The Dementia Care Pathway

Appendices and helpful resources

NATIONAL
COLLABORATING
CENTRE FOR
MENTAL HEALTH

Updated October 2018; amendments were made to Appendix C, Section 2.3.2 and Section 3.2.

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Appendix A: The dementia care pathway

Figure 1: The full dementia care pathway

Person or family/carer suspects dementia

Initial assessment in non-specialist settings

Is further investigation required?

No

Yes

Referral to memory assessment service

Pathway starts when: memory assessment service receives referral

Referral accepted?

No → Pathway ends: Inappropriate referral

Yes

Initial contact is made. Person is offered a dementia assessment

Proactive attempt to engage

DNA or cancellation?

Yes

Dementia assessment

Dementia assessment completed

Diagnosis:

Pathway stops (review) when: Review of care plan (at least once every 12 months)

Dementia:
Pathway stops when:
1. A diagnosis of dementia is made and given, **and**
2. Person has met a named coordinator of care, **and**
3. A care plan of NICE-recommended care has been agreed with the person (and, if appropriate, their family/carer)

Mild cognitive impairment:
Pathway stops when:
1. A diagnosis of mild cognitive impairment is made and given, **and**
2. A care plan of NICE-recommended care has been agreed with the person (and, if appropriate, their family/carer)

Not dementia or mild cognitive impairment:
Pathway stops when:
1. Person is informed of results, **and**
2. Onward referral to appropriate service or discharge

DNA = did not attend

Appendix B: NICE-recommended care

Table 1, Table 2, Table 3 and Table 4 provide summaries of the interventions from Dementia: Assessment, Management and Support for People Living with Dementia and their Carers NICE clinical guideline.

Table 1: Interventions for diagnosing well	
Intervention	**Summary**
Initial assessment in non-specialist settings and referral	- Take the history (including cognitive, behavioural and psychological symptoms, and the impact of symptoms on daily life) of the person with suspected dementia and, if possible, from someone who knows the person well. - If dementia is still suspected: - conduct a physical examination and carry out appropriate blood and urine tests - use cognitive testing with a validated structured cognitive instrument in line with NICE recommendations. - Do not rule out dementia solely because the person has a normal score on a cognitive instrument. - Once the reversible causes of cognitive decline have been investigated, if dementia is still suspected refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service). - If the person is suspected of having a rapidly progressive form of dementia, refer them to a neurological service that has access to tests for Creuzfeldt-Jakob disease and similar conditions. - Be mindful of and work towards equality of access to treatment for people from different ethnic groups and cultural backgrounds.
Diagnosis in specialist settings	- If initial specialist assessment rules out reversible causes of cognitive decline, diagnose a dementia subtype. - If Alzheimer's disease is suspected, include a test of verbal episodic memory in the assessment. - If it is unclear whether the person has cognitive impairment or their cognitive impairment is caused by dementia, or what the subtype diagnosis is, consider neuropsychological testing. - Use validated criteria to guide clinical judgement when diagnosing dementia subtypes, in line with NICE recommendations. - Offer structural imaging to rule out reversible causes of cognitive decline and assist with subtype diagnosis. - Only consider further diagnostic tests if they would help diagnose and support management of a dementia subtype. See the Dementia NICE guideline for recommendations about further tests.
Information about the diagnosis and consent	- Offer the person and their family members or carers oral and written information that explains: - what their dementia subtype is and the changes to expect as the condition progresses - which healthcare professionals and social care teams will be involved in person's care and how to contact them - how dementia affects driving - their legal rights and responsibilities - their right to reasonable adjustments (in line with the Equality Act 2010) if they are working or looking for work - how local support groups, online forums and national charities, financial and legal advice services, and advocacy services can help. - At diagnosis, ask the person for their consent to share information, which people they would like services to share information with, and what information they would like services to share. Document these decisions in the person's records. - After diagnosis, direct people and their family members or carers to relevant services for information and support.

Table 2: Interventions for supporting well and living well	
Intervention	**Summary**

Advance care planning	• Offer early and ongoing opportunities for people living with dementia and the people involved in their care to discuss:
	  ○ the benefits of planning ahead
	  ○ lasting power of attorney
	  ○ an advance statement about their wishes, preferences, beliefs and values regarding their future care
	  ○ advance decisions to refuse treatment
	  ○ their preference for place of care and place of death.
	• At each care review, offer people the chance to review and change any advance statements and decisions the person they have made.
	• Encourage and enable the person to give their own views and opinions about their care. Use additional or modified ways of communicating such as visual aids or simplified text.

Care coordination	• Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care. Named professionals should:
	  ○ arrange the initial face-to-face assessment of needs
	  ○ provide information on how to access available services
	  ○ involve the person's family members or carers in support and decision-making, where possible
	  ○ consider the views of people who do not have the capacity to make decisions about their care, in line with the principles of the Mental Capacity Act 2005
	  ○ ensure that people are aware of their rights including advocacy
	  ○ develop a care and support plan, and:
	    – agree and review it collaboratively
	    – agree on the frequency of the care plan reviews
	    – ensure it covers any comorbidities
	  ○ provide a copy of the plan to the person and their family members or carers.
	• Staff involved in the care of people living with dementia should:
	  ○ maximise continuity and consistency of care
	  ○ support access to relevant services, including memory services and equivalent hospital and primary care-based multidisciplinary dementia services
	  ○ follow the Transition Between Inpatient Hospital Settings and Community or Care Home Settings for Adults with Social Care Needs NICE guidance.
	• If admission to a hospital is being considered for a person living with dementia, take into account:
	  ○ any advance care and support plans
	  ○ the value of the person remaining in a familiar environment.

Maintaining good physical health	• Encourage eye tests every 2 years. • Encourage healthy nutrition. • Consider involving a speech and language therapist if there are concerns about the person's safety when eating and drinking.

Psychological, psychosocial and environmental interventions	• Offer:
	  ○ a range of activities to promote wellbeing that are tailored to the person's individual preferences
	  ○ group cognitive stimulation therapy for people with mild to moderate dementia.
	• Consider:
	  ○ group reminiscence therapy for people with mild to moderate dementia
	  ○ cognitive rehabilitation or occupational therapy to support functional ability in people with mild to moderate dementia.

Cont.

Table 2 (cont.): Interventions for supporting well and living well (cont.)	
Intervention	**Summary**

Pharmacological interventions for people with Alzheimer's disease	• Offer:
	  ○ AChE inhibitors (donepezil, galantamine or rivastigmine) for mild to moderate Alzheimer's disease
	  ○ memantine monotherapy for people with moderate symptoms who are intolerant of or have a contraindication to AChE inhibitors or for people with severe Alzheimer's disease.
	• See the NICE guideline for recommendations on the use of AChEs in people with Alzheimer's disease.

Pharmacological interventions for people with dementia with Lewy bodies	• Offer donepezil or rivastigmine for people with mild to moderate dementia with Lewy bodies. • Only consider galantamine for people with mild to moderate dementia with Lewy bodies if donepezil and rivastigmine are not tolerated. • Consider donepezil or rivastigmine for people with severe dementia with Lewy bodies. • Consider memantine for people with dementia with Lewy bodies if AChE inhibitors are not tolerated or are contraindicated.

Interventions for agitation, distress and psychosis in people with dementia	• If a person living with dementia is agitated or distressed, offer:
	  ○ psychosocial and environmental interventions to reduce distress
	  ○ personalised activities to promote engagement, pleasure and interest in people who experience agitation or aggression.
	• Only offer antipsychotics to people who are either at risk of harming themselves or others or experiencing agitation, hallucinations or delusions that cause them severe distress. For recommendations on using antipsychotics in people with dementia, see NICE guidance.

Interventions for depression and anxiety	• Consider psychological interventions for people who have mild to moderate dementia and mild to moderate depression and anxiety. (Do not routinely offer antidepressants, unless they are indicated for a pre-existing severe mental health problem.)
Interventions for sleep problems	• Consider a personalised multicomponent sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.
Interventions for pain	• Consider using a stepwise treatment protocol that balances pain management and potential adverse events.

Interventions for falls	• See the Falls in Older People NICE quality standard; when using the quality standard:
	  ○ consider the additional support people living with dementia may need to participate effectively
	  ○ be aware that multifactorial falls interventions may not be suitable for a person living with severe dementia.

Interventions **not** recommended	• The following are **not** recommended for use in people living with dementia:
	  ○ diabetes medicines, hypertension medicines, statins and non-steroidal anti-inflammatory drugs, including aspirin, to slow down the progress of Alzheimer's disease
	  ○ acupuncture, ginseng, vitamin E supplements or herbal formulations to treat dementia
	  ○ cognitive training to treat mild to moderate Alzheimer's disease
	  ○ interpersonal therapy to treat cognitive symptoms of mild to moderate Alzheimer's disease
	  ○ non-invasive brain stimulation to treat mild to moderate Alzheimer's disease
	  ○ AChE inhibitors or memantine for people with frontotemporal dementia
	  ○ valproate to manage agitation or aggression in people with dementia, unless indicated for another condition
	  ○ antidepressants for people who have mild to moderate dementia and mild to moderate depression and anxiety, unless they are indicated for a pre-existing severe mental health problem
	  ○ melatonin to manage insomnia in people with Alzheimer's disease.

AChE = acetylcholinesterase

Table 3: Interventions for dying well	
Intervention	**Summary**
Palliative care	• From diagnosis, offer needs-based palliative care that takes into account the unpredictable nature of the progression of dementia. • For people approaching the end of life, use an anticipatory healthcare planning process. • For standards and measures on palliative care, see the End of Life Care for Adults NICE quality standard. • For health and social care staff caring for adults approaching the end of life, see the Care of Dying Adults in the Last Days of Life NICE guidance.

Table 4: Interventions for carers	
Intervention	**Summary**

Support and advice	• Support and advice should allow carers to understand their legal rights better, support their individual needs and be designed to help carers support people with dementia. It should also be:
	  ○ tailored to their needs and preferences
	  ○ designed to help them support the person living with dementia
	  ○ available at a location they can get to easily
	  ○ provided in a format suitable to the carer
	  ○ available from diagnosis, and as needed thereafter.
	• Advise carers about their right to a formal assessment of their own needs (a 'carer's assessment') and an assessment of their need for short breaks and other respite care.

Psychoeducation and skills training	• This should include:
	  ○ education about dementia, symptoms, and the changes to expect as the condition progresses
	  ○ developing personalised strategies and building carer skills
	  ○ training to provide care, including how to understand and respond to changes in behaviour
	  ○ adaptation of their communication styles
	  ○ how to look after their own physical and mental health, and emotional and spiritual wellbeing
	  ○ advice on planning enjoyable and meaningful activities
	  ○ information about relevant services and how to access them
	  ○ advice on planning for the future.

