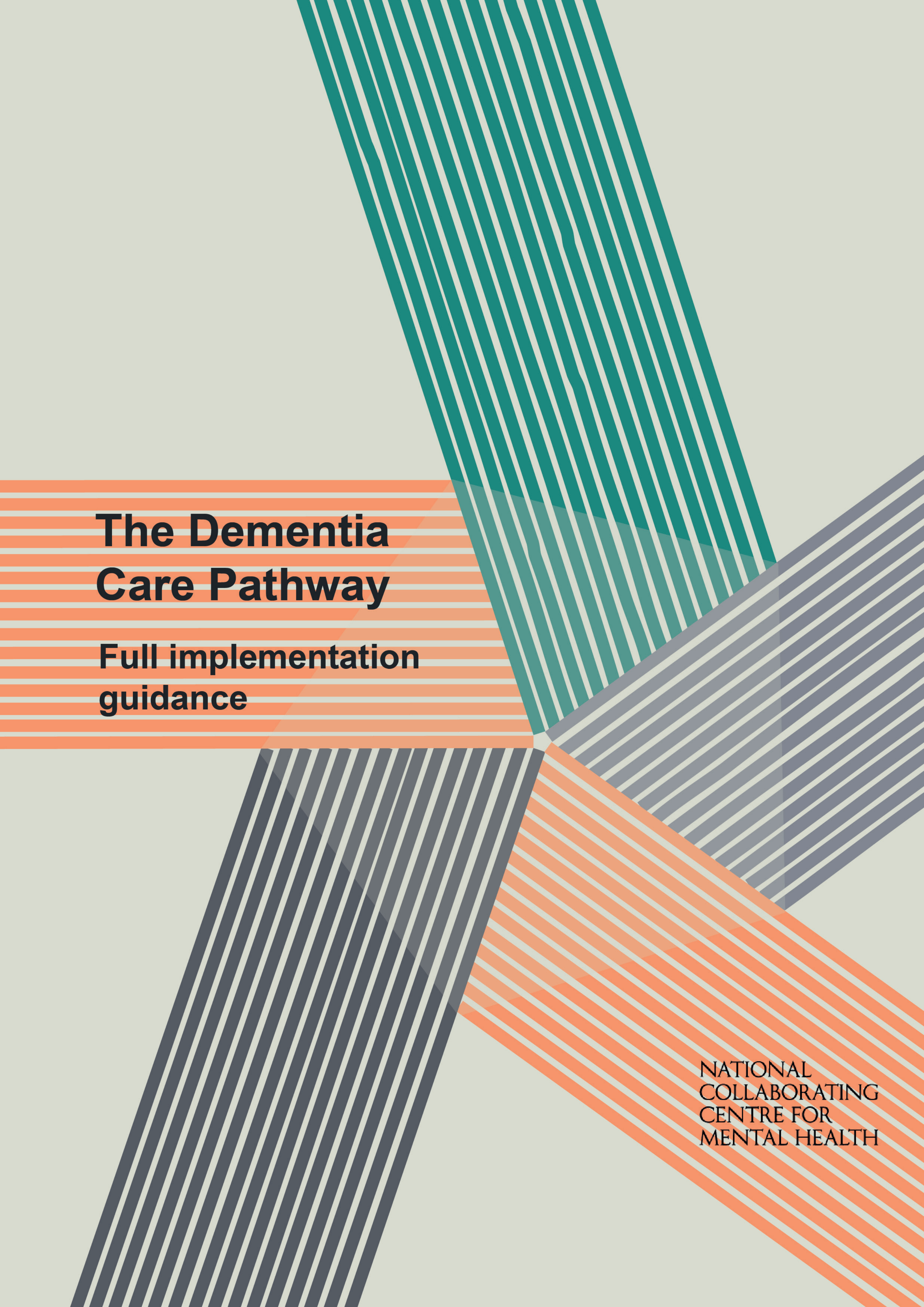

The Dementia Care Pathway

Full implementation guidance

NATIONAL
COLLABORATING
CENTRE FOR
MENTAL HEALTH

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Foreword

With around 700,000 people living with dementia in England, and that figure expected to grow each year, dementia is one of the biggest challenges we currently face. We face it as individuals, families and carers, practitioners and commissioners, and as a society.

Since the NHS embarked on the national challenge on dementia to increase access to formal diagnosis from less than half to two-thirds of people affected, considerable progress has been made. Together, we will harness and build on this momentum to achieve the next ambition for 2020: to be the leading nation for dementia care and support. The NHS Mandate commits us to increasing the number of people receiving a diagnosis within 6 weeks of a GP referral, and to improving the quality of post-diagnostic treatment and support for people with dementia and their carers.

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. Early diagnosis gives people the best opportunity to plan for the future, and can help prevent crises. There are also a growing number of treatments available that may slow the progression of the disease. That is why it's so important that people don't have to wait more than 6 weeks between being referred to a memory assessment service and receiving a diagnosis and developing and agreeing a care plan. Not only do delays add considerable costs to the NHS, waiting months for a diagnosis is unacceptable and detrimental to the long-term mental health of people living with dementia, and for their families and carers. We would not tolerate such a long wait for a cancer diagnosis, for example.

Once a diagnosis has been made, each person and their family and/or carer should be offered a consistent level of post-diagnostic support that is in line with NICE-recommended care. This will help them live well and is why all people living with dementia, along with their families and carers, should be supported by a named coordinator of care with whom they co-create a meaningful care plan in which they feel invested. The care plan should be reviewed at least once a year, and refreshed as and when the person's needs change.

Delivering this scale of ambition by 2020 will be challenging. We will fall short if we try to make a giant leap, so, instead, a series of bold steps need to be taken. Reducing the amount of time that people wait between their referral until they start evidence-based treatment is one such step. Moving into this new era, local plans will need to be forward-looking and sustainable. We will have to be flexible and creative in our use of resources, and place a strong emphasis on monitoring and evaluation.

Working together transparently and collaboratively across systems we will be able to ensure that timely, consistent, person-centred care can be delivered to all.

Professor Tim Kendall
National Clinical Director for Mental Health

Professor Alistair Burns
National Clinical Director for Dementia

Key statements

The key statements in bullet lists below expand on the 'I' statements (in bold) from NHS England's Well Pathway for Dementia. Under each of these, are the key messages of this implementation guide, as agreed by the Expert Reference Group. These key messages highlight the need for person-centred care, and so are phrased as 'We' statements to include not only the person living with dementia but also their family and/or carer. This acknowledges the integral role of families and carers for people living with dementia.

Diagnosing well

'I was diagnosed in a timely way'

- We know that if I am referred for an assessment for dementia, I will receive a timely diagnosis and agree on an initial care plan.

'I am able to make decisions and know what to do to help myself and who else can help'

- We know that I will have a personal choice in decisions affecting my care and support.
- We know that I will be able to jointly develop my care plan.
- We know that if I need help, I will be supported to make a decision, for example through the use of independent advocacy services.

Supporting well

'I am treated with dignity and respect'

- We know that services are designed around us and our needs, and that they will be appropriately staffed and staff will have the right levels of training.
- We know that services will provide the best possible care, and will be regularly reviewed by other agencies.

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

- Once I am diagnosed, we know that we will have a named coordinator of care who will jointly review my care plan with us as our needs change. This will happen at least once a year.

Living well

'I know that those who are around me and looking after me are supported'

- We know that my care plan will cover my own needs as well as those of the people who support me. This will include our emotional, psychological and social needs.
- We know that a carer's assessment will be offered.

'I feel included as part of society'

- We know that my care plan will give us the support we need to live well. This may include helping me build relationships, be involved in my community or engage in activities that I enjoy.

Dying well

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

'I can expect a good death'

- We know that my care plan will help us to plan for the future, including my end-of-life wishes.

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1 Introduction

The pathway values statement

This guidance represents a commitment to ensuring that mental health care is delivered in a **person-centred**, **compassionate** and **supportive** way, promoting **safety** and **wellbeing** at the forefront. Mental health service provision should be **needs-led**, **outcome-focused**, **responsive** and delivered in a way that **empowers** people to build on their strengths, promotes **recovery**, supports **families and carers**, and ensures **equality and fairness** for all.

1.1 Background

This is one of a suite of mental health care pathways developed on behalf of NHS England to support the delivery of the ambitions of The Five Year Forward View for Mental Health[8] and the Next Steps on the NHS Five Year Forward View.[9] These reports set out a clear rationale for delivering good dementia care, and complement previous objectives outlined in the Prime Minister's Challenge on Dementia 2015[10] and the Prime Minister's Challenge on Dementia 2020.[11] This includes improving and maintaining the current diagnosis rates, and increasing access to high-quality, post-diagnostic care and support.

