

The Pharmaceutical Care of People with Dementia



About this package

This pack has been designed to meet the education and training needs of pharmacists and pharmacy technicians who deliver services to people with a diagnosis of dementia, their families and carers.

Format

The pack is organised into six main sections. The first three sections focus on the subtypes of dementia, the risk factors and early signs, the screening and diagnostic processes. Sections 4 and 5 cover living with dementia, from the early stages, through the progression to requiring more help and support. The final section focuses on symptoms most often (but not exclusively) associated with the later stages of dementia, end of life care and dying well.

Aim

This pack is intended to help pharmacists and pharmacy technicians gain the knowledge and skills required to achieve the *Dementia Informed Practice Level* and the *Dementia Skilled Practice Level* from the NES/SSSC Promoting Excellence Framework as explained in the introduction to the pack. It supports delivery of care that is evidence based and up-to-date, while providing you with many additional sources of useful information.

This pack should take approximately 10 hours to complete.

Activities

Throughout the main text, you will be prompted to complete activities. Some of the activities will require that you look at a document or access a particular website. By completing these activities, you will find that the practical tips and learning points from them will prove extremely valuable in your day to day work.

Case scenarios

There are several case scenarios throughout the pack. A sample pharmaceutical care plan is developed as the patient journey proceeds in each case to illustrate the potential for meaningful pharmaceutical care planning and intervention in different care settings and different professional roles. The need for effective and timely communication between sectors and care settings as the patient moves from different care environments is emphasised throughout.

Multiple choice questionnaire

On completion of the pack, the multiple choice questionnaire should then be attempted and completed via your Portal account at www.portal.scot.nhs.uk. If you do not already have a NES portal account, you can register at the above address.

Feedback

We hope you find this pack a useful background and/or update in relation to the role you play in supporting people with a diagnosis of dementia, their families and carers. Please help us to assess the value and effectiveness of the pack by adding any comments in the relevant section of the MCQ on Portal.

How this package can assist your CPD

At the beginning of each section, the learning outcomes describe what you should be able to do when you complete that particular section. This helps you monitor your progress through the pack. We suggest that you also note down on your personal CPD record, any specific future learning needs which arise as you study each section.

Keeping up to date

The information is accurate at time of publication but you may wish to keep up to date with completed and ongoing current research by checking the websites of the organisations detailed within the pack.

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Contents

Section 1 Background

1.1	What is dementia?	15
1.1.1	Alzheimer's disease	16
1.1.2	Vascular dementia	16
1.1.3	Mixed dementia	17
1.1.4	Dementia with Lewy Bodies	17
1.1.5	Frontotemporal dementias	17
1.1.6	Subcortical dementia syndromes	18
1.2	Who is affected?	20
1.3	Role of the pharmacist and pharmacy technician	21
1.3.1	The 10 Essential Shared Capabilities (ESC)	25
1.3.2	The 5 Pillar Model and the 8 Pillar Model	27

Section 2 Risk factors for dementia

2.1	Can anything be done to prevent dementia?	
2.1.1	Regular exercise	32
2.1.2	Healthy diet	32
2.1.3	Maintaining a healthy weight	32
2.1.4	Stop smoking	32
2.1.5	Reduce alcohol intake	32
2.1.6	Mental stimulation	33
2.1.7	Stress management	33
2.1.8	An active social life	33
2.2	Role of dietary supplements and herbal remedies in treatment/prevention of dementia	33
2.2.1	Ginkgo	34
2.2.2	Salvia	34
2.2.3	Souvenaid®	35

Section 3 Finding out it is dementia

3.1	Early signs of dementia	39
3.2	Illustrative cases	41
3.2.1	David	41
3.2.2	Pauline	43
3.2.3	Jenny	47
3.3	What happens when a patient presents to their GP with memory problems?	52
3.3.1	History taking and initial investigations	52
3.3.2	Montreal cognitive assessment (MoCA)	53
3.3.3	Mini-mental state examination (MMSE)	53
3.3.4	Addenbrooke's cognitive examination (ACE III)	53
3.3.5	Alzheimer's disease assessment scale – cognitive (ADAS – Cog)	54
3.3.6	Screening tests for reversible causes of symptoms	54
3.4	Differential diagnosis	55
3.4.1	Delirium	56
3.4.2	Depression	57
3.4.3	Mild cognitive impairment (MCI)	57
3.5	Referral to mental health services	58
3.5.1	What happens at a memory clinic?	59

Section 4 Living well with dementia

4.1	Receiving a diagnosis	63
4.1.1	Driving and dementia	64
4.1.2	Care planning	65
4.1.3	Power of attorney	65
4.1.4	Advanced directives	66
4.1.5	Advance statement	66
4.1.6	Guardianship orders	66
4.1.7	Risk assessment	67
4.2	Medication for cognitive symptoms of dementia where appropriate	67
4.2.1	Acetylcholinesterase inhibitors (AChEIs)	68
4.2.2	Differences between AChEIs	68
4.2.3	Cautions with AChEIs	70
4.2.4	Monitoring procedures for AChEIs	70
4.3	Illustrative cases	72
4.3.1	Peter	72
4.3.2	Pauline (we met in section 3)	75

Section 5 Living well with increasing help and support

5.1	Medication in moderate to severe dementia	85
5.1.1	Memantine	85
5.1.2	AChEIs for BPSD	87
5.1.3	Role of antipsychotic drugs	88
5.1.4	Role of antidepressants	92
5.1.5	Role of anti-epileptic drugs	93
5.1.6	Role of hypnotics and anxiolytics	93
5.1.7	Role of analgesics	94
5.2	Illustrative cases	96
5.2.1	Peter (we met in section 4)	96
5.2.2	Jane	99
5.3	Role of non-drug therapies in dementia	101
5.3.1	Evidence based psychological interventions in dementia	104
5.4	Cases revisited	106
5.4.1	Pauline (we met in sections 3 and 4)	106
5.4.2	Peter (6 weeks on)	110
5.4.3	Jane (1 year on)	115

Section 6 End of life and dying well

6.1	Gold standards framework (GSF)	123
6.2	Liverpool care pathway for the dying patient (LCP)	125
6.3	Experiences of end of life care in dementia	127
6.4	Anticipated issues in advanced dementia	128
6.5	Cases revisited	131
6.5.1	Pauline (we met in sections 3, 4 and 5)	131
6.5.2	Jane (we met in section 5)	132
6.6	Cases followed-up, last days	134
6.6.1	What happened to Pauline?	134
6.6.2	What happened to Jane?	135
6.6.3	Pharmaceutical care issues at the end of life for Pauline and Jane	135
6.6.4	Other care issues in the last days and hours	137

Section 7 Summary of practice points in dementia for pharmacists and pharmacy technicians

140

Section 8 References

143

Section 9 Resources

9.1	Educational resources for professionals, patients and carers	152
9.2	For pharmacy staff	152

Introduction

Regardless of their role, or work setting most pharmacists and pharmacy technicians will come into contact with people with a diagnosis of dementia, their families or carers (or those showing early signs of the illness, but not yet diagnosed).

