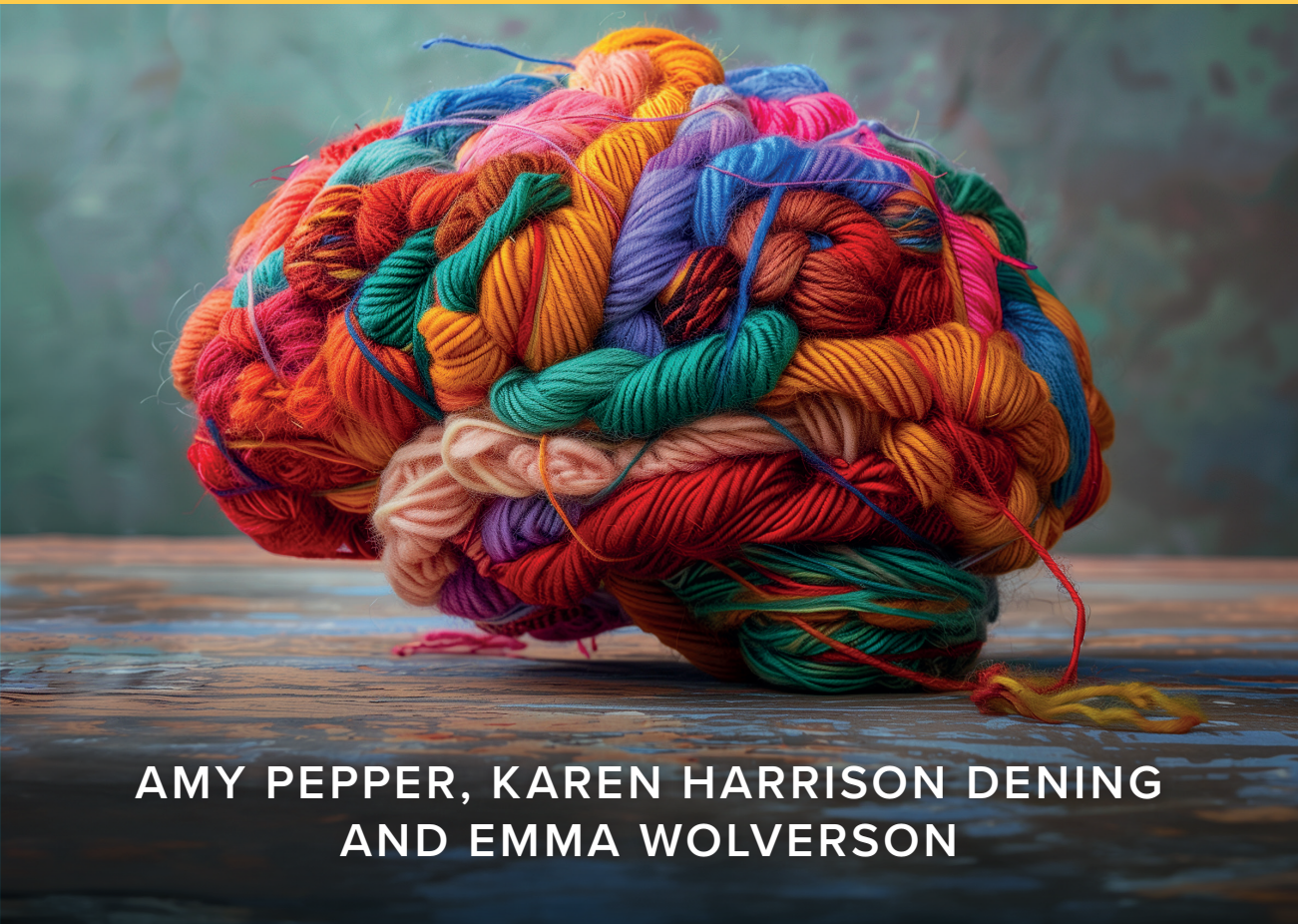
ESSENTIALS

DEMENTIA

An introduction for nursing, health and social care



AMY PEPPER, KAREN HARRISON DENING
AND EMMA WOLVERSON

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Note to readers: throughout the book, and especially in many of the *Activities*, you will notice the use of quicklinks, such as bit.ly/3X5wc9c