1.2 Purpose and scope of this document

This guidance outlines the dementia care pathway and associated benchmarks to support improvements in the delivery and quality of care and support, for people living with dementia and their families and carers. It accompanies and builds upon a shorter guide published by NHS England.[12]

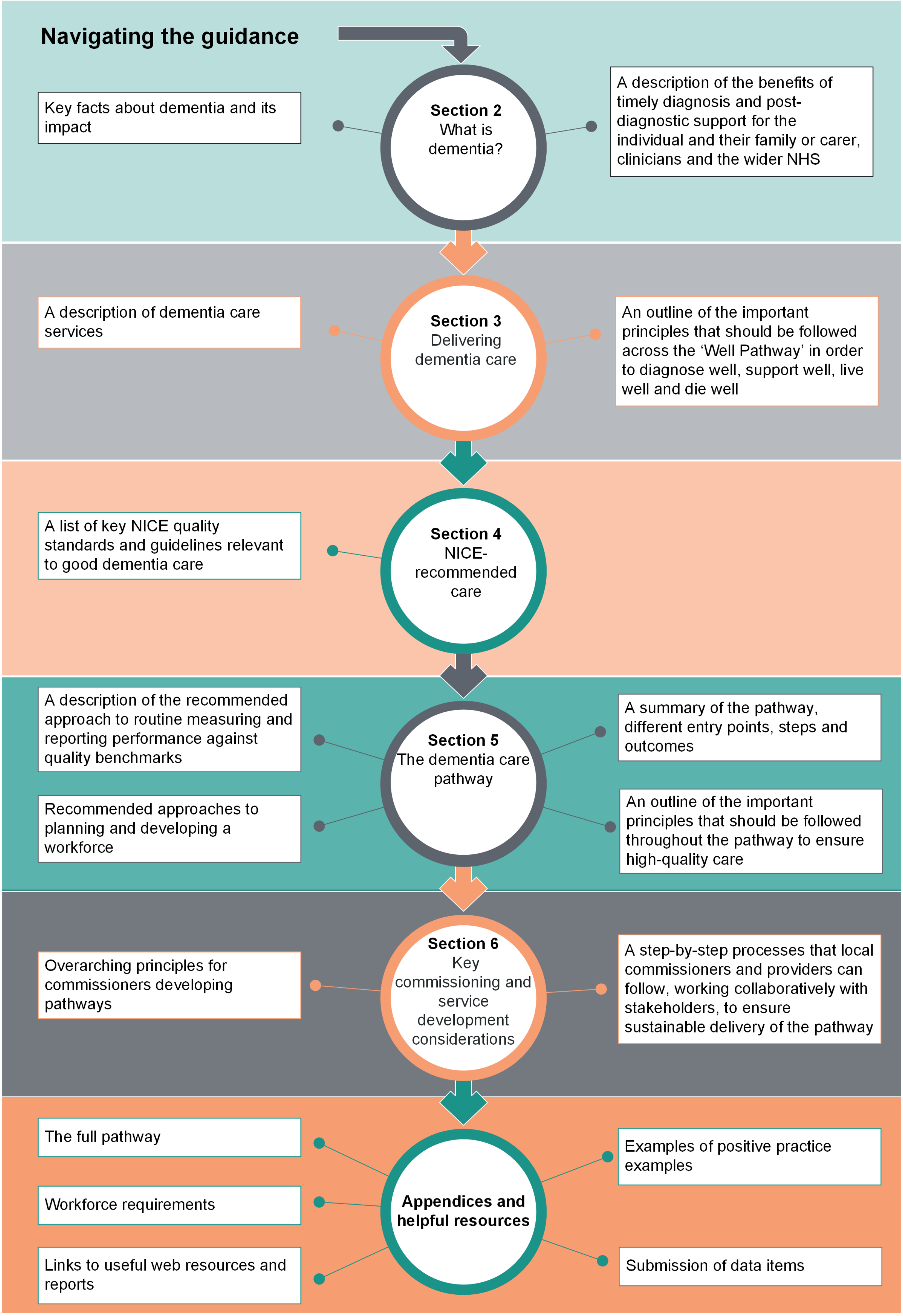
While good dementia care should be seen across each step of the Well Pathway for Dementia (see Section 3), in line with the Next Steps on the NHS Five Year Forward View, the scope of this work focuses on **diagnosis and post-diagnostic support**. Information on primary prevention can be found on the Public Health England website.

This guidance is primarily aimed at clinical commissioning group (CCG) physical and mental health commissioners and providers who work collaboratively with the people who use the services and their families and carers. See the diagram opposite for an outline of the content of this guidance, and the accompanying appendices and helpful resources.

Other key initiatives and policy documents

- CCG Improvement and Assessment Framework 2016/17[1]
- Closing the Gap: Priorities for Essential Change in Mental Health[2]
- Delivering the Forward View: NHS Planning Guidance 2016/17 – 2020/21[3]
- Five Year Forward View for Mental Health: One Year On[4]
- Implementation Guide and Resource Pack for Dementia Care[5]
- Implementing the Five Year Forward View for Mental Health[6]
- Prime Minister's Challenge on Dementia 2020: Implementation Plan[7]

Navigating the guidance



Key facts about dementia and its impact

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What is dementia?

A description of the benefits of timely diagnosis and post-diagnostic support for the individual and their family or carer, clinicians and the wider NHS

A description of dementia care services

Section 3
Delivering dementia care

An outline of the important principles that should be followed across the ‘Well Pathway’ in order to diagnose well, support well, live well and die well

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NICE-recommended care

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1.3 How was this document developed?

NHS England commissioned the National Institute for Health and Care Excellence (NICE) to provide a package of implementation support for the mental health care pathways, including implementation guidance. NICE then asked the National Collaborating Centre for Mental Health (NCCMH)[a] to develop this guidance. The NCCMH set up an Expert Reference Group, comprising a group of experts with a variety of experience and expertise who were convened by the NCCMH to support the development of the implementation guidance and the pathways.

This guidance, and the access and quality benchmarks set out within it, was developed based on NICE guidelines and quality standards, published literature evidencing best practice, existing services demonstrating positive practice and expert consensus from a variety of stakeholders.

A list of Expert Reference Group members is provided at the end of this document.

1.4 Expectations of commissioners and providers

Commissioners and providers are already taking action to ensure that services are being developed and improvement plans put in place in accordance with Refreshing NHS Plans for 2018/19[13] and Implementing the Five Year Forward View for Mental Health. To deliver these, national variations in diagnosis rates and access to post-diagnostic support need to be addressed through a locally led improvement process.

Key to this will be local system leadership and close collaboration between health and social care providers and partners, and people living with dementia and their families and carers. This should lead to clear, integrated health care pathways that are easy to access and monitor for the person living with dementia, their family and/or carer, and their team of health and social care professionals.

Integrated Care Systems and Sustainability and Transformation Partnerships (STPs) are vehicles for the transformation of all health and care services in a specific geographic footprint. Plans should be aligned with the principles and ambitions set out in The Five Year Forward View for Mental Health, the key deliverables of its implementation plan, and the NHS planning guidance.

As well as ensuring that mental and physical health are valued equally, commissioners should also ensure that services:

- are **co-produced** and implemented in collaboration with the people using the services, their families and carers, as well as local mental health providers, staff and partner organisations
- **ensure equity of access for all adults** – local commissioners should make explicit how they have taken into account their duties in relation to the Equality Act 2010,[14] and with regard to reducing health inequalities as set out in the Health and Social Care Act 2012.[15] Service design and communications should also be appropriate and accessible, to meet the needs of diverse communities (see Guidance for NHS Commissioners on Equality and Health Inequalities Legal Duties[16]).

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[a] The NCCMH, a partnership between the Royal College of Psychiatrists and University College London, was one of the national collaborating centres first established by NICE in 2001 to develop clinical guidelines.

The dementia care pathway

The dementia care pathway introduced in this guidance outlines how services can ensure that people living with dementia or mild cognitive impairment get timely access to a diagnosis and post-diagnostic support and treatment.

The focus of the past 6 years has been on improving the rates of diagnosis and reducing variability. While this is welcome, it is only one step towards the more important issue of how best to provide post-diagnostic support to people living with and those affected by dementia. This ethos is captured in the five 'We' statements of the National Dementia Declaration.[17]

The standard of care and access to timely diagnosis continue to vary across England, as demonstrated by the Department of Health 'Dementia Atlas'. Today, a person's opportunity to be diagnosed well and live well with dementia depends on factors including their location, ethnicity, age and whether they have a carer[b] living with them.[10] [11]

The following benchmarks for timely access to dementia care are expansions of the national goals for 2020 outlined in the NHS Operational Planning and Contracting Guidance and Refreshing NHS Plans for 2018/19 with recommendations made by the Expert Reference Group:

> **Benchmark 1:** *Achieve and maintain a* ***diagnosis rate of at least two-thirds***.
>
> **Benchmark 2:** *Increase the number of people being diagnosed with dementia, and starting treatment,* ***within 6 weeks of referral****.*

The Expert Reference Group has defined 'starting treatment' as the person having met with their named coordinator of care and agreed an initial care plan of NICE-recommended care. It is important that the length of time it takes to reach a diagnosis is guided by the person's needs and the complexity of their condition. It is not possible (or advisable) for all people to be diagnosed within the timeframe of 6 weeks.

