CPPE

CENTRE FOR PHARMACY
POSTGRADUATE EDUCATION

Dementia

A focal point learning programme

Book 1

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Content contributors
Justine Raynsford, specialist mental health pharmacist and lecturer, University of Bradford
Denise Taylor, senior lecturer, University of Bath and immediate past President of the College of Mental Health Pharmacy

CPPE programme developer
Anne Cole, regional manager, South West, CPPE

Reviewers
Maureen Chivers, dementia friends champion
David Tomlinson, dementia project pharmacist, Avon local pharmaceutical committee
Terri Turner, locality lead pharmacist, Avon and Wiltshire Mental Health Partnership NHS Trust

CPPE reviewers
Maria Bell, regional manager, Yorkshire & Humber and North East
Layla Fattah, pharmacist, learning and development
Diana Taylor, regional tutor, Yorkshire and learning community lead

Piloted by
Diana Taylor, regional tutor, Yorkshire and learning community lead, CPPE

Edited by
Ange Brennan, assistant editor, CPPE

We have used some content from the CPPE Dementia learning@lunch programme in this focal point. CPPE recognises the contribution made by the authors and reviewers of the original programme.

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We have developed this learning programme to support your practice in this topic area. We recommend that you use it in combination with other established reference sources. If you are using it significantly after the date of initial publication, then you should refer to current published evidence. CPPE does not accept responsibility for any errors or omissions.

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Learning with CPPE

The Centre for Pharmacy Postgraduate Education (CPPE) offers a wide range of learning opportunities in a variety of formats for pharmacy professionals from all sectors of practice. We are funded by Health Education England to offer continuing professional development for all pharmacists and pharmacy technicians providing NHS services in England. For further information about our learning portfolio, visit **www.cppe.ac.uk**

CPPE 1 2 3

We recognise that people have different levels of knowledge and not every CPPE programme is suitable for every pharmacist or pharmacy technician. We have created three categories of learning to cater for these differing needs:

CPPE 1 Core learning (limited expectation of prior knowledge)

CPPE 2 Application of knowledge (assumes prior learning)

CPPE 3 Supporting specialties (CPPE may not be the provider and will direct you to other appropriate learning providers).

This is a CPPE 2 learning programme and assumes that you already have some knowledge of the topic area.

Continuing professional development (CPD) – You can use this focal point unit to support your CPD. Consider what your learning needs are in this area. Go to **www.uptodate.org.uk** to plan and record your learning.

Programme guardians – A programme guardian is a recognised expert in an area relevant to the content of a learning programme. They will review the programme every six months to ensure quality is maintained. We will post any alterations or further supporting materials that are needed as an update on our website. We recommend that you check for these updates if you are using a programme more than six months after its initial publication date.

Feedback – We hope you find this learning programme useful for your practice. Please help us to assess its value and effectiveness by visiting the *my CPPE record* page on our website. Alternatively, please email us at **feedback@cppe.ac.uk**.

About CPPE focal point programmes

We have developed focal point to give you short, clinically focused learning sessions. It will help you learn with your colleagues and improve the services you offer your patients. Each unit presents information and activities that are relevant for pharmacy professionals working in primary care and in the community. There are two types of learning event for you to choose between when using focal point units – you can either attend a CPPE tutor-led event or you can learn as part of a CPPE learning community. Have a look at the CPPE website: **www.cppe.ac.uk** for more information about how to set up a learning community.

Reference sources for all the books, articles, reports and websites mentioned in the text can be found at the end of the programme. References are indicated in the text by a superscript number (like this [3]).

This book gets you started. It provides key information to help you meet the learning objectives presented on the following pages, but it also encourages you to identify your own learning needs. It then challenges you to relate what you have learnt to your own area of practice and professional development. We have included practice points and talking points to stimulate your thinking and we will refer to these again at the focal point event. Make sure you have studied these activities before your event.

You will receive Book 2 when you attend the focal point event. It uses case studies and clinical vignettes to help you apply what you have learnt and encourages you to make changes to improve your practice. We also include some suggested answers to the learning activities.

A note about web links

Where we think it will be helpful we have provided the web links to take you directly to an article or specific part of a website. However, we are also aware that web links can change. A new website **www.gov.uk/government** encompasses the Department of Health website, as well as the new executive agency, Public Health England. To search for any Department of Health publication of information mentioned in this programme either visit the **gov.uk** home page and enter the title into the search facility, or search via Google or your preferred internet search provider.

If you have difficulty in accessing any other web links, please go to the organisation's home page and use appropriate key words to search for the relevant item.

About this focal point unit on dementia

In this unit we consider:

- the different types of dementia and their presentation, assessment and diagnosis
- conditions or other factors that may mimic the signs of dementia
- the holistic and pharmacological treatment options for patients with dementia
- ways in which the care of patients with dementia can be improved, and how to support families and carers.

Learning objectives

You can meet the learning objectives that we identify here by reading the information that we provide and refer you to, undertaking the various activities that we suggest and putting what you have learnt into practice. We have split our learning objectives into appropriate sections. This should help you determine how to meet them. We have linked the learning objectives in this programme to the General Level Framework (GLF) and the NHS Knowledge and Skills Framework (KSF) dimensions. We have suggested some competences, but you may be able to apply your learning to other aspects of these frameworks.

Moving into focus and reading

Objective	KSF	GLF
Recognise the signs and symptoms of the different types of dementia and describe their progression.	Quality Level 2	Cluster: Problem solving Competency: Knowledge
Describe the investigations and clinical features used to diagnose dementia.	Quality Level 2	Cluster: Problem solving Competencies: Knowledge, Analysing information
Demonstrate an understanding of the medicines used to treat dementia and their place in therapy.	Quality Level 2	Cluster: Delivery of patient care Competency: Medicines information and patient education Cluster: Problem solving Competency: Knowledge
Describe the lifestyle changes that can improve the overall health of people with dementia.	Quality Level 3	Cluster: Delivery of patient care Competency: Medicines information and patient education Cluster: Problem solving Competency: Knowledge
Describe the behavioural and psychological symptoms of dementia (BPSD) and the management of these symptoms.	Quality Level 3	Cluster: Delivery of patient care Competency: Medicines information and patient education, Monitoring drug therapy, Evaluation of outcomes Cluster: Problem solving Competency: Knowledge

Practice points, talking points, case studies and clinical vignettes

You'll find these in this book and Book 2, and will work on them during the event.

Objective	KSF	GLF
Describe the risks associated with antipsychotic medicines in patients with dementia.	Quality Level 3	Cluster: Delivery of patient care Competencies: Medicines information and patient education, Monitoring drug therapy, Evaluation of outcomes Cluster: Problem solving Competency: Analysing information
Optimise medicines in patients with dementia	Quality Level 3	Cluster: Delivery of patient care Competency: Medicines information and patient education, Monitoring drug therapy, Evaluation of outcomes Cluster: Problem solving Competency: Analysing information

Directing change scenarios and follow-up activities

You will achieve practical outcomes after completing this unit, when you apply what you have learnt to your everyday practice. You will find advice in Book 2.

Objective	KSF	GLF
Identify patients who use your practice, and give recommendations on how you can support them and their carers	Quality Level 3	Cluster: Delivery of patient care Competency: Medicines information and patient education Cluster: Problem solving Competency: Gathering information

Useful resources

We have selected some resources that you can use when developing improved pharmacy services for people with dementia.

Support for healthcare professionals

Clinical Knowledge Summaries for dementia – http://cks.nice.org.uk/dementia

The CKS website includes the following scenarios:

- Screening, diagnosis and assessment
- Prescribing information
- Ongoing management
- Managing end-of-life problems
- Supporting carers

National Institute for Health and Clinical Excellence (NICE) www.nice.org.uk

NICE and Social Care Institute for Excellence (SCIE) Clinical guideline 42 (CG42) ***Dementia: supporting people with dementia and their carers in health and social care***[1]

NICE Technology appraisal 217 (TA217) ***Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease***[2]

NICE Quality standard 21 (QS1) ***Dementia***[3]

The quality standard for dementia requires that dementia services should be commissioned from, and coordinated across, all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.

NICE Quality standard 30 (QS30) ***Supporting people to live well with dementia***[4]

A person-centred and integrated approach to providing care and services is fundamental to delivering high-quality care for people with dementia. The quality standard acknowledges the vital importance of involving carers of people with dementia. Services should consider how to ensure carers are involved in the implementation of each quality statement.