Appendix C: Workforce, education and training – essential skills and knowledge

C.1 The Dementia Training Standards Framework

Research has shown that education and training can improve staff knowledge, skills and confidence, and this can have a positive impact on those they provide care for.

The Dementia Training Standards Framework (formerly the Dementia Core Skills Education and Training Framework) was commissioned by the Department of Health and developed by Skills for Health, Skills for Care and Health Education England (HEE) in collaboration with a number of key stakeholders and experts in dementia care. The framework is a comprehensive resource to support health and social care staff, educators and carers who work with and care for people living with dementia. It sets out the essential skills and knowledge necessary for all staff involved in the dementia care pathway and will enable organisations to:

1. standardise the interpretation of dementia education and training
2. guide the focus and aims of dementia education and training delivery through key learning outcomes
3. ensure the educational relevance of dementia training
4. improve the quality and consistency of education and training provision.

The training, teaching and assessment methodology is not prescribed in the framework, the aim being that education and training should be developed to suit the local context or setting.

The framework is applicable across services and sectors (for example, health, social care, local authorities, housing) and across different types of organisations (for example, public, private, not-for-profit).

C.2 About the three tiers of the framework

The framework is designed to underpin the implementation of the Prime Minister's Challenge on Dementia 2020 and is structured into three tiers:

- **Tier 1:** relevant to the entire health and social care workforce including ancillary staff. This could form part of induction training and also provide a foundation for more advanced practice
- **Tier 2:** relevant to all health and social care staff in settings where they are likely to have regular contact with people living with dementia. This underpins the more specialist skills and knowledge required at tier 3.
- **Tier 3:** relevant to staff working intensively with people affected by dementia including those who take a lead in decision-making and developing or disseminating good practice.

Further information on each of the tiers can be found in Table 5.

The Dementia Training Standards Framework is part of a suite of core skills frameworks. The Person-Centred Care Framework articulates what it means to be person-centred and how to develop and support the workforce to work in this way. The approaches set out in the Person-Centred Care Framework underpin existing dementia, learning disabilities, mental health and end of life care core skills frameworks. All frameworks are available on the HEE website. The HEE website

Table 5: Summary of framework subjects			
Subject	Tier 1	Tier 2	Tier 3
Dementia awareness	●	●	●
Dementia identification, assessment and diagnosis		●	●
Dementia risk reduction and prevention		●	●
Person-centred dementia care		●	●
Communication, interaction and behaviour in dementia care		●	●
Health and wellbeing in dementia care		●	●
Pharmacological interventions in dementia care		●	●
Living well with dementia and promoting independence		●	●
Families and carers as partners in dementia care		●	●
Equality diversity and inclusion in dementia care		●	●
Law, ethics and safeguarding in dementia care		●	●
End of life dementia care		●	●
Research and evidence-based practice in dementia care		●	●
Leadership in transforming dementia care			●

also includes a range of education and training resources that are available for organisations to use free of charge.

C.3 'What works' in dementia education and training? research study

The 'What works' in dementia education and training? research study led by Leeds Beckett University was commissioned on behalf of HEE by the Department of Health Policy Research programme. While research has shown education and training can help staff to feel more confident about dementia care, improve their knowledge and skills and lead to better care, other studies have shown training does not always lead to benefits.

Therefore, HEE wanted to understand 'what works' when it comes to dementia training, by identifying the programmes and approaches that lead to the best outcomes for people with

dementia and their families and carers. The aim of the study was therefore to find out what factors contribute towards an effective training and education programme for health and social care staff.

The outcomes of the research include the key components of effective dementia education training, including:

- tailoring training to the specific service setting and to the staff who are attending the training
- using face-to-face delivery methods with the opportunity for interactive activities and group discussion
- inclusion of opportunities to apply learning within practice, or practice-based situations
- having training that is at least 3.5 hours' duration, with even longer training showing greater benefits
- delivery by an experienced training facilitator who is also experienced in training and in dementia care.

C.4 Quality assurance of dementia education and training

Quality assurance can be delivered with the help of the Dementia Training Design and Delivery Audit Tool (DeTDAT) and Auditor's Manual, commissioned by HEE. DeTDAT provides care and training for providers, commissioners and others involved in training design, delivery or purchasing with an evidence-based set of criteria that reflect good practice in the design and delivery of dementia training. The audit tool enables them to assess how well a training package meets the good practice identified in the 'What works' study. This may lead to money being invested in programmes that are most likely to be effective in supporting better care for people with dementia.

This audit tool has been adopted by HEE as its standard method for assessing dementia education and training materials and packages that it recommends via its dementia training website.

Both the 'What works' research findings and the DeTDAT, which is free to use, can be found on the Leeds Beckett University website and the HEE website.

Appendix D: Submission of data items

D.1 Guidance for recording dementia care pathway benchmarks in the Mental Health Services Data Set (MHSDS) v3.0

D.1.1 Recording 'pathway starts' in the MHSDS

The 'pathway starts' is recorded in tables MHS101 Service or Team Referral and MHS102 Service or Team Type Referred To; all required fields should be completed in line with the data standard, including Primary and Foreign Keys to link the tables. Table 6 identifies referrals to be assessed for the pathway benchmarks and the date when the pathway starts.

D.1.2 Recording 'pathway stops' in the MHSDS

First, a diagnosis is made for dementia or mild cognitive impairment (MCI), which identifies the referral for inclusion in the measurement. (Any other diagnosis will exclude the referral from the dementia care pathway measurement.) This diagnosis could be recorded as the primary or secondary diagnosis.

Next, a care package is agreed. It must be on or after the date the diagnosis is recorded. The date the care package is agreed is the 'pathway stops' date.

To measure when the 'pathway stops', the dates shown in Table 7 (under 'MHSDS data item') need to be recorded. 'Pathway stops' is the MHSDS data item 'Care Contact Date'. Both dates must be the same as, or come after, the 'pathway starts' date and the 'Care Contact Date' will be the same as, or come after, the MHSDS data item 'Diagnosis Date'. This is the date when the dementia care plan is agreed.

All the required data items in MHSDS tables MHS604 and MHS201 must be recorded in line with the information standard. In addition, as shown in Table 8, data items and national codes will be used to show that the person has been diagnosed with dementia or MCI and that a dementia care plan has been agreed.

Table 6: Recording for dementia			
MHSDS table	**MHSDS data item name**	**National code**	**Notes**
MHS101 Service or Team Referral	Primary reason for referral	08: Organic brain disorder	These two items identify that this is a 'Dementia' pathway
MHS102 Service or Team Type Referred To	Service or team type referred to	A17: Memory services/clinic	
MHS101 Service or Team Referral	Referral request received date	Date received	'Pathway starts' date

Table 7: Recording the dates for when the 'pathway stops'	
MHSDS table	**MHSDS data item**
MHS604 Primary Diagnosis **or** MHS605 Secondary Diagnosis	Diagnosis Date
MHS201 Care Contact	Care Contact Date

Table 8: Recording data items and national codes for diagnosis and care plan			
MHSDS table	**MHSDS data item name**	**National code**	**Notes**
MHS201 Care Contact	Care Professional Team Local Identifier		Will be used to identify the Memory Services/Clinic team contact, linking to the Care Professional Team Identifier in Table MHS102 Service or Team Type Referred To
MHS201 Care Contact	Consultation Medium Used	01: Face to face communication (unless not appropriate)	Will identify appropriate type of contact to agree the care plan
MHS201 Care Contact	Attended or Did Not Attend Code	5: Attended on time or, if late, before the relevant professional was ready to see the patient 6: Arrived late, after the relevant professional was ready to see the patient, but was seen	As above
MHS102 Service or Team Type Referred To	Care Professional Team Local Identifier		Will be used to link to Care Professional Team Identifier in Table MHS201 Care Contact
MHS102 Service or Team Type Referred To	Service or Team Type Referred To	A17 Memory Services/Clinic	Identifies that patient has been accepted on to dementia service caseload and (via link to MHS201 Care Contact) has been assessed by dementia service
MHS202 Care Activity	Procedure Scheme in Use	06	Indicates Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT®) is the schema in use
MHS202 Care Activity	Coded	956841000000106	Code is SNOMED CT code for Dementia care plan agreed
MHS604 Primary Diagnosis	Diagnosis Scheme in Use	Must be completed	Defines coding schema in use for diagnosis
MHS604 Primary Diagnosis	Primary Diagnosis (Coded Clinical Entry)	See Appendix for lists of dementia or MCI codes	Identifies diagnoses that will stop the pathway

D.2 Codes for dementia and mild cognitive impairment diagnosis

Diagnosis can be recorded using any of the following systems:

- codes from ICD-10[a]
- SNOMED CT codes
- Read Version 2[b] codes
- CTV3[c] codes.

See Table 9, Table 10, Table 11 and Table 12 for the codes and code descriptions for a diagnosis of dementia or MCI. More information can be found on the NHS Digital website.

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a Codes from the International Statistical Classification of Diseases and Related Health Problems, 10th revision.

b The coded thesaurus of clinical terms used in the NHS since 1985.

c Clinical Terms Version 3, also known as Read Version 3.

Table 9: ICD-10 codes		
Diagnosis area	**ICD-10 description**	**ICD-10 code**
Dementia		
	Dementia in Alzheimer disease with early onset	F00.0* (G30.0†)
	Dementia in Alzheimer disease with late onset	F00.1* (G30.1†)
	Dementia in Alzheimer disease, atypical or mixed type	F00.2* (G30.8†)
	Dementia in Alzheimer disease, unspecified	F00.9* (G30.9†)
	Vascular dementia of acute onset	F01.0
	Multi-infarct dementia	F01.1
	Subcortical vascular dementia	F01.2
	Mixed cortical and subcortical vascular dementia	F01.3
	Other vascular dementia	F01.8
	Vascular dementia, unspecified	F01.9
	Dementia in Pick disease	F02.0** (G31.0†)
	Dementia in Creutzfeldt-Jakob disease	F02.1** (A81.0†)
	Dementia in Huntington disease	F02.2** (G10†)
	Dementia in Parkinson disease	F02.3** (G20†)
	Dementia in human immunodeficiency virus [HIV] disease	F02.4** (B22.0†)
	Dementia in other diseases classified elsewhere	F02.8***
	Lewy body (ies) (disease)	F02.8*** (G31.8†)
	Unspecified dementia	F03
	Delirium superimposed on dementia	F05.1
MCI		
	Mild cognitive disorder	F06.7

* F00.0–F00.9 would each occur together with the listed dagger (†) code indicating the type of Alzheimer disease.

** F02.0–F02.4 would each occur together with the listed dagger (†) code indicating the underlying cause.

*** F02.8 would occur together with a dagger (†) code indicating the underlying cause – example given of Lewy body disease.