> **Benchmark 3:** *Improve the quality of post-diagnostic treatment and support for people with dementia and their carers.*

The Expert Reference Group recommends that the 'post-diagnostic treatment and support' offered should be NICE-recommended, and the support needs should be outlined in the initial care plan. This care plan should be reviewed within at least 12 months of being agreed, then reviewed every 12 months in accordance with changes in the person's needs. Revisions should be jointly developed and agreed with the person (and, if applicable, their carer).

Figure 1 is an overview of the pathway. A full description of the pathway and benchmarks can be found in Section 5.

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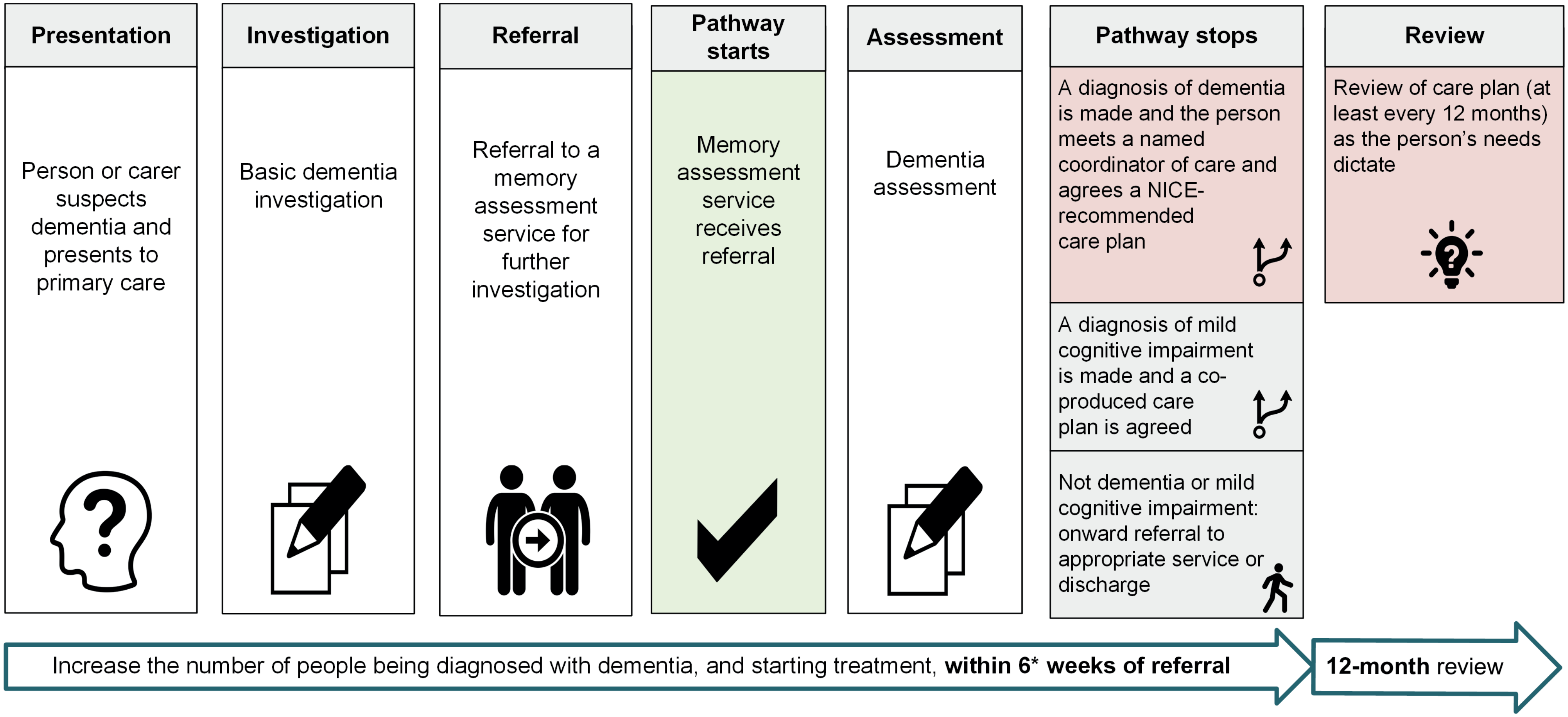
[b] Carer is defined in the Care Act 2014 as 'an adult who provides or intends to provide care for another adult (an "adult needing care")'.

Figure 1: Summary diagram of the dementia care pathway



* Where clinically appropriate (see Section 5.1).

2 What is dementia?

> ***If there is indeed an emerging sense – finally – that we've stopped pussyfooting around dementia and can now bear to utter its name, we nevertheless find a cloud of unknowing persists. People read, watch and hear more about it than ever before. They know it's out there. They know it will claim more of us as we continue to age. They fear it. Dementia vies with cancer in an unsavoury battle of the scariest, but it must be said that some lucky people will survive cancer. But I suspect many still don't understand dementia or, at least, understand it only as an insidious memory loss. The fear, perhaps, is a fear of the unknown.***
>
> Source: Terry Pratchett, Dementia blog, what's the point of it all?, at Alzheimer's Research UK

Dementia is an umbrella term used to describe chronic widespread cognitive impairment, associated with significant changes to functional abilities.[18] The impairments may have a number of causes, including Alzheimer's disease, and they are progressive and largely irreversible (see the Dementia NICE guideline[19] for more information).

The presentation, course and rate of progression vary greatly, with each person experiencing a unique set of symptoms and level of need depending on which areas of the brain are affected. Symptoms often include: impaired memory; speech and language problems; disorientation; and behavioural and psychological symptoms such as depression, anxiety, hallucinations, sleep problems, restlessness and agitation.[19]

2.1 How common is dementia?

Around 850,000 people in the UK have dementia,[c] with numbers predicted to rise to over 1 million by 2025.[20] They are supported by approximately 700,000 informal carers.[21]

Each year in the UK there are about 210,000 new cases[d].[22] The most common type of dementia is Alzheimer's disease (62%), followed by vascular dementia (17%) and mixed dementia (10%).

2.1.1 Risk factors

There are a number of risk factors that influence the occurrence of dementia, some of which are modifiable and some of which are not.[23] Ageing is still the single greatest risk factor for the onset of most types of dementia.[19] Although there has been a fall in the incidence of dementia, as life expectancy continues to increase the number of people living with dementia is expected to grow markedly.[24 25] A small minority of people will develop early-onset dementia (before the age of 65). About 42,000 people have a diagnosis of early-onset dementia in the UK.[26] Of these, many will also have comorbid learning disabilities.

About 30% of risk factors for dementia are preventable and modifiable.[22] Higher rates of dementia are associated with vascular risk factors (such as hypertension and diabetes), lifestyle factors (sedentary lifestyle, smoking and heavy alcohol consumption), and other factors such as social engagement and educational attainment.[25 27 28]

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[c] This is the 'prevalence', or total number of people living with dementia within a period or on a particular date in time. The Dementia Prevalence Calculator DPCv3 is available from the Primary Care Web Tool website.

[d] This is the 'incidence' or number of new or newly-diagnosed cases of dementia that occur within a period of time.

Understanding local demand

Certain groups of people will have different levels of risk of developing dementia and specific needs, such as those with early-onset dementia, people from black, Asian and minority ethnic backgrounds and people with learning disabilities. Commissioners should capture this variance in a Joint Strategic Needs Assessment and local Dementia Needs Assessment (see Section 6.2).

Further information on how care can be delivered for these groups can be found in the positive practice examples in the appendices and helpful resources.

A high proportion of people living with dementia (72%) will also have multiple mental and physical health comorbidities, the most common of which are arthritis, hearing problems, heart disease or a physical disability.[29]

2.2 The impact of dementia

Dementia is reported to be the most feared disease in people over the age of 55, and it is recognised around the world as a public health priority.[11 30] Dementia can have an enormous impact on a person's identity, their ability to function and their roles and relationships both in the family and in society.[19]

Currently, there is no cure for dementia. As the challenges that it poses are set to increase in line with our ageing population,[25] this impact is compounded by inadequate or absent treatment. For example:

- Delays to psychological and pharmacological interventions are associated with an earlier decline in functioning.[25]
- Poorly managed behavioural and psychological symptoms (which accompany dementia) may lead to increased distress, accelerated cognitive decline, inappropriate antipsychotic prescribing, unnecessary use of restraint and earlier admission to residential care.[19 31 32]
- Poorly managed physical and mental health comorbidities may lead to more mental health crises and hospitalisation in people with dementia.[25]

> ***No one seeks or wants dementia, or indeed its diagnosis, but what people do require is an accurate diagnosis delivered in a sensitive, considerate way which meets the needs of the person and those closest to them.***
>
> Source: A person living with dementia

- Hospital admissions (especially when extended) can exacerbate the symptoms of dementia, permanently reduce independence, and increase the likelihood of discharge to residential care and readmission to hospital.[33 34] It is estimated that people with dementia occupy 25% of hospital beds, often when the medical need is not acute, and their hospital stays tend to be on average 1 week longer than others. This results in poorer outcomes and notable costs.[35]
- Families and carers can experience significant strain, especially when the person they care for is in the later stages of dementia and can no longer participate in activities of daily living without support.[36] Without support, carers' quality of life, wellbeing, and physical and mental health are adversely affected.[25 37]

The cost of dementia across the UK is an estimated £26.3 billion each year (equivalent to £32,250 per person annually).[17] Of this, £11.6 billion is from unpaid care, usually spent by people living with dementia and their carers. £10.3 billion is spent by social care and £4.3 billion by the NHS.[20]

2.3 Diagnosing dementia: equal access

National goals for **diagnosis** by 2020:

- Achieve and maintain a **diagnosis rate of at least two-thirds**
- Increase the number of people being **diagnosed** with dementia and **starting treatment within 6 weeks of referral**.