NICE Pathway *Dementia*[5]

NICE Pathways is an interactive tool for health and social care professionals providing fast access to NICE guidance and associated products. NICE Pathways is for anyone who needs to use NICE guidance. It brings together all related NICE products on a topic in a simple-to-read, user-friendly interface.

This pathway includes recommendations for the identification, treatment and care of people with dementia and the support of carers.

e-learning

The Social Care Institute for Excellence (SCIE) - *Open dementia e-learning programme*

This e-learning programme is aimed at anyone who has contact with someone with dementia and covers the causes, diagnosis, emotional impact and experiences of living with dementia. The e-learning can be accessed at: **www.scie.org.uk/publications/elearning/dementia/index.asp**

Medicines and Healthcare Products Regulatory Agency (MHRA) *Antipsychotics learning module*

This e-learning programme identifies the most important hazards of antipsychotics and informs you about the actions you can take to anticipate, minimise and manage the risks for patients. The e-learning can be accessed at: **www.mhra.gov.uk/ConferencesLearningCentre/LearningCentre/Medicineslearningmodules/Reducingmedicinerisk/Antipsychoticslearningmodule/Antipsychotics%20learning%20module**

CPPE *Antipsychotic reviews in dementia*

This e-learning programme provides you with the knowledge and skills to support reviews of patients with dementia who have been prescribed antipsychotic medication. The e-learning can be accessed at: **www.cppe.ac.uk/learning/Details.asp?TemplateID=Antipsych-E-01&Format=E&ID=115&EventID=41200**

CPPE *Quality counts - from NICE quality standards to high quality outcomes*

This e-learning programme raises your awareness and understanding of NICE quality standards and how these are relevant to your practice and patient outcomes. The e-learning can be accessed at: **www.cppe.ac.uk/learning/Details.asp?TemplateID=CPOPTALL-E-01&Format=E&ID=115&EventID=42692**

Safeguarding

Examples of abuse of an older person include:

- not caring for someone properly (neglect)
- pressuring someone to give away money or property
- psychological (eg, threats, harassment or forcing someone to live somewhere they don't want to)
- physical (eg, violence)
- sexual.

Reporting abuse of an older person:

Contact your local authority - you should have details of the local arrangements for reporting suspected adult safeguarding concerns and emergency contact details available; search for these on your local authority's website.

The GOV.UK website also provides useful information at:
www.gov.uk/report-abuse-of-older-person

See also:

- The Royal Pharmaceutical Society Protecting vulnerable adults quick reference guide (you have to be a member of RPS to access this resource): **www.rpharms.com/support-resources-a-z/protecting-vulnerable-adults-quick-reference-guide.asp**
- CPPE safeguarding programmes at: **www.cppe.ac.uk** (enter safeguarding into the search box)
- Age UK **www.ageuk.org.uk**

Patient, family and carer support

Alzheimer's Society – http://alzheimers.org.uk/

The Alzheimer's Society is a charity that works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland. Their website has a lot of useful resources that can benefit patients, families, carers and healthcare professionals including training resources, factsheets, information about the different types of dementia, news, RSS feed, a helpline, an online forum and local support groups and meetings.

Dementia Friends - www.dementiafriends.org.uk

This is a national initiative that is being run by the Alzheimer's Society that aims to improve people's understanding of dementia and its effects. The Alzheimer's Society is working with volunteers and other organisations to recruit Dementia Friends and create dementia-friendly communities.

Dementia UK – www.dementiauk.org

Dementia UK is a charity, committed to improving quality of life for all people affected by dementia. They:

- promote and develop Admiral Nursing - a specialist nursing intervention providing psychological support, practical advice and information on dementia, its impact and how to cope and referrals to other appropriate services
- unite carers through a national network
- promote good practice in dementia care
- work in partnership with the NHS, social services, other voluntary groups, carers and people with dementia
- contribute to national policy on dementia, older people and carers' issues.

Age UK – www.ageuk.org.uk

The Age UK website has practical information and advice on finance, legal matters, travel, lifestyle, work and learning and is particularly useful for information about residential care.

Dementia Action Alliance – www.dementiaaction.org.uk

The Dementia Action Alliance is the coming together of over 700 organisations to deliver the National Dementia Declaration; a common set of seven outcomes informed by people with dementia and their carers. The Declaration provides an ambitious and achievable vision of how people with dementia and their families can be supported by society to live well with the condition.

NHS Choices – www.nhs.uk

The NHS Choices website has been developed to enable patients to make positive choices about their health. It provides facts about lifestyle decisions such as stopping smoking, reducing alcohol consumption, healthy eating and exercise. In addition there is information about finding and using NHS services.

Checklist for planning

To meet the learning objectives you will need to carry out the activities listed in the table below. We've given you this list now so that you can start to plan your learning. Although it will only take you about two hours to work through Book 1, feedback from other users suggests that it is useful to plan your activities over a timescale that suits you - perhaps over several days. Try to set yourself a realistic deadline for each task.

You will need to:	**This will take about:**	**I will do this by:** (Insert date)
Answer the Moving into focus questions	5 minutes	
List three learning needs	5 minutes	
Read the whole book	60 minutes	
Undertake the practice points	20 minutes	
Make notes for the talking points	10 minutes	
Work through the Directing change exercise.	20 minutes	

Moving into focus

Consider the following questions. Use them to focus your thoughts and stimulate your learning. Are you confident you know the answers?

1. List the most common types of dementia and their main features and symptoms.

2. What assessment tools for cognitive function are used as part of the assessment process for dementia?

3. At what stage of dementia does NICE guidance currently advocate using acetylcholinesterase inhibitors?

4. List a number of lifestyle changes that are thought to delay the progression of dementia.

5. People with dementia may be viewed as vulnerable adults. Where can you go to find more information and guidance on how to manage this issue?

What do you want to learn?

Write down three things that you would like to gain from this focal point learning unit. These will help you plan your own CPD entry. You will need to tell others about them at the focal point event.

1.

2.

3.

Now you have completed your reflection and planning for this focal point unit, it's time to undertake the background reading.

Reading

1. Dementia

1.1 Epidemiology

Dementia is a progressive and irreversible condition that represents a major challenge to health and social care services in the UK and around the world.

An Alzheimer's Research Trust commissioned report by the University of Oxford in 2010 suggests that there are just over 820,000 people in the UK living with dementia.[6] This number is projected to rise to over 1 million by 2021 and over 1.7 million by 2051, due to the UK's ageing population. It is estimated that 670,000 family and friends are acting as primary carers.[7]

The prevalence of both early- and late-onset dementia increases with age. One in 14 people over 65 years of age has dementia, rising to 1 in 6 people over 80 years and 1 in 3 of those aged over 95 years. It is more common in women than men. Over 17,000 younger people (under the age of 65 years) in the UK have dementia. This is called early-onset or young-onset dementia.[8]

An estimated two-thirds of care home residents have some form of dementia but two-thirds of all the people with dementia in the UK live in the community.[7] Surveys show that, at any one time, approximately a quarter of hospital beds are occupied by people over the age of 65 years with dementia.[9]

In 2010 the financial cost of dementia to the NHS, local authorities and families was £23 billion per year; more than cancer (£12 billion per year) and heart disease (£8 billion per year) combined,[6] and this is estimated to grow to £27 billion by 2018.[7]

1.2 Definitions, pathogenesis and symptoms

The term 'dementia' is used to describe a collection of symptoms that may include memory loss, planning, problem-solving, language, communication and reasoning difficulties along with changes in mood or behaviour.[8] There is often an associated deterioration in the person's ability to carry out activities of daily living.[10]

The World Health Organisation (WHO) International Classification of Diseases (ICD-10) classifies dementia as:

'a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgment. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation'.[11]

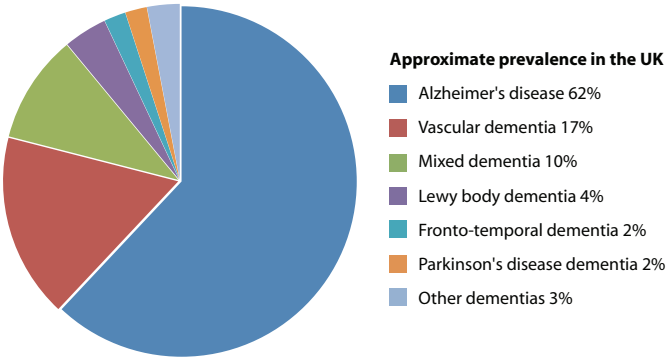
The ICD-10 states that dementia *'occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain'*.[11]

Key point:

Dementia is not a normal part of ageing. It occurs when the brain is affected by a disease. There are many types of dementia; the most common ones are Alzheimer's disease, vascular dementia, dementia with Lewy bodies and mixed dementia (a combination of different types of dementia).[8]

There are many different types of dementia.