We have used these shortened versions to save you having to re-key long web addresses. Just type them into any browser and you will be taken straight to the relevant webpage. In the case of the sample quicklink above, this will take you to the Functional Assessment Staging Tool (FAST) scale at www.dementiamap.com/fast-scale-functional-assessment-staging-tool/#:~:text=The%20FAST%20Scale%20is%20a,the%20different%20stages%20of%20dementia

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with
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About the authors

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Karen Harrison Dening has over 45 years' experience in nursing, most of those being in dementia care in a variety of settings and contexts. She is head of research and publications at Dementia UK. She gained her PhD at UCL in advance care planning and end-of-life care in dementia. Through her role at Dementia UK, she is a collaborator, co-applicant and expert advisor to several national and international research studies. She served on both the National Institute for Health and Care Excellence (NICE) dementia guideline committees. Her research interests include dementia care, case management, carer resilience, palliative and end-of-life care and advance care planning.

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Madeleine Walpert completed her PhD at the University of Cambridge in 2018, investigating retinal biomarkers of Alzheimer's disease in individuals with Down's syndrome. Since then, she has worked in research policy for Alzheimer's Research UK, leading work on improving the research landscape and clinical trials for dementia, and the impact of dementia on women. She is currently employed as a Research Fellow at Dementia UK, and her research interests include investigating inequalities and disparities in dementia, including in diagnosis and access to care and support services.

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Abbreviations

ACE-III	Addenbrooke's Cognitive Examination version three
AChEI	acetylcholinesterase inhibitor
ACP	advance care planning
ADI	Alzheimer's Disease International
ADL	activities of daily living
APA	American Psychiatric Association
AT	assistive technology
BNF	*British National Formulary*
BPSD	behavioural and psychological symptoms of dementia
CAM	Confusion Assessment Method
CAT	computer-assisted tomography
CBT	cognitive behavioural therapy
CHC	continuing healthcare
COPD	chronic obstructive pulmonary disease
CRP	C-reactive protein
CST	cognitive stimulation therapy
DH	Department of Health
DHSC	Department of Health and Social Care
DLB	dementia with Lewy bodies
DMT	disease-modifying treatment
DSD	delirium superimposed on dementia
DSM-5	*Diagnostic and Statistical Manual of Mental Disorders*, 5th edition
ECG	electrocardiograph

ESR	erythrocyte sedimentation rate
FAST	Functional Assessment Staging Tool
GPCOG	General Practitioner Assessment of Cognition
GSF	Gold Standards Framework
ICD-11	International Classification of Diseases, 11th revision
ICS/ICB	integrated care system / integrated care board
IQ	intelligence quotient
LA	local authority
LPA	lasting power of attorney
MCA	Mental Capacity Act 2005
MCI	mild cognitive impairment
MCS	Major Conditions Strategy
MMSE	mini mental state examination
MoCA	Montreal Cognitive Assessment
MRI	magnetic resonance imaging
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NPI	Neuropsychiatric Inventory
OPG	Office of the Public Guardian
PET	positron emission tomography
PHE	Public Health England
SALT	speech and language therapist
SCIE	Social Care Institute for Excellence
START	Strategies for Relatives programme
T_4	thyroid hormone
TBI	traumatic brain injury
TSH	thyroid-stimulating hormone
WHO	World Health Organization

Chapter 4
Diagnosis of dementia

Karen Harrison Dening

LEARNING OUTCOMES

By the end of this chapter, you should be able to:

- Understand other conditions and illnesses that can mimic dementia and what tests and investigations can be used to rule these out.
- Have an understanding of the assessment and common tests used in diagnosing dementia.
- Have an awareness of mild cognitive impairment and its relationship to dementia.

4.1 Introduction

For many people worried about memory loss, their first port of call may be their GP, or perhaps other health and social care professionals already involved in the care of other conditions, such as their practice nurse. It is often someone close to them who is first to recognise that something is not quite right, such as becoming more forgetful, misplacing and losing items, changes in behaviour (for example, becoming suspicious or paranoid) or perhaps getting lost in a familiar local place. The person with the possible dementia and/or their close family members may then seek the advice of a GP, who may as a first action take some tests themselves to rule out any other causes that might mimic dementia.