While the national ambition for a diagnosis rate of two-thirds has been consistently met since July 2016,[7] [38] there continues to be unwarranted variation in rates across and within CCGs.[11] There also continues to be a notable delay between the person, or their family member or carer, first having concerns and when they reach out for help.[39]

Barriers that delay people from seeking help and being diagnosed with dementia include:

- **poor recognition and understanding of symptoms**, particularly in groups where dementia remains misunderstood and stigmatised,[40] or in atypical presentations, such as early-onset dementia or dementia associated with learning disabilities, where symptoms are commonly attributed to another cause[26]
- **a reluctance to seek help or disclose symptoms** due to stigma[41]
- **poor understanding of the benefits of and need for timely diagnosis**: this is particularly the case in care homes where, despite high rates of identification, diagnosis rates are relatively low[42]
- **a reluctance in healthcare professionals to make a diagnosis**: particularly when there is a perceived lack of follow-up support and uncertainty as to whether the person will understand and retain the information that is conveyed to them.[43] [19]

> ***People's experience of living with dementia or caring is significantly determined by characteristics such as their ethnicity, age, pre-existing disabilities or whether they have a carer living with them. Local commissioners and providers need to continue to improve their understanding of the best ways to tailor post-diagnosis support services to diverse needs.***
>
> Source: Department of Health, Prime Minister's Challenge on Dementia 2020

2.4 Post-diagnostic support

National goals for **post-diagnostic support** by 2020:

- **Improve quality** of post-diagnostic treatment and support for people with dementia and their carers.

The delivery of post-diagnostic support for dementia is complex, spanning public, private and third sectors with funding from public agencies, direct payments and self-funding (see Section 3.2).[44] Access to dementia care can be greatly facilitated by a named coordinator of care who has a good understanding of the person and their needs along with how to navigate the health and social care system.[19] [45]

However, it is not unusual for people who are diagnosed with dementia not to have a named coordinator of care. People who navigate the health and social care system alone are more likely to receive care that is of lower quality, or to not be able to access care at all.[46]

A 2016 survey reported that 57% of carers felt that the person they cared for was not treated with understanding and dignity, and 92% felt that hospital environments were frightening.[35]

Reasons for poor or limited access to post-diagnostic support for dementia include:

- **An absence of named coordinators of care**: this means that families and carers often have to follow up on or chase appointments themselves, or that the person living with dementia and their family or carer lose touch with the system.[20 47] This risk of falling through the cracks in the system can be heightened in certain groups who might have less immediate contact with services, including those with vascular dementia or mild cognitive impairment, and people without carers.[48 49 50]
- **Over-reliance on families and carers to manage and facilitate appointments**: this is often combined with a lower provision of social support.[46]
- **Inconsistent understanding and provision of evidence-based interventions**: despite existing NICE-recommended interventions, many care homes and hospitals have a limited understanding and use of NICE guidance.[33 46]
- **Poor recognition and management of comorbidities**, including medical management: if a person has a comorbidity, there may be a poor exchange of information. For example, in 2015, 49% of admissions to inpatient care did not record a diagnosis of dementia where there was one.[51]
- **Inadequate use of care plans**: a recent analysis found that one in three people living with dementia either did not have a care plan on record, or had not had a care plan review in the last 12 months.[52]
- **High staff turnover and variance in training**, especially in social care: many staff reported feeling unprepared when working with people with dementia and requested specific training, particularly in working with people with existing comorbidities.[46]

2.5 The case for change

Although there is no cure for dementia, much can be done to enable each person living with it, and their family or carer, to lead as content and satisfying a life as possible in a place of their choosing.[17 33 53] Combined with enabling people to live well, Table 1 contains measurable outcomes that provide a clear rationale to deliver timely access to high-quality dementia care across the system.

2.6 Reducing costs to health and social care

Investing in delivering the right care at the right time is beneficial for society and has the potential to reduce a number of costs. An NHS dementia RightCare scenario[54] estimated that delivering optimal care could halve the costs of dementia care over a 10-year period. Maintaining physical and mental health can also offset additional costs that result from premature cognitive decline, for example:

- Untreated physical comorbidities accelerate cognitive decline in people living with dementia by about 1 to 2 years.[32] This leads to an increase in healthcare and other annual costs of untreated diabetes (by £337 million), untreated urinary tract infections (by £116 million) and untreated depression (by £502 million).
- If we could delay the individual onset of dementia for as long as 36 months, this would save the UK as much as £4.9 billion per year.[55]

It is important to note that the impact of such savings is not yet well understood, and balancing the savings and costs associated with health and social care and informal carers will need to be considered. Research in this area is currently underway, one example being the Modelling Outcome and Cost Impacts of Interventions for Dementia (MODEM) trials (see the MODEM website for more information).

Table 1: Potential benefits of good-quality, prompt, evidence-based dementia care

Benefits for all
● Reduces uncertainty, and fosters autonomy and the development of positive coping strategies.[53 56] ● Improves delivery of person-centred care, increases quality of life and reduces non-cognitive symptoms.[19 46 57] ● Minimises premature cognitive decline and the distress associated with coexisting physical and mental health comorbidities.[58] ● Helps promote the wellbeing and overall health of the carer, as well as their competency and ability to care,[58] which can delay the need for costly residential care.[25 59 60 61] ● Promoting continuity of care can reduce the need for the person living with dementia, or their family or carer, to have to repeatedly provide basic information to services, which reduces the frustration they might feel.[33] ● Enables short- and long-term person-centred care planning, including advance care planning,[25] which enables people with dementia to live and die with dignity and in the place of their choosing while giving support to their families and carers.[19 62 63] ● Enables optimal pharmacological and psychological interventions, including cognitive stimulation therapy, acetylcholinesterase inhibitors and memantine, which can slow the progression of dementia.[19 25 29 64] ● Reduces the number and length of avoidable hospital admissions and readmissions, which can reduce poorer outcomes and the need for costlier crisis care.[25 55 65] ● Increases early-phase research opportunities.[25]

3 Delivering dementia care

Figure 2: Phases of the Well Pathway for Dementia*

Good dementia care should be personalised and life-long, taking into account the individual needs and preferences of the person living with dementia and, where applicable, their family or carer. It should cover multiple phases of the Well Pathway (see Figure 2). In each phase, NICE-recommended, evidence-based care should be offered (see Section 4). The degree of support needed by each person with dementia will vary from person to person, and over time. Care and support services need to be flexible and responsive to the individual's needs.[44]

> ***Being given more information and help at the beginning would have helped enormously …. Someone there to guide me through the mountains of questions and paperwork.***
>
> Source: A person living with dementia

3.1 Diagnosing well

> ***'I was diagnosed in a timely way'***
>
> ***'I am able to make decisions and know what to do to help myself and who else can help'***

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 and their families and carers.

3.1.1 Initial assessment in non-specialist settings

When a person, their family member or carer suspects dementia, **primary care services** are often the first point of contact. According to the NICE guideline,[19] they should:

- carry out an initial assessment involving history taking of cognitive, behavioural and psychological symptoms to understand the impact on the person's life
- conduct a physical examination and carry out appropriate blood and urine tests
- use cognitive testing in line with the NICE guideline.

A referral to a memory assessment service should be made if dementia is still suspected

3.1.2 Assessment

A **memory assessment service** is any service that provides assessments and diagnosis for people with suspected dementia. Key functions include:

- conducting assessments and/or reviewing investigations from the referrer
- arranging specialist investigations where indicated, including neuropsychological assessment, brain scans and/or test of verbal episodic memory
- providing a validated diagnosis of dementia subtype, including atypical presentations, and mild cognitive impairment
- after diagnosis, developing and initiating a care plan with the person and all relevant carers and providers of care.

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* This guidance and pathway focuses on the phases from diagnosing well to dying well.

Diagnosis in primary care
There has been an increased use of integrated delivery of care models involving primary care and other agencies. In England, there is considerable local variation in the degree of this integration. Some GPs take a very active role in diagnosis and the initiation of treatment, but not all do this. An example of diagnosis in primary care is in the positive practice examples in the accompanying appendices and helpful resources.

Memory assessment services should focus on the individual needs of the person and be able to diagnose dementia types including atypical presentations. The length of time it takes to reach a diagnosis should be guided by the person's needs and the level of complexity of their condition (see Section 5.1). Joint working with other services, including neurology and learning disability services, is regarded as good practice.