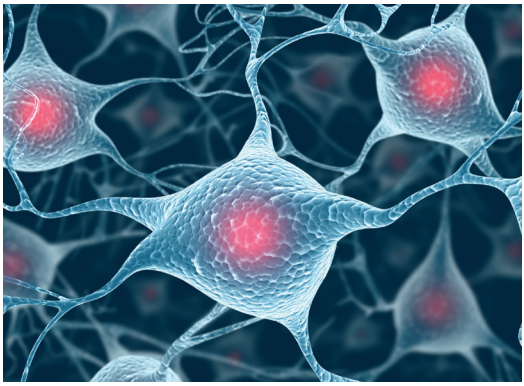
Figure 1: **Types of dementia**



From Alzheimer's Society 2013. Demography: **www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=412**

Notes

Alzheimer's disease (AD)



The most common type of dementia accounting for approximately 2 in 3 cases and slightly more common in women than men. The disease is named after Dr Alois Alzheimer, a German neurologist who described the brain pathology of a 51-year-old woman who died of a 'dementing type' illness in 1907.

The 'Amyloid Cascade Hypothesis' has been proposed as the cause of AD by Klafki et al. This is based on evidence which shows that AD is associated with various forms of abnormal material within the brain - neurofibrillary tangles and amyloid plaques; this affects how nerve cells work and communicate with each other, reducing levels of chemical messengers and causing cells to die.[12]

AD usually has a gradual onset with very mild symptoms initially; memory often being affected first, especially for learning new information, reflecting deterioration in the functioning of the medial temporal lobe and hippocampus areas of the brain. Early symptoms may include: forgetting names, appointments and recent events. As the disease progresses over many years, memory loss continues and other functions of the cerebral cortex become affected, including language, planning, thinking and carrying out actions. Behavioural and psychiatric disturbances may also occur, including depression, apathy, agitation, disinhibition, psychosis (delusions and hallucinations), wandering, aggression, incontinence and altered eating habits.[1]

People with AD may:

- experience mood swings, feel sad, angry, scared or frustrated by their increasing memory loss
- become more withdrawn, due either to a loss of confidence or to communication problems
- have difficulty carrying out everyday activities - they may get muddled checking their change at the shops or become unsure how to work the TV remote.

As AD progresses, people will need more support from those who care for them.

Eventually, people will need help with all their daily activities. People often live ten years or more after diagnosis. While there are some common symptoms of AD, it is important to remember that everyone is unique. No two people are likely to experience AD in the same way.[13]

Vascular dementia (VaD)

The second most common cause of dementia accounting for approximately 1 in 5 cases. VaD occurs because the blood supply to the brain is reduced or interrupted as a result of narrowing of the arteries, or because of a stroke or series of strokes that cause brain cells to die. VaD is associated with sudden onset and stepwise decline in functioning. Risk factors for VaD include smoking, diabetes, hypertension, raised cholesterol and obesity. The symptoms of VaD vary depending on what part of the brain is affected and may include:

- problems with speed of thinking, concentration and communication
- depression and anxiety
- symptoms of stroke, such as physical weakness or paralysis
- memory problems (although this may not be the first symptom)
- seizures
- periods of severe (acute) confusion
- visual mistakes and misperceptions (for example, seeing a rug as a pond)
- changes in behaviour (such as restlessness)
- difficulties with walking and unsteadiness
- hallucinations (seeing or hearing things that aren't there) and delusions (believing things that are not true)
- problems with continence
- psychological symptoms such as becoming more obsessive.[14]

Dementia with Lewy bodies (DLB)

DLB is caused by tiny spherical protein deposits that develop inside nerve cells called 'Lewy bodies' in areas of the brain that control particular aspects of memory and motor control. These disrupt the way the brain functions, reducing levels of chemical messengers and causing cells to die. DLB accounts for approximately 1 in 25 cases of dementia and is more common in men. In the early stages people usually have symptoms similar to Parkinson's disease (tremors, especially in the hands, stiffness, shuffling gait, slowness, blank facial expression and reduced mobility).

Notes

Problems with attention, confusion and alertness are very common and vary (fluctuate) widely over the course of the day, by the hour or even every few minutes. Other symptoms may include:

- difficulties in judging distances and perceiving objects in three dimensions
- problems with planning and organising
- depression
- memory problems (less likely in the early stages than in early AD)
- visual hallucinations occur in most people with DLB, and can be distressing. These are often of people or animals, and are experienced as detailed and convincing. Auditory hallucinations (hearing sounds that are not real, such as knocking or footsteps) can happen but are less common. Hallucinations and visual difficulties partly explain why many people with DLB have delusions (thinking things that are not true). Someone may believe they are being persecuted, that there are strangers living in the house, or that a spouse has been replaced by an identical imposter. Relatives and carers may find such delusions very distressing
- falls - due to motor symptoms and problems with balance
- sleep disorders and restless nights including violent movements as the person tries to act out nightmares. This night-time sleep pattern is called rapid eye movement sleep behaviour disorder. For bed partners it can be very distressing or even physically harmful.[15]

Frontotemporal dementia

This also used to be known as Pick's disease and although overall it is a less common type of dementia it can be a significant cause in people aged under 65 years. Frontotemporal dementia is caused when nerve cells in the frontal and/or temporal lobes of the brain die and the pathways that connect them change. Over time, the brain tissue in the frontal and temporal lobes shrinks. Frontotemporal dementia has a more profound effect on behaviour and personality than on the memory because the frontal and temporal lobes of the brain control behaviour, emotional responses and language skills.[16] There is a strong genetic component to the disease and it often runs in families.[1]

Mixed dementia

About 10 percent of people with dementia have a type known as mixed dementia. A diagnosis of mixed dementia means that there is a mixed cause of damage to the brain such as AD and VaD, or AD and DLB. The symptoms of mixed dementia are variable and should be managed according to the condition that is thought to be the predominant cause of dementia.[1]

Other rarer types or causes of dementia include:

- Alcohol-induced dementia and Korsakoff's syndrome
- Corticobasal degeneration
- Creutzfeldt-Jakob disease
- Down's syndrome
- Head injury
- HIV-related cognitive impairment
- Huntington's disease
- Motor-neurone disease
- Multiple sclerosis
- Niemann-Pick disease type C
- Normal pressure hydrocephalus
- Parkinson's disease
- Posterior cortical atrophy
- Progressive supranuclear palsy

Behavioural and psychological symptoms of dementia (BPSD) or behaviour that challenges

Even in the early stages of dementia, people may display personality changes. They may become more irritable, more withdrawn or suspicious, but as the disease progresses behavioural and psychological disturbances are seen, including the following:

- depression and apathy
- agitation and/or aggression
- disinhibition (loss of control of behaviour, or inappropriate behaviour)
- psychosis (hallucinations and delusions)
- eating pattern changes.

These symptoms are what families and carers find most difficult to cope with and are the main reason for patients being admitted to care homes. Managing BPSD will be looked at in more detail later in this programme.

Talking point A

Is the use of antipsychotics ever appropriate for the management of BPSD?

Notes

1.3 Risk factors

Risk factors associated with the development of dementia can be split into non-modifiable and modifiable:[1]

Examples of non-modifiable risk factors for dementia

- Increasing age
- E4 allele of ApoE gene (for Alzheimer's disease)
- Learning disability (especially Down's syndrome)
- Parkinson's disease

Examples of modifiable risk factors for dementia

- Excessive alcohol consumption
- Smoking
- Hypertension
- Obesity
- Lack of exercise
- Raised cholesterol
- Diabetes
- Vitamin B12 or folate deficiency

2. Diagnosing dementia

Dementia is differentiated from the normal ageing process by the severity and widespread nature of the cognitive decline. Healthcare staff should consider referring people who show signs of mild cognitive impairment (MCI) for assessment by memory assessment services to aid early identification of dementia, because more than 50 percent of people with MCI later develop dementia.[1]

Cognitive function refers to a group of mental processes including attention, memory, producing and understanding language, learning, reasoning, thinking, problem solving, and decision making.

