maria. Maria explains the non-clinical role of a Dementia Adviser as someone who makes it easier for people with dementia to self-manage, live more independently and seek out the right support at the right time. They help to deliver high quality, personalised dementia care.

i. **Information Point 5: Advance care planning is discussed at diagnosis and each health and social care review**
As dementia is a progressive condition, it is important for people to be able to make decisions about their future care early on before they find it difficult to communicate or they lack the capacity to do so. This is known as advance care planning. It is important that there are opportunities to review and change the plan as the dementia progresses and if the preferences or needs of the person change. Having an advance care plan ensures that the person with dementia can receive treatment and care according to their preferences, even when they can no longer express them.

Maria discusses with them the benefits of having an advance care plan in place as well as the importance of doing this early in Tom's dementia journey, adding that it can be updated if Tom's preferences change. She also advises them on how to begin the process of agreeing a Lasting Power of Attorney, for both health and welfare and property and financial affairs, when they feel ready.

Areas of the RightCare Scenario optimal pathway covered within this Pillar include:

- ✓ Referral process
- ✓ Coordinated support
- ✓ Advance care plan.

#4

Pillar Four: Supporting Well

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

"I am treated with dignity and respect"

"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

Pillar 4a: Supporting Well in the community

What we already know

- People with dementia benefit from a meaningful, coproduced care plan, which should be reviewed annually[33]
- A multidisciplinary approach, with the inclusion of Occupational Therapists, is key to enabling people with dementia to live well by remaining independent in their homes[34]
- People living in care homes often experience unplanned and avoidable admissions to hospital, with many of these at the end of life when hospital care may be inappropriate and increase their suffering.[35]

> **"Once a diagnosis of dementia has been made, each person and their family and/or carer should be offered evidence-based post-diagnostic support, with a named coordinator of care as a primary point of contact. If not documented earlier, consent for services to share information about the person's diagnosis and their care plan should be sought from the person living with dementia."[32]**

What we have learnt

- Accessibility to written and verbal communications should accommodate those who are visually or hearing impaired
- A structured and validated tool should be used for assessing people with dementia who are in crisis, considering challenges they may have with standard methods of communication.

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[32] Dementia Care Pathway 2018

[33] Dementia Care Pathway 2018

[34] Alzheimer's Society (2022): Left to Cope Alone: The unmet support needs after a dementia diagnosis

[35] NHS Getting it right first time (2021): Geriatric Medicine Programme National Specialty Report

The building blocks necessary to realise Pillar 4a

Post-diagnostic continuity of care

Services should be based on the principle of aiming to optimise a person's functioning which in turn supports well-being. For example, this is the basis for intermediate care (rehabilitation, reablement and recovery) provided to people with new or increased needs on a short-term basis as outlined in the Community rehabilitation and reablement model.[36]

Multidisciplinary health and social care support teams may consist of clinicians, social workers, therapists and skilled support workers as well as relevant voluntary and community organisations. Support may include home visits, where and when appropriate, from Older Adults Mental Health Teams or other allied health professionals as symptoms increase or condition deteriorates.

Continuity of care aids avoiding unnecessary escalation and interventions; and can be a strong enabler to keeping people with dementia at home and out of hospital.

In the event of distress, a validated assessment tool should be used to explore possible reasons for the person's distress and check for and address clinical or environmental causes (for example pain, delirium or inappropriate care).

The prescription of anti-psychotic medications should be reviewed at least every 6 weeks with the aim being to de-prescribe and prescribing practices should be monitored, linking with the criteria in the building block "Monitoring well" within Pillar 1, Leading Well.

Supportive care

Where people with dementia are living at home, carers should be made aware of community activities and services available and facilitate access to these.

When a person living with dementia is no longer able to live in their own home, access to suitable activities should be identified and facilitated by those that are responsible for their care.

People with dementia can benefit from consideration to the environment around them; and care homes should aim for dementia-friendly environments, which may include colour co-ordinated spaces, doors, and rooms that are clearly defined.

Personalised care 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.

Commissioned services for dementia need to ensure consideration is given to support those living alone, or in diverse home settings.

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[36] NHSE (2024): A community rehabilitation and reablement model

Access to care packages should be equitable and should be assessed in a standardised manner, based on individual needs of the person with dementia and their unpaid carer. These assessments benefit from a multi-disciplinary review inclusive of the views of the person living with dementia and their carers.

Once care packages are in place, processes should be established to enable annual review, or more often as required.