Memory assessment services may be configured in a range of ways:

- cognitive neurology clinics or neurology services
- geriatric or old-age medicine clinics/services, through acute (medical) trusts
- GP-led clinics/services supported by specialist advice and assessment from one or more of the services above
- integrated services, with co-location and/or joint working between one or more of the providers above
- via secondary mental health care providers, either as stand-alone memory clinics or services, or integrated with older adult community mental health services.

3.2 Supporting well

'I am treated with dignity and respect'

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

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.

3.2.1 Named coordinator of care and care plan

Core components of person-centred dementia care are support from a named coordinator of care and the presence of a flexible, up-to-date care plan.[19] Here, a named coordinator of care is any professional with lead responsibility for a person's treatment and care. They are the point of contact for the person with dementia and their family and/or carer when they need advice, information or help.

Allocation of a named coordinator of care should be made based on individual need, and may come from settings including primary care, the voluntary sector or memory assessment services. Their main functions are to:

- **Facilitate choice, independence and person-centred care**, including seeking informed decision-making and valid consent where appropriate through use of advance statements and decisions and the Mental Capacity Act 2005.[66]
- **Signpost** people with dementia and their families and carers to local support services, to ensure continuity of care.
- **Jointly develop and review the care plan** with the person and their family and/or carer at least every 12 months, to ensure that it is still applicable and effective.
- **Ensure the person's physical and mental health is monitored** and that they can **access appropriate treatment** (see Appendix B on NICE-recommended care in the appendices and helpful resources).

While an initial care plan may be agreed at a memory assessment service, the follow-up review may take place in primary or secondary care settings. The review should occur at least once within 12 months of the care plan first being agreed. It should consider whether the care plan is wholly applicable to the needs of the person living with dementia and their family or carer, and it should be updated as required.

Further information on care plans can be found in Appendix B in the appendices and helpful resources).

3.2.2 Management of non-cognitive symptoms and behaviour that challenges

Non-cognitive symptoms of dementia and the associated behaviours that challenge are very common in people living with dementia and can cause significant distress and costs.[19]

Community mental health teams can:

- offer interventions for people living with dementia who have specialist mental health needs (such as comorbid behavioural and psychological symptoms) including managing medication
- provide ongoing treatment for older adults who have a primary diagnosis of a functional mental health problem (such as schizophrenia or bipolar disorder) and have developed dementia.

Many community mental health teams can provide treatment and support to people living with dementia during crises, which may arise as a result of severe behavioural and psychological symptoms, and severe carer stress. The aim of the intervention will be to improve outcomes and reduce the need for inpatient admission. In some areas, this support may also be delivered by rapid response teams or crisis resolution and home treatment teams.

3.2.3 Acute and general hospital inpatient care

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 for people living with dementia (see Section 2.2).

3.2.4 Liaison mental health

Liaison mental health services can provide assessment and interventions for people with suspected or diagnosed dementia who are in a general hospital. Key functions of these services include:

- giving support and advice on assessment and diagnosis, including referral to memory assessment services
- giving support and advice on care planning, and managing the behavioural and psychological symptoms of dementia and delirium
- working closely with other mental health services so that people who are seen in hospital and require ongoing assessment and treatment are followed up.

3.3 Living well

> ***'I know that those who are around me and looking after me are supported'***
>
> ***'I feel included as part of society'***

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, and it may be provided via health and social care, local authorities or voluntary organisations.

3.3.1 Person-centred support

Person-centred support may include:

- **appropriate housing provision** such as extra care housing
- **support in maintaining relationships** at home and in the wider community

- **support in maintaining independence**, including dementia-friendly communities, advocacy services, homecare services, campaign services and information provision
- **support in engaging in meaningful daily activities** that are person-centred and may take place on an individual or group basis, in a variety of settings
- **support, training and advice for carers**, including respite care, peer support groups and training courses, or support provided in the work environment
- **practical support**, such as with transport.

3.3.2 Support for carers

Dementia affects not only the individual but also their friends, family and local community. In England, it is estimated that over 540,000 people act as primary, unpaid carers for people living with dementia. The role of the carer is pivotal in enabling the person to live well with dementia, but in doing so they may face considerable emotional and economic pressures.[60 67]

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.

As part of this, carers should:

- be informed about their eligibility for publicly funded care and support under the Care Act 2014[68]
- be made aware of opportunities for respite, education and training
- be signposted to services providing carer support and information
- have their emotional, psychological and social needs regularly assessed as part of the care plan review.

3.4 Dying well

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

'I can expect a good death'

3.4.1 End of life care

People with dementia have the right to live as well as possible and die with dignity. End-of-life care is part of palliative care, provided as the person nears the end of their life. Care may be provided in hospitals, hospices, care homes or in the person's own home.

The key roles of staff involved in the end-of-life care of the person with dementia include:

- managing physical and psychological needs
- supporting social, practical and emotional needs; this should include spiritual or religious support where applicable
- supporting the family through the end-of-life period and after the death of the person with dementia.

End-of-life care can also include support with legal or administrative needs.

> ***I built up a brick wall and tried to do it all myself, hiding behind a mask that everything was ok but it wasn't. My Admiral Nurse skilfully and gently chipped bits away.***
> ***I learnt to trust her and because of her actions I realised that if I wanted to be an effective carer, which I want to be, I've got to acknowledge that I have needs and I've got to do something about it and to ask for help.***
>
> Source: A carer for a person living with dementia from Dementia Action Alliance, The Carers' Call to Action

4 NICE-recommended care

A key element of the dementia care pathway is the delivery of high-quality, evidence-based (NICE-recommended) care. Good-quality dementia care is described in the following NICE guidance and quality standards:

- Dementia: Support in Health and Social Care NICE quality standard[69] (see Table 2 for quality statements)
- Dementia: Independence and Wellbeing NICE quality standard[70] (see Table 2 for quality statements)
- Dementia NICE clinical guideline
- Donepezil, Galantamine, Rivastigmine and Memantine for the Treatment of Alzheimer's Disease NICE technology appraisal.[64]

Note that NICE quality standards may be subject to change following updates to the Dementia NICE guideline. Further information on NICE-recommended care can be found in Appendix B in the appendices and helpful resources.

Other policy documents highlighting good quality care

- The five 'We' statements of the National Dementia Declaration
- Joint declaration on post-diagnostic dementia care and support[71]
- Dementia Assessment and Improvement Framework[72]
- Dementia: Good Care Planning[73]

Table 2: Quality statements (QS) from the Dementia NICE quality standards on dementia

	Dementia: Support in Health and Social Care NICE quality standard	Dementia: Independence and Wellbeing NICE quality standard
Diagnosing well	● People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia. (QS2)	● People worried about possible dementia in themselves or someone they know can discuss their concerns, and the option of seeking a diagnosis, with someone with knowledge and expertise. (QS1)
Living well	● People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local areas. (QS3) ● People with dementia who develop non-cognitive symptoms that cause them significant distress, or develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan. (QS7) ● People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health. (QS8) **Care planning and review** ● People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator* and addresses their individual needs. (QS4) ● Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs. (QS6) **Joint decision-making** ● People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of: ○ advance statements ○ advance decisions to refuse treatment ○ Lasting Power of Attorney ○ Preferred Priorities of Care. (QS5)	● People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing. (QS6) **Care planning and review** ● People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change. (QS3) **Joint decision-making** ● People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support. (QS2) ● People with dementia are enabled, with the involvement of their carers, to access independent advocacy services. (QS9) **Involvement in research** ● People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services. (QS8)

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* Referred to in this guidance as a 'named coordinator of care'.

Table 2 cont.: Quality statements (QS) from the Dementia NICE quality standards on dementia

	Dementia: Support in Health and Social Care NICE quality standard	Dementia: Independence and Wellbeing NICE quality standard
	Appropriately trained staff ● People with dementia receive care from staff appropriately trained in dementia care. (QS1)	
Supporting well	● Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia. (QS10)	● People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice. (QS4) ● People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships. (QS5) ● People with dementia live in housing that meets their specific needs. (QS7) ● People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community. (QS10)
Dying well	● People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs. (QS9)	

5 The dementia care pathway

5.1 Timely access to evidence-based care

The dual focus of the dementia care pathway is timely access to diagnosis and evidence-based post-diagnostic support. The three pathway benchmarks describe what is required from services:

Benchmark 1: Achieve and maintain a **diagnosis rate of at least two-thirds**.

Benchmark 2: Increase the number of people being diagnosed with dementia, and starting treatment, **within 6 weeks of referral**.

Benchmark 3: Improve the quality of **post-diagnostic treatment** and support for people with dementia and their carers.

In **Benchmark 2**, 'starting treatment' was defined by the Expert Reference Group as the person having met with their named coordinator of care and agreed with them an initial care plan of NICE-recommended care. The length of time it takes to reach a diagnosis should be guided by the person's needs and the level of complexity of their condition. Sometimes, the suggested 6-week response time will not be appropriate. For example, the person may be physically unwell or choose to postpone their clinic appointment, or a complex diagnosis may need several investigations and assessments. If the recommended response time is exceeded, it is important that in all cases the reasons for the delay are clearly recorded. Records should be monitored and managed jointly by the commissioner and provider, and improvements should be made where possible.