Population screening in primary care is not currently advocated, but early recognition and diagnosis when a decline in cognitive function is observed, together with effective intervention and support for people diagnosed with dementia, can enable people to live well, for example improving their quality of life and delaying or preventing unnecessary admissions into care homes.[17]

It also allows people and families the opportunity to make plans, get their affairs in order and make any advance decisions about the care they would like to receive in the later stages of the disease.

It is therefore important to:

- make the diagnosis well
- break the diagnosis well to the person with dementia and their family
- provide appropriate care, treatment, support and information (verbal and written) at the time of diagnosis.[17]

Forgetfulness and confusion can be a symptom of other conditions, or have a modifiable cause, for example:

- depression and anxiety
- brain tumour
- hypothyroidism
- vitamin B deficiency
- pain
- poor sight or hearing
- stress
- sudden life changes
- delirium - that could be due to:
  - anaemia
  - low blood sugar
  - diarrhoea / constipation
  - medicines or combinations of medicines
  - infection
  - post surgery

Therefore at the time of presentation of MCI, the following screening should be carried out to eliminate other causes:[1]

- haematology (including vitamin B12 and folate serum levels)
- biochemistry tests (electrolytes, calcium, glucose, and renal and liver function)
- thyroid function tests
- a midstream urine test should always be carried out if delirium is a possibility

Notes

- a review of medication in order to identify and minimise use of drugs, including over-the-counter products that may adversely affect cognitive functioning.

Once any other causes for MCI have been eliminated the person should be assessed by a specialist for the presence of dementia. There is no single laboratory test that can confirm dementia. Clinical diagnosis is made by a combination of the following:[1]

- careful history taking
- cognitive and mental state examination
- physical examination and other appropriate investigations
- brain scan (usually an MRI scan) to confirm pathology, exclude other causes such as a brain tumour and to help establish the type of dementia.[1]

Practice point 1

Which medicines or groups of medicines may cause delirium, confusion or other signs that could be mistaken for dementia?

Diagnosis of the type of dementia

A diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria.[1]

Confirmation of the suspected cause of dementia can only be made at post mortem or, in very rare instances, through a brain biopsy.[18]

2.1 Assessment tools in dementia

Many assessment tools have been developed for use in dementia. Their primary purpose is to reduce subjectivity and increase the objectivity of a diagnosis, helping to differentiate dementia from normal age-related cognitive change.

NICE guidance highlights that the severity of a person's dementia should not be determined by cognition scores alone, but by a more holistic view of the patient's condition.[1]

Some of the most commonly used tools are outlined below.

Initial assessment tools

The Abbreviated Mental Test Score (AMTS) is commonly used as an initial assessment tool to rapidly assess people for the possibility of dementia. It involves asking a series of 10 questions for which each correct answer scores one point. Usually scores of seven or eight are used as an indicator for further investigation.

The General Practitioner Assessment Of Cognition (GPCOG) is an assessment tool commonly used in primary care, and requires the patient's carer to be present as there is evidence that interviewing both the patient and their carer improves accuracy.

The Mini-Mental State Examinsation (MMSE)

The MMSE is the assessment tool advocated by NICE to assist in the assessment of dementia, and to determine whether it is appropriate to prescribe an acetylcholinesterase inhibitor or memantine to a patient.[1]

The MMSE is used by clinicians along with other tests and clinical signs to diagnose dementia and to help assess its progression and severity. The MMSE is a series of questions and tests, each of which scores points if answered correctly. If every answer is correct, a maximum score of 30 points is possible.

The MMSE tests a number of different mental abilities, including a person's memory, attention and language.

Notes

In general, scores of 27 or above (out of 30) are considered normal. However, getting a score below this does not always mean that a person has dementia; in some cases the MMSE is less valid, examples are: [1,19]

- people who have learning disabilities, or other disabilities such as deafness or blindness
- people who have difficulty speaking (for example, after a stroke) or other difficulties with communicating
- if English is not the patient's first language, in which case the result of the MMSE will not fairly reflect the presence of disease or the severity
- people who are highly educated or uneducated.

A factsheet on the MMSE is available from the Alzheimer's Society at: **http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=121**

Sample questions

The MMSE is made up of a range of different questions and tests. The full MMSE can be purchased from the Psychological Assessment Resources (PAR) Inc. website at: **www4.parinc.com**. Below are four sample questions that give an indication of the style of the MMSE:

Figure 2: **Mini-Mental State Examination**

Orientation to time

"What is the date?"

Registration

"Listen carefully. I am going to say three words. You say them back after I stop. Ready? Here they are…

APPLE (pause), PENNY (pause), TABLE (pause). Now repeat those words back to me."

[Repeat up to 5 times, but score only the first trial.]

Naming

"What is this?" [Point to a pencil or pen.]

Reading

"Please read this and do what it says." [Show examinee the words on the stimulus form.]

CLOSE YOUR EYES

Figure 3: **Severity of Alzheimer's disease defined by MMSE score**[2]

mild Alzheimer's disease: MMSE 21–26

moderate Alzheimer's disease: MMSE 10–20

severe Alzheimer's disease: MMSE less than 10.

(**Note:** The MMSE is not used in all settings due to copyright issues. Other scales such as the Alzheimer's Disease Assessment Scale cognitive subscale (ADAS-cog), the Addenbrooke's Cognitive Examination III (ACEIII), the Mini-cog and the Six Item Cognitive Impairment Test (6CIT) are coming into more common use.)

Further information about the content of these cognitive assessment tools and their use in practice can be found here: **www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1661**

Notes

3. Background and policy documents

In recent years in the United Kingdom (UK), public awareness of the increasing prevalence of dementia as our population ages, the burden posed by dementia, both financially and its impact on society has been raised by several strategy documents, reports and initiatives. The release of these influential reports by national charities has been accompanied by coordinated media campaigns. This has led to mainstream press and broadcasters being more willing to discuss the issues surrounding the increasing prevalence of dementia, such as the costs to caregivers and society and the need for improved recognition and the benefits of an early diagnosis. Several public figures have talked openly about coping with a diagnosis of AD in themselves or a close relative.[20]

3.1 *Dementia UK: The full report* (2007)[10]

In 2006, the Alzheimer's Society commissioned a report from King's College London and the London School of Economics on the future social and economic impact of dementia in the UK. The report aimed to assess the numbers of people with dementia and make predictions for the future in the hope of preparing the health services. In addition, the Alzheimer's Society set out its plans to raise public and professional awareness of the disease.

3.2 *Living well with dementia: A National Dementia Strategy* (2009)[17]

The National Dementia Strategy for England, *Living well with dementia: A National Dementia Strategy* was published by the Department of Health in 2009. The aim of the strategy was to ensure that significant improvements were made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.

The *National Dementia Strategy* identified a lack of early diagnosis services to be a major concern. In many areas secondary care psychiatric services were found to be primarily focused on the severe end of the spectrum, with a lack of support for the newly diagnosed, less severe cases.

The National Dementia Strategy advised that specialist services should be commissioned locally to improve the care of those with a diagnosis of dementia.

Local specialist services should provide:

- initial diagnosis support
- referral pathways
- ongoing care.

The strategy identified 17 key objectives which when implemented should result in significant improvements in the quality of services provided to people with dementia and promote greater understanding of the causes and consequences of the disease.

In 2008, in response to widespread concern at the inappropriate use of antipsychotic drugs for people with dementia, the government commissioned a review by Professor Sube Banerjee, the joint lead of the National Dementia Strategy (which will be covered in further detail in section 5).

3.3 *Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015*[21]

Published in 2012, the Prime Minister's challenge on dementia set out an ambitious programme of work to deliver major improvements in dementia care and research by 2015, building on the achievements of the *National Dementia Strategy* (2009). The three key focus areas were:

- driving improvements in health and care
- creating dementia friendly communities that understand how to help
- better research.