In June 2010, the Scottish Government launched *Scotland's National Dementia Strategy* (www.scotland.gov.uk/Publications/2010/09/10151751/17) as dementia was recognised as a national priority for the Scottish Government. The strategy built on work already underway in Scotland in relation to early diagnosis, improving care pathways and public awareness of dementia. It was hoped that the strategy would transform dementia services by developing common standards of care for the first time, producing a framework to ensure that all staff who provide care and support services for people with dementia are skilled and knowledgeable about dementia, and strengthen the integration of health and social care services – including information sharing.

In June 2013, The Scottish Government launched its second dementia strategy: *Scotland's National Dementia Strategy: 2013-16* (www.scotland.gov.uk/Topics/Health/Services/Mental-health/Dementia/DementiaStrategy1316) building on the work undertaken so far. The fact that a second strategy has been launched recognises the fact that dementia is one of the foremost public health challenges for Scotland. The new strategy acknowledges the excellent work undertaken thus far in improving diagnosis rates for dementia in Scotland, and highlights the need to build on this work by improving post diagnostic support.

NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC), in conjunction with Alzheimer Scotland developed Promoting Excellence: A framework for health and social services staff working with people with dementia, their families and carers (www.scotland.gov.uk/Publications/2011/05/31085332/12) to support delivery of the aspirations outlined in Scotland's dementia strategy. The NES/SSSC Promoting Excellence framework details four knowledge and skill levels those working in health and social services should aspire to achieve in relation to supporting people with a diagnosis of dementia, and their families, and carers. The level expected of an individual professional depends on the level of contact they have with individuals with a diagnosis of dementia as follows:

- » The *Dementia Informed Practice Level* provides the baseline knowledge and skills required by all staff working in health and social care settings including a person's own home.
- » The *Dementia Skilled Practice Level* describes the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers.
- » The *Enhanced Dementia Practice Level* outlines the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services.
- » The *Expertise in Dementia Practice Level* outlines the knowledge and skills required for health and social care staff who by virtue of their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia.

The framework is structured detailing the knowledge required at each stage in the dementia journey and describing alongside this the skills/capabilities and abilities required to apply the knowledge to help people with dementia. The stages of the dementia journey are classified as follows:

- » Keeping well, prevention, and finding out it's dementia
- » Living well with dementia
- » Living well with increasing help and support
- » End of life and dying well.

It is intended to be used by individuals, service providers and organisations to improve knowledge and skills in this practice area. The framework also recognises the existence of various sector and professional group specific standards and frameworks e.g. the NHS Knowledge and Skills Framework, and is thus integrated with other competence frameworks available to pharmacists.

The Promoting Excellence framework emphasises the rights of people with dementia and was developed alongside the development of *Standards of Care for Dementia in Scotland* (www.scotland.gov.uk/Publications/2011/05/31085414/0) led by the Mental Welfare Commission for Scotland. The standards and this framework are based on *The Charter of Rights for People with Dementia and their Carers' in Scotland* developed by Alzheimer Scotland (www.dementiarights.org/charter-of-rights/). Included within the Standards of Care is the right to availability of high quality pharmaceutical care and safe medicines management systems for people with dementia in all settings. To support implementation of this standard, the Royal Pharmaceutical Society has declared a commitment to create an expert working group that will define the pharmacists' contributions to the implementation of this strategy.

A number of resources are available to health and social care staff to assist them to meet the learning needs expected of them. NES/SSSC have produced a dementia skilled learning resource (www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources/publications-repository/dementia-skilled-improving-practice.aspx.)

An Informed About Dementia DVD is also available through this link. The dementia Managed Knowledge Network (MKN) is available at www.knowledge.scot.nhs.uk/dementia.aspx. This provides up to date information, new resources and opportunities for discussion, and is an excellent way of keeping informed about developments in dementia.

There is also a dementia webinar available from NES Pharmacy at www.nes.scot.nhs.uk/education-and-training/by-discipline/pharmacy/about-nes-pharmacy/educational-resources/resources-by-topic/mental-health/dementia/dementia-webinar.aspx. You will need to register with the NES portal to access this if you have not already done so. The process is simple, and only takes a few minutes.

In addition, dementia specialist roles have been developed. Dementia Champions are NHS and social care staff trained as change agents to improve the care of people with dementia in hospitals. Dementia Nurse Consultants are available in the acute hospitals, and the Dementia Ambassador role has been developed in social services.

Involvement of pharmacy staff across all health care settings will be required to help achieve the key goals highlighted in the new strategy, and it is vital that pharmacists and pharmacy technicians acquire the skills they need.

Key areas highlighted in the new strategy are:

- » Improving post diagnostic support for people with dementia, their families and carers
- » Reducing unnecessary hospital admissions for people with dementia
- » Working closely with the Life Changes Trust (an independent charity investing in supporting changes which benefit people with dementia in Scotland (www.lifechangestrust.org.uk/) to help build dementia aware local communities
- » Help people to remain longer in their own homes or in a homely setting rather than hospital environments
- » Provision of community based health treatment wherever possible, including supported self-management of health conditions

- » Commitment to improve staff skills and knowledge by taking forward a second 'promoting excellence' training plan across the period of this strategy
- » A 10 point action plan to support implementation of the Standards of Care for Dementia in acute care settings
- » To finalise and implement a national commitment on the prescribing of psychoactive medication in people with dementia to ensure that such medication is only used where there is no appropriate alternative and where there is clear benefit to the person
- » Commitment to extend this work to improve services in other hospitals and NHS settings, home care services, adult day services and care home settings.