The Expert Reference Group recommends that after diagnosis the person should be offered NICE-recommended treatment and support with their support needs recorded in the initial care plan. This care plan should be reviewed within at least 12 months of it first being agreed, and every 12 months thereafter, according to the person's needs. Revisions should be jointly developed and agreed with the person living with dementia (and, if applicable, their family and/or carer).

5.2 Starting the pathway

When a person or their family or carer suspects dementia, they often first go to a primary care service. They may have concerns about impaired memory, mood and personality changes or psychosis that could be caused by dementia. The GP will conduct an **initial assessment** to rule out any underlying physical or mental health causes.

If further investigation is required, an onward referral will be made to a memory assessment service.

Principles of initial assessment in non-specialist settings

The Dementia NICE guideline recommends that initial assessment should involve:

- history taking, including cognitive, behavioural and psychological symptoms, and the impact symptoms have on daily life, from the person with suspected dementia and, if possible, from someone who knows them well
- a physical examination and appropriate blood and urine tests
- cognitive tests using a validated brief structured cognitive instrument.

The **pathway starts** when the memory assessment service receives the referral (see Figure 3).

The referral should be accompanied by a range of information, including current concerns and risks, recent memory and blood tests, and the person's consent to the referral and informing their family and/or carer. If applicable, contact details for families and carers should be provided to facilitate a timely response from the memory assessment service.

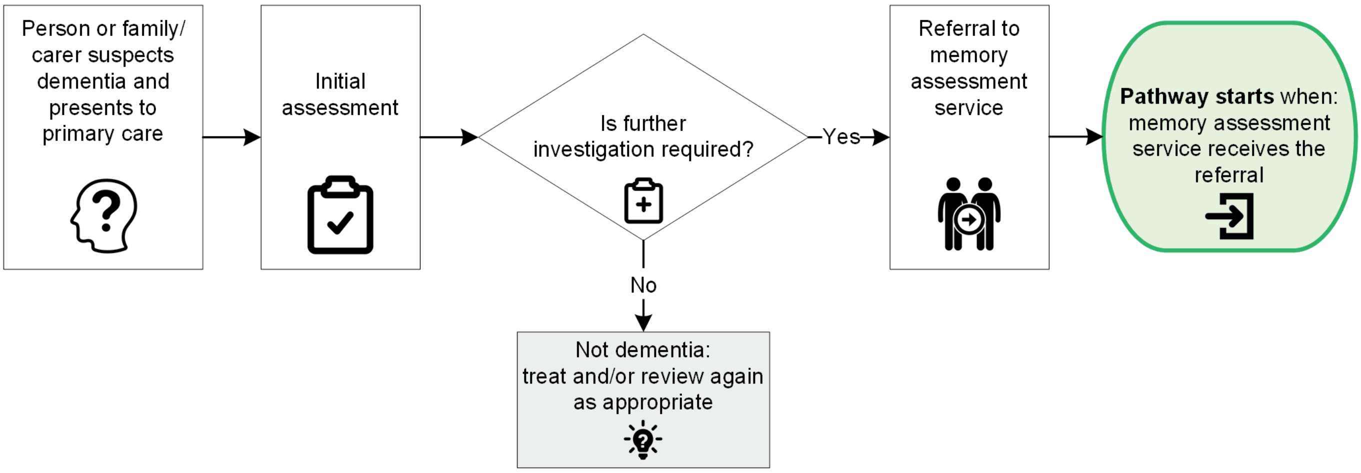
A small number of referrals may also be made from other areas of the NHS, including acute care and liaison mental health teams. General hospitals should have protocols in place to manage people with dementia, including follow-up after discharge.

5.3 Referral accepted by memory assessment service

Once the referral is accepted, initial telephone contact should be made with the person (and, if appropriate, their family and/or carer) (see Figure 4). As part of this, the purpose of the referral and the assessment process should be explained to them. Consent should also be confirmed, and the person with suspected dementia should be asked if they wish to know the outcome of the diagnosis as well as with whom they want this information shared. Their wishes should be noted and recorded.

If the referral is rejected, the person leaves the pathway. Where possible, the referral should be returned to the referrer with the appropriate next steps set out.

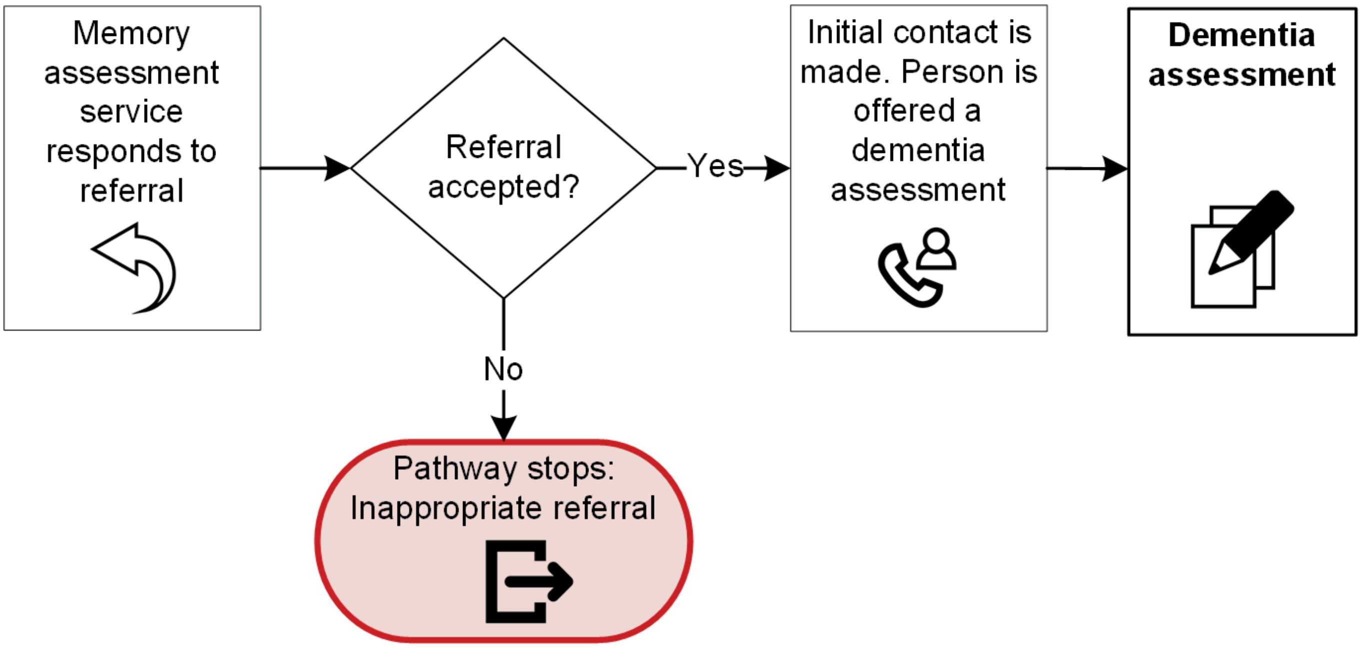
Figure 3: The start of the dementia care pathway



Principles of 'do not attends'

When a person refuses to attend or misses an initial assessment, every effort should be made to understand the reasons why. Attempts to engage them (and their family and/or carer), including follow-up phone calls and reminders, should continue to be made. This is especially important when the person appears confused or has trouble remembering the purpose or time of the appointment.

Figure 4: Assessment



5.4 Assessment

At the start, results from the initial assessment should be reviewed and any missing information collected. As part of this, medication should be reviewed to ensure that **vascular risk factors** are treated appropriately and to identify and minimise any **drugs that may impair cognitive functioning**.

An appropriate cognitive examination and assessment of functional abilities should be completed by an appropriately qualified member of staff (see Appendix C in the appendices and helpful resources for workforce skills and knowledge).

Cognitive assessment typically includes the use of standardised instruments, such as the Mini-Mental State Examination, Montreal Cognitive Assessment[73] and Addenbrooke's Cognitive Examination, and should examine: attention and concentration, orientation, memory, praxis, language, visuospatial/perceptual skills and executive function as dictated by the clinical presentation.

If mild dementia is found or there are questions around whether it is dementia, further neuropsychological and structural imaging may be necessary to help establish the dementia subtype and exclude other cerebral pathologies. This may include:

- cranial CT and MRI
- cranial SPECT (including DaTscan™ for suspected dementia with Lewy bodies) or FDG-PET.

Principles of assessments

- **A holistic approach to assessment** should be used. Where appropriate, assessments should be conducted in conjunction with family members, friends, and informal and formal carers (including domiciliary support).
- Interpretation of assessments should fully take into account **other factors known to affect performance**, including educational level, skill, language and any sensory impairments, psychiatric illness or physical/neurological problems.
- **Specialist input should be sought where necessary**, including for the interpretation of investigations and scans in atypical presentations such as people with learning disabilities or early onset dementia.
- The assessment should also seek to **identify the carer's needs**, including support under the Care Act 2014.

5.5 Diagnosis and initial care plan

After assessment the person will usually leave the pathway. However, if there is any doubt about the presence or risk of dementia, the **person should remain on the pathway** in the care of the memory assessment service.