Communication

Written and verbal communications must be accessible in multiple languages and for those who are visually or hearing impaired. Additional communication aids can be beneficial, such as charts with pictures, symbols, letters or words or applications that run on tablets and mobile phones.

How this links to the RightCare Scenario optimal pathway

This Pillar links to three of the seven Information Points within the RightCare Scenario.

i. **Information Point 1: Supporting family members and others caring for people with dementia**
Unpaid carers often have high levels of stress due to the physical and mental challenges of caregiving and coping with other responsibilities. It is essential that informal carers have culturally appropriate support, considering their cultural preferences and needs, to enable them to manage the stresses and demands of caregiving and to fulfil their role. As per the duty in the Health and Care Act 2022, it is important to involve carers in all decisions around care.

Maria signposts Barbara to a range of support groups and resources including Dementia Together and TiDE (together in dementia every day) for support and information on living well with dementia. She also encourages her to join the local Strategies for Relatives (START) programme (an eight week programme of individual therapy sessions aimed to reduce depression and anxiety in family carers of a person with dementia) and makes their son, John, aware of the Alzheimer's Society's Dementia Talking Point (Dementia Support Forum), an online community that anyone affected by dementia can join and share experiences with other people also affected.

Maria refers Tom and Barbara to the Admiral Nurse and explains what support they can provide. Admiral Nurses are specialists in dementia and support families with the many complex challenges of the condition, providing free, specialist health advice, compassionate emotional and psychological support and understanding and support to plan for the future.

i. Information Point 3: People with dementia have a single named practitioner to coordinate their care

Dementia is a progressive condition with symptoms and care and support needs that change over time. People with dementia often have other long-term conditions and many different practitioners might be involved in supporting their health and social care needs. To ensure that people with dementia experience person-centred care, it is important that there is a person responsible for supporting them through the disease course. The type of support needed will depend on the stage of dementia. During the earlier stages, this might be signposting to different services and support, whereas later it might be coordinating all aspects of their health and social care. The person with dementia can also develop and review a care and support plan with their named person.

Dr Fisher introduces Tom and Barbara to their Dementia Adviser, Maria. Maria explains the non-clinical role of a Dementia Adviser as someone who makes it easier for people with dementia to self-manage, live more independently and seek out the right support at the right time. They help to deliver high quality, personalised dementia care.

ii. Information Point 7: A structured assessment should take place before starting treatment for distress

People with dementia can become distressed, which can lead to symptoms such as increased aggression, anxiety, apathy, agitation, depression, delusions, hallucinations and sleep disturbances. But these behaviours may have other causes, including pain, delirium or inappropriate care. Understanding the causes of these behaviours and addressing them before offering non-pharmacological and pharmacological treatment can prevent things getting worse and avoid harm.
It can minimise the use of pharmalogical interventions such as antipsychotic medication and antidepressants.

On the advice of Maria, Barbara calls the Urgent Community Response team, who after an initial assessment at their home, recognise that Tom is presenting signs of delirium and refers him to the local virtual ward for treatment. They know that admitting Tom to hospital would exacerbate his symptoms.

Areas of the RightCare Scenario optimal pathway covered within this Pillar include:

- Referral process
- Advance care plan
- Activities for wellbeing.

Pillar 4b: Supporting Well in hospitals

What we already know

- Hospital admissions can be stressful and confusing for a person with dementia and can contribute to a decline in functioning and a reduced ability to return home to independent living[38]
- Personalised and advance care plans should be reviewed or created during each hospital admission[39]
- At any one time one in four hospital beds are occupied by people living with dementia.[40]

> **"Inpatient units provide acute physical and mental health care when care in the community is not possible and/or the person living with dementia is assessed as being a risk to themselves or others. If admission is necessary, it should be planned and as brief as possible, to minimise the adverse consequences hospitalisation can have"[37]**

What we have learnt

- Basic awareness training needs to include all staff in the hospital setting, such as receptionists and security – not just those involved in direct care
- A named dementia care specialist should be available and these can operate from a variety of roles within the multi-disciplinary team
- Policies and processes need to ensure staff know when the Deprivation of Liberty Safeguards procedures (Mental Capacity Act 2005) are appropriate for use.

The building blocks necessary to realise Pillar 4b

Emergency Department

Suitable adaptations should be in placewithin the Emergency Department to the needs of people with dementia. In particular, departments should review how they minimise disorientation by assessing ways to offer alternative waiting environments, which can significantly reduce the risk of distress. Swift processing and progression along the pathway additionally prevents patients from being left in uncomfortable positions for extended periods and ensures management of hydration, nutrition, pressure care, and medication.