This resource is intended to help pharmacists and pharmacy technicians gain the knowledge and skills required to achieve the skill level appropriate to their role as defined in the framework (the levels expected of pharmacy staff are discussed in more detail later). The resource is designed to have a very strong focus on the pharmaceutical care needs of individuals with dementia, taking account of the needs of their family and carers. It is illustrated with fictitious patient examples. A sample pharmaceutical care plan is developed as the patient journey proceeds in each case, to illustrate the potential for meaningful pharmaceutical care planning and intervention in different care settings and different professional roles. The need for effective and timely communication between sectors and care settings as patients move between different care environments is emphasised throughout.

The resource has been structured to follow the dementia journey through diagnosis to end of life care. These stages are not, however, clearly defined and each patient's experience of dementia will be unique. Patients may experience behavioural and psychological symptoms such as agitation at earlier stages, or develop physical problems such as incontinence or swallowing difficulties at any stage. This should be borne in mind when working through the pack.

Section 1 Background

Learning outcomes

At the end of this section you should be able to:

- » Understand the changes that take place in the brain in dementia
- » Describe the different subtypes of dementia and how they differ in presentation
- » Discuss the prevalence of dementia now, and the projected prevalence in the future and how this is likely to impact on health and social services as the population ages
- » Gain an understanding of the knowledge and skills expected of pharmacists and pharmacy technicians as detailed in the NES/SSSC Promoting Excellence Framework for staff working with people with dementia, their families and carers.

1.1 What is dementia?

Dementia is an umbrella term used to describe a syndrome (i.e. a distinct pattern of symptoms and signs) where there is progressive impairment in two key areas:

- » Cognitive functions including memory, language, attention, thinking, orientation, calculation and problem-solving
- » Activities of daily living such as dressing, driving, shopping, eating etc.

Behavioural and psychological symptoms such as changes in personality, emotional control, social behaviour, depression, agitation, hallucinations, and delusions may also be present.

The symptoms are caused by biological changes within the brain causing damage to brain cells. The problems are severe enough to interfere with daily living such that work, social function and relationships are affected. The impairment in functioning should be present for at least 6 months and other causes such as delirium (acute confusional state) or other psychiatric disorders such as depression or schizophrenia should be excluded as a cause.

Dementia is generally irreversible, and leads to progressive inability to carry out activities of daily living. From initial mild impairment of memory and social functioning there is progression to lack of ability to communicate effectively, sequence tasks, remember recent events or learn new material, to eventual loss of ability to self care. In addition, emotional, personality or psychiatric symptoms such as delusions and hallucinations may emerge. The different sub-sets of dementia have different characteristics in terms of early symptomatology and progression, but the inevitable decline to the end of life stage tends to be similar. The ability to recognise faces and to communicate verbally is often completely lost in the final stages. Mobility is impaired and there is loss of bowel and bladder control. Constant care is eventually required. Timelines can vary markedly between individuals, and each experience of dementia will be unique.

1.1.1 Alzheimer's disease (AD) is the most common cause of dementia, accounting for around 50% of all cases. In AD the brain is progressively damaged by the formation of amyloid plaques and neurofibrillary tangles (NFTs). Amyloid is a general term for a family of proteins found in the brain. In a healthy brain, these would be broken down and eliminated, but in AD the fragments accumulate and form hard insoluble fragments in the brain. NFTs primarily consist of tau protein, which forms part of a structure called a microtubule. The microtubules help transport nutrients and other important substances from one part of the nerve cell to another. In Alzheimer's disease the tau protein is abnormal and the microtubule structure collapses. As the disease progresses it leads to the death of more and more nerve cells, and the progressive impairment in functioning described previously as it spreads through the brain structure. Observation of plaques and tangles on post mortem examination is required to confirm the diagnosis of AD. Shrinkage of brain tissue is also observed.

The cholinergic system is critical to normal memory and cognitive functions. In AD there is selective loss of acetylcholine (ACh) producing cells in the basal forebrain. When the first symptoms of AD occur, there is already a significant deficit in ACh. Levels eventually decline by 40-90% in moderate to severe AD. Other affected neurotransmitter systems are: noradrenaline; dopamine; serotonin; glutamate and gamma aminobutyric acid (GABA).

1.1.2 Vascular dementia (VaD) is the second most common form of dementia after AD. It accounts for around 20% of cases. It is not a single disease but a group of syndromes relating to different vascular mechanisms. Risk factors include – family history; male gender; hypertension; history of stroke or transient ischaemic attack (TIA); diabetes mellitus; smoking or atrial fibrillation (AF). Vascular dementia is preventable, and hypertension may be the cause in as many as 50% of cases. *The National Service Framework for Coronary Heart Disease* education programme aims to improve the control of hypertension, AF and diabetes in primary care. An improvement in these areas may help to reduce the number of cases of VaD observed. Prescription of clopidogrel (where there has been a proven infarct) or a statin may be beneficial. Evidence indicates that introduction of a statin may lower the risk of developing VaD in patients 50 years or over by up to 50%, independent of the presence or absence of untreated hyperlipidaemia.

In contrast to AD, VaD tends to have a rapid onset and follow a step-wise progression with periods of stability and periods of rapid decline. Insight is often maintained, at least in the early stages, and this can lead to distress for the person diagnosed with the condition as they are aware of the condition worsening. There tends to be neurological signs present such as gait disturbance, exaggeration of deep tendon reflexes or weakness of an extremity. As the disease progresses there can be continued episodes of cerebral ischaemia, (manifesting as transient ischaemic attacks) seizures and development of a wide shuffling gait. CT scans usually (but not always) indicate ischaemia and/or multiple infarctions.

1.1.3 Mixed dementia is diagnosed when patients have AD and cerebrovascular disease either clinically or based on neuroimaging evidence of ischaemic lesions. Growing evidence suggests that these two forms of dementia often co-exist, and may actually mutually induce each other, especially in older patients. One third of patients with VaD are found to have significant AD pathology with cholinergic deficits, which can influence the treatments used in individual cases.