The dementia assessment may ascertain whether the person:

- has dementia
- has no dementia, but has mild cognitive impairment
- has no dementia and no mild cognitive impairment.

Before the person leaves the pathway, the outcome of the diagnosis (if they wish to know) should be communicated to them in a sensitive and appropriate manner.

Before the diagnosis is discussed, the person should be asked if they wish to bring someone with them to the appointment, as well as to the first sessions afterwards.

When letting the person know about the outcome of their diagnosis, consideration should be given to where and when it is being communicated, and that the person may have difficulty in understanding and remembering the diagnosis.

See Figure 5 for the outcomes of the assessment and end of the pathway.

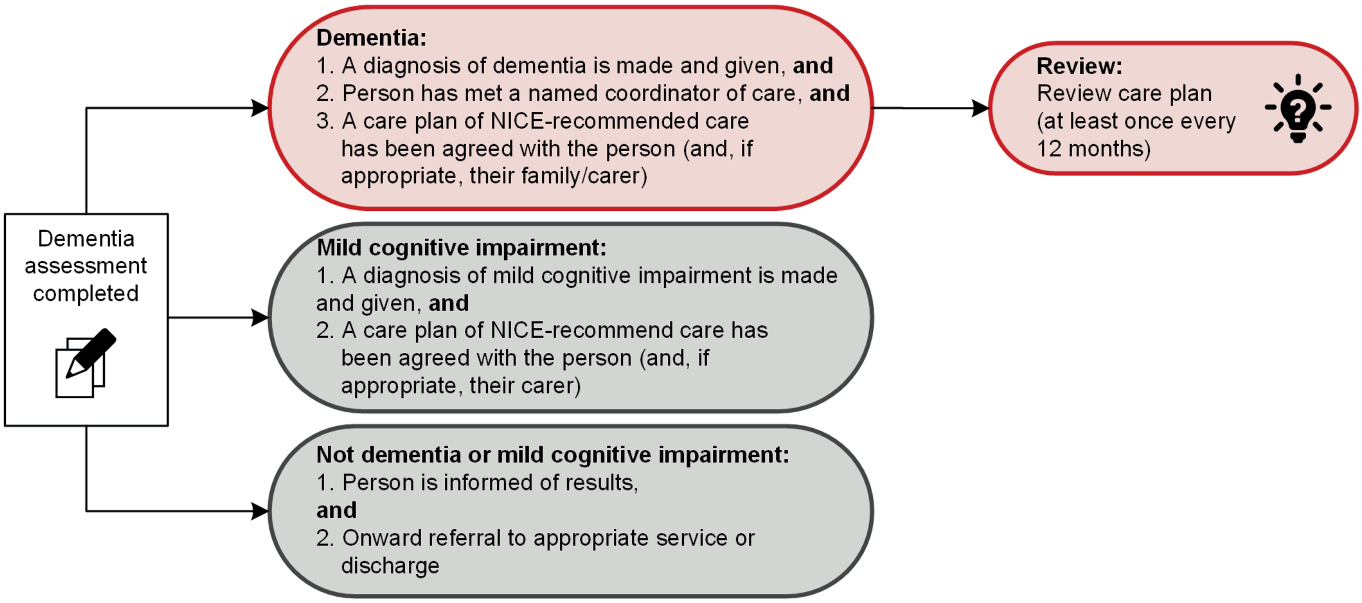
5.5.1 Dementia

If the person is diagnosed with dementia, they **leave the pathway** when:

- they have met with a named coordinator of care (see Section 3.2.1) **and**
- a care plan of NICE-recommended care for dementia has been agreed with them (and, if appropriate, their family and/or carer).

It is important that a coordinated care plan that covers aspects of supporting well, living well and dying well is developed and agreed jointly by the person, their family and/or carer, and their health and social care professionals/team. As part of this, NICE-recommended care should be offered (see Appendix B in the appendices and helpful resources). Details of the care plan and named coordinator of care should be communicated to the person's GP in writing, along with the recommended next steps.

Figure 5: The end of the dementia care pathway



5.5.2 Mild cognitive impairment

If the person has mild cognitive impairment and not dementia, they **leave the pathway** when a care plan has been co-produced with them, their family and/or carer if appropriate, and their health and social care professional/team. This may include treatment and follow-up.

The care plan should include ongoing access to information and follow-up appointments. Cognitive decline and other signs of possible dementia should be monitored routinely, so that care can be planned at an early stage.

5.5.3 Not dementia or mild cognitive impairment

If the person does not have dementia or mild cognitive impairment, they will leave the pathway when they have been informed of the results. The service should still ensure that the person receives any additional help they need, which may include a referral to primary or secondary care.

5.6 Post-diagnostic support

For every person diagnosed with dementia, after the initial care plan has been agreed it should be reviewed at least once within 12 months to ensure that it is aligned with the needs of the person living with dementia and their family and/or carer. Where needed, revisions to NICE-recommended post-diagnostic support should be agreed and jointly developed with the person living with dementia, their named coordinator of care and, where applicable, their family and/or carer. As part of this, new review dates should be set up (at most once every 12 months, or more often if the person's needs change) and the care plan adjusted as needed (see Figure 5).

5.7 Measuring and reporting performance against the dementia care pathway

5.7.1 Submission of data items

The Mental Health Services Dataset (MHSDS), set up and managed by NHS Digital, will be used to support the implementation of the dementia care pathway. Providers are required to collect data that will show how services perform against the standards outlined in this guide.

The MHSDS will also capture the provision of interventions that have been recommended by NICE. For this, providers will need to ensure that intervention codes are recorded to reflect the activities carried out during a clinical contact. These will then need to be submitted in national data (see Appendix D in the appendices and helpful resources).

5.7.2 Quality assessment and improvement programme

All memory assessment services are advised to participate in a quality assessment and improvement programme. The recommendations in this guidance (see Section 5.1) are incorporated into the standards of the Memory Services National Accreditation Programme (MSNAP), a quality network for memory assessment services based within the Royal College of Psychiatrists' College Centre for Quality Improvement (CCQI).

MSNAP aims to assure and improve the quality of memory services for people living with dementia and their families and carers. The process of self- and peer-review can support services to meet the recommendations in this guide, as well as reviewing the service in its wider context.

In addition to quality improvement, MSNAP offers accreditation to high-performing memory services. Accreditation assures staff, people living with dementia and their families and carers, commissioners and regulators of the quality of the service being provided. It is also an approved information source for the Care Quality Commission.

5.8 Outcome measurement

Clearly defined outcomes that are collected routinely are an essential part of measuring and monitoring the performance and the effectiveness of a service. The Expert Reference Group recognises that the needs of people living with dementia, and their families and carers, and the means by which they will be assessed could vary in frequency and duration depending on what they are being assessed for and the purpose of the assessment. For most treatment interventions, routine sessional assessment should be the norm.

With this in mind, the Expert Reference Group has recommended that **three outcome tools should be used routinely** in memory assessment services. The following measures, which provide ratings of the clinician's assessment, as well as service users and carers' views of their needs and experience, have been chosen because they have been well-researched and are wide-ranging, while also being brief and practical to use in clinical settings.

The following should be collected at diagnosis, and on a sessional basis:

- Health of the Nation Outcome Scale-65 (HoNOS-65):[75] a 12-item scale measuring behaviour, impairment, symptoms and social functioning in older adults
- Friends and Family Test (FFT):[76] a single-item scale measuring service user experience.

The following should be collected at diagnosis and each care plan review:

- New Models for Measuring Patient Experience Questionnaire:[77] a 20-item scale that measures service user experience.

The three outcome measures can be found in Section 3 of the appendices and helpful resources. For further information see the International Consortium for Health Outcome Measurement.

5.9 Planning and developing the workforce required to provide NICE-recommended care

The right workforce, with the right capacity and skill mix, is essential for ensuring the delivery of NICE-recommended care. The Dementia Training Standards Framework sets out the essential skills and knowledge necessary for all staff involved in dementia care. It sets out standards needed in dementia education and training, including raising dementia awareness, knowledge and skills for those that have regular contact with people living with dementia, and their families and carers. It also sets out knowledge and skills for those in leadership. These roles and standards are summarised in Appendix C in the appendices and helpful resources.

6 Key commissioning and service development considerations

Ageing populations, constraints on budgets and growing expectations from regulators and people living with dementia add to the challenges that commissioners and providers face when preparing to deliver the new dementia care pathway by 2020/21. While some initial investment may be required in key areas of the pathway, the economic evidence shows that in the long term it is likely that effective implementation will demonstrate value and be, at least, cost neutral.

Since 2012, many health economies have introduced effective and sustainable change, the pace and impact of which continue to accelerate. To ensure that the full impact of this change can be achieved by 2020/21, similar leadership, insight and determination is required across all local health and social care partners. This will need to include the expansion of levers and incentives, as well as the sharing of good practice (see the appendices and helpful resources for service-led examples).