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[37] Dementia Care Pathway 2018
[38] Right Care Dementia Scenario
[39] Alzheimer's Society (2016): Fix Dementia Care: Hospitals
[40] High Impact Change (2024)

Consideration also needs to be given for those who are undiagnosed and how the identification of frailty within Emergency Departments could further support this.[41]

Admission

Clinical teams should have access to a dementia specialist, to provide advice or review the patient where required. This specialist can be from across the multi-disciplinary team, including neurology, psychiatry or a specialist dementia nurse, allied health professional or another professional with appropriate dementia training and expertise.

The dementia care specialist facilitates good communication on admission and follows the person throughout their inpatient stay. They aid health care professionals in drawing up care plans, ensuring they are personalised and patient-centred by facilitating the use of accurate and up-to-date information. Their continued facilitation and interaction throughout the inpatient stay will give the person living with dementia and their families and carers the reassurance that they are being listened to and understood. Hospital Trusts should have robust systems and mechanisms in place to identify patients with dementia; and records should be updated by the dementia care specialist.

Inpatient stay

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.

Hospitals should be signed up to John's Campaign[42] to ensure carers are respected as experts in the person for whom they care; and are welcomed to work in partnership with the medical or social professionals. Extensive research, including by the Alzheimer's Society and The King's Fund, found that the physical environment can have a significant impact on the cognitive function, recovery and distress levels of a person living with dementia. The 'DHSC Dementia-friendly Health and Social care Environment Health Building Note' (2015)[43] provides guidance on key considerations.

The 'High Impact Change Model: Improving the timely and effective discharge of people with dementia and delirium into the community'[44] encourages providers to consider suitable signage and orientation cues that support navigation and ease decision making for people living with dementia. This can further be helped by accent colours and access to natural light.

Person-centred, dementia inclusive activities should be available and facilitated to support recovery, improve emotional wellbeing and reduce the risk of deconditioning, and isolation.

It is critical that people with dementia receive increased monitoring to ensure hydration and nutrition are maintained. Where possible, people with dementia should have discussed and documented an advance decision about future emergency care and the hospital team should be mindful of any care plans already in place prior to admission. The FRAIL Strategy[45] recommends that Comprehensive Geriatric Assessments are initiated in hospital (but should be finalised in the community) and this includes considering future emergency care, and this should be documented using tools such as ReSPECT.

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[41] NHSE: FRAIL Strategy (2024)
[42] John's Campaign (2024)
[43] DHSC: Dementia-friendly Health and Social Care Environment (2015)
[44] High Impact Change (2024)
[45] NHSE: FRAIL Strategy (2024)

Communication

Written and verbal communications must be accessible in multiple languages and for those who are visually or hearing impaired. Additional communication aids can be beneficial, such as charts with pictures, symbols, letters or words or applications that run on tablets and mobile phones.

Safeguarding

Hospital staff need to be trained in the six safeguarding principles outlined in the Care Act 2014[46], ensuring they are skilled and able to prevent and stop both the risks and experience of abuse or neglect. Training should include identification of financial, physical, verbal, sexual and emotional abuse. The NHS Safeguarding app is available as a comprehensive resource providing up-to-date guidance and legislation.

Hospital Trusts must ensure that Deprivation of Liberty Safeguards (DoLS) procedures (Mental Capacity Act 2005)[47] are documented as part of safeguarding policies and that staff are trained in how to follow them. The Care Quality Commission (CQC) inspects hospitals against matters relating to safeguarding.

Discharge

The Neighbourhood Health Guidelines core components include integrated intermediate care with a ‘home first’ approach. This includes ensuring referrals can be made directly from the community or as part of out-of hospital discharge planning, with assessments and interventions delivered at home where possible, working closely with urgent neighbourhood services (as described within Pillar 5).

When a person living with dementia is admitted to hospital, discharge planning should be started at the point of admission, with early involvement from the multi-disciplinary team, as outlined in the hospital discharge and community support guidance, in order to reduce the potential for delay. Planning should include both the dementia care specialist, the person living with dementia, and their carers and families where applicable.

Families and unpaid carers of people living with dementia should be supported with relevant information on discharge. As a minimum this information should contain a copy of the discharge summary, with details of medication and any future appointments.

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.

Needs assessments relating to short-term intermediate care (rehabilitation, reablement and recovery) can be completed after being discharged, rather than in hospital. Information around this should be readily available for families and unpaid carers, along with information regarding long-term care assessments (NHS Continuing Healthcare or Care Act assessments) should it look like this may be required.