1.1.4 Dementia with Lewy Bodies (DLB) accounts for approximately another 20% of cases. It is named after the German physician Fritz Heinrich Lewy, who first described distinctive extranuclear inclusions on microscopic brain tissue examination at the beginning of the 20th century. These became known as Lewy bodies. The findings can only be confirmed on post-mortem examination of brain tissue so the diagnosis is based on symptoms. An understanding of the difference between the symptoms of this form of dementia and the others is important, as those with the Lewy body form of dementia are particularly sensitive to antipsychotic drugs. Studies suggest around 50% of patients develop severe extrapyramidal symptoms, such as rigidity, altered consciousness, pyrexia and collapse when exposed to these agents. This has important implications for management of psychotic symptoms in these patients. In DLB the characteristic decline in cognitive and social or occupational functioning is present and there may or may not be prominent memory and visuospatial deficits (these deficits are common in AD and affect the ability of the person to process and interpret where objects are in space, affecting way-finding and ability to accurately reach for objects or shift their gaze to different points in space).

At least two of the following three symptoms must also be present to confirm the diagnosis:

1. Recurrent visual hallucinations (which are typically well detailed)
2. Fluctuating cognition
3. Spontaneous motor features of Parkinsonism.

There is also frequently a history of falls, syncope and transient loss of consciousness.

The remaining 10% of the dementias are generally subdivided into two further classifications:

1.1.5 Frontotemporal dementias (including Pick's disease, frontal lobe dementia with or without motor neurone disease, and the primary aphasia). This type of dementia is rare, but more commonly affects those under 65 years old and is the second or third most common form of dementia in this age group. Damage to the frontal and temporal areas of the brain is associated with personality changes. In the early stages the memory may remain intact, but the person may become uncharacteristically tactless or rude as they lose empathy with others. Inhibitions may be suppressed resulting in sexually inappropriate, aggressive or ritualistic behaviour. The person is also likely to develop language difficulties such as finding it difficult to find the right words or using lots of words to describe something simple. They may also stop verbally communicating spontaneously at all. As the illness progresses, the damage to the brain is more generalised, and the symptoms resemble the later stages of AD.

1.1.6 Subcortical dementia syndromes (that is those involving the basal ganglia, midbrain and brainstem such as Huntington's chorea; Parkinson's disease (PD) and/or possibly Parkinson's disease dementia (PDD); hypoparathyroidism; multiple sclerosis; AIDS dementia complex and normal pressure hydrocephalus). It is more common to see changes in personality and a slowing down of thought processes with this classification of dementia. Language and memory functions appear largely unaffected, at least in the initial stages.

There are many other diverse causes of dementia including multiple sclerosis, Creutzfeldt-Jakob disease, HIV infection, progressive supranuclear palsy, and Korsakoff's disease.

Individuals with good social skills may be able to maintain a high level of social functioning despite quite marked impairment in early dementia by developing strategies for masking or dealing with their impairment. More socially isolated individuals or those with visual or hearing impairment are less likely to manage to compensate, and may need help at an earlier stage.

Medical treatment is generally targeted at arresting or delaying progression of the disease by increasing the function of deficient neurotransmitter pathways and managing any associated behavioural and psychiatric problems. These interventions are aimed at treating a biomedical model of dementia, where reducing the impact of neuro-degeneration is the goal, but there are other models of dementia. Psychosocial models strongly support the idea that the way people with dementia are treated by others has a significant effect on their presentation. These models may explain why the extent of neuronal damage at post mortem does not necessarily correlate with the impact of dementia in an individual during life. Kitwoods 'Personhood model' formed the basis of the person centred care model widely adopted by health services today. Sabat and Harré developed the self-hood model which encourages an understanding of an individual as a person with a unique history, which forms the context of their behaviour and influences their reaction to the impact of dementia. These models emphasise the importance of factors such as social support networks, suitability of the environment for people with dementia and even the attitudes of different cultures to their ageing population. Having an understanding of the role of these factors in delaying the progression of dementia allows us to better understand the need to treat people with respect, and to consider their socio-economic, environmental needs and personal history as well as their medical needs.

Activity



Do some research on Kitwood's Personhood model and Sabat and Harré's self-hood model, and consider how it changes your view of the needs of people with dementia.

People with dementia, their family and carers should be supported through diagnosis, the increasing disability and requirement for extra help and care, and end of life care. The joint aim of all services involved should be to:

- » Maintain a structured and safe environment for the patient throughout their dementia journey
- » Maximise their remaining functional abilities
- » Ensure that nutritional needs and any appropriate medical care for concomitant physical pathology are met (including dental, eye and hearing care)
- » Maintain the dignity of the patient and promote choice throughout the illness (for them and their family and carers) and adhere to accepted principles of palliative care at the end stages of the disorder.

1.2 Who is affected?

There are an estimated 84,000 people with dementia in Scotland. It is a diagnosis primarily affecting older people (but is not an inevitable part of ageing) with the prevalence doubling every 5 years over the age of 65. Men are more likely to be affected up to the age of 75, but the overall lifetime risk is higher in females. This is partly due to the longer life expectancy in females. Due to the ageing population, the number of people with dementia is increasing, with an estimated 127,000 people likely to be affected by 2031 in Scotland (figures from Alzheimer Scotland).

In some people there is a genetic predisposition to AD. The apolipoprotein E (APOE) gene is the major genetic risk factor for inheriting the late onset form of the disease. This gene also increases the risk of heart attack and strokes. On the other hand, the early-onset form of AD is linked to three genes that are different from the APOE gene (this form of AD is rare).

Other genetic risk factors for dementia include having a family history of Huntington's disease, Creutzfeldt-Jakob disease and Pick's disease.

Those with cardiovascular disease and diabetes are more at risk of developing vascular dementia.

Excessive alcohol consumption increases the risk of developing dementia, especially Korsakoff's dementia as it reduces the amount of oxygen reaching the brain and interferes with the effectiveness of neurotransmitters. Alcohol abuse also worsens the cognitive abilities of individuals who already have dementia.

Brain injury can cause or worsen dementia and studies suggest that head trauma at any point in life significantly increases the risk of developing AD.

Although dementia is most common in older people, some people are more at risk than others of developing the illness at a younger age e.g. those with Down's syndrome, and those with the rare genetic predisposition to Alzheimer's disease.