The ambition was that as well as driving up the quality of care, work in these three areas should help to reduce future pressures on the NHS and social care. Central to the challenge was the requirement to improve diagnosis rates across the country, to make early diagnosis the rule rather than the exception and to have robust and affordable local plans.

3.4 Alzheimer's Society: *Dementia 2012: a national challenge*[7]

This annual report from the Alzheimer's Society looked at the quality of life for people with dementia. One third of people said that they struggled to get a diagnosis; 68% of people experienced a gap of longer than a year between noticing their symptoms and getting a diagnosis with 8% of people waiting 5 years or more for a diagnosis.

Notes

Other data showed that only 43% of people with dementia had been formally identified in the UK. Seventeen percent of people with dementia said that they were not living well with dementia, 55% said they were living quite well with dementia and only 22% said that they were living very well with dementia.

3.5 Alzheimer's Society: *Dementia 2013: the hidden voice of loneliness*[22]

This report demonstrated that some progress has been made towards improving the quality of life for people with dementia and carers; however quality of life remained extremely varied for substantial numbers of people.

Key findings:

- 44% of people with dementia in England, Wales and Northern Ireland had a diagnosis – only a slight increase since the previous year.
- 17% of people said they were not living well with dementia.
- 33% of people with dementia said they lost friends following a diagnosis.
- 39% of people with dementia said they felt lonely rising to 62% of those who lived on their own.
- The number of inappropriate prescriptions for antipsychotic medication to people with dementia reduced by 52% between 2008 and 2011.[22]

3.6 Clinical guidelines and support

There are many clinical guidelines and sources of information to support for healthcare professionals, patients, families and carers. You can find a selection of these on pages 9-12 of this book.

3.7 NICE quality standards for dementia

NICE released two quality standards for dementia; QS1 *Dementia*[3] and QS30 *Supporting people to live well with dementia*.[4] QS1 and QS30 should be read in conjunction with one another as together they address areas relevant to all patients with dementia. There is also a related quality standard, QS50 *Mental wellbeing of older people in care homes*.[23]

The rationale for NICE quality standards is to provide:

'specific, concise quality statements, measures and audience descriptors to provide patients and the public, health and social care professionals, commissioners and service providers with definitions of high-quality care'.

Practice point 2

Access the NICE quality standards for dementia: QS1 *Dementia* and QS30 *Supporting people to live well with dementia* at **http://guidance.nice.org.uk/QS1** and **http://guidance.nice.org.uk/QS30**

Use these quality standards to draw up a list of your key responsibilities in relation to patients with dementia in your area of practice.

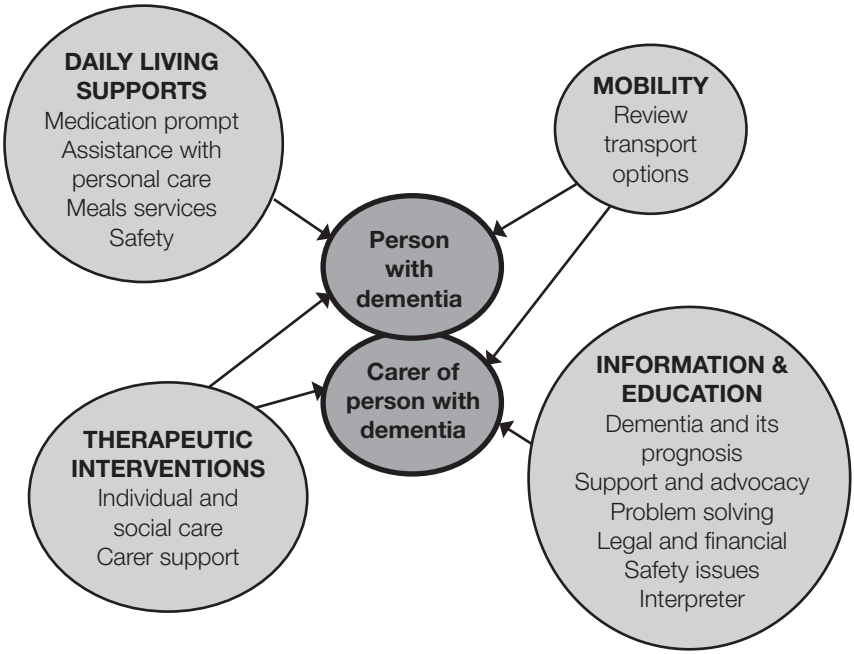
What are the criteria for referral into memory assessment services in your local area?

Notes

4. Management of dementia

There is currently no cure for dementia. The management of dementia should take a holistic approach, and consider the value of both non-pharmacological and pharmacological interventions.

Figure 4: **Holistic management of a person with dementia**[1]



4.1 Non-pharmacological management of dementia

The non-pharmacological management of dementia includes social support, increasing assistance with day-to-day activities, information and education, carer support groups, community dementia teams, home nursing and personal care, community services such as meals-on-wheels, befriending services, day centres, respite care and care homes.

NICE recommend that people with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme.[1]

4.2 Pharmacological management of dementia

Currently, pharmacological treatment options for Alzheimer's disease are symptom-treating rather than disease-modifying and fall into two categories:[2]

- Acetylcholinesterase (AChE) inhibitors, eg, donepezil, rivastigmine and galantamine
- N-methyl D-aspartate (NMDA) receptor antagonists, eg, memantine.

NICE guidance on drug treatments for Alzheimer's disease:[2]

- donepezil, galantamine and rivastigmine are recommended as options for managing mild and moderate Alzheimer's disease
- the least expensive AChE inhibitor should be prescribed first. However, an alternative AChE inhibitor can be used if considered appropriate, taking into account adverse event profile, expectations about adherence, medical co-morbidity, possibility of drug interactions and dosing profiles
- memantine is recommended as an option for managing moderate Alzheimer's disease for people who cannot take AChE inhibitors and as an option for managing severe Alzheimer's disease.

Treatment should be started by a specialist in the care of people with dementia and continued for as long as it is judged to be having a worthwhile effect on the patient's cognitive, functional or behavioural symptoms. Carers' views on the patient's condition at baseline should be sought. Patients should be reviewed regularly by an appropriate specialist team, unless there are locally agreed protocols for shared care. The review should include:

- an assessment of the patient's cognition, behaviour and ability to cope with daily life
- the views of carers on the patient's condition.[1]

Notes

4.2.1 Acetylcholinesterase (AChE) inhibitors

The cholinergic hypothesis of Alzheimer's disease is based on the observation that the cognitive deterioration associated with the disease results from progressive loss of cholinergic neurons and decreasing levels of the neurotransmitter acetylcholine (ACh) in the brain. This premise has served as the basis for the majority of treatment strategies and drug development approaches for Alzheimer's disease to date.[24,25]

When patients develop the degeneration of cholinergic neurones that occurs in Alzheimer's disease, there is a reduced release of acetylcholine and under-stimulation of post-synaptic neurones.[12] Following neurone stimulation, ACh is rapidly inactivated by the enzyme acetylcholinesterase.[26] The AChE inhibitors (donepezil, galantamine, rivastigmine) are licensed in the UK for the symptomatic treatment of mild to moderate Alzheimer's disease. In addition rivastigmine (via the oral route) is indicated for the treatment of mild to moderate dementia in Parkinson's disease.

Donepezil is a reversible inhibitor of AChE, galantamine is a reversible inhibitor of AChE and also has nicotinic receptor agonist properties, and rivastigmine is a reversible inhibitor of AChE and also inhibits butyrylcholinesterase.[1] The AChE inhibitors preserve a greater concentration of acetylcholine in the brain, thereby improving cholinergic function.