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[46] Care Act (2014)

[47] Mental Capacity Act (2005)

How this links to the RightCare Scenario optimal pathway

This Pillar links to Information Point 5 within the RightCare Scenario:

Advance care planning is discussed at diagnosis and each health and social care review

As dementia is a progressive condition, it is important for people to be able to make decisions about their future care early on before they find it difficult to communicate or they lack the capacity to do so.
This is known as advance care planning. It is important that there are opportunities to review and change the plan as the dementia progresses and if the preferences or needs of the person change. Having an advance care plan ensures that the person with dementia can receive treatment and care according to their preferences, even when they can no longer express them.

Areas of the RightCare Scenario optimal pathway covered within this Pillar include:

- ✓ Polypharmacy
- ✓ John's Campaign
- ✓ Hydration

The ward is also signed up to John's campaign which means Barbara is able to stay the night with Tom and visit him whenever she needs to. This makes Tom feel much more relaxed and Barbara feel included in his care. She is happy and relieved that she is with him as she knows she wouldn't be able to relax if she was at home.

Best practice case study: Co-ordinated Care for patients with dementia in an acute setting

- ✓ Named dementia care specialist
- ✓ Communication with carers on admission and throughout their inpatient journey
- ✓ Dementia-friendly, person-centred activities.

East Lancashire Hospitals NHS Trust has employed a Dementia Lead Nurse, responsible for monitoring patients who are admitted into hospital with a dementia diagnosis. All patients with a known diagnosis of dementia (added in manually on admission) or a positive Six-Item Cognitive Impairment test (6CIT) dementia screen during the admission process are automatically referred into the Dementia Lead Nurse and triaged for follow-up and advice on their personalised care and activity plan if required.

The Dementia Lead Nurse also oversees the dementia and safeguarding training provided to staff and produces a monthly Dementia Report for the Trust. This report details how many patient referrals have been made to the Dementia Lead Nurse, incidents logged involving patients with dementia, actions and improvements made, ward compliance with the Butterfly Scheme to help identify patients with dementia, an update on the National Audit of Dementia, an update on the Dementia Champions initiative, and Dementia training compliance.

#5

Pillar Five: Living Well

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

> **“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

What we already know

- Peer support groups and social connections can reduce loneliness and isolation as well as reducing stress and pressure for families and unpaid carers.[49]
- Meaningful activities should be linked to hobbies or interests the person enjoyed before the diagnosis of dementia therefore need to be tailored to the person[50]
- Systems priorities should include avoiding inappropriate hospitalisation[51]
- When needs are unmet in the community, risk of crisis and hospitalisation increases[52]
- Families and unpaid carers should be given support not only to cope with their caring responsibilities but also to enable them to have an independent life alongside caring[53]
- Unpaid carers report considerably higher levels of anxiety and depression than are reported in the general population[54]

"Dementia care should enable people living with dementia, and their families and carers, to live meaningful and independent lives. Support should be person-centred and holistic.

"Dementia affects not only the individual but also their friends, family and local community... The role of the carer is pivotal in enabling the person to live well with dementia"[48]

What we have learnt

- Dementia-inclusive communities need practical infrastructures, such as accessible toilets, clear signage and benching or seating in open spaces
- A variety of out of hospital services, 24/7 specialist advice, and clearly documented referral pathways all support people to receive care in their home and the community
- Both carer strategies and carer assessments are critical to ensure appropriate commissioned services are available; and individuals can access them
- Positive support around maintaining quality of life needs to be core to discussions with families and unpaid carers, to support them to enjoy time with their loved one whilst living with dementia

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[48] Dementia Care Pathway 2018
[49] Willis, Semple & Waal (2018): Quantifying the benefits of peer support for people with dementia
[50] Dementia UK (2021): Meaningful activities for a person with dementia
[51] NHS Getting it right first time (2021): Geriatric Medicine Programme National Specialty Report
[52] Alzheimer's Society (2016): Fix Dementia Care: Hospitals
[53] Dementia Care Pathway 2018
[54] Alzheimer's Society (2016): Fix Dementia Care: Hospitals

The building blocks necessary to realise Pillar 5

Inclusive neighbourhoods

This building block focuses local authorities to ensure adequate infrastructures are in place to facilitate safe and welcoming neighbourhoods for people living with dementia. The Alzheimer's Society defines a dementia-friendly community as a city, town or village where people with dementia are understood, respected and supported by organisations in their local environment. Accessibility of the physical environment is a key factor and includes a range of considerations, including transport and access to natural and open spaces. Wellbeing activities and community peer groups can be valuable both for the person living with dementia and also their families and unpaid carers. Feedback should be utilised to select and plan these events, to meet the needs of the community.