4.2 Ruling out conditions that can mimic dementia

There are many other conditions that can mimic the presentation of dementia. Normal ageing-related forgetfulness, poor education attainment, learning difficulties, drugs, deafness and poor vision are some conditions that have to be considered. Two other major conditions to also consider and rule out are depression and delirium. It is essential that any conditions underlying a person's symptoms are ruled out and treated before initiating dementia diagnostic assessments (see *Table 4.1*). Failure to diagnose and treat other conditions can lead to a false positive dementia diagnosis and the potential worsening of the other condition.

Table 4.1 *Illnesses and conditions that can mimic dementia (Moore* et al.*, 2023)*

Condition	Presentation
Hypothyroidism	An underactive thyroid can present as memory difficulties and low mood, which may be misinterpreted as symptoms of dementia.
Delirium	This may be particularly common in the acute hospital setting but can occur anywhere. Delirium can present as either hyperactive (overactive) or hypoactive (underactive) states which can lead to decreased cognitive functioning, agitation, restlessness and disorientation to time and place. Also apathy, as in hypoactive delirium, can be mistaken for progression in diagnosed dementia. See *Chapter 13* for more on delirium.
Infection	Infections can present with some of the same features as delirium and so be misinterpreted as dementia. The most common infections in older people are of the urinary tract or pneumonia.
Loss of sleep	Can lead to reduced concentration, agitation and restlessness which may seem to mimic some symptoms of dementia.
Anxiety and/or depression	Either of these can lead to withdrawal from usual social activities and anxiety with familiar day-to-day activities, which may also be a feature of dementia.
Vascular disease	Vascular-related disease such as stroke can be mistaken for dementia.
Vitamin deficiencies	Vitamin deficiencies, such as of B12 or folate, can lead to memory disturbances and increased confusion, and thus be mistaken for dementia.
Kidney and liver function	Symptoms of kidney or liver dysfunction include disorientation, confusion, poor concentration and sleepiness.
HbA1c (a test for diabetes)	HbA1c is the amount of blood sugar (glucose) attached to haemoglobin. Hyper- or hypoglycaemia (glucose in the blood) can present as increased confusion and drowsiness and difficulty with coordination.
Polypharmacy (high numbers of medications)	Some medications and/or a large number of medications can lead to reduction in the ability to carry out day-to-day tasks, and to falls and cognitive impairment.

ACTIVITY 4.1

Before reading on, visit bit.ly/3yEPCry to find out what tests a GP might do to rule out many of these conditions.

It is usual for a person's GP to have carried out certain tests before they make an onward referral for a memory assessment. Some patients may undertake a brief cognitive test, such as the general practitioner assessment of cognition (GPCOG) (Brodaty *et al.*, 2002); many other tests will be blood tests (see *Box 4.1*). An onward referral needs the agreement and consent of the person with the suspected dementia (see *Chapter 10*). In the case of the person's symptoms being identified in the course of a nursing intervention (for example on a hospital ward or in a community nursing context) you may be involved in ruling out some of the potential physical causes for the symptoms, and as such an awareness of what these might be and how to test for them is important (see *Box 4.1*).

BOX 4.1: TESTS TO EXCLUDE OTHER POSSIBLE CAUSES BEFORE CONSIDERING ASSESSMENT FOR DEMENTIA

- Full blood count – to identify anaemia and for signs of infection
- Erythrocyte sedimentation rate (ESR), C-reactive protein (CRP) – to determine infection and inflammatory responses
- Thyroid hormone (T_4) and thyroid-stimulating hormone (TSH) – to rule out hypothyroidism (underactive thyroid)
- A blood biochemical screen – including urea and creatinine (to test renal function), electrolytes, liver function tests and albumin
- Glucose levels – to test for diabetes
- Vitamin B12 and folate levels – to test if there are deficiencies
- Sometimes tests for venereal disease and HIV may be carried out, but these are not routine
- Chest X-ray and electrocardiograph (ECG) may be ordered to rule out infection and/or heart-related problems
- Sometimes a urine test will be carried out (standard dipstick) or microorganism urinalysis for infection
- Neuroimaging (brain scans) – there are a range of scans that may be ordered, such as a CAT scan (computer-assisted tomography) or MRI (magnetic resonance imaging) to rule out conditions such as stroke and brain tumour.

When other possible causes for the symptoms have been excluded, usually by a person's GP, then the person should be referred to a memory assessment service, which may be based within local old age psychiatry services or neurology services. This will often depend upon local commissioning and service configurations. Consent for the referral would be sought at this stage, either from the person themselves, or their family member if they no longer have capacity to consent (see *Chapter 10*).