Activity



Briefly describe the four most common forms of dementia

Think of a person you know who has dementia. Which type of dementia do you think they might have? What symptoms do you notice most? What stage in their dementia journey do you think they are at?

What impact do you think dementia has had on the person and their family/carers?

1.3 Role of the pharmacist and pharmacy technician

Regardless of their role, the majority of pharmacists and pharmacy technicians will come into contact with people with a diagnosis of dementia, their family or carers. Pharmacists working in community pharmacies and acute hospitals should aspire to be achieving the *Dementia Informed Practice Level* and the *Dementia Skilled Practice Level* as they will come into direct contact with people with dementia and their family/carers (www.scotland.gov.uk/Publications/2011/05/31085332/12).

Some pharmacists are giving support to people using support services such as 'care at home', housing support, those living in sheltered housing and those living in care homes. Others work in specialist mental health services. These pharmacists should aspire to achieve at least the *Dementia Informed Practice Level*, and some may aspire to the *Enhanced Practice Level* because of the level of contact they have with people with dementia, or because they are providing specific interventions or are involved in production of guidelines and policies in their practice setting. Prescribing Support Pharmacists (PSPs) should achieve at least the *Dementia Skilled Practice Level*, but if they have direct contact with people with dementia, they should achieve the *Informed Practice Level*.

Most pharmacy technicians should achieve the *Dementia Skilled Practice Level*, and some very specialised pharmacy technicians may wish to aspire to a higher level depending on their role and level of contact with people with dementia. The *Expertise in Dementia practice level* is unlikely to be relevant to pharmacy staff as it more appropriate for those who have daily direct care roles with people with dementia such as nursing and care home staff, or those providing support in a person's own home.

This resource is intended to provide pharmacists and pharmacy technicians with the knowledge and skills to equip them to achieve the *Dementia Informed Practice Level* and the *Dementia Skilled Practice Level*. The information is presented with a particular focus on the pharmaceutical care needs of people with dementia, and therefore complements other resources available to health and social care staff, but meets the particular training needs of pharmacy professionals. The *Dementia Enhanced Practice Level* and *Expertise in Dementia Practice Level* are outwith the scope of this pack.

A good starting point for pharmacists and pharmacy technicians with little knowledge of dementia and how it affects people is the 'Through our eyes' DVD produced by the Scottish Dementia Working Group (SDWG). It features seven members of the SDWG and lets viewers see what it's like to live life with dementia from the perspective of people with dementia. It is intended primarily for use as a training and awareness-raising tool for professionals at all levels within the health and social care sectors working in dementia care, but it can be used effectively in awareness-raising with all allied health professionals and the general public as well as those newly diagnosed with the condition. The DVD gives a very positive message and emphasises ways in which people with dementia, their families and carers can plan for a positive future and find ways of adjusting their lives to cope with the illness. The DVD is available through Alzheimer Scotland at www.alzscot.org/store/pages/Training%20materials for a small charge. A number of excellent fact sheets are also available on this website.

The web-links mentioned in the introduction i.e. the dementia skilled learning resource, the Informed about dementia DVD, the dementia webinar and the dementia Managed Knowledge Network (MKN) are also excellent resources. In addition, NHS Education for Scotland has produced The Acute Care Dementia Learning Resource www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources/publications-repository/acute-care-dementia.aspx.

Pharmacists and pharmacy technicians should be able to recognise the early signs and symptoms of dementia and be able to signpost people to appropriate services. They will be directly involved in the pharmaceutical care of those with a diagnosis of dementia and should therefore have a good understanding of the role of medication in the treatment of the cognitive and other symptoms associated with dementia. They should also understand the risks and benefits of the different medications available and have some understanding of the factors that influence the choice of medication in each individual patient.

Pharmacists should be able to develop a pharmaceutical care plan for an individual patient taking into account factors such as co-morbidities, drug interactions and impairments that may affect their concordance with medication, such as memory and visual impairment.

Pharmacy technicians may be involved in carrying out assessments to improve access to, and concordance with medication e.g. suitability for compliance devices or other systems.

In addition, all pharmacists should be aware of the recommendations of the Bannerjee project published in 2009 by the Department of Health which highlighted concerns regarding the over prescribing of antipsychotic drugs to people with dementia. These drugs are often prescribed to treat the behavioural and psychological symptoms of dementia (BPSD), but the report found that of 180,000 people with dementia prescribed these drugs, two thirds of the prescriptions were inappropriate.

In recognition of the role pharmacists can play in working with patients, carers, health and social care teams to reduce inappropriate prescription of antipsychotics in this group, the Royal Pharmaceutical Society of Great Britain launched *Dementia (the Right Prescription): Pharmacy and the Call to Action* (www.rpharms.com/dementia/dementia-pharmacy-and-call-to-action.asp)

A toolkit was launched in England to encourage (particularly community) pharmacists to question all prescriptions for antipsychotic drugs in those with a diagnosis of dementia or in those over 65 years old, by March 2012. All pharmacists were encouraged to establish joint working practices in order to facilitate discussion with doctors about appropriate prescribing, become better informed about best practice guidelines for prescribing and alternative interventions for people with dementia and familiarise themselves with resources to help support and signpost people with dementia to appropriate services. Hospital pharmacists were requested to ensure that up to date information was transferred to GPs after hospital admissions and that all antipsychotic prescriptions were clearly flagged and marked with review dates on discharge letters. Prescribing Support Pharmacists in GP practices were also asked to investigate and audit prescribing of antipsychotics in over 65 year olds.

As part of the new Scottish Dementia Strategy, a Joint Royal Pharmaceutical Society and Royal College of Psychiatry Old Age Faculty Pharmaceutical Care for People with Dementia Expert Working Group have been asked:

To agree and recommend a national commitment on the prescribing of psychoactive medications (excluding cognitive enhancers), as part of ensuring that such medication is used only where there must be a likelihood of benefit to the person with dementia and where there is no appropriate alternative.

The commitment in Scotland is to look at **psychoactive** medication as opposed to antipsychotics in isolation. This is due to the fact that it was highlighted in 'Remember I'm still me', (the Care Commission and Mental Welfare Commission joint report on the quality of care for people with dementia living in care homes in Scotland published in 2009) that patients were often being inappropriately treated with other sedative agents such as trazodone rather than antipsychotics.