Urgent neighbourhood services

Ensuring a range of suitable urgent community-based services are available, including crisis prevention, urgent, and intensive support services, is a national priority criteria. The Neighbourhood Health Guidelines emphasise how critical it is for integrated neighbourhoods to ensure urgent community response and hospital at home services are aligned to local demand and work together to deliver a co-ordinated service.

For a person with dementia to Live Well in the community, the Foundation of 'Seamless Pathways' comes into focus. Demand and capacity modelling is necessary to ensure the right community-based capacity is available to meet the demand. Services need to be planned, commissioned and delivered in a way that enables community provision to keep people with dementia in the place they live for as long as possible, receiving as much care, support and treatment as they can within the community.

This must include crisis prevention, urgent and intensive support teams; as well as access to specialist advice out of hours. When ambulance services are required to attend to a person with dementia, specialist advice and out of hospital pathways should be available to them, with clear referral processes in place and communicated.

The High Impact Change Model advises that active risk management should take place across organisations, to reach a reasonable balance between safety and independence. It is critical to also consider implications for unpaid carers and families, recognising where additional responsibilities could contribute to carer crises.

Supporting carers

Systems and providers need to ensure provision is available to support families and unpaid carers to stay healthy and safe. This includes ensuring needs assessments consider the unpaid carer and that respite services are available and facilitated. Within the Dementia 100, it is a priority criteria to ensure that carers’ needs are considered and that respite services are available and facilitated. Sign-posting unpaid carers to dementia specific social spaces, such as dementia cafes, provides an opportunity for social interaction and peer support. Interventions on offer should be co-designed and should be tailored to the individual and the local population.

How this links to the RightCare Scenario optimal pathway

This Pillar links to Information Points 1 and 4 within the RightCare Scenario:

i. **Information Point 1: Supporting family members and others caring for people with dementia**
Unpaid carers often have high levels of stress due to the physical and mental challenges of caregiving and coping with other responsibilities. It is essential that carers have good culturally appropriate support, taking into account their cultural preferences and needs, to enable them to manage the stresses and demands of caregiving and to fulfil their role. As per the duty in the Health and Care Act 2022, it is important to involve carers in all decisions around care.

Maria signposts Barbara to a range of support groups and resources including Dementia Together and TiDE (together in dementia every day) for support and information on living well with dementia.

ii. **Information Point 4: Access to a range of tailored activities to promote wellbeing**
The symptoms of dementia make it harder for a person to take part in activities, to engage socially, to maintain their independence, to communicate effectively, to feel in control and to care for themselves. Providing enjoyable and health-enhancing activities that are suitable for the stage of dementia can help with this. Understanding the activities that a person prefers, and thinks are suitable and helpful, with the input of family and carers if needed, and adapting them to their strengths and needs, will make a person more likely to engage with the activities offered.

Barbara makes their son, John, aware of the Alzheimer's Society's Dementia Talking Point, an online community that anyone affected by dementia can join and share experiences with other people also affected.

Areas of the RightCare Scenario optimal pathway covered within this Pillar include:

- ✓ Activities for Wellbeing

Best practice case study: Dementia Crisis and Intensive Support Services

- ✓ Living Well in the community
- ✓ Inclusive environments
- ✓ Admission avoidance.

Across Mid and South Essex residents benefit from a multi-disciplinary Dementia Crisis and Intensive Support Services, made up of qualified mental health professionals including Psychiatrists, Nurses and support workers all of whom have vast mental health experience. The team aims to reduce a person's need to access hospital visits or admission during a crisis period. They manage this through engaging with the person living with dementia and their carer in their own home or usual place of residence with rapid assessment, intervention, treatment and short term follow up for a maximum of six weeks

The crisis team carry out assessment and safety reviews, signpost for support with physical illnesses, provide carer and family support, facilitate onwards referrals to other agencies and carry out medication reviews in conjunction with general practice.

This vital service is available not only for people diagnosed with dementia but also for those with suspected memory problems or cognitive impairment; and is available for self-referral as well as through professional referral routes. Referrals can be made 24/7, by telephone and email, and leaflets available in multiple languages, braille and large print to ensure the service is accessible as possible to all people requiring their support.