Table 10: SNOMED CT codes		
Note that SNOMED CT codes may be subject to change, and any changes will automatically update on supplier systems. The latest diagnosis codes are available as part of a SNOMED CT Dementia Diagnoses Reference Set.		
Diagnosis area	**SNOMED CT description**	**SNOMED CT code**
Dementia		
	Dementia (disorder)	52448006
	Senile dementia (disorder)	15662003
	Uncomplicated senile dementia (disorder)	191449005
	Senile dementia with depressive or paranoid features (disorder)	191457008
	Senile dementia with delirium (disorder)	191461002
	Presbyophrenic psychosis (disorder)	231438001
	Senile and presenile organic psychotic conditions (disorder)	268612007
	Senile degeneration of brain (disorder)	45864009
	Alzheimer's disease (disorder)	26929004
	Primary degenerative dementia of the Alzheimer type, presenile onset (disorder)	416780008
	Primary degenerative dementia of the Alzheimer type, senile onset (disorder)	416975007
	Vascular dementia (disorder)	429998004
	Vascular dementia of acute onset (disorder)	230285003
	Multi-infarct dementia (disorder)	56267009
	Subcortical vascular dementia (disorder)	230286002
	Mixed cortical and subcortical vascular dementia (disorder)	230287006
	Frontotemporal dementia (disorder)	230270009
	Frontotemporal degeneration (disorder)	230273006
	Subcortical leukoencephalopathy (disorder)	90099008
	Progressive aphasia in Alzheimer's disease (disorder) Synonym Binswanger's disease	230280008
	Kuru (disorder)	86188000
	Pick's disease (disorder)	13092008
	Dementia due to Pick's disease (disorder)	21921000119103
	Dementia due to Creutzfeldt-Jakob disease (disorder)	429458009
	Dementia due to Huntington chorea (disorder)	442344002
	Jakob-Creutzfeldt disease (disorder)	792004
	Sporadic Creutzfeldt-Jakob disease (disorder)	713060000
	Dementia associated with Parkinson's Disease (disorder)	425390006

Table 10 (cont.): SNOMED CT codes		
Diagnosis area	**SNOMED CT description**	**SNOMED CT code**
Dementia		
	Dementia co-occurrent with human immunodeficiency virus infection (disorder)	713844000
	Chronic alcoholic brain syndrome (disorder)	191475009
	Diffuse Lewy body disease (disorder)	80098002
	Senile dementia of the Lewy body type (disorder)	312991009
	Lewy body dementia with behavioral disturbance (disorder)	135811000119107
	Diffuse Lewy body disease with spongiform cortical change (disorder)	42769004
	Dementia associated with another disease (disorder)	191519005
	Dementia associated with alcoholism (disorder)	281004
	Drug-induced dementia (disorder)	191493005
	Psychoactive substance-induced organic dementia (disorder)	111480006
	Inhalant-induced persisting dementia (disorder)	32875003
	Sedative, hypnotic AND/OR anxiolytic-induced persisting dementia (disorder)	59651006
	Dementia of frontal lobe type (disorder)	278857002
	Focal Alzheimer's disease (disorder)	230269008
	Mixed dementia (disorder)	79341000119107
	Presenile dementia (disorder)	12348006
	Presenile dementia associated with acquired immunodeficiency syndrome (disorder)	421023003
	Presenile dementia co-occurrent with human immunodeficiency virus infection (disorder)	713488003
	Presenile dementia with delirium (disorder)	191452002
	Primary degenerative dementia of the Alzheimer type, presenile onset, with delirium (disorder)	65096006
	Presenile dementia with delusions (disorder)	31081000119101
	Presenile dementia with depression (disorder)	191455000
	Presenile dementia with psychosis (disorder)	1089501000000102
	Primary degenerative dementia of the Alzheimer type, presenile onset, with depression (disorder)	10532003
	Presenile dementia with paranoia (disorder)	191454001
	Familial Alzheimer's disease of late onset (disorder)	230267005
	Non-familial Alzheimer's disease of late onset (disorder)	230268000
	Familial Alzheimer's disease of early onset (disorder)	230265002

Table 10 (cont.): SNOMED CT codes		
Diagnosis area	**SNOMED CT description**	**SNOMED CT code**
Dementia		
	Non-familial Alzheimer's disease of early onset (disorder)	230266001
	Uncomplicated presenile dementia (disorder)	191451009
	Primary degenerative dementia (disorder)	22381000119105
	Semantic dementia (disorder)	230288001
	Senile dementia with paranoia (disorder)	191458003
	Senile dementia with depression (disorder)	191459006
	Uncomplicated arteriosclerotic dementia (disorder)	191463004
	Arteriosclerotic dementia with delirium (disorder)	191464005
	Arteriosclerotic dementia with paranoia (disorder)	191465006
	Arteriosclerotic dementia with depression (disorder)	191466007
	Cerebral degeneration presenting primarily with dementia (disorder)	279982005
	Primary degenerative dementia of the Alzheimer type, presenile onset, uncomplicated (disorder)	6475002
	Primary degenerative dementia of the Alzheimer type, senile onset, uncomplicated (disorder)	66108005
MCI		
	Mild cognitive disorder (disorder)	386805003

Table 11: Read v2 codes		
Diagnosis area	**Read codes v2 description**	**Read code v2**
Dementia		
	Senile and presenile organic psychotic conditions	E00..%
	[X]Vascular dementia	Eu01.%
	[X]Dementia in other diseases classified elsewhere	Eu02.%
	Other alcoholic dementia	E012.%
	[X]Dementia in Alzheimer's disease	Eu00.%
	Alzheimer's disease	F110.%
	Jakob-Creutzfeldt disease	A411.%
	Drug-induced dementia	E02y1
	Dementia in conditions EC	E041.
	[X]Delirium superimposed on dementia	Eu041
	Pick's disease	F111.
	Senile degeneration of brain	F112.
	Lewy body disease	F116.
	Frontotemporal degeneration	F118.
	Binswanger's disease	F21y2
	Kuru	A410.
MCI		
	Mild cognitive impairment	28E0.

Note: % denotes that concept and any of the subtypes.

Table 12: CTV3 codes		
Diagnosis area	**CTV3 code description**	**CTV3 code**
Dementia		
	Alzheimer's disease	F110.%
	[X]Dementia in other diseases classified elsewhere	Eu02.%
	Senile and presenile organic psychotic conditions	XE1Xr%
	Dementia	X002w%
	Drug-induced dementia	E02y1
	Vascular dementia	XE1Xs
	Dementia of frontal lobe type	Xa0sE
MCI		
	Mild cognitive impairment	Xaagi

Note: % denotes that concept and any of the subtypes.

Helpful resources

1 Purpose of this resource pack

This resource pack accompanies The Dementia Care Pathway full implementation guidance. It has been put together to give commissioners and providers information and links to websites that support the implementation of the dementia care pathway.

1.1 Positive practice example services

Section 2 provides examples of positive practice occurring in existing dementia services. Each example corresponds to a phase of the Well Pathway for Dementia, and the corresponding delivery of one or more key statements from NICE quality standards (QS): Dementia: Support in Health and Social Care (QS1), and Dementia: Independence and Wellbeing (QS30).

1.2 Outcome measures

Section 3 features extracts of the outcome measures recommended for use with people living with dementia and their families and carers:

- Health of the Nation Outcome Scales for Older Adults (HoNOS 65+)
- New Models for Measuring Patient Experience Patient Experience Questionnaire (MOPE-PEQ)
- Friends and Family Test (FFT).

1.3 Dementia: good care planning

Section 4 covers the key components of dementia care planning, including:

- the definition of a care plan, and
- core elements that constitute the minimum information to be included in a good care plan.

1.4 Other helpful web-based resources

Section 5 contains links to helpful web-based resources, including:

- national guidance on mental health
- national guidance on dementia
- NICE guidance
- useful websites for commissioners and providers
- other useful websites
- useful organisations.

2 Positive practice example services

The services described in this section demonstrate positive practice across each phase of the Well Pathway framework. The services deliver one or more of the key statements from NICE quality standards Dementia: Support in Health and Social Care (QS1) and Dementia: Independence and Wellbeing (QS30). The variation in population reported for each service is due to different service provision across the country.

2.1 NICE quality statements

All quality statements from NICE QS1 and QS30 are listed in Table 13 and Table 14, and are referred to, where relevant, within each service description. Each quality statement may be applicable to more than one phase of the Well Pathway framework. NICE quality standards may be subject to change following updates to the Dementia NICE guideline. See the Dementia NICE guideline for more details

Table 13: Dementia: Support in Health and Social Care (QS1) – quality statements	
1	People with dementia receive care from staff appropriately trained in dementia care.
2	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3	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 area.
4	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.
5	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 for Care.
6	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.
7	People with dementia who develop non-cognitive symptoms that cause them significant distress, or who 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.
8	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.
9	People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
10	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.

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

Table 14: Dementia: Independence and Wellbeing (QS30) – quality statements	
1	People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.
2	People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
3	People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.
4	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.
5	People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
6	People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
7	People with dementia live in housing that meets their specific needs.
8	People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
9	People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
10	People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

2.2 Map of the services

Tailored care:
The Meri Yaadain Dementia Outreach Support Service, Bradford

Dying well:
The Central Manchester Dementia Palliative Care Service

Diagnosing well:
Stockport Memory Assessment Service

Tailored care:
*The Lancashire Memory Assessment Service:
Learning Disabilities*

Supporting well:
Sheffield Memory Service

Living well:
The Debenham Project

Tailored care:
The Wokingham Memory Service: Early Onset

Diagnosing well:
South Bucks Memory Service

Diagnosing well:
The Islington Memory Service

Dying well:
The Oxleas Advanced Dementia Service

2.3 Diagnosing well

Three services provide examples of good practice for 'diagnosing well':

- Islington Memory Service
- South Bucks Memory Service
- Stockport Memory Assessment Service.

2.3.1 Islington Memory Service

Islington Memory Service (see Table 15) is based within Ageing and Mental Health Services in Camden and Islington NHS Foundation Trust.

Steps to delivering a timely diagnosis and care plan

1. Within 2 weeks of referral, an **initial assessment** is arranged with the team doctor at the person's house. This is typically in the presence of a family member or carer. During the assessment, the person with suspected dementia is asked if they wish to know the results of the diagnosis and who else should be informed. The process of assessment, potential outcomes and corresponding care-planning options are then discussed.
2. A **full assessment** is conducted. If dementia is suspected and the person has not had a **CT scan** in the past 6 months, a scan is arranged to confirm the diagnosis and dementia subtype.
3. If they wish to know, the person is told their **diagnosis** by a team doctor. They are given verbal and written information on the diagnosis, and an overview of the local post-diagnosis pathway and intervention options (see Table 16).
4. The **care plan** is discussed and agreed with the person.