The group is due to report its finding in 2014. There is a commitment to then implement the findings of this group, and pharmacists and pharmacy technicians across the care settings are likely to be involved in carrying out this work.

Pharmacy staff can also be involved in helping meet the commitments of the new strategy by:

- » Being aware of the early signs of dementia, knowing where and when to signpost patients to services
- » Being aware of patients who have been newly diagnosed, and who their link workers are, and if appropriate contributing to their person centred care and supported self management plans
- » Helping patients and carers make informed decisions about medication, and promoting concordance are also important, as is providing information and support for carers, including supporting them with their own health needs
- » Providing a 'dementia aware' environment for patients and carers – community pharmacies are at the heart of the communities they serve, and staff with a good knowledge of the condition can help
- » Promoting public health interventions to keep people fit and active, and be aware of how to link with local services and signpost people to community resources to help people with dementia and their carers to continue to be active members of their communities
- » Providing support for those in care homes or using support services in the community, and those working in hospital settings should aspire to improve their own knowledge and skills so that they can contribute to improvements in services and care for people with dementia in their care setting.

1.3.1 10 Essential Shared Capabilities (ESC)

It is useful for pharmacists and pharmacy technicians to also be aware of the 10 Essential Shared Capabilities (ESC). The 10 ESCs were originally developed and published by a partnership involving the Department of Health, the Sainsbury Centre for Mental Health, the National Institute for Mental Health in England and the NHS University in 2004. It is important to note that these organisations worked closely with service users and carers to develop the ESCs to ensure that they reflected their priorities. The aim of the 10 ESCs is to set out the shared capabilities that all staff working in mental health services should achieve as best practice and enable service users and carers to have increased awareness of what to expect from staff and services. Although they were developed for mental health services, the principles apply to those working with people with a diagnosis of dementia regardless of the care setting.

The 10 ESCs are listed below:

1. Working in partnership
2. Respecting diversity
3. Practising ethically
4. Challenging inequality
5. Promoting recovery
6. Identifying people's needs and strengths
7. Providing service user-centred care
8. Making a difference
9. Promoting safety and positive risk taking
10. Personal development and learning

In 2011 NES developed The 10 Essential Shared Capabilities for Mental Health Practice: Learning Materials (Scotland), which can be accessed at: www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources/publications-repository/the-10-essential-shared-capabilities.aspx

Activity

Look at the 10 ESC and think about how you could apply them in your own practice to improve the care of people with dementia.



Diagram of the 5 pillars model courtesy of Alzheimer Scotland



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1.3.2 The 5 Pillar Model and the 8 Pillar Model

In response to the commitment in the Scottish Dementia Strategy 2010-13 to improve post diagnostic support for people with dementia, Alzheimer Scotland developed a 5 Pillars Model of Community Support. This model was intended to help a person diagnosed with dementia make a person centred plan, help promote better self management and community support and reduce and delay the need for care services.

The 5 Pillars are as follows:

1. Understanding the illness and managing symptoms
2. Supporting community connections
3. Peer support
4. Planning for future care
5. Planning for future decision making.

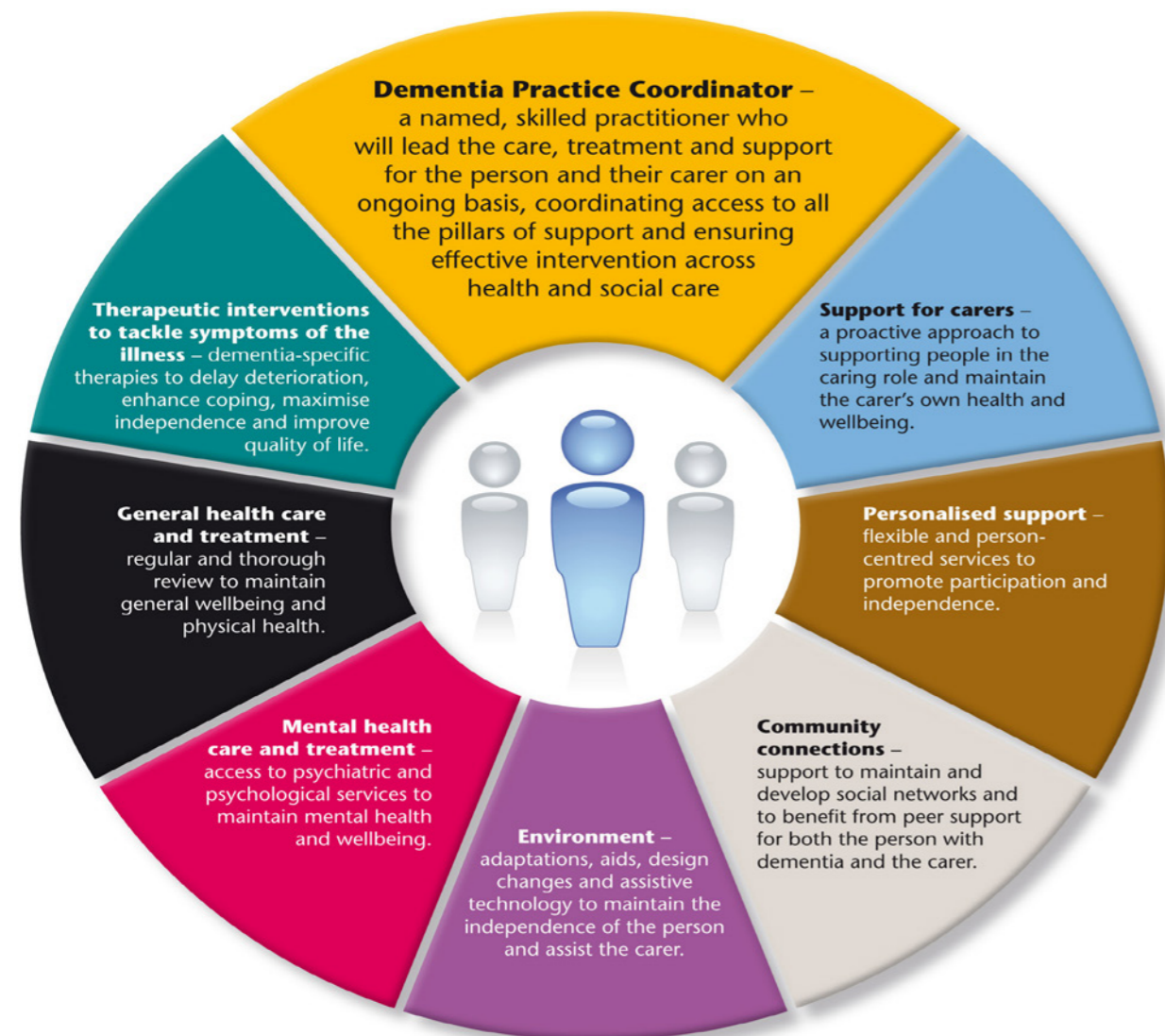
In April 2013 the Scottish Government made a commitment to a minimum of one year post diagnostic support provided by a named link worker for every person diagnosed with dementia.