#6

Pillar Six: Dying Well

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

"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

What we already know

The importance of palliative care and end of life care is documented within the Well Pathway and the Dementia Care Pathway with a focus on supporting the person with dementia and their families and unpaid carers. The Ambitions for Palliative and End of Life Care Framework[55] calls for care that is coordinated, with the right help at the right time from the right people, where all staff are prepared to deliver skilled and expert care that is competent, confident, and compassionate.

- Staff delivering palliative and end of life care should be trained and equipped to manage both the physical and psychological needs of people living and dying with dementia[56]
- Support should be available for the person's families and unpaid carers through to the final stages of life and after the death of the person with dementia[57]
- High quality palliative care should be available in all settings, including the patient's own home, the hospice, a care home or in hospital[58]
- Palliative care should be well planned, from diagnosis through to the last few weeks and months of life, underpinned by early advance care planning where possible[59]
- Planning and decision making should include the perspectives of families and unpaid carers wherever appropriate and possible.[60]

What we have learnt

- The nature of dementia as a progressive brain disease that affects a person's memory and decision-making abilities presents unique challenges for palliative and end of life care
- People living with dementia benefit from health and social care professionals who are providing dementia care being skilled in identifying those who may be in the last 12 months of life, and providing relevant support
- Advance care planning for people living with dementia is complex and requires a specific set of communication skills. It is important that the approach to these challenging conversations is tailored to the wishes of the person with dementia and their family.

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55 Ambitions for Palliative and End of Life Care (2021)
56 Dementia Care Pathway 2018
57 Dementia Care Pathway 2018
58 Ambitions for Palliative and End of Life Care (2021)
59 Universal Principles for Advance Care Planning (2022)
60 NICE guideline [NG142]

The building blocks necessary to realise Pillar 6

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 will maximise and enhance the choice and control they have over their treatment and care preferences, in preparation for a time when they may not be able to express these preferences themselves due to progression of the condition. Personalised care and support plans are a way of capturing and recording conversations, decisions and agreed outcomes or goals in a way that makes sense to the person. These plans should be proportionate, flexible and coordinated and adapted to a person's health condition, situation and care and support needs. They should include a description of the person, what matters to them and all the necessary elements that would make the plan achievable and effective.

Health and social care professionals should be 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. Whilst it is accepted that this can be complex and challenging to achieve, a wide range of tools can be used to support this assessment, and identification can provide benefits in ensuring that the person living with dementia is receiving the best care possible.

> **"Advance Care Planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversation about these. The process, which is likely to involve a number of conversations over time, must have due consideration and respect for the person's wishes and emotions at all times. As a result, the person should experience a greater sense of involvement and the opportunity to reflect and share what matters most to them."[61]**

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. Joined up care will require a system-wide response, using a full range of coordinated services deployed in the community. It will be important to ensure that these are implemented in ways that do not restrict responsiveness by adding layers to effective delivery of care.

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[61] Universal Principles for Advance Care Planning (2022)

Joined up care also means placing an emphasis on responding effectively to the widest range of difficulties people experience, and an awareness of the need for anticipatory and proactive care. The palliative needs of people who are frail, including in older age and people living with dementia, require specific consideration from local Systems because these needs are often more complex and less predictable in their prognosis and trajectory.[62]

Partnership working is key to joined up care and the kind of joined up thinking that will be required by individuals and by organisations. These will be partnerships of both commissioning and service provision and should include joint accountability for outcomes. This is at the core of Integrated Care Systems

Knowledge and skills

Many health and social care staff look after people who are nearing death and this is particularly true of those who care for frailer patients who are more likely to be experiencing dementia. There is therefore clear crossover between these two areas of expertise. In addition, there are certain cohorts of health and social care staff who will encounter those dying with and from dementia more readily, for example within acute and care home settings and it is advised that these groups of staff may require additional consideration when implementing this building block.

NICE guideline NG97 (section1.13.6 Staff Training and Education) recommends that all health and social care professionals who are responsible for caring for people living with dementia should be trained in starting and holding difficult and emotionally challenging conversations. This training would support continued conversations aimed at planning for disease progression, including Advance Care Planning, and ensure the person living with dementia and their family are central to decision making.