ACTIVITY 4.2

See if you can locate your local memory assessment services and their website and find out what the referral pathway is. For example, the local memory services for those located in Nottinghamshire have this website: www.nottinghamshirehealthcare.nhs.uk/memory-assessment-service-for-older-people-/, accessible via quicklink at: bit.ly/3yAWi9X

4.3 Mild cognitive impairment

Mild cognitive impairment (MCI) is a condition in which people have more memory or thinking problems than other people their age. It is considered to be an intermediate state and can progress to dementia, mostly in the form of Alzheimer's disease. MCI is a clinical state in which a person is cognitively impaired but does not have a full clinical diagnosis of dementia. Therefore it is not a disease or a mental disorder, as people with MCI are functioning more or less normally, and is likely due to a range of causes, among which it being the early signs of Alzheimer's disease is just one. Only approximately 10% of people with MCI go on to develop dementia a year later (Sandilyan and Dening, 2019). For many their MCI remains static over time and some actually improve and move out of MCI and into normal ranges of cognition at follow-up. Therefore clinicians tend to view MCI as a state of being at risk of dementia. Whilst treatment of MCI with anti-dementia medications (see *Chapter 5* for medications used in dementia) shows little benefit, there is growing research interest in the use of brain training and activities to improve cognition (Savulich *et al.*, 2017).

4.4 Why diagnose dementia?

Whilst there is currently no cure for dementia it is important, where dementia is suspected, for people to undergo a memory assessment as soon as possible. This has been a central tenet in national policy and guidance for over two decades, in the National Dementia Strategy (Department of Health (DH), 2009) and in clinical guidelines for dementia (National Institute for Health and Care Excellence (NICE), 2018). Getting a timely diagnosis of dementia can give the person with dementia and their family carers and supporters a better understanding of the condition and what to expect. Importantly, a timely diagnosis can help families prepare for their future and make important decisions about treatment, support and care.

Being diagnosed with dementia is a life-changing event and as such, requires careful and thorough assessment to enable a full care and support plan to be put in place (see *Chapter 6* on post-diagnostic support).

However, too often people still experience difficulties accessing a diagnosis and this may be for several reasons. The person may be reluctant to see a GP or be afraid of getting a dementia diagnosis; dementia is now the most feared of conditions, even above cancer. There may be other fears that underlie their reluctance, such as loss of independence, fear of being forced to stop driving, or that a diagnosis of dementia

means they will have to go into care. The person experiencing the possible early signs of dementia may lack insight into their difficulties (see *Chapter 10* on capacity and decision-making), may not recognise the extent of change, or may simply consider the changes an inevitable part of the ageing process. Family members may have no anxiety about the changes, or they may attribute them to other factors or life events, although it is often a family member or those close to the person who are the first to suspect that something is wrong. Conversely, a family member, such as a spouse, may overcompensate for the memory and functional failures in an attempt to protect the person from criticism or embarrassment.

In some areas across the UK, there are waiting lists for a memory assessment appointment, with these waits extended as a result of the Covid-19 pandemic. However, whilst waiting, clinicians can advise families to do certain things, such as keeping a symptom diary (not just of the days of the week but times of day that things happen or seem worse) or keep a note of any changes in a relative or friend. This will provide useful information that will build a recent picture of the changes and concerns and may also help in identifying the type of dementia the person is likely to have. This might, for example, include a record that shows night-time disturbances such as nightmares that may be indicative of dementia with Lewy bodies.

4.5 What does an assessment for dementia involve?

Memory assessment services are available across the country, though they may be provided in different clinical settings, as we have already noted. However, there are key components to a memory assessment service. The clinical team often comprise various disciplines, such as doctors (they may be an old-age psychiatrist, geriatrician or neurologist), nurses, psychologists, occupational therapists and social workers. Some teams may have input from a speech and language therapist (SALT), Admiral Nurses, voluntary or charity sector workers and support workers. Assessments can take place in a clinic or hospital setting, GP practice, or in the person's own home.

ACTIVITY 4.3

Go back to the local memory assessment website that you located in *Activity 4.2* and see if it mentions the range of disciplines within the clinical team, and what the person who is referred may expect to happen.