Between 40 and 70 percent of people with Alzheimer's disease benefit from AChE inhibitor treatment, but it is not effective for everyone and may improve symptoms only temporarily, between 6-12 months in most cases.[27]

Donepezil

Donepezil was the first oral AChE inhibitor to receive a UK product licence, in March 1997 and is available as tablets and orodispersible tablets. Treatment is usually taken in the evening to minimise adverse effects, although if sleep disturbance occurs the dose can be taken in the morning. The starting dose of 5 mg once daily should be maintained for one month to allow clinical response to treatment to be assessed and the dose can be increased to a maximum of 10 mg once daily if necessary. Peak serum concentrations are reached in three to four hours, but the elimination half-life is 70 hours, which means that steady state levels will not be reached for approximately two to three weeks.[28]

Adverse effects[28,29]

The most common adverse effects are nausea, vomiting, anorexia, diarrhoea, fatigue, insomnia, headache, dizziness, syncope, abnormal dreams, hallucinations, agitation, aggression, muscle cramps and urinary incontinence. These are, however, generally mild and transient and normally disappear within a few days of continued treatment. Maintaining the starting dose for four weeks may reduce the initial tolerability problems. Donepezil has been linked to increased risk of gastrointestinal problems,

and patients with previous history of ulcers or those on non-steroidal anti-inflammatory drug therapy should be monitored for any symptoms. Because of their pharmacological action, AChE inhibitors may cause a slow heart rate, or bradycardia leading to a risk of syncope (fainting) or seizures. The potential for this action may be particularly important to patients with sick sinus syndrome or other supraventricular cardiac conduction conditions, such as sinoatrial or atrioventricular block. Donepezil should be used with caution in patients with mild to moderate hepatic impairment.

Rivastigmine

Rivastigmine is available as tablets, oral solution or transdermal patches. The oral starting dose is 1.5 mg twice a day with meals, increasing in steps of 1.5 mg twice a day at minimum intervals of two weeks providing the dose increases are tolerated.[30]

Rivastigmine patches are applied once every 24 hours and may be associated with less gastrointestinal adverse effects[29] and can also be considered for patients with swallowing difficulties. The dosing schedule for rivastigmine patches and advice on switching patients from oral rivastigmine to patches can be found in the current BNF: **www.bnf.org**

Adverse effects[29,30]

The most common adverse effects are drowsiness, nausea, vomiting, abdominal pain, dyspepsia and diarrhoea, which occur most commonly when the dosage is increased. If gastrointestinal adverse reactions occur or extrapyramidal symptoms (eg, tremor) in patients with dementia associated with Parkinson's disease are observed during treatment, they may respond to omitting one or more doses. If adverse reactions persist, the daily dose should be temporarily reduced to the previous well-tolerated dose or the treatment may be discontinued.

Notes

There are also reports of anorexia, weight loss, gastrointestinal haemorrhage, headache, insomnia, sweating, dizziness, syncope, agitation, anxiety, increased salivation, tremor, worsening of Parkinson's disease and a potential to cause bladder outflow obstruction and urinary incontinence.

Rivastigmine should be used with caution in patients with moderate renal impairment, mild to moderate hepatic impairment, sick sinus syndrome, cardiac conduction abnormalities, or those with a history of asthma, chronic obstructive pulmonary disease, recent duodenal or gastric ulceration or bladder flow obstruction.

Rivastigmine is available in a transdermal formulation as patches which should be applied to clean, dry, hairless, intact healthy skin on the upper or lower back, upper arm or chest, in a place which will not be rubbed by tight clothing. It is not recommended to apply rivastigmine patches to the thigh or to the abdomen due to decreased bioavailability when the patch is applied to these areas of the body.

The transdermal patch should not be applied to skin that is red, irritated or cut. Reapplication to the exact same skin location within 14 days should be avoided to minimise the potential risk of skin irritation.

Galantamine

Galantamine is available as tablets and oral solution, the starting dose is 4 mg twice a day with meals, increasing at four weekly intervals up to a maximum of 12 mg twice daily.[31] Modified release capsules are also available, with a starting dose of 8 mg once daily, usually in the morning with food, increasing at four weekly intervals to a maximum of 24 mg once daily.[32]

Adverse effects[29,31]

Very common adverse effects include nausea and vomiting – the latter sometimes projectile, and often severe enough to cause substantial weight loss.

Common adverse effects include diarrhoea, abdominal pain, dyspepsia, anorexia, weight loss, fatigue, dizziness, headache, drowsiness and somnolence (at twice the rate of placebo). These effects generally last for less than a week. Confusion, insomnia, tremor, depression, hallucinations, muscle spasm, syncope and bradycardia may also occur. Galantamine should be used with caution in moderate to severe hepatic impairment and is contraindicated in severe renal impairment.

4.2.2 Memantine

Memantine is licensed for the treatment of moderate to severe Alzheimer's disease. Memantine is an N-methyl-D-aspartate (NMDA)-receptor antagonist and blocks the effects of pathologically elevated levels of glutamate that cause neuronal dysfunction.[2]

Memantine is available as tablets and oral solution and the starting dose is 5 mg once a day for a week, increasing by 5 mg once a day at weekly intervals up to a maximum of 20 mg daily.

Adverse effects[29,33]

The most common adverse effects are headache, constipation, somnolence, dizziness, balance disorders, hypertension, dyspnoea and elevated liver function tests. Memantine should be avoided in severe hepatic impairment and used with caution in patients with a history of seizures or any renal impairment.

Combining memantine with an AChE inhibitor

In their technology appraisal NICE looked at pooled data of the available trial information of memantine in combination with an AChE inhibitor and concluded there was no additional benefit from combination therapy.[2]

4.2.3 Treatment of other dementias

Vascular dementia (VaD)[14]

Although the brain damage that causes VaD cannot be reversed, it may be possible to slow the progression of the disease in a number of ways. These include:

- medication to treat any underlying conditions, such as stroke, high blood pressure, high cholesterol, diabetes or heart problems
- adopting a healthier lifestyle by stopping smoking, taking regular exercise, eating healthily, and drinking alcohol only in moderation
- rehabilitative support, such as physiotherapy, occupational therapy and speech therapy, to help the person maximise their opportunities to regain their lost functions.

Notes

NICE Technology appraisal 217 specifically states that acetylcholinesterase inhibitors or memantine should not be used for cognitive decline in vascular dementia except as part of properly constructed clinical studies.[2]

Mixed dementia

NICE advise that mixed dementia should be managed according to the likely dominant condition.[2]

Dementia in Parkinson's disease

The side effects of some drugs used to treat Parkinson's disease may make symptoms of dementia worse, so a review of medication is sometimes of benefit. Rivastigmine (via the oral route) is indicated for the treatment of mild to moderate dementia in Parkinson's disease.

Talking point B

Should information regarding medication and disease management be given directly to a patient with dementia or to their carer?

4.3 Complementary, alternative or other treatments for dementia

Many people with dementia, and those who care for them, are interested in using complementary or alternative therapies to their conventional treatments often due to the perceived benefits that they may bring and the image of being 'safe' and 'natural'. The Alzheimer's Society factsheet: *Complementary and alternative therapies for dementia* outlines some options that people with dementia could try, although at present the evidence to support their use is limited.[34] You can access the leaflet at: **www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=134**

Cochrane reviews of some alternative approaches to the management of dementia:

Exercise programmes

A review concluded that there was promising evidence that exercise programs can significantly improve the cognitive functioning of people with dementia and their ability to perform daily activities, but there was a lot of unexplained variation between trial results. Further well-designed research is required to examine these outcomes and to determine the best type of exercise program for people with different types and severity of dementia.[35]

Other Cochrane reviews have found insufficient or inconclusive evidence to support the use of:

- Aromatherapy, music therapy or melatonin for the management of agitation and neuropsychiatric symptoms[36, 37, 38]
- Acupuncture for people with vascular dementia[39]
- Transcutaneous electrical nerve stimulation (TENS) for the treatment of neuropsychological and/or behavioural aspects of dementia[40]
- Vitamin B12 supplementation in people with dementia or cognitive impairment and low blood levels of vitamin B12[41]
- Fish oils for the prevention of dementia in older people[42]
- Aspirin to improve symptoms in people with vascular dementia[43]
- Huperzine A for the treatment of vascular dementia[44]
- Ginkgo biloba for the treatment of people with dementia and cognitive impairment[45]
- Light therapy for the management of cognitive, sleep, functional, behavioural, or psychiatric disturbances in dementia people with dementia[46]

- Massage or touch interventions for the management of anxiety, agitation, depression or cognitive decline in people with dementia or associated problems[47]

Vitamin E

A Cochrane review in 2012 found no convincing evidence that vitamin E is of benefit in the treatment of AD or mild cognitive impairment.[48] However, high dose vitamin E has recently been found to significantly slow functional decline, translating into a delay in progression of 6.2 months.[49] Caution has been expressed about these results because functional decline is non-specific to AD, the primary outcomes were not confirmed by the secondary outcomes and

Notes

this trial used a high dose of alpha-tocopherol; much higher than the recommended daily allowance (RDA). The mechanism and value of vitamin E in AD is uncertain and further research is required.