How this links to the RightCare Scenario optimal pathway

The following Information Points, as referenced earlier in this document, are all pertinent to ensuring a person with dementia is appropriately supported at in the final months of life:

- Information Point 1: Supporting family members and others caring for people with dementia
- Information Point 3: People with dementia have a single named practitioner to coordinate their care
- Information Point 5: Advance care planning is discussed at diagnosis and each health and social care review

When Tom dies at the age of 90, Barbara and the care home staff are able to ensure his wishes are fulfilled as they have been documented in his advance care plan. Barbara and John, whilst devastated by their loss, are able to take comfort in the knowledge that they had supported and cared for Tom, in accordance with his wishes, enabling him to 'live well' and 'die well'.

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[62] Universal Principles for Advance Care Planning (2022)

System Partners: Your next steps

The Dementia 100 Pathway Assessment Tool has been designed to bring together the existing guidance and best practice that is currently dispersed across a number of platforms and forums in order to support the delivery of high-quality dementia care.

This resource will enable you to benchmark, review and understand, where your service or System may be right now; and gives you a clear path of support for those areas where you need to improve. Most importantly, this is designed to be a collaborative tool. Just as people with dementia access multiple services and encounter health and social care professionals, volunteers, communities, so this too brings all those parties together.

Leadership

The first foundation presented within this pathway assessment tool is that of leadership. Whether your leadership is across a System, Place, Neighbourhood or service, your support is critical to help to realise the pillars contained within this document. Your communities and everyone affected by dementia can benefit from your leadership.

System leaders:

Make dementia a system-wide priority, lead your partners through the self-assessment tool, analyse the results and themes, and ensure a robust strategy and plan to move forward.

Reviewing achievement levels within the minimum standards provides an opportunity to focus on the priority criteria across all elements of the pathway, within all localities across the System.

Place leaders:

Support each service in your area to add their contributions to the pathway assessment tool, break down any organisational boundaries and look together at the whole picture of the services received by the people living with, and caring for, dementia in your Place.

Services:

Consider honestly and bravely the services you offer against the criteria within the Dementia 100 Pathway Assessment Tool. Ensure you are evidence-based in your approach to completion. If you cannot demonstrate fully achieving any criteria then it is likely you still have improvements to make. Use feedback from your patients and service users; and data where it is available, to understand how your service is currently performing. See this as an opportunity to improve and be transparent about your gaps.

Roles and responsibilities

The following provide example roles which can be adapted to best meet the needs of your System or Place:

- **Senior Sponsor(s)** to approve and champion the effective partnership working to complete the tool across the System and/or Place
- **Overall assessment tool coordinator / lead for a System,** with oversight and coordination of the completion of the tool
- **Overall assessment tool coordinator / lead for a Place,** with oversight and coordination of the completion of the tool within a Place, such as collating information and engaging with partners
- **Pillar coordinator / lead** (across a single or multiple Places) based on their specific area of focus such as from a Local Authority or NHS organisation to coordinate the completion of their assigned Pillars and ensuring inclusion of all relevant parties
- **Independent Facilitator** from within or outside of the System or Place to assist moderating harmonised scores, if/as necessary
- **Support** on administrative activities such as organising meetings to discuss specific pillars and sharing communications.

Training materials

Alongside this implementation guidance, a range of training materials are available to support you to get the most of out the Dementia 100 Pathway Assessment Tool.

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- **Alzheimer's Society**
- **Alzheimer's Society Health & Social Care Partnerships Team Steering Group**
- **Dementia UK**
- **Dementia Pathfinders Black Country (Sandwell)**
- **NHS London Dementia Clinical Network**
- **IDEAL - University of Exeter**
- **National Audit of Dementia, HQIP.**

Expert Advisory and Oversight Group Membership

Development of the Dementia 100 Pathway Assessment Tool was reviewed, influenced and steered by an Expert Advisory and Oversight Group, chaired by Samantha Singh (Clinical Lead for Nursing and Urgent Care – Midlands and Lancashire Care System Support). We are extremely grateful to the members of the Expert Advisory and Oversight Group for providing their time, expertise and support towards this work.