5. Two weeks after diagnosis, an appointment is arranged with a '**dementia navigator**' (named coordinator of care). The dementia navigator works jointly with the person, signposting them to relevant local services and providing information. Every effort is made to promote easily accessible and flexible care. If a person has been prescribed medication then ongoing monitoring, signposting and support will be provided by a nurse. If a person is not prescribed or does not tolerate medication, or chooses not to take up treatment, ongoing signposting and support is provided by the dementia navigator.

Meeting the recommended response time of 6 weeks

The average response time to diagnosis is 11 weeks, with a maximum of 12 weeks. The service is working proactively with commissioners to promote efficiency across the diagnosis pathway and further reduce waiting times. Waiting times for CT scans have been identified as the source of most delays, and a clinical support worker has been appointed to support and improve this process. This includes booking the scans, prompting people to attend (and accompanying them to their appointment when necessary), requesting the results and booking the post-diagnostic appointment.

Further information

Further information about Islington Memory Service can be found in Table 17 and by contacting Helen Souris, Clinical Team Manager (helen.souris@candi.nhs.uk).

Table 15: Overview of Islington Memory Service	
Population	215,600 (18,000 over the age of 65)
Referrals per year	650
Dementia diagnosis rate	93.2%
Dementia care pathway	The service is proactively working towards a recommended response time of 6 weeks. The current average response time is 2 weeks to first assessment and 11 (maximum 12) weeks to diagnosis
Relevant NICE quality standards	QS1: statements 1, 2, 3 and 6 (see Table 13) and QS30: statement 1 (see Table 14)

Table 16: Interventions delivered by Islington Memory Service	
1. Pharmacological 2. Cognitive stimulation therapy groups 3. Memory strategies groups, to promote positive strategies for coping with memory loss 4. Interventions to promote and maintain independence, typically delivered by an occupational therapist	5. Tailored psychological interventions for the person living with dementia, including systemic or cognitive behavioural therapy 6. Tailored psychological interventions for the carer, including the START (STrAtegies for RelaTives) programme

Table 17: Further information about Islington Memory Service	
Monitoring and measurement of outcomes	A satisfaction questionnaire is offered to all service users (and carers where applicable): • following the post-diagnostic feedback session • at the end of an intervention • 6 months after the end of an intervention. At the end of psychological interventions, the service also administers the following: • Hospital Anxiety and Depression Scale • Carers of Older People in Europe Index • Patient Health Questionnaire 9-item • Generalized Anxiety Disorder scale (7 items). Outcome measurement data are gathered quarterly and at the end of interventions.
Staff training and supervision	Staff members receive regular structured supervision, individually or as part of peer group meetings. There are also monthly multidisciplinary team forums/symposia to discuss topics of interest, and business meetings to focus on development.
Workforce (WTE hours and roles)	• 2.95 medical (1.25 consultant psychiatrist, 1 specialist trainee, 0.50 GP trainee, 0.20 core trainee) • 3.6 nursing (1.6 AfC band 6, 2.0 AfC band 5) • 5.1 psychology (0.5 AfC band 8a, 0.8 AfC band 7, 3.8 assistant psychologists) • 3.8 dementia navigator (1 team leader AfC band 6, 2.8 dementia navigators AfC band 4) • Other healthcare professionals: 0.2 occupational therapist (AfC band 6), 2 assistant practitioners (AfC band 4), 1 clinical support worker (AfC band 3) • Administration and management: 0.8 team manager, 2 team administrators AfC band 4

AfC = Agenda for Change; WTE = whole-time equivalent

2.3.2 South Bucks Memory Service

Until the Clinical Commissioning Group (CCG) merger in early 2018, South Bucks Memory Service operated across two sites in High Wycombe and Amersham using a 'one-stop assessment' framework for diagnosis. An overview of the service can be found in Table 18.

Steps to delivering a timely diagnosis and care plan

1. Before the initial assessment, a physical examination and dementia blood screening are carried out at the **GP practice**. Referrals are then made to a **single point of access**, and triaged daily to ensure they are appropriate and complete. A decision is made regarding the best place of assessment – either at the main clinic, the GP surgery or at home.

2. A protocol developed in collaboration with radiologists is used to decide whether to offer the person a **CT scan** or **MRI** before the assessment.

3. A **personal registration form** is sent to the person to collect information on:
   ○ demographic factors
   ○ personal history
   ○ preferences about sharing the diagnosis with family members and agencies such as social services
   ○ whether they wish to be contacted about future research opportunities.

4. The **initial assessment** is carried out by a doctor and a nurse, or by an assistant psychologist. The person with suspected dementia and their family/carer are interviewed jointly and separately. During the appointment, results and investigations are viewed on an electronic database. Head scans may be viewed via a picture archiving and communication system, and shown to the person to demonstrate brain changes in a more detailed way. A quarterly review of scans is conducted in a meeting with a consultant neuroradiologist.

5. Where the person exhibits an unusual, complex or early-onset form of dementia, a **referral for detailed neuropsychological assessment** is made.

6. A **diagnosis** is made in a supportive and sensitive manner, and time is set aside to address the person's questions and concerns. General recommendations are made to slow the rate of progression, including:
   ○ healthy living advice
   ○ cognitive stimulation
   ○ monitoring of vascular risk factors
   ○ avoidance of high-risk factors (such as excessive alcohol consumption)
   ○ advice on the prompt treatment of infections should they occur.

7. The clinician who completed the assessment acts as the person's **key worker** (or named coordinator of care) and develops a **care plan** with them (see Table 19 for interventions offered).

8. After 2 weeks, telephone contact is made with the person and/or their family/carer to **assess progress** and ask about any side effects. Further medication is then prescribed as appropriate.

9. A 3-month **review of medication** (where applicable) occurs with the key worker. Afterwards, the person is often **discharged to their GP's care**.

10. **Routine review** is expected to occur once or twice a year as stipulated in the local shared-care protocol.

Meeting the recommended response time of 6 weeks

South Bucks Memory Service had an average wait of 4.3 weeks in 2017, well within the recommended response time for diagnosis. In addition to using a 'one-stop assessment' framework, the service introduced a 'choose and book' service (now known as NHS e-referral) in January 2014. This was used in 20% of referrals to the service and offered a greater choice of venue and time of appointment, shorter waiting time to assessment and a more positive patient experience. As part of this, the 'Memory Assessment Closer to Home' clinic also ran from rural GP surgeries.

The service promoted efficiency by also ensuring that high-quality referral information was received. Specific training was offered to local primary care services to improve awareness and the quality of referrals.

Further information

Further information can be found in Table 20 or by contacting Dr Brian Murray, Consultant Older Adult Psychiatrist and Associate Medical Director (Brian.Murray@oxfordhealth.nhs.uk), or Dr Rohan Vanderputt, Consultant Older Adult Psychiatrist (Rohan.Vanderputt@oxfordhealth.nhs.uk).

Table 18: Overview of South Bucks Memory Service	
Population	55,000 over the age of 65
Referrals per year	1,140
Dementia care pathway	The service met the recommended response time, with an average of 4.3 weeks to diagnosis in 2017, with 98% seen in 5.7 weeks.
	The latest diagnostic audit showed that 81% of referrals received a diagnosis of either MCI or dementia and were offered appropriate treatment; 10% required further investigations before the diagnosis; and 8% received a diagnosis of no cognitive impairment.
NICE quality standards	QS1: statements 1, 2, 3 and 6 (see Table 13) and QS30: statement 1 (see Table 14)

Table 19: Interventions delivered by South Bucks Memory Service	
1. Pharmacological interventions 2. Cognitive stimulation therapy groups 3. Tailored psychological interventions, including cognitive behavioural therapy (delivered by the trust's psychological services)	4. Referrals to Alzheimer's Society memory support service, which is commissioned by a CCG to provide post-diagnostic support 5. Referrals to Buckinghamshire County Council for carers' assessments, social services and telecare

Table 20: Further information about South Bucks Memory Service	
Monitoring and measurement of outcomes	Routine collection of patient, staff and referrer (GP) experience measures. Well-established clinical research network, with good opportunities for people living with dementia and their family/carers to participate in and influence research.
Staff training and supervision	Training delivered on a trust-to-trust basis to all staff members in the memory assessment service. Cases discussed weekly and regular supervision provided by a clinical nurse.
Workforce (WTE hours and roles)	• 1.1 medical (0.8 consultant psychiatrist, 0.2 core trainee year 3, 0.1 specialist trainee year 6) • 3.4 nursing (2.8 AfC band 6, 0.6 AfC band 7) • 0.1 clinical psychologist (0.1 AfC band 8a) • 0.4 team manager (0.4 AfC band 7), 1.6 administrators (1 AfC band 4, 0.6 AfC band 3)

AfC = Agenda for Change; WTE = whole-time equivalent

2.3.3 Stockport Memory Assessment Service

Stockport Memory Assessment Service is based within the Pennine Care NHS Foundation Trust. Stockport has the oldest age profile in Greater Manchester: currently 19.4% of people are aged 65 or older, which is likely to rise to 21.8% by 2024. Stockport has the highest dementia prevalence of Greater Manchester. An overview of the service can be found in Table 21.

Steps to delivering a timely diagnosis and care plan

People are usually seen within 6 weeks of referral. The assessment takes place in the patient's home or a clinic, and is carried out by an appropriately skilled person from a multidisciplinary team. Following this assessment, a **provisional diagnosis** is given.

The service minimises its non-attendance rate by carrying out a high volume of home visits. These visits can also improve the quality of the assessment by enabling clinicians to get a better

picture of how the person and carer are coping. A **formal diagnosis** is confirmed and finalised within 12 weeks, supported by CT or MRI scan results. The consultant delivers the diagnosis and organises a **treatment plan** as necessary.

Post-diagnostic interventions

Once diagnosed, the person with dementia and their family or carer receive an **information pack** with relevant services and support. A **dementia link nurse** will visit the person with dementia and will follow-up with them regularly if they are prescribed medication.

Each GP practice has a named dementia specialist link nurse from the memory service to offer bespoke training, review the dementia register together with the lead GP, share information and discuss access to **post-diagnostic support**. In addition, people living with dementia are referred back to their GP when they are stable on medication and have received all relevant information and advice. A full range of post-diagnostic interventions are given in Table 22.

Meeting the recommended response time of 6 weeks

The service currently meets the recommended response time, with 98% of people seen and diagnosed within 6 weeks of referral. This has been achieved by:

- carefully triaging all referrals to ensure a timely appointment is offered
- obtaining scans within a 6-week period
- dementia link workers working in partnership with local GPs
- strong links between the memory service, local authority and the third sector, which all contribute to a coordinated post-diagnosis work stream
- seeing people living with dementia in their own homes and other places of residence (care homes).

The service has developed a shared-care pathway, which allows people living with the early stages of dementia to be managed in primary care (with support from the memory service). People are often only referred back to the memory service on average 4 years after diagnosis, when their needs have changed.