Having piloted the 5 pillar model, and after considerable research, Alzheimer Scotland suggested an extension to it, adding a new linked 8 pillar model to bridge the gap from the self management period to the period where the person may require to access community care services. In the 8 pillar model, the central pillar is the role of a *Dementia Practice Co-ordinator* who will be a named, skilled practitioner who will lead the care, treatment and support for the person and their carer on an ongoing basis, co-ordinating access to all the pillars of support and ensuring effective intervention across health and social care. This person will be a key contact for anyone working with the person with dementia, their family or carers, including pharmacy staff.

The *Dementia Practice Co-ordinator* is the central Pillar in the model. The other 7 pillars are as follows:

- Pillar 1:** Therapeutic interventions to tackle the symptoms of the illness
- Pillar 2:** General health care and treatment
- Pillar 3:** Mental health care and treatment
- Pillar 4:** Personalised support
- Pillar 5:** Support for carers
- Pillar 6:** Environment
- Pillar 7:** Community connections

Diagram of the 8 pillars model courtesy of Alzheimer Scotland



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The models will link together to provide a seamless and person-centred approach. Testing this approach to providing intensive support, which is centred on a care co-ordinator role, has been listed as one of the priorities of the new Scottish Dementia Strategy 2013 – 2016.

See the Scottish Dementia Strategy 2013 – 2016 Proposition Paper (Feb. 2013), www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DSPropositionPaper2013-16 and Scotland's National Dementia Strategy 2013-2016 www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316

Pillars 2, 3 and 4 of the 8 pillar model are particularly relevant to pharmacy staff as they are associated with health promotion and providing therapeutic interventions including drug therapy. In addition, pharmacy staff will help deliver pillars 5 and 6 by assessing and addressing the information needs of people with dementia, their family and carers and helping them find the information they seek. They also have a role in identifying people at risk in the community as dementia progresses, and ensuring that they do not become vulnerable to exploitation, neglect or environmental risks. There is also a role as advocates for patient's rights as they become less able to express their needs or wishes, and a major role in supporting carers (with whom pharmacy staff often have very regular contact) with their own physical and mental health needs. Becoming more knowledgeable about the needs of people with dementia can help address pillar 7 as the impact of the environment on the person becomes clearer (this will be discussed in more detail later). Pharmacy staff can also support the person and their carers to maintain community connections (pillar 8) by building awareness of local resources and being able to signpost patients and carers to these.

Awareness of the Mental Health (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2000 and the Patient's Rights (Scotland) Act 2011 and how they apply to people who lack capacity to make decisions for themselves will be discussed later in this resource. The new Care Co-ordinator role will make it much easier for pharmacy staff to have a formal role as a team member caring for an individual with dementia. This is an exciting opportunity to be involved in improving care for people with dementia.

Throughout this resource, examples will be used to illustrate the difficulties experienced by people with dementia as their illness progresses, and ways in which the pharmacist can assist in reducing the impact of these problems and helping people access other services and resources. Appropriate use of drug therapy for the cognitive symptoms and behavioural and psychological symptoms will be discussed. A pharmaceutical care plan will be built up for each example as the resource progresses.

Summary Box

What have you learned from this section?



- » The definition of dementia and how it impacts on the patient at the various stages of the dementia journey.
- » The main classifications of dementia and their prevalence and different presentations, the most common types being Alzheimer's disease and vascular dementia.
- » The NES/SSSC Promoting Excellence framework details four knowledge and skill levels for those working in health and social services to aspire to achieve in relation to supporting people with a diagnosis of dementia, and that pharmacists and pharmacy technicians should aspire to achieve the level relevant to their contact with people with dementia.
- » A basic understanding of some of the expectations of the *Promoting Excellence Informed and Skilled Practice Levels* and how they relate to pharmacy practice.
- » Awareness of the recommendations of the Bannerjee report, and the resultant *call to action* of pharmacy staff to reduce inappropriate prescribing of antipsychotic drugs in people with dementia and how the recommendations will be implemented in Scotland.
- » Awareness of the 10 Essential Shared Capabilities and how they should be applied to your interactions with people with a diagnosis of dementia, their families and carers.
- » An understanding of the 5 pillar model to improve post diagnostic support, and the 8 pillar model proposed by Alzheimer's Scotland (and due to be piloted by the Scottish Government in the new dementia strategy), to help deliver integrated care in the community for those with a diagnosis of dementia.

Section 2 Risk factors for dementia

Learning outcomes

At the end of this section you should be able to:

- » Understand what action can be taken to help prevent dementia, or to slow progression of the illness
- » Know how to help people with dementia make informed choices about lifestyle changes and dietary supplements to reduce the impact of the illness and improve quality of life.

2.1 Can anything be done to prevent dementia?

It is not easy to prevent dementia because often the cause is unknown. The main preventable form of dementia is VaD. However, even in those with a genetic pre-disposition to AD there is evidence that lifestyle changes can protect against the development of the disease or slow progression. The following are lifestyle interventions that have been shown to be of benefit:

2.1.1 Regular exercise Studies suggest that taking regular exercise can reduce the risk of developing AD and slow progression in those who have already been diagnosed. The recommendation is to aim for 30 minutes of aerobic exercise five times per week. It is useful to consider including balance and co-ordination exercises as these can decrease the risk of falls especially in older adults. It is also useful to ensure that the head is protected when, for example, cycling as head injury increases the lifetime risk of developing dementia.