Anti-inflammatory agents

Prior to 2010 several retrospective, epidemiologic studies have found that patients treated with anti-inflammatory agents, for diseases such as arthritis and leprosy, had a reduced risk of developing Alzheimer's disease. However, the picture is complicated, and a study in September 2010 found that chronic NSAID use was linked to increased neuritic plaque accumulation which may actually increase the risk of dementia.[50] The NICE-SCIE clinical guideline CG42 does not recommend using NSAIDs to treat dementia.[1]

Angiotensin converting enzyme (ACE) inhibitors

A recent study suggests that the use of ACE inhibitors in older adults with AD is associated with a slower rate of cognitive decline independent of baseline or subsequent hypertension.[51] These results leave open the question of whether treatment with ACE inhibitors might play a role in the management of older adults with AD. More research is required to confirm the role of ACE inhibitors in AD.

Immunotherapy

The current theory of Alzheimer's disease pathology – the 'amyloid cascade theory' – has postulated that the build-up of amyloid-beta (Aβ) peptide sets off a cascade that ultimately leads to neuronal cell death. Research to assess if the aggregation of Aβ peptide can be blocked by the use of monoclonal antibodies is ongoing.

The World Alzheimer Report 2011: the benefits of early diagnosis and intervention[52] includes a chapter on which pharmacological or non-pharmacological interventions are effective for people in the early stages of dementia. An executive summary can be accessed free at: **www.alz.co.uk/worldreport2011**

5. Living with dementia

5.1 Impact on patients and carers

Dementia has a devastating impact on both the patients involved and their carers. However, it is essential for society to remember that individuals with a diagnosis of dementia can still enjoy many pursuits that they previously enjoyed, and that amendments to a person's routine can ensure a fulfilling, stimulating environment.

The Alzheimer's Society produces a monthly magazine that chronicles the stories of a wide variety of patients and carers and offers some insight into their difficulties. This can be found online at: **www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200241**

The burden of care for many patients falls upon family members, many of whom can no longer work due to the requirements of the patient. As healthcare professionals, we can make some positive interventions and offer useful advice to those caring for a patient with dementia.

Practice point 3

Watch the following video clip on living with dementia, which will give you a better understanding of the impact the disease has on patients and their carers:

How to live with dementia - People with dementia speak out **www.youtube.com/watch?v=WR74FEyc9KY&feature=related**

Note down anything about living with dementia that you had not previously considered.

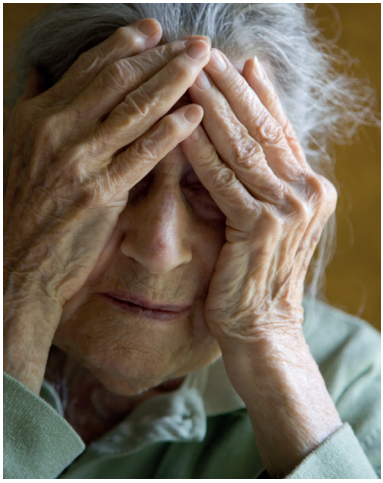
Notes

5.2 Management of the behavioural and psychological symptoms of dementia (BPSD)

As discussed in Section 1, there are often non-cognitive symptoms of dementia, which can cause a great deal of distress for both the patients and carers. These are known as behavioural and psychological symptoms of dementia (BPSD) or, according to NICE-SCIE Clinical guideline CG42, 'behaviour that challenges'.[1] Over 90 percent of people with dementia will develop behavioural problems or psychiatric symptoms at some point during their illness.[53] There are three distinct BPSD syndromes: psychotic symptoms (delusions and hallucinations), mood disorders (depression, anxiety, apathy, hypomania) and agitation.

When these symptoms occur, NICE-SCIE Clinical guideline CG42 advocates a full assessment of the patient at the earliest opportunity.[1] This assessment should be carried out by a trained healthcare professional, and include the following:

- physical health
- depression
- possible undetected pain or discomfort
- adverse effects of medication
- religious, cultural and social beliefs
- psychosocial factors
- physical and environmental factors.



Non-pharmacological treatments for BPSD

The NICE-SCIE Clinical guideline CG42 recommends that, where possible, a patient displaying BPSD or 'behaviour that challenges' should be offered non-pharmacological first-line therapies including:[1]

- aromatherapy
- massage
- therapeutic music/dancing
- animal assisted therapy (pet therapy)
- multi-sensory stimulation
- distraction or reminiscence therapy.

Some patients may benefit more from one therapy than another, and care should be taken not to force patients into activities that may make them feel more frustrated. As outlined earlier, other patients may not benefit from these interventions so individual assessment is required.

Pain and discomfort

Pain is one of the most common but under-recognised and under-treated symptoms in dementia. People with dementia experience physical and psychological pain, but may struggle to express this, particularly in advanced stages of the disease.

It is important to recognise non-verbal ways that people might express pain. The signs that someone might be in pain include:

- facial expressions (frowning, looking frightened, grimacing)
- vocalisations (groaning, signing, breathing noisily or becoming verbally abusive)
- body movements (rigid posture, tension, rocking, gait changes)
- behaviour changes (refusing food, changes in routines, wandering or pacing)
- mental status changes (confusion, crying, irritability, distress).

It is also worth noting that people are often assessed for pain when they are lying or sitting, whereas most pain occurs on movement. The Royal College of Nursing suggests that pain should be assessed systematically when people are moving, as well as when they are still.[54] Analgesia should be given to patients before doing anything that may cause pain. Wherever possible, self-reported pain assessment scales should be used in people with mild to moderate dementia and observational pain tools in severe dementia. The Abbey Pain Tool and Doloplus 2 pain assessment tools are commonly used.

A study found that a systematic approach to the management of pain can significantly reduce agitation in residents of nursing homes with moderate to severe dementia. The authors concluded that effective management of pain can play an important part in the treatment of agitation and could reduce the number of unnecessary prescriptions for psychotropic drugs in this population.[55]

Notes

Pharmacological treatments for BPSD

When managing BPSD it is important to remember that it must be the patient who is being treated. Medication should not be prescribed to the patient to help the staff manage the person more easily. Historically, BPSD were treated with a range of medicines, including benzodiazepines, antipsychotics and antidepressants. Risperidone currently has a licence for short-term use of up to six weeks for persistent aggression in patients with moderate to severe Alzheimer's dementia that is unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others. It should be prescribed only by specialists who have considered the recognised risks and put in place a process for review. Other antipsychotics are not licensed for BPSD.

In March 2004, the Medicines and Healthcare products Regulatory Agency (MHRA) advised that the risk of using risperidone and olanzapine in people with dementia was unfavourable.[56] This was because of studies highlighting an increased risk of cardiovascular and cerebrovascular (stroke) events in this population group.

In 2009, the MHRA issued further advice, stating *'there is a clear increased risk of stroke and a small increased risk of death'* associated with the use of antipsychotics (typical or atypical) in elderly people with dementia.[57]

***The use of antipsychotic medication for people with dementia: time for action* – Professor Sube Banerjee**[58]

As described in section 3.2, in 2008 the government commissioned a report to examine the use of antipsychotics in people with dementia in response to concerns about their safety. The report was published in October 2009.

The report concluded that the risks of antipsychotics in patients with dementia outweigh the benefits (in most cases) and that too often antipsychotics were used as a first-line response to difficult behaviour in dementia (most often agitation), rather than as a considered second-line treatment when other non-pharmacological approaches have failed.

The report made several recommendations, including that people with dementia should receive antipsychotics only when they really need them, and that reducing their use in this group should be a priority for the NHS. It suggested this could be achieved by various means including training carers and medical staff to use alternatives to antipsychotics, providing psychological therapies for people with dementia and their carers, carrying out further research into alternative treatments, and audits. On the basis of these findings, the government pledged to reduce the use of antipsychotics in people with dementia by two thirds by November 2011.