The service received additional funding to increase capacity and to support GPs in undertaking dementia monitoring reviews and attend training. As a result of this, many GPs report feeling more confident about managing dementia. The shared pathway is supported through the appointment of four link nurses in the memory service and an Alzheimer's Society post-diagnostic support worker for vascular dementia.

The service has implemented a 'dementia local enhanced service' since 2013. This includes developing a 'dementia action plan' for each practice, training staff to undertake dementia reviews and raising dementia awareness.

Further information

For further information see Table 23 or contact Nicole Alkemade, Older People's Joint Commissioning Manager at NHS Stockport CCG (nicole.alkemade@nhs.net).

Table 21: Overview of Stockport Memory Assessment Service	
Population	288,000 (total)
Referrals per year	1000 for dementia specialist assessments and diagnosis; 750 for treatment and management of those with memory concerns
Dementia diagnosis rate	74%
Dementia care pathway	The service currently meets the recommended response time, with over 98% of those referred seen and diagnosed within 6 weeks of receipt of referral.
NICE quality standards	QS1: statements 1, 2, 3 and 6 (see Table 13) and QS30: statement 1 (see Table 14)

Table 22: Interventions delivered by Stockport Memory Assessment Service

1. Pharmacological
2. Carer support
3. Support worker from the local Alzheimer's Society for people with vascular dementia and attendees to the information group (see point 7)
4. Up to two dementia monitoring reviews per year (by GP practices)
5. Named dementia specialist link nurses from the memory service attached to each GP service
6. Frontotemporal dementia support group
7. Information groups on vascular dementia and Lewy body dementia
8. Young-onset dementia peer support group run by Pennine Care NHS Foundation Trust
9. Lewy body group run with the Stockport NHS Foundation Trust's Parkinson's nurse
10. Support from Signpost Stockport for Carers through the Dementia Carer Advice and Support Service
11. Information sessions for people with mild cognitive impairment in partnership with colleagues from other organisations
12. Drop-in clinics for carers

Table 23: Further information about Stockport Memory Assessment Service

Monitoring and measurement of outcomes	The service regularly collects patient satisfaction data.
Workforce (WTE hours and roles)	Core staff: • 4 link nurses • 2 support workers • 0.5 administrators. Other staff contributing to the service: old age psychiatrists, neuropsychologist, occupational therapist, social worker.

AfC = Agenda for Change; WTE = whole-time equivalent

2.4 Post-diagnostic support: supporting well

Two services provide examples of positive practice for the area of supporting well:

- Bexley Dementia Pathway
- Sheffield Memory Service.

2.4.1 Bexley Dementia Pathway

The Alzheimer's Society (Bexley) offers a range of national and local dementia support services for people living with dementia and their carers. One example of local support is the Bexley Dementia Pathway (see Table 24).

A cost–benefit analysis of dementia adviser services in Bexley and West Lancashire indicated the cost effectiveness of implementing this integrated approach.

Delivering NICE-recommended care: named coordinator of care and care planning

At the point of diagnosis, each person is offered an appointment with a dementia adviser (or named coordinator of care) who can signpost them to a range of individualised support (see Table 25). Support may be given face to face, over the telephone or by email, and varies depending on individual circumstances. The dementia adviser also provides emotional support and helps the person work through, or make sense of any difficulty or distress they may be experiencing.

As the person's dementia progresses, they are offered a one-to-one dementia support service assessment and a care and support plan. The dementia support service is delivered to people living in their own home or in the home of their family or carer. However, the service can be delivered in a memory clinic, hospital, or residential home environment in line with the eligibility criteria and the identified outcomes of the care and support plan.

Appropriate referrals to other health and social care services and/or external organisations can then be made by the dementia support service on behalf of the person living with dementia. Reviews are scheduled in at 6 weeks, 12 weeks and 6 months to ensure that the person and their family or carer have managed to access the required support. Individuals are also encouraged to contact their dementia adviser as required.

Further information

Further information can be found in Table 26, on the Alzheimer's Society (Bexley) and the Alzheimer's Society website and by contacting Jo Vavasour, National Business Development Manager (jo.vavasour@alzheimers.org.uk).

Table 24: Overview of the Bexley Dementia Pathway	
Population	230,000 (49,900 over the age of 65)
Dementia prevalence	2,749 per year
Dementia care pathway	Care planning: supporting well
NICE quality standards	QS1: statements 1 to 8 (see Table 13) and QS30: statements 2, 3, 6, 8 and 9 (see Table 14). The service particularly provides a good example of a named coordinator of care, QS1: statement 4 (see Table 13)

Table 25: Support provided by the dementia adviser	
1. Information on a wide range of areas including: diagnosis, legal rights and welfare benefits 2. A carers' information and support programme to help develop coping strategies 3. Referrals to other health and social care services	4. An online support and discussion forum Talking Point, which includes facilitated peer support and information sharing 5. A local and national helpline

Table 26: Further information about the Bexley Dementia Pathway	
Monitoring and measurement of outcomes	The service captures and monitors a number of outcomes and outputs aligned to contract deliverables
Workforce (WTE hours and roles)	• 0.5 dementia support manager • 3 dementia support workers

WTE = whole-time equivalent

2.4.2 Sheffield Memory Service

Sheffield Memory Service offers a range of post-diagnostic interventions to support the mental and physical health and wellbeing of people living with dementia and their families and carers (see Table 27). Care is delivered across the system, with strong links to social services.

Steps to delivering and reviewing a care plan

1. Following diagnosis, a **collaborative care plan** is developed and agreed with a nurse (or occupational therapist), the person living with dementia and their family or carer.
2. A range of **interventions** may be offered (see Table 28).
3. A follow-up appointment is scheduled within 6 months to **review the care plan** (including current medication). The service also offers a daily nurse helpline for intermediate support, using a case management model.

4. The person living with dementia remains with the service, discharged only when in 24-hour care under the local commissioned agreement of GP support.

Interventions for behaviour that challenges

The service works collaboratively with specialist teams in the Sheffield Health and Social Care NHS Foundation Trust (including the community mental health team) to provide support to people living with dementia and coexisting behaviour that challenges. This includes educational interventions as well as access to a rapid response home treatment team. This team works with people who have a diagnosis (or working diagnosis) of dementia and are experiencing some degree of crisis or difficulty affecting their wellbeing. The service is open 365 days a year, from 8.00 a.m. to 8.00 p.m. The team also provides home treatment outside of these hours to people for whom it is part of their treatment plan.

Delivering care in acute or general hospitals and emergency departments

If an older person with suspected or known dementia is admitted to an acute or general hospital inpatient service or emergency department, they will be seen by the older people's liaison service. The service works with the emergency department and medical admission unit to avoid hospital admission and reduce the length of hospital stays. As part of this, they:

- proactively assess people in a timely manner, which facilitates the likelihood of discharge to home

- engage community services from the point of admission
- provide supported discharge (up to 2 weeks), to reduce risks and monitor people's mental health.

Further information

Further information can be found in Table 29 and by contacting Susan Burns, Clinical Manager (susan.burns@shsc.nhs.uk).

Table 27: Overview of Sheffield Memory Service	
Population	563,749 (85,000 over the age of 65)
Referrals per year	1,500–2,000
Dementia care pathway	Care planning: supporting well
NICE quality standards	QS1: statements 1 to 8 (see Table 13) and QS30: statements 2, 3, 6, 8 and 9 (see Table 14). The service provides a particularly good example of interventions for behaviour that challenges, QS1: statement 7 and delivering care in acute or general hospitals and emergency departments, QS1: statement 8 (see Table 13).

Table 28: Interventions delivered by Sheffield Memory Service	
1. Cognitive stimulation therapy 2. Pharmacological interventions 3. Psychoeducation groups aimed at developing coping strategies 4. Interventions for behaviours that challenge	5. Coping with forgetting for coexisting anxiety or low mood in people newly diagnosed with dementia 6. Cognitive behavioural therapy for carers 7. Assistive technology/telecare interventions

Table 29: Further information about Sheffield Memory Service	
Monitoring and measurement of outcomes	The Generalized Anxiety Disorder Assessment 7-item, Patient Health Questionnaire and Geriatric Depression Scale are applied before and after interventions. All tools are used with the person using the service and their carer in their initial assessment to guide future care provision.
Staff training and supervision	The team has regular supervision between sessions. The trust offers basic, intermediate and more expert level of dementia training.
Workforce (WTE hours and roles)	• 1.25 medical (0.4 consultant, 0.55 associate specialist, 0.3 specialty doctor) • 15.68 nursing (8.78 AfC band 5; 1.6 AfC band 6; 0.9 AfC band 7; 2.4 AfC band 2; 2 AfC band 5) • 0.8 clinical psychologists (0.4 AfC band 7; 0.4 AfC band 8b) • 4.01 admin (2.01 AfC band 3; 1 AfC band 4; 1 modern apprentice)

AfC = Agenda for Change; WTE = whole-time equivalent

2.5 Post-diagnostic: living well

One service provides an example of good practice for the area of living well:

- The Debenham Project.

2.5.1 The Debenham Project

The Debenham Project is a community-based and community-led voluntary organisation for people with suspected or diagnosed dementia and their families and carers (see Table 30). It provides advice services and support groups that aim to facilitate the maintenance of social integration and the promotion of independence. The project works closely with professional agencies when required. It is a member of the new Dementia Together Suffolk statutory support service.

The project has been praised by NHS England for its unique approach to caring and supporting people living with dementia and their families and carers. It provides varying levels of support, ranging from straightforward information and advice to active involvement in its groups and services, to about 65% of the estimated number of people living with dementia and their families and carers in its catchment.

Promoting independence and community engagement

The Debenham Project helps people with dementia live independent lives for as long as possible. A range of leisure and community-based activities and support groups are offered (see Table 31). These, together with information and advice, one-to-one support and other services, seek to minimise distress and social isolation for the person living with dementia and their family member or carer. By providing 'something to look forward to', the community groups aim to improve psychological wellbeing, stimulate positive thinking and enhance social integration.

Supporting carers

As well as offering advice and information, the Debenham Project offers carers short-term support (see QS1, statement 6 in Table 13). This includes assistance and transport for both the carer and person living with dementia, as well as emotional and practical support including outings, events, afternoon teas, music and games.

Each element of the project fosters social integrity and relationship-building through encouraging positive communication, enjoyment and new coping skills, as well as offering individual support.

Further information

Further information can be found in Table 32 and by contacting Lynden Jackson, Project Chair (lynden.jackson@the-debenham-project.org.uk).