Name	Role	Organisation
Alison Iliff	Health and Wellbeing Programme Lead at OHID	Office for Health Improvement & Disparities DHSC
Barbara Stephens	Chief Executive Officer	Dementia Pathfinders Black Country (Sandwell)
Bikram Raychaudhuri	GP Clinical Lead for Dementia	NHS England South East Region
Farooq Khan	Consultant Psychiatrist	Birmingham & Solihull Mental Health NHS FT
Fiona Bladen	Carer Ambassador	Devon Carer Ambassadors
Helen Nicholson	Senior Research Fellow - Paramedic Science	University of the West of England
Linda Hughes	Carer Ambassador	Devon Carer Ambassadors
Sarah James	CHC Appeals & Retrospective Review Clinical Manager	NHS Midlands and Lancashire
Tim Baverstock	Head of Local Systems Influencing	Alzheimer's Society

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Name	Role	Organisation
Anna Volkmer	Speech and Language Therapist and Senior Research Fellow	University College London
Gemma Harrison	Social Worker	Midlands and Lancashire Care System Support
Jackie Nixon	Public Health Practitioner - Ageing well	Sunderland City Council
Dr Sara Humphrey	Clinical Lead	Yorkshire & Humberside Clinical Network (Dementia and OPMH)

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References

All statements within this guidance are either evidenced within the reference list below, or findings from the extensive testing and stakeholder engagement throughout the development of the Dementia 100 Pathway Assessment Tool. It is to be noted that this does not constitute a full literature review and the references drawn on for the purpose of this document are not exhaustive of the existing knowledge on the topics presented.

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Glossary

What do we mean by "people with dementia and their carers"?

The following definition is taken from the Department of Health and Social Care work towards the Dementia Challenge 2020 and applies to the definitions applied within the Dementia 100 Pathway Assessment Tool.

> **"When we talk about 'people with dementia and their carers' we mean those involved on a day by day basis – the person with the condition, the person or people living with them (who we tend to simply refer to as "the carer") or the person who probably lives close by who takes on that responsibility."**

What do we mean by "carer"?

The following definition is taken from the NHS England guidance on 'Who is considered a Carer?' and applies to the definitions within the Dementia 100 Pathway Assessment Tool.

> **"A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid."**

Other terms contained within the guidance:

Advance Care Plan: A written documents that documents an individual's wishes for how they wish to be cared for in the final months of their life and when they are dying Care Plan: A written document that outlines the support needed by an individual along with how this support will be given.

Community: For the purposes of this report, the term 'community' is used to describe the smaller geographical areas within a neighbourhood or Place, where an individual may interact with social groups or activities and shopping and public facilities.

Dementia Diagnosis Rate (DDR):
NHS Digital definition has been used for the purposes of this guidance. Diagnosis rates are calculated by comparing recorded diagnoses to estimated dementia prevalence. From October 2022, this publication series was superseded by the Primary Care Dementia Data series.

Deprivation of Liberty Safeguards (DoLS): A set of checks that are part of the Mental Capacity Act 2005. The DoLs procedure protects a person receiving care whose liberty has been limited and supports health and social care staff to identify a deprivation of liberty.

End of life: The NHS consider people to be approaching the end of life when they are likely to die within the next 12 months, although this is not always possible to predict. End of life can also include people whose death is imminent, as well as people who have an advanced incurable illness or are generally frail and have co-existing conditions that mean they are expected to die within 12 months.

John's Campaign: A campaign for extended visiting rights for families and unpaid carers of patients with dementia in hospitals in the United Kingdom, founded on a principle that carers should be welcomed and their presence is crucial to the health and wellbeing of the person with dementia.

Joint strategic needs assessment (JSNA): The means by which local leaders work together to understand and agree the needs of all local people, with the joint health and wellbeing strategy setting the priorities for collective action.

Lasting Power of Attorney: A lasting power of attorney is a way of an individual someone they trust the legal authority to make decisions on their behalf should they no longer able to make them, or choose not to.

Modifiable factors: Risk factors for dementia that can be reduced or removed through changes that are in the control of an individual, service or System. These may include smoking, obesity, physical activity and air pollution.

Multi-agency: Teams consisting of individuals from different agencies who come together to discuss work with a collective goal.

Multi-Disciplinary Team (MDT): Teams consisting of individuals from different professional groups who come together to discuss or work with a collective goal.

NHS Talking Therapies: This term covers a range of evidence-based psychological therapies, and includes such services as Cognitive Behavioural Therapy and Mindfulness-based cognitive therapy (MBCT).

Place: The term 'Place' is used throughout this document in reference to a geographical area that has been pre-determined within a System. It is noted these may be referred to in different areas of the country as localities, places or alliances.

Providers/ Services: For the purposes of this report, the term 'providers' or 'services' refers to a place or organisation where health or social care or support provision is directly given to a person living with dementia or their carer. This may be in a community or hospital location.

Social determinants of health: As defined by the World Health Organization, the social determinants of health are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and Systems shaping the conditions of daily life.

System(s): The term System is used throughout this document in reference to an Integrated Care System and the organisations that work within and alongside it.

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