Commissioners should continue to actively engage in local system leadership. An improvement agenda should be developed jointly with key partners, including healthcare providers, social care, local government, and the voluntary and independent sectors. At the heart of this agenda lies people living with dementia and their families and carers, as well as the ‘triple aim’ of:

- improving the health and wellbeing of the whole population
- better quality for all service users, through care redesign
- better value for taxpayers in a system that is sustainable.

This section describes how commissioners can identify what needs to be done to develop dementia care services to meet the requirements of the new pathway.

6.1 Strategic planning

A set of clear, outcome-focused, strategic priorities and investment plans that highlight the short-, medium- and long-term goals linked to achieving the new pathway should be developed. Plans and decisions for change should be based on evidential data, and co-produced with key partners (including social care), people living with dementia and their families and carers, and the wider public.

> ***Involving people with dementia and carers in developing dementia services can often be a tick-box exercise with no real meaning. I am fortunate as I live in an area that puts me and my wife and people like us at the centre of everything that concerns dementia. ... in fact, I am busier now than when I was working!***
>
> ***Doing ‘with’ rather than doing ‘to’ is vitally important to ensure services are developed that people with dementia and their families not only want and need, but deserve and expect.***
>
> ***So in summary, to be successful for the people you need to work with the people.***
>
> Source: Dr Trevor Jarvis, Dementia Ambassador and person living with dementia

6.2 Assessing local need and demand

Effective approaches to reducing differences in access, experience of care and clinical outcomes are designed after considering the best available evidence on why and how such variations occur. Commissioners should develop a complete picture of the current and future needs of the local population. This should be outlined in a Joint Strategic Needs Assessment and a local Dementia Needs Assessment (see Section 5 in the appendices and helpful resources).

As part of this, in addition to acknowledging the role of current national prevalence estimates (see Technical Definitions for Commissioners 2016/17) in the agreement of planning trajectories and assurance, commissioners should also:

- **Estimate local overall dementia incidence rates** using sources such as NHS Digital and the dementia calculator.[e]
- **Understand local referral rates**, collaborating with providers, people living with dementia, their families and carers, their health and social care professionals/team and the public to build a realistic understanding of how many people are referred, and when and how they are referred.
- **Understand the local demographic profile, and variance in incidence and referral rates**: incidence and referral rates will vary, so a local Dementia Needs Assessment and an Equality Impact Assessment should be carried out to **highlight the needs of specific groups at risk of inequality and identify solutions**. This includes people with learning disabilities, populations who are referred to as hard-to-reach, or those with any protected characteristics. This should take into account the overall predicted ageing of the population.
- **Arrive at a local estimate** by combining the factors above.

6.3 Building a case for change

Based on an assessment of local need, commissioners should work with providers and wider stakeholders to agree an objective or future service model. This should be done in the context of nationally agreed planning trajectories and assurance processes. Proposed models should be driven by evidential data and best practice, as detailed in:

- NICE guidelines and quality standards
- other principles, including the National Dementia Declaration and the MSNAP standards
- positive practice example, such as those in the appendices and helpful resources.

Following the development of an outline service model and assessment process, a plan should be produced that sets out the short-, medium- and long-term steps required to close the gaps between the existing model and the new model required by the pathway by 2020/21.

Commissioners should:

- **Apply their understanding of local need to develop a workforce model** that includes staffing complements and competences. The outline should contain the number of teams, management, clinical leadership and any characteristics the team will need to address demographic considerations. The workforce planning tool can be used to help with this (see Section 5.9 and Appendix C in the appendices and helpful resources).
- **Outline a service model of the optimal pathway and systems (mapping)**. This should include protocols for referral, diagnosis and access to post-diagnostic support, and map out who does what, when they do it, how it is done, the outcomes that are achieved and what resources are required. As part of this, commissioners should:
    - **Compile a list of external and internal referral sources**, consulting with stakeholders to ensure it is comprehensive

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[e] The Dementia Profile and Dementia Prevalence Calculator DPCv3 are available from the Public Health England website and Primary Care Web Tool website, respectively

> ***Across the country, there are pioneering initiatives and potentially life-changing partnerships in research and in frontline care. From local programmes to national or international ones, there is a clear sense of enormous momentum in response to the [Prime Minister's] Challenge. Our goal… is to build on this momentum, harness it and use it in a co-ordinated way, so accelerating progress to our shared goal.***
>
> Source: Department of Health, Prime Minister's Challenge on Dementia 2020: Implementation Plan

  - **Ensure that the pathway promotes equal access, parity of esteem and ageless and integrated services**, as described in Section 2.3. This should include relevant protocols and guidance
  - **Ensure that shared-care arrangements include robust plans for communication** and clear delineation of responsibility for different aspects of the pathway
  - **Promote the use of assistive technology, aids and adaptations** for people living with dementia
  - Encourage and support **local research opportunities**. Consider the Joint Dementia Research NHS toolkit
  - **Provide referrers** (particularly GPs) and providers of support services **with education and training programmes**, such as Dementia Revealed: What Primary Care Needs to Know[78]
  - **Consider a public awareness campaign**, working with local authorities and other partners to raise the overall levels of awareness in the population about preventing and living well with dementia. This should include the five key messages outlined in the Dementia Friends Campaign.

Where there is less choice of providers, commissioners should work with them and the local economy. This may include using investment choices and levers to influence service delivery, stimulate the market and ultimately increase choice.

6.4 Managing the local system

Once future quality standards, performance and workforce requirements have been outlined, an options appraisal for service reconfiguration, recruitment and workforce development will need to be jointly considered with providers. This should include assurance that providers have plans to routinely collect and use outcome measures as specified in Section 5.8.

Appropriate programme and project management arrangements will be required to ensure the necessary changes are made and reviewed regularly until 2020/21.

Commissioners should:

- **Agree service redesign plans** with providers. This may involve major or minor redesign, and investment may need to be considered in some areas. It should include arrangements to ensure that:
  - **interventions** are provided by suitably qualified staff who are appropriately supervised
  - **patient-rated outcome measures, clinician-rated outcome measures and patient experience measures** are routinely collected and used to improve care. They will include measures that assess families' and carers' needs and outcomes.
- **Agree recruitment plans with providers**, including how they will address any specific demographic issues. For example, in culturally and ethnically diverse areas, providers should actively try to ensure that the workforce is culturally competent.
- **Agree training plans and associated costs with providers**, engaging local education and training boards as necessary, and ensuring that there are sufficient numbers of people trained to level 1, 2 or 3, as appropriate.

6.5 Monitoring the new system

6.5.1 Data quality improvement and performance monitoring plans

NHS England is working with NHS Digital to update the MHSDS and support national reporting against the dementia care pathway. These improvements will need to enable system-wide monitoring that can capture follow-up monitoring in multiple services, including acute hospitals and primary care.

Commissioners should:

- **Agree a data quality improvement plan** with their providers to ensure they will be able to fully report performance in line with the pathway, including timescales and milestones.
- **Agree a schedule for performance reporting**, which may be worked into existing performance reporting and management arrangements and should be planned until 2020/21.

> ***We have a double opportunity: to narrow the gap between the best and the worst, whilst raising the bar higher for everyone… we can do more by measuring what matters, requiring comprehensive transparency of performance data and ensuring this data increasingly informs payment mechanisms and commissioning decisions.***
>
> Source: The Five Year Forward View

6.5.2 Electronic care records and information systems

The MHSDS will support the monitoring of the dementia care pathway (see Section 5.7.1). Commissioners should ensure that their local providers have made the necessary updates to their electronic care record system, so that clinicians can enter the data required to monitor performance against the pathway.

The electronic care record system should enable collection and submission of data in three key areas:

- referral-to-treatment **response time** performance (see Section 5.1)
- performance against the requirement that the care accessed is in line with **NICE recommendations** (see Section 5.7)
- **routine measurement of outcomes**, as specified in Section 5.8.

6.5.3 Benefits realisation plan

A benefits and realisation plan should identify key benefits and value, setting out how the benefits will be delivered, measured and reported in the context of a multi-year development trajectory. Key benefits of providing a memory assessment service include:

- **reduced response times** for people accessing services, through meeting the 6-week recommended response time by 2020
- **improved care and outcomes** (including 'living well') for people living with dementia and their families and carers through routine access to the full range of NICE-recommended interventions delivered by suitably qualified and supervised staff
- **improved mental health, physical health and social outcomes** for people living with dementia and their families and carers
- **improved experience of services** for people living with dementia and their families and carers
- **greater value**, including potential for reduced costs, through reductions in acute activity (primary care, urgent and emergency mental health and acute services), decreased deaths in hospital and fewer care home placements (see the Healthcare Costing for Value Institute)
- **improved awareness and satisfaction** among referrers.

> ***My whole emphasis is on wellness. While I'm never going to get better, I want to keep well. It is a progressive slope and the long-term outcome is as it is. However, I can live as well as I possibly can for as long as I possibly can.***
>
> Source: A person living with dementia

Abbreviations

Abbreviation	Full term
CCG	clinical commissioning group
CCQI	College Centre for Quality Improvement
MHSDS	Mental Health Services Dataset
MSNAP	Memory Services National Accreditation Programme
NCCMH	National Collaborating Centre for Mental Health
NICE	National Institute for Health and Care Excellence
QS	quality standard

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