Table 30: Overview of the Debenham Project	
Population	8,500
Referrals per year	10–15
Dementia care pathway	Care planning: living well
NICE quality standards	QS1: statement 10 (see Table 13) and QS30: statements 4, 5, 7 and 10 (see Table 14)

Table 31: Support offered by the Debenham Project	
1. Cognitive activities, aimed at maintaining intellectual and memory capability, accessed via reminiscence therapy and social sessions 2. Physical therapy, aimed at reducing stress and physical discomfort, and improving mobility and coordination, by encouraging individually tailored chair-based exercises 3. Integrating and community-enhancing activities are available from a carers' club, an 'Info Café', activities and reminiscence groups, and lunch clubs	4. Assistance with transport to and from medical or related appointments 5. Individual continuing support through a one-to-one network of retired experienced health and social care professionals 6. A register of carers, domestic helpers and other locally available professional support

Table 32: Further information about the Debenham Project	
Monitoring and measurement of outcomes	The service records the total number of people who currently are and previously have been supported by the project. The views of the family, carers and person with dementia are collected via semi-formal and informal day-to-day comments and discussions. Lessons learned are translated into building better services for people living with dementia and their families and carers.
Training	Specific training is provided as and when needed, including dementia awareness, food hygiene and safety.
Workforce (volunteers)	The project has a total of 75 regular (about half a day per month) and 40 occasional volunteers delivering sessions of support to over 200 people. Most volunteers are retired and have personal experience of providing dementia care on an informal basis as a family member or friend carer, or formally as a professional.

2.6 Post-diagnostic support: dying well

Two services provide example of good practice for dying well:

- Oxleas Advanced Dementia Service
- Central Manchester Dementia Palliative Care Service.

2.6.1 Oxleas Advanced Dementia Service

Oxleas Advanced Dementia Service specialises in looking after people with advanced dementia in their own homes. The people who use the service are typically in their last year of life and have complex mental and physical comorbidities that require a palliative care approach. See Table 33 for an overview.

The service has won an NHS innovation award for its excellent outcomes and was included as a model example of integrated care in a King's Fund report.

Delivering a palliative care plan

The service uses a palliative care framework, which focuses on maximising quality of life, minimising risks (such as hospital admissions), reducing carers' stress, and supporting the person to live and die in their preferred place.

As part of this, the named coordinator of care works with the family and carers to develop a holistic palliative care plan that addresses the person's physical, mental and social care needs, as well as the needs of their family and carer(s). The care plan is regularly reviewed, taking into account the person's changing needs and that the person living with dementia may have limited capacity.

The person's family and/or carer(s) are well informed of the care plan and possible risks, including what may happen and what they need to do (**advance care planning**). If there is a crisis, families and carers can contact the care coordinator. A quick (often same day) response occurs, which includes putting in place the required interventions and offering support and reassurance. If the person requires a hospital admission, the care coordinator works with the ward team to try to ensure that the admission is as short as possible.

Care coordinators promote **continuity of care** and help people living with dementia and their families and carers to navigate services (see Table 34).

Further information

Further information can be found in Table 35 and by contacting Dr Adrian Treloar, Consultant in Old Age Psychiatry (adrian.treloar@oxleas.nhs.uk).

Table 33: Overview of Oxleas Advanced Dementia Care Service	
Population	28,000 (3,000 estimated to have dementia and 400 advanced dementia)
Referrals per year	90
Dementia care pathway	Care planning: dying well
NICE quality standards	QS1: statement 9 (see Table 13)

Table 34: Interventions for people with advanced dementia and their carers	
1. Facilitating access to dietitians, speech and language therapists, physiotherapists and tissue viability nurses 2. Providing equipment (for example, hospital bed, pressure relieving mattress, hoist, slide sheets, commode) 3. Initiating changes to care packages and arranging respite 4. Promoting resilience and offering bereavement support to relatives	5. Prescribing medication and nutritional supplements 6. Providing education and information about different aspects of care to families and carers 7. Improving access to local community by providing mobility aids, ramps and so on 8. Facilitating access to palliative care services in the last days of life, including anticipatory prescribing

Table 35: Further information about Oxleas Advanced Dementia Care Service	
Monitoring and measurement of outcomes	Carers give feedback via the FFT (see Section 3.3), and the results have demonstrated a high level of satisfaction. Formal feedback is not sought from people living with dementia who are receiving care.
Staff training and supervision	Staff are supervised by a line manager and there are regular multidisciplinary team meetings, as well as joint visits when necessary. The staff are trained in a mental health setting, but there is also access to joint learning with specialist palliative and physical healthcare colleagues.
Workforce (WTE hours and roles)	• 0.2 medical (consultant psychiatrist) • 1.3 nursing (AfC band 6) • 0.5 occupational therapist (AfC band 6) • 0.3 administrator (AfC band 3)

AfC = Agenda for Change; FFT = Friends and Family Test; WTE = whole-time equivalent

2.6.2 Central Manchester Dementia Palliative Care Service

Central Manchester Dementia Palliative Care Service specialises in person-centred inpatient palliative care, to help people living with dementia and their families and carers in their last years, months or days of life (see Table 36). The service prioritises compassion and kindness.

Delivering a palliative care plan

Throughout the progression of the person's dementia, a holistic and flexible approach is applied. The care plan aims to provide as much comfort as possible to the person living with dementia and their family or carer; it follows the Priorities of Care for the Dying Person: – Individualised Care Plan and Communication Record. Regular reviews and updates are made to ensure that the person's psychological, physical, spiritual and religious needs are met.

Following the death of the person, the service provides ongoing support for the family and carers, including onward referrals to bereavement counselling services. To avoid additional distress for family members and carers, the service will also inform all relevant agencies of the person's death including social care, the ambulance service, allied healthcare professionals and any others. Where possible, staff from the service will attend the funeral.

Further information

Further information can be found in Table 37 and by contacting Nicola Johnson, Dementia Nurse Practitioner at Manchester University NHS Foundation Trust (nicola.johnson@cmft.nhs.uk), or Sue Heatley, Matron/Lead for Palliative and End of Life Care, Manchester University NHS Foundation Trust (susan.heatley@cmft.nhs.uk).

Table 36: Overview of Central Manchester Dementia Palliative Care Service

Population	503,127 (total)
Referrals per year	75–100
Dementia care pathway	Care planning: dying well
NICE quality standards	QS1: statement 9 (see Table 13)

Table 37: Further information about Central Manchester Dementia Palliative Care Service

Monitoring and measurement of outcomes	Regular audits are conducted to assess compliance in the use of the Priorities of Care for the Dying Person – Individualised Care Plan and Communication Record.
Staff training and supervision	A wide range of training is available for staff, carers and people living with dementia. Recommended training for health and social care staff includes: physical, psychological, spiritual and social care, symptom control, advance care planning, caring for carers, priorities for care of the dying person, bereavement support and the Mental Capacity Act 2005. After the death of their patient, staff are supported through clinical supervision/reflective practice sessions provided by the local team.
Workforce (WTE hours and roles)	• 1 consultant psychiatrist (0.4 hospice consultant, 0.6 Manchester University NHS Foundation Trust consultant) • 1 nurse (dementia nurse practitioner AfC band 7) • 1 occupational therapist (AfC band 8a) • 1 manager (matron AfC band 8a) • 3.4 band 7 clinical nurse specialists • 5 band 6 clinical nurse specialists • 1 administrator (AfC band 3)

AfC = Agenda for Change; WTE = whole-time equivalent

2.7 Tailored care

Three examples of good practice in tailored care are included, all covering different areas of treatment:

- Wokingham Memory Service
- Lancashire Memory Assessment Service
- Meri Yaadain Dementia Outreach Support Service

2.7.1 Wokingham Memory Service: early-onset dementia

Wokingham Memory Service offers assessment and local community-based interventions for people living with dementia, including early-onset dementia (see Table 38). The service aims to be a 'one-stop assessment', usually delivering initial assessment and diagnosis to people on the same day. For people with early-onset dementia, care is delivered by a multidisciplinary healthcare team. The service also works in partnership with the local charity Younger People with Dementia (a Berkshire charitable incorporated organisation), which supports younger people with dementia and their families and carers through a range of psychosocial interventions and support.

Delivering a timely diagnosis for people with early-onset dementia

The service has a dedicated care pathway specifically for those with suspected early-onset dementia. When a person under the age of 60 presents with symptoms suggestive of dementia a referral is usually made to a neurologist. The service works jointly with the neurology service to ensure this process is efficient. The pathway is as follows:

- GPs make a referral to the neurology clinic. This may include a physical examination, brain scan, lumbar puncture or another intervention tailored to individual examinations.
- Once reversible causes or comorbidities (such as depression, learning disabilities or previous brain injuries) have been excluded, an initial assessment at a Younger People with Dementia clinic is arranged.
- If the GP refers the person to the memory service directly, the service can directly refer to the neurologist or carry out an assessment before referring.
- At the initial assessment, the person and their family or carer(s) are interviewed separately. There is a review of medical history (including blood tests), as well as specialist assessment and screening.
- Further examination will then take place at the local memory clinic involving referral for a brain scan and a neuropsychometric test. At this stage, the diagnosis will be given.
- The person will then be assigned a key worker (or named coordinator of care) to agree a personalised care plan. Time from referral to diagnosis is minimised through strong communication with the neurologists. This includes quarterly joint meetings, discussion of complex cases and reciprocal learning and teaching. If necessary, the service can obtain an opinion from a neurologist on the same day as memory clinic assessments by email.

Delivering post-diagnostic support for people with early-onset dementia

As part of a tailored care plan, the service offers a range of interventions to support the young person with dementia and their family and/or carer. Care plans are typically reviewed within 6 months.

The service is a joint working model between the NHS and the third sector. As well as offering generic support (including counselling, access to local day services and signposting and support for carers), the service offers age-specific interventions including:

- 14 sessions of age-specific cognitive stimulation therapy
- a 6-week education course for families and carers, and a parallel course for people with early-onset dementia
- a dementia care adviser for people with early-onset dementia
- a mental health practitioner and community support worker dedicated to working with early-onset dementia
- a Younger People with Dementia Admiral Nurse
- carer support groups

- charity-led group workshops that provide meaningful activity, psychosocial intervention and one-to-one assistance.

The workshops provided by the Younger People with Dementia clinic enable people to maintain or learn new skills while also offering respite to families and carers. For those who do not wish or are unable to participate in group activities, the clinic provides one-to-one support that encourages people to choose an activity of personal interest to them that can then be carried out with the support of a respite worker.

Successful joint working between the NHS and the Younger People with Dementia clinic has enabled the service to run effectively. This includes joint supervision and training as well as a shared clinical record that facilitates communication and avoids duplicating assessments and reviews for people with early-onset dementia.

Further information

Further information can be found in Table 39 and by contacting Vicki Matthews, Older People's Mental Health Services Development Manager (vicki.matthews@berkshire.nhs.uk).