During the initial assessment information is collected on a variety of things: the person's background (family history, education, employment, etc.), general functioning, other health conditions, any medications they are currently taking, and details about their current memory complaints as well as any other mental health issues, such as anxiety or low mood. This may be referred to as 'taking a history'. There may also be various questionnaires, tests and measures used, in order to assess mood, anxiety, memory, cognitive function, behaviours and general functioning in a person's activities of daily living.

4.5.1 Cognitive testing

The mini mental state examination (MMSE) and the Montreal Cognitive Assessment (MoCA) (see *Figure 4.1*) are among the most widely-used brief cognitive tests.

There are other tests, such as the Addenbrooke's Cognitive Examination version three (ACE-III), which is widely used and has more detailed tests on the cognitive domains than the MoCA, including memory, attention, language and spatial orientation (see *Chapter 2* on 'what is dementia?'). A total score is 100 and anything between 82 and 88 is considered suspicious for a diagnosis of dementia.

However, there should be caution when applying such tests, as they do have limitations, and factors such as level of education, language, culture, and hearing and sight loss can affect a person's score.

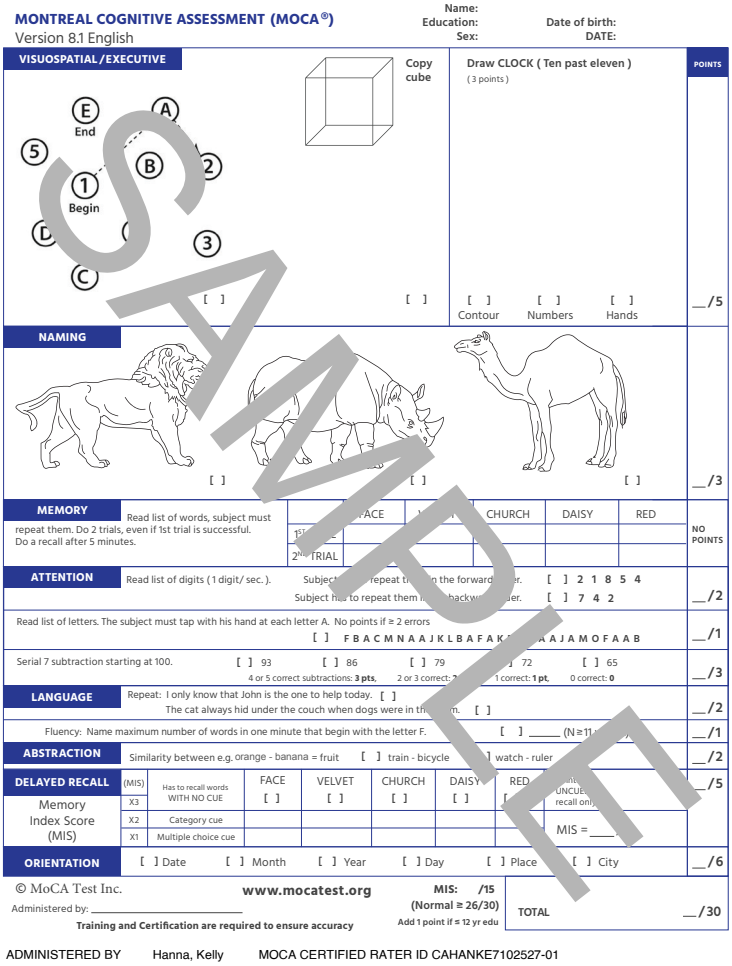

Figure 4.1 *The Montreal Cognitive Assessment (MoCA) (Nasreddine* et al.*, 2005). Copyright Z. Nasreddine MD. Reproduced with permission. It is mandatory to follow the online MoCA© Training and Certification Program to administer and score the MoCA©. Copies are available at www.mocacognition.com.*

4.5.2 Other tests

There are other neuropsychological tests that may be required, such as to establish a person's intelligence quotient (IQ) before the onset of dementia symptoms, such as in learning disabilities or neurodiverse conditions, such as dyslexia (Mather and Schneider, 2023). These are specialised tests and are usually carried out by a psychologist. It may also be necessary to assess a person using a behaviour measure, such as the Neuropsychiatric Inventory (NPI) which is a tool based on carer report (either professional or family carers), used if there is thought to be the possible presence of non-cognitive symptoms, such as delusions, hallucinations or agitation (Cummings, 2020). A person's level of everyday functioning, known as their activities of daily living (ADL) may require assessment if it is felt they are not able to perform any of these to a level they may normally have done. Additionally, if there are blood tests that require repeating from the initial screen, then these may be undertaken.