A 52 percent reduction in the prescribing of antipsychotic medication for people with dementia was achieved between 2008 and 2011.[59]

Advice and support for healthcare and social-care professionals

The Alzheimer's Society, Department of Health, Dementia Action Alliance, Royal College of General Practitioners, Royal College of Psychiatrists and College of Mental Health Pharmacy have produced an *Optimising treatment and care for people with behavioural and psychological symptoms of dementia: a best practice guide*.[60] This includes clinical checklists, information about prevention of BPSD, and information about specific interventions, together with pathways for determining appropriate treatment for someone who has a current antipsychotic prescription and someone who does not.

The MHRA issued further advice in 2012
***Antipsychotics: initiative to reduce prescribing to older people with dementia*[61]**

For prescribers considering using antipsychotics in older people with dementia without a current prescription:

- Carefully consider, after a thorough clinical examination including an assessment for possible psychotic features (such as delusions and hallucinations) whether a prescription for an antipsychotic drug is appropriate - see appropriate pathway in best practice guide.[60]

For prescribers considering continuing antipsychotics in older people with dementia with a current prescription:

- Identify and review patients who have dementia and are on antipsychotics, with the purpose of understanding why antipsychotics have been prescribed.
- In consultation with the patient, their family and carers, and clinical specialist colleagues such as those in psychiatry, establish: whether the continued use of antipsychotics is appropriate; whether it is safe to begin the process of discontinuing their use; and what access to alternative interventions is available.
- Consult the best practice guide.[60]

Notes

The NICE-SCIE Clinical guideline CG42 advises that patients with non-cognitive symptoms or behaviour that challenges should not be prescribed antipsychotics in the first instance. However if patients display severe distress or are an immediate risk to themselves or others, then the following must be undertaken:[1]

- a full discussion with either the patient or carer regarding the risks and benefits of using antipsychotics, and in particular the increased risk of stroke or transient ischaemic attack (TIA)
- target symptoms should be identified, and assessed regularly
- antipsychotics should be initiated at a low dose and titrated very slowly
- treatment should be time limited and reviewed regularly (ie, at six weeks and then every 12 weeks, or according to clinical need).

NICE published a key therapeutic topics document, *Low dose antipsychotics in people with dementia*, in January 2013.[62] While this is not formal NICE guidance, it summarises the evidence base on this topic, which has been identified to support the Quality, Innovation, Productivity and Prevention (QIPP) medicines use and procurement work stream, and provides a lot of useful information.

Practice point 4

Using the NHS England dementia map at:
http://dementiachallenge.dh.gov.uk/map

Find out what proportion of diagnosed dementia patients were prescribed an antipsychotic drug within the first year of diagnosis in your local CCG (For around 5% of people with dementia antipsychotic drugs are considered the right treatment).

Bring the information you have found to the workshop to compare with your colleagues.

Antipsychotics are still inappropriately prescribed in dementia. Why do you think this is? Make some notes below.

Notes

Pharmacy teams continue to have a vital contribution in working with patients, carers, health and social care teams to reduce inappropriate use of antipsychotics in dementia, particularly those in a care environment.

Can acetylcholinesterase inhibitors be used for the treatment of BPSD?

The evidence base for using the acetylcholinesterase inhibitor medicines for the treatment of BPSD is weak. The advice from NICE-SCIE Clinical guideline CG42 is that patients with dementia with Lewy bodies should be offered acetylcholinesterase inhibitors in preference to antipsychotics for 'behaviour that challenges' (due to their increased risk of extrapyramidal side-effects with antipsychotics). In addition, patients with Alzheimer's disease should be offered acetylcholinesterase inhibitors when 'non-drug treatments or antipsychotics are inappropriate or ineffective'.[1]

5.3 Planning for the future

As dementia is a progressive disease, there will come a point at which the patient is no longer said to have the 'capacity' to make informed decisions. A person is thought to be unable to make an informed decision if they cannot do all four of the following:

- understand information being given to them
- retain information long enough to be able to make a decision
- weigh up the information necessary to make a decision
- communicate their decision by any possible means, eg, blinking, squeezing a hand.

The Mental Capacity Act (MCA) 2005 provides a statutory framework to protect people who no longer have the capacity to make decisions about their own care.[63]

The Alzheimer's Society has a detailed factsheet on their website at **www.alzheimers.org.uk/factsheet/460** which covers the Mental Capacity Act and other important legal issues such as lasting power of attorney (LPA), which gives the chosen attorney the power to make decisions about the patient's welfare (including medical treatment).

Pharmacy professionals should be fully aware of the implications of the MCA in relation to decisions to take medicines and requests from other healthcare professionals and care home staff for information about the covert administration of medicines.

Advance decisions

Advance decisions are also known as advance directives or living wills. They are legally binding statements that enable a person to state their wishes with regard to their treatment in the event that they become unable to communicate. Often advance decisions will cover topics such as resuscitation or end-of-life treatments.

Summary of background reading

- Dementia is not a normal part of ageing. It occurs when the brain is affected by a disease. There are many types of dementia; the most common ones are Alzheimer's disease, vascular dementia, dementia with Lewy bodies and mixed dementia.
- The prevalence of dementia is increasing as our population ages.
- The impact of dementia on the patient and their families can be devastating.
- The diagnosis of dementia and its severity should be made by healthcare professionals with expertise in diagnosis using international standardised criteria.
- Early diagnosis and identification of dementia allows people time to make plans for their future and access treatments that may delay progression, and support and services.
- There is currently no cure for dementia. The management of dementia should take a holistic approach, and consider the value of both non-pharmacological and pharmacological interventions.
- NICE guidelines, technology appraisals, pathways and quality statements provide a structure to the approach to the holistic care of people with dementia, their families and carers.
- The pharmacy team has a key role to play in supporting patients with dementia and their carers, including lifestyle advice, medicines optimisation, use of support networks and signposting to patient support groups.

You should now complete the Directing change exercise on the next page to prepare for the workshop, where this will be discussed.

Directing change

Here we offer you three scenarios that you can use to inform the way you plan to change your practice.

These consider:

- **Skill mix - the right person for the task.** This scenario is about encouraging pharmacists and pharmacy technicians to work together and share responsibilities.
- **Medicines use reviews (MURs).** This scenario is about achieving the maximum benefit for patients and pharmacists.
- **Advanced practice.** This scenario is about preparing for the profession's future roles or your own future specialty.

Read through the scenarios and choose the one that you would like to discuss further with colleagues at the focal point event. Write down how you would respond to the situation, structuring your response around the following themes:

- The resources you expect to use
- The training required
- The evidence supporting your decision
- The government or national guidelines supporting you
- Any local initiatives relevant to the scenario.

Skill mix – the right person for the task

Edith is a 72-year-old lady with dementia who has been a regular customer at your community pharmacy for many years. Edith's daughter asks you how her mother can be assisted in remembering to take her medicines, as she often forgets to take them.

How could you and your team improve medicines management for Edith?

In answering this, you may want to consider the following questions:

- How would you manage the issues of confidentiality and discussing the patient's medication with a carer or family member?
- Could your team assist in the ordering and delivering of prescriptions?
- Does your team offer monitored dosage systems – and are they used appropriately considering the risks and benefits associated with them?
- Is your pharmacy team aware of Shared Care Protocols for the prescribing of acetylcholinesterase inhibitors in your area?

Medicines use reviews (MURs)

As a pharmacy professional with an interest in dementia how could you adopt a more systematic approach to addressing issues when undertaking MURs for patients receiving medicines for dementia?

In addition to the questions covered on the MUR form, what questions could you ask to improve the quality of life and outcomes for patients with dementia?

Advanced practice

You have been asked to give a talk to the community mental health team (CMHT) about acetylcholinesterase inhibitor medicines in the treatment of people with Alzheimer's disease

Consider what information a multidisciplinary team would need regarding the different AChE inhibitors and their place in therapy.

Checklist for action

At this point in the learning programme you will have carried out the following.

	I completed this on:
I have answered the Moving into focus questions	
I have listed three learning needs	
I have read the whole book	
I have undertaken the practice points	
I have made notes for the talking points ready to share at the event	
I have worked through the Directing change exercise	

Signed: .....

Date: .....

Take this book with you to your focal point event. Make sure that you know when and where it is and what time it starts. Enjoy your learning.

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Notes

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Email
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Centre for Pharmacy Postgraduate Education (CPPE)
Manchester Pharmacy School
1st Floor, Stopford Building
The University of Manchester
Oxford Road
Manchester M13 9PT

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