Table 38: Overview of Wokingham Memory Service	
Population	161,400 (27,200 over the age of 65)
Referrals per year	452, of which 16 were suspected early-onset dementia
Dementia care pathway	Delivering NICE-recommended care for people with early-onset dementia

Table 39: Further information about Wokingham Memory Service	
Monitoring and measurement of outcomes	Tests of cognition to monitor change: the Mini Addenbrooke's Cognitive Examination; Montreal Cognitive Assessment; and a clock-drawing test. Assessment of Activities of Daily Living, Basic Assessment of Daily Living and Health of the Nation Outcome Scales 65+ (HoNOS 65+) are incorporated into a clustering tool. As well as the Neuropsychiatric Inventory and the Caregiver Stress Scale, depression rating scales include the Hospital Anxiety and Depression Scale, the Geriatric Depression Scale and the Short Warwick-Edinburgh Mental Wellbeing Scale for group interventions. People living with dementia and their families and carers are asked to complete the FFT. A survey is carried out via the Younger People with Dementia clinic every 6 months and they hold two 'Our Say, Your Say' sessions per year.*
Staff training and supervision	All staff will receive specialist training and group/clinical supervision, plus weekly one-to-one supervision from the consultant. There is a 6-week training programme for staff on rarer dementias and weekly group supervision for staff to discuss early-onset dementia specifically.
Workforce (WTE hours and roles)	**Memory service establishment** • 1.0 consultant psychiatrist • 0.2 management (AfC band 8a) • 1.0 memory clinic nurse (AfC band 6) • 1.0 occupational therapist (AfC band 6) • 0.9 speech and language therapist (AfC band 7) • 0.8 psychologist (AfC band 8b) • 0.7 psychology assistant (AfC band 4) • 2.0 memory clinic assistants (AfC band 4) • 0.8 administrator (AfC band 4) **Posts specific to YPWD** • 0.5 consultant psychiatrist (WTE from memory clinic establishment dedicated to early-onset diagnosis and follow-up) • 0.6 YPWD Admiral Nurse (AfC band 7 West of Berkshire) • 0.8 YPWD mental health practitioner (AfC band 6) • 0.8 YPWD community support worker (AfC band 3) • 0.5 YPWD dementia care adviser (West of Berkshire; local authority employed)

AfC = Agenda for Change; FFT = Friends and Family Test; WTE = whole-time equivalent; YPWD = Young People with Dementia

* Scores on the Neuropsychiatric Inventory (including mood, apathy, agitation and psychotic symptoms) reduced by over half in the first year of the project. This reduction in symptoms was sustained over the following year despite deteriorating cognition scores.

2.7.2 Lancashire Memory Assessment Service: learning disabilities

[Lancashire Memory Assessment Service](#) specialises in providing assessment and diagnosis for people with suspected dementia. The service uses a specialised consultation model to maximise the capacity and flow by reducing the waiting time between the initial assessment and the diagnosis. There is a standard pathway and an enhanced pathway, which is tailored to meet the needs of people from specific populations, including people with learning disabilities. For general information about the service, see [Table 40](#).

Delivering NICE-recommended care for people with learning disabilities

- **Referrals** are made to a *single point of contact* and are screened for risk indicators. They are then passed to the memory assessment service and triaged via telephone, to identify whether the standard or enhanced pathway is more appropriate. All people with suspected dementia and identified learning disabilities are allocated to the *enhanced pathway*.
- The *specialist interest nurse* ensures that **assessments** for people on the enhanced pathway are booked within 3 weeks and have designated time for meeting with the specialist learning disabilities psychologist.

- An **initial assessment** is then undertaken, which involves taking a comprehensive medical history, symptomatology, performing risk assessment and blood testing. On the enhanced pathway, people are allocated to a specialist nurse and a wider multidisciplinary approach to assessment is used, which includes psychologists, occupational therapists and learning disability services. Referrals may also be made for brain scans.
- **Diagnosis** is made by the psychologist or the doctor. *Easy-read materials*, including pictures, are used to share the diagnosis with the person with learning disabilities, and an *agreed care plan* is developed with them.
- Following diagnosis, the person has one session of **post-diagnostic support** focusing on exploring the diagnosis and the support that is available. Training is also provided to families and carers on how to support the wellbeing of the person living with dementia. If the person is prescribed medication, they will remain under the care of the specialist nurse. Alternatively, the person may be discharged and referred back to the learning disabilities team or their GP for regular review.

Further information

Further information can be found in [Table 41](#) and by contacting Linda Dickens, Team Manager (linda.dickens@lancashirecare.nhs.uk).

Table 40: Overview of Lancashire Memory Assessment Service	
Population	30,000
Referrals per year	500–600, of whom 1% of people have learning disabilities
Dementia care pathway	Most people are seen within 6 weeks of referral, but people on the enhanced pathway are booked for initial assessment within 3 weeks of referral
NICE quality standards	Delivering NICE-recommended care for people with coexisting dementia and learning disabilities

Table 41: Further information about Lancashire Memory Assessment Service	
Monitoring and measurement of outcomes	The FFT is given to all people living with dementia and their families and carers at the post-diagnostic session. A qualitative feedback form is also given, to elicit specific data regarding involvement with the service.
Staff training and supervision	All non-medical staff are provided with clinical supervision and a team manager. Psychologists and occupational therapists are supervised by their medical leads and there is professional peer supervision for nurses.
Workforce (WTE hours and roles)	• 2 medical (1 consultant, 1 associate specialist) • 2.88 nursing (2 community mental health nurses AfC band 6; 0.88 band 5) • 0.5 advanced practitioner/non-medical prescriber (AfC band 7) • 0.3 neuropsychologist • 1 occupational therapist • 1 team manager AfC band 7 • 2.3 administrative staff (1.8 AfC band 3; 0.5 AfC band 2)

AfC = Agenda for Change; FFT = Friends and Family Test; WTE = whole-time equivalent

2.7.3 Meri Yaadain Dementia Outreach Support Service, Bradford

The Meri Yaadain Dementia Outreach Support Service illustrates how NICE-recommended care can be delivered more effectively to meet the needs of black, Asian and minority ethnic populations. See Table 42 for an overview.

The service is a local authority-based team, working across Bradford District Care NHS Foundation Trust. The service works to improve vulnerable people's access to tailored care and support services.

Delivering NICE-recommended care tailored to black, Asian and minority ethnic populations

● Meri Yaadain Dementia Outreach Support Service aims to **raise awareness** of dementia in the black, Asian and minority ethnic communities, with particular focus on the South Asian community. The service has a public awareness campaign that works with religious, cultural and ethnic organisations, networks and events, as well as local radio stations.

● The service also works with colleagues in memory clinics to encourage **community-friendly**, **culturally competent** and **appropriate assessments**. This includes culturally appropriate information on accessing care and educational sources (including leaflets, websites, forums and newsletters), which are available in English, Urdu, Punjabi, Bangla, Hindi and Gujarati.

● The service provides **multilingual outreach workers** to help the person living with dementia to make informed choices about their care, as well as to continue to remain engaged in their community. This helps to minimise social isolation and enables the person to remain independent for as long as possible. The service also offers multilingual educational peer support groups.

- The service **supports carers**, helping them develop coping skills and adapt to the changing demands associated with caring for a person living with dementia. Monthly person-centred support groups are offered, both at home and via telephone, where ongoing issues can be addressed. The service also offers relaxation for people living with dementia and their families and carers.

Further information

Further information can be found in Table 43 and by contacting Akhlak Rauf, Team Manager (akhlak.rauf@bradford.gov.uk).

Table 42: Overview of Meri Yaadain Dementia Outreach Support Service	
Population	512,000 (total)
Referrals per year	120 (70% of these are from black, Asian and minority ethnic populations, with a high proportion of people of South Asian origin)
Dementia care pathway	Diagnosing well and care planning
NICE quality standards	Delivering NICE-recommended care for black, Asian and minority ethnic populations

Table 43: Further information about Meri Yaadain Dementia Outreach Support Service	
Monitoring and measurement of outcomes	People who use the service are asked to give input and feedback on a daily basis. They are also encouraged to participate in university research, visit forums and act as peer educators to new carers and people living with dementia.
Staff training and supervision	Supervision, including monthly meetings, is provided by the team manager. All staff are qualified to NVQ level 3 in dementia (awareness)
Workforce (WTE hours and roles)	• 1 part-time team manager • 3 part-time officers • 4 full-time equivalent care navigators (providing generic support)

NVQ = national vocational qualification

3 Outcome measures

3.1 Health of the Nation Outcome Scales for Older Adults (HoNOS 65+)

HoNOS has been developed by the Royal College of Psychiatrists. The College allows (without express permission) the free use, copy and reproduction of HoNOS score sheets in NHS-funded care. For use, copy or reproduction of HoNOS score sheets for any other purpose, contact the Royal College of Psychiatrists for permission. Information can be found online.

There are 12 scales that are used to rate older adult mental health service users. Together, they rate various aspects of behaviour, impairment, symptoms and social functioning, each on a scale of 0–4. This measure is designed to be used by clinicians before and after interventions, so that changes attributable to the interventions (outcomes) can be measured.

Scales:

1. Overactive, aggressive, disruptive or agitated behaviour
2. Non-accidental self-injury
3. Problem drinking or drug-taking
4. Cognitive problems
5. Physical illness or disability problems
6. Problems associated with hallucinations and delusions
7. Problems with depressed mood
8. Other mental and behavioural problems
9. Problems with relationships
10. Problems with activities of daily living
11. Problems with living conditions
12. Problems with occupation and activities

All scales are scored using the following format:

0 = no problem
1 = minor problem requiring no action
2 = mild problem but definitely present
3 = moderately severe problem
4 = severe to very severe problem

Each scale is rated in order, from 1 to 12. Information rated in an earlier item is not included except for item 10, which is an overall rating. The rating is made on the basis of all information available to the rater (whatever the source) and is based on the most severe problem that occurred during the period rated (usually the 2 weeks leading up to the point of rating).

3.2 New Models for Measuring Patient Experience – Patient Experience Questionnaire (MOPE-PEQ)

The MOPE-PEQ has been developed by the Picker Institute Europe and the University of Oxford. Below is an extract of the questionnaire which can be accessed in full on p. 124 of the Development of New Models for Collection and Use of Patient Experience Information in the NHS final report.

YOUR EXPERIENCE

1. How easy did you find it to get the care you needed when you wanted it?

   1 ☐ Very easy

   2 ☐ Fairly easy

   3 ☐ Not very easy

   4 ☐ Difficult

   5 ☐ Very difficult

2. Were you given clear and understandable information about your *condition and treatment*?

   1 ☐ Yes, definitely

   2 ☐ Yes, to some extent

   3 ☐ No

   4 ☐ I was offered information but chose not to take it

3. Were you involved as much as you wanted to be in decisions about your condition and treatment?

   1 ☐ Yes, definitely

   2 ☐ Yes, to some extent

   3 ☐ No

4. Were you given the opportunity to talk about your worries and fears with regards to your condition?

   1 ☐ Yes, definitely

   2 ☐ Yes, to some extent

   3 ☐ No

   4 ☐ I had no worries or fears

5. Did the different people treating and caring for you work well together to give you the best possible care?

   1 ☐ Yes, always

   2 ☐ Yes, sometimes

   3 ☐ No, never

   4 ☐ Can't remember

   5 ☐ Not relevant

6. Did the healthcare staff offer your family, carers or friends the opportunity to be involved in decisions about your condition and treatment?