4.6 Giving a diagnosis of dementia

When all tests have been completed (this may take more than one appointment) the person will be called back for an appointment to share the diagnosis. Often a person is accompanied by a family member or someone else close to them. The diagnosis of dementia, and which of the subtypes it is, should be disclosed in a sensitive manner. It is important that information on various aspects of the diagnosis and its implications are imparted, but it must be at the pace of acceptance and understanding of the individual. The giving of the diagnosis is not the endpoint in itself, but what follows matters much more. Sometimes the person with dementia and their family are relieved, in that they now know there is a name and a reason for what they have been experiencing, and the diagnosis provides long-awaited answers for a failing memory, communication problems and changes in behaviour. There should be time built into this key appointment to allow the person newly diagnosed and their family member and/or supporter to ask questions as part of post-diagnostic support (see *Chapter 6*).

ACTIVITY 4.4

Imagine you, or someone close to you, have just received a diagnosis of dementia of the Alzheimer's type. What do you think your immediate questions and need for information might be?

4.7 Prognosis of dementia

Dementia is a progressive, neurodegenerative condition (degeneration of the nervous system, especially the neurons in the brain). Many people newly diagnosed often want to know more about what to expect as they advance into the condition. It is important to provide such information without causing them distress. Often this information is not given at the diagnosis appointment but as part of their planned post-diagnostic counselling. However, there are several features to each stage of dementia if we use a lens to focus on the mild, moderate or severe stages.

Table 4.2 *The course of dementia and examples of features/symptoms at each stage (adapted from Sandilyan and Dening, 2019)*

	Mild	Moderate	Severe
Cognition	Difficulty in learning new information and in word-finding Poor attention	Worsening memory loss Problems in language, use of words and phrases Inability to recognise objects and faces	Severe memory loss Loss of ability to perform purposeful activities Inability to recognise common objects and familiar faces Severe language problems
Function	Misplacing items Forgetting appointments and recent conversations Taking longer to do complex mental activities Repetitive	Difficulty in performing ADLs such as cooking, using electrical equipment, handling money Losing way in local area Unable to hold a fluent and coherent conversation	Unable to recognise even close family Unable to perform basic ADLs Incontinent of urine and faeces Swallowing difficulties
Non-cognitive	Apathy, lack of motivation Anxiety, low mood	Delusions Increasing social withdrawal Irritability, depression, sleep problems, loss of appetite	Agitation, disinhibited behaviours, verbal and physical aggression, hallucinations, delusions

However, every person is an individual and how they experience dementia is also unique to them (Kitwood, 1997), so whilst information in *Table 4.2* may be useful for health and social care staff to understand the progressive nature of dementia, it may not be a useful way of presenting this to families affected by dementia. Sensitivity and explanations are required at all times.

ACTIVITY 4.5

There are several frameworks that offer a description of the stages of dementia. The Functional Assessment Staging Tool (FAST) scale offers an approach where dementia can be viewed on a continuum, from normal ageing through seven stages to severe dementia. Go to bit.ly/3X5wc9c to see how the FAST scale compares with the information given in *Table 4.2*.

Eventually, if the person lives into the later stages of dementia, it can lead to also experiencing other illnesses and conditions, such as frailty, poor swallowing and infections.

CHAPTER SUMMARY

Key points to take away from *Chapter 4*:

- There are various illnesses and conditions that can mimic dementia that require detection and treatment to then rule them out as possible causes for symptoms, before a dementia diagnosis is considered.
- Memory assessments can take place in a range of settings, and teams usually comprise a range of professionals, such as doctors, nurses, psychologists and occupational therapists.
- Once a person is given a diagnosis, they require a range of information and support.
- Dementia is a progressive, neurodegenerative condition which can be described in different stages. These stages can be used to support prognosis discussions with people with dementia and their families.
- Mild cognitive impairment is not a diagnosis of dementia, but in some cases it can progress to dementia.

RESOURCES

Dementia UK (2023) *How to get a diagnosis of dementia*. Available at: www.dementiauk.org/information-and-support/specialist-diagnosis-and-support/how-to-get-a-diagnosis-of-dementia (accessed 9 August 2024)

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