   1 ☐ Yes, always

   2 ☐ Yes, sometimes

   3 ☐ No, never

   4 ☐ There were no family members, carers or friends available to be involved

   5 ☐ I didn't want my family, carers or friends to be involved in decisions about my care and treatment

7. Did healthcare staff respond to your individual needs?

   1 ☐ Yes, at all times

   2 ☐ Yes, most of the time

   3 ☐ Yes, some of the time

   4 ☐ No, never

8. Did healthcare staff do everything they could to make you feel physically comfortable?

   1 ☐ Yes, at all times

   2 ☐ Yes, most of the time

   3 ☐ Yes, some of the time

   4 ☐ No, never

9. Did you have confidence and trust in the healthcare staff?

   1 ☐ Yes, always

   2 ☐ Yes, sometimes

   3 ☐ No

10. How helpful has your care been in dealing with the problem(s) you sought help for?

    1 ☐ Extremely helpful

    2 ☐ Very helpful

    3 ☐ Helpful

    4 ☐ A little helpful

    5 ☐ Not at all helpful

11. Have health services helped you to better understand and manage your own health?

    1 ☐ Yes, definitely

    2 ☐ Yes, to some extent

    3 ☐ No

12. Overall, were you treated with kindness and understanding?

    1 ☐ Yes, always

    2 ☐ Yes, sometimes

    3 ☐ No

13. Overall, did healthcare staff keep you informed about what would happen next?

    1 ☐ Yes, completely

    2 ☐ Yes, to some extent

    3 ☐ No

3.3 Friends and Family Test (FFT)

The FFT is free to use within the NHS and no permission is needed. Below is an extract of the test, which can be found in full on the NHS England website.

THE NHS FRIENDS AND FAMILY TEST

NHS

We would like you to think about your recent experience of our service.

How likely are you to recommend our service to friends and family if they needed similar care or treatment?

Extremely Likely	Likely	Neither likely or unlikely	Unlikely	Extremely Unlikely	Don't Know
☐	☐	☐	☐	☐	☐
☺	⟵————————⟶			☹	?

Thinking about your response to this question, what is the main reason why you feel this way?

4 Good care planning

This section includes a brief overview of the core elements that constitute the **minimum information** to be included in a good care plan. Further information can be found in NHS England Dementia: Good Care Planning.

> *"Personalised care and support planning encourages care professionals and people with long-term conditions and their carers to work together to clarify and understand what is important to that individual. They agree goals, identify support needs, develop and implement action plans, and monitor progress. This is a planned and continuous process, not a one-off event."*
>
> From the Introduction to Personalised Care and Support Planning Handbook: The Journey to Person-Centred Care – Core Information, Person Centred Care/Coalition for Collaborative Care/ Medical directorate, NHS England

4.1 Components of dementia care planning: the fundamentals

Essentially, the output of the care-planning process is a written plan that is clear, simple and precise. It explains what care the person is having, contingency plans for future and arrangements for review. A summary of the core elements of a dementia care plan is given in Table 44. For a more detailed view of the depth and breadth of the core elements to address in dementia care planning, and respective codes and descriptions, please refer to the supporting resource Dementia Care Plan: Coding.

Table 44: The core elements of a dementia care plan		
D	**Diagnosis review**	Has the correct diagnosis been given? Does the person, as well as their family and carer (if appropriate) understand the diagnosis?
E	**Effective support for carers review**	Is the person with dementia willing for their information to be shared with other people? Do they have an identified carer? If yes, is the carer aware of their right to a carer's assessment? Who is the next of kin? Has the person been signposted to local services? Have they been provided with all the information they need to make decisions about their care? This may include legal and financial advice as well as information on research opportunities.
M	**Medication review**	Has a review been conducted on the person's mental and physical health needs? This may include a medication review, dietary advice and other health needs, such as dentistry or physiotherapy.
E	**Evaluate risk**	Are there any additional risk factors which need to be identified, such as safeguarding issues, carer stress or long-term conditions?
N	**New symptoms enquiry**	At follow-up reviews, are there any new symptoms that should be investigated and treated or managed?
T	**Treatment and support**	Is the person able to access appropriate post-diagnostic support? This may include access to assistive technology, talking therapies, pharmacological management.
I	**Individuality**	What are the person's interests, hobbies and activities of daily life? How can these be maintained? How can the person be empowered to manage their own health and wellbeing?
A	**Advance care planning**	What are the person's wishes about what happens in the future when their capacity is impaired? It may include questions about their future care and treatment or it may relate to end-of-life decisions and issues.

5 Other helpful web-based resources

The following resources were recommended by the Expert Reference Group. Other existing and new resources will also be relevant and helpful, and this list is not exhaustive.

5.1 National policy on dementia

Dementia Action Alliance: The Carers' Call to Action

Guidance for Commissioners of Dementia Services. Volume Two: Practical Mental Health Commissioning

Joint Declaration on Post-diagnostic Dementia Care and Support

Models of Dementia Assessment and Diagnosis: Indicative Cost Review

National Dementia Declaration: A Call to Action

Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015

Prime Minister's Challenge on Dementia 2020

Prime Minister's Challenge on Dementia 2020: Implementation Plan

5.2 Other NICE guidance

Care of Dying Adults in the Last Days of Life NICE guideline (NG31)

Dementia, Disability and Frailty in Later Life – Mid-life Approaches to Delay or Prevent Onset NICE guideline (NG16)

Delirium: Prevention, Diagnosis and Management NICE clinical guideline (CG103)

End of Life Care for Adults in the Last Year of Life: Service Delivery (expected 2018; update of Improving Supportive and Palliative Care for Adults with Cancer NICE cancer service guideline, CSG4)

Home Care for Older People NICE QS123

Multimorbidity: Clinical Assessment and Management NICE guideline (NG56)

Service User Experience in Adult Mental Health:

Improving the Experience of Care for People Using Adult NHS Mental Health Services NICE clinical guideline (CG136)

5.3 Useful websites for commissioners and providers

In addition to the websites and organisations listed below, local dementia roadmaps and many Strategic Clinical Networks offer a comprehensive list of local resources on their websites. Examples include: London Clinical Networks and Yorkshire and Humber – documents and links.

Understanding prevalence rates

Dementia Core Skills Education and Training Framework (Skills for Health)

Dementia Prevalence Calculator (Dementia Partnerships)

Dementia Profile (Public Health England)

Focus on Dementia (Health and Social Care Information Centre)

Examples of joint strategic needs assessments (supporting well)

Creating Dementia Friendly GP Surgeries – iSPACE (Wessex Academic Health Science Network)

Dementia in Bradford and Airedale: A Health Needs Assessment and Strategy for 2015–2020

Joint Strategic Needs Assessment 2013: Dementia Health Needs Assessment

Diagnosing well

'Coding clean-up' Exercise: Guidance to GPs to Improve Dementia Coding, and Raise Diagnosis Rates. A Step by Step Approach (NHS London Clinical Networks)

Dementia (London Memory Assessment Network)

Dementia Quality Toolkit YouTube webinar (Yorkshire and the Humber Strategic Clinical Networks)

Development of Minimum Referral Criteria for Memory Services (Yorkshire and the Humber Strategic Clinical Network)

Guidance on Dementia and Delirium Coding in GP practices (NHS England, North region)

Guidance on Neuro-imaging in Dementia (Yorkshire and the Humber Strategic Clinical Network)

Toolkit for Dementia 'Direct Enhanced Service' and 'Quality Outcomes Framework' (Yorkshire and Humber Strategic Clinical Network for Dementia)

Commissioners

Commissioners' Checklist for Dementia (London Dementia Strategic Clinical Network)

London Dementia Diagnosis Rate (London Dementia Strategic Clinical Network, July 2016)

Peer Support for People with Dementia: A Social Return on Investment (SROI) Study (Health Innovation Network)

Public awareness campaigns

Alzheimer's Society's Dementia Friends programme

Alzheimer's Society's Dementia Friendly Communities

Dementia Action Alliance

5.4 Other useful websites

Professionals

Actifcare (ACcess to TImely Formal Care) – European research project

Dementia Core Skills Education and Training Framework

Dementia Evidence Toolkit (MODEM)

Dementia Revealed: What Primary Care Needs to Know. A Primer for General Practice

Joint dementia research toolkit

Making Reasonable Adjustment to Dementia Services for People with Learning Disabilities

The National Gold Standards Framework Centre in End of Life Care (NHS National End of Life Care Programme)

Services for Younger People with Alzheimer's Disease and Other Dementias (Royal College of Psychiatrists and Alzheimer's Society)

Person-Centred Care Core Skills Framework

'What Works' in Dementia Education and Training? Research

People living with dementia

Dementia Connect services directory (Alzheimer's Society)

Living Well with Dementia (Coventry and Warwickshire Dementia Portal)

MyBrainBook (Health Innovation Network)

Peer Support for People with Dementia Resource Pack (Health Innovation Network)

What you can do to prevent Alzheimer's (TED talk)

Carers and care workers

DeAR-GP (Dementia Assessment Referral to GP)

Dementia Awareness Training in Care Homes using 'Barbara's Story'

DiADeM Tool (Diagnosing Advanced Dementia Mandate, for care home setting)

Guide to Dementia Training for Health and Social Care Staff in London: Improving Quality of Care

5.5 Useful organisations

Age UK

Alzheimer's Research UK

Alzheimer's Society

Care Quality Commission

Carers Trust – A charity for carers

Dementia Action Alliance

Dementia Partnerships: Clinical Networks

Dementia UK

Health Education England

Memory Service National Accreditation Programme (MSNAP) (CCQI)

Mental Health Innovation Network

Mind

NHS Improvement

Public Health England

Social Care Institute for Excellence (SCIE)

Tide (Together in Dementia Everyday)

Young Dementia UK

Abbreviations

Abbreviation	Definition
CCG	Clinical Commissioning Group
CCQI	College Centre for Quality Improvement
DeTDAT	Dementia Training Design and Delivery Audit Tool
FFT	Friends and Family Test
ICD-10	International Statistical Classification of Diseases and Related Health Problems (10th revision)
MCI	mild cognitive impairment
MHSDS	Mental Health Services Data Set
MOPE-PEQ	New Models for Measuring Patient Experience – Patient Experience Questionnaire
MRI	magnetic resonance imaging
NICE	National Institute for Health and Care Excellence
QS	quality standard
PROM	patient-reported outcome measures
SNOMED CT	Systematized Nomenclature of Medicine – Clinical Terms