2.1.2 Healthy diet There is some evidence to suggest that a diet low in saturated fats and high in omega-3 fatty acids protects both the heart and brain, and reduces the risk of developing dementia. Other healthy eating advice would be to aim for 5 a day of a variety of fruit and vegetables. VaD is the main type of dementia preventable with lifestyle changes, but there is evidence that a healthy diet can reduce the risk of developing AD too.

2.1.3 Maintaining a healthy weight Being overweight can increase blood pressure, which increases the risk of VaD. The risk is even higher in obese individuals as they are likely to also have increased cholesterol, and are at risk of heart disease and strokes.

2.1.4 Stop smoking Studies suggest that heavy smoking in mid-life almost doubles the risk of AD and VaD in later life, and so is one of the most preventable risk factors for developing dementia. The brain benefits from improved circulation almost immediately, regardless of age, when smoking is discontinued.

2.1.5 Reduce alcohol intake Some studies have suggested that light to moderate drinking (i.e. the equivalent of 1-2 units per day) may be neuro-protective against dementia. There is debate over the mechanism of this protection, and whether it applies to any type of alcoholic drink, or specifically to wine. What is clear is that alcohol in excess significantly increases the risk of dementia by affecting cognitive function and causing neuro-degenerative disease. Consumption of alcohol by those diagnosed with dementia may also affect cognitive function and increase the risk of falls and injuries. Recommended limits of alcohol are 1-2 units per day for women and 3-4 units per day for men.

2.1.6 Mental stimulation There is some evidence that the rates of dementia are lower in people who remain mentally and physically active throughout their lives. Activities that have been shown to reduce risk include learning a foreign language, playing a musical instrument, reading, writing for pleasure, and joining adult education courses. There is no evidence that playing "brain training" computer games reduces the risk.

2.1.7 Stress management Reducing stress reduces the risk of hypertension and cardiovascular disease, reducing the risk of VaD. Some studies have also suggested a link to a decreased risk of AD.

2.1.8 An active social life Some forms of social exercise such as playing tennis, golf or group sports have been shown to reduce the risk of dementia. This may be partly because of the protective effect of the exercise, but once the diagnosis of dementia is established, more socially active individuals tend to fare better than those who are socially isolated. They are less likely to become withdrawn and depressed, and the interaction with others means they have to use their verbal and social skills, which helps them to maintain them for longer.

Activity

Search for local groups and initiatives in your area available to people with a diagnosis of dementia and their carers on www.alzscot.org/services_and_support



2.2 Role of dietary supplements and herbal remedies in treatment/prevention of dementia

In the context of a neuro-degenerative condition with no known cure, many patients are interested in the role of alternative medicines, both in prevention and management of the symptoms of dementia.

2.2.1 Ginkgo Ginkgo biloba, is a herbal remedy extracted from the leaves of the maidenhair tree. It is used in traditional Chinese medicine for a range of conditions including memory and concentration problems, confusion, depression, anxiety, dizziness, tinnitus and headache. The mechanism of action is thought to include increasing blood supply by dilating blood vessels, reducing blood viscosity, modification of neurotransmitter systems, and reducing the density of oxygen free radicals. A Cochrane review of the use of Ginkgo biloba in 2007 concluded that 'The evidence that Ginkgo biloba has predictable and clinically significant benefit for people with dementia or cognitive impairment is inconsistent and unreliable'. Despite this, there was still interest in conducting more reliable placebo controlled trials.

The Alzheimer's Society (a leading UK care and research charity supporting those with a diagnosis of AD and other dementias) conducted a placebo controlled trial of Ginkgo biloba in people with mild to moderate dementia in a community setting over a 6 month period in the UK in 2008 and concluded that Ginkgo biloba was of no benefit in the treatment of dementia. Although relatively safe in terms of side effect profile, potential drug interactions should be considered (it should not be used with aspirin or anticoagulants as it may potentiate their effects, can raise blood pressure when combined with thiazides and may cause coma when combined with trazodone) it is reasonable to inform people of the lack of scientific evidence to support this treatment for memory problems. The financial implications for people with dementia of self-medicating with such products should also be taken into account when giving advice.

2.2.2. Salvia The herb *salvia officinalis* has been used as a herbal remedy for its calming, relaxing properties and for its ability to improve cognitive function, especially memory. In one small study of salvia for agitation in dementia there was a small but insignificant benefit.

Both of these products are available without prescription in the UK. SIGN 86, the Scottish national guideline for Management of Patients with Dementia published in 2006 suggests that people with dementia using these products should consult a qualified herbalist.

2.2.3 Souvenaid®, a pharmacy only nutritional supplement available as a yoghurt drink, has recently been claimed to have benefits on memory function in mild dementia. The results of two trials to date have been promising, but only memory function was measured in the trials so the impact on other symptoms of the illness such as executive functioning or quality of life is unknown.

The combination of nutrients in Souvenaid® including omega-3 fatty acids, uridine and B vitamins is claimed to slow the loss of synapses in the nervous system, and thus reduce memory problems in mild AD. Pharmacists are urged to be cautious by the Alzheimer's Society who is concerned about the financial impact and lack of compelling supporting evidence for the product. It will cost more than £800 per year to take Souvenaid® daily as directed. As a nutritional supplement, this product does not need to undergo the same rigorous testing as a drug before being brought to market. There is therefore, much more robust evidence for the drug therapies available for mild to moderate AD.

The Alzheimer's Society would prefer pharmacists to promote healthy lifestyle advice instead, as there is better evidence for this as an intervention in the early stages of the illness. Inevitably, however, there will be those who are keen to try this product and it is important that pharmacy staff are aware of the pros and cons. At the moment, pharmacists must undertake training from the company before they are able to stock this product.

Activity

Do some research into the evidence and cost effectiveness of dietary and herbal remedies promoted to improve memory and form an opinion on whether you would recommend these.



Summary Box

What have you learned from this section?



- » The most preventable form of dementia is vascular dementia, but that the course and impact of all forms of dementia can be altered by healthy lifestyle choices such as good diet, social exercise classes, abstaining from smoking and reducing alcohol consumption. Reducing stress levels, having an active social life and taking part in mentally stimulating activities are also beneficial.
- » Dietary supplements available from health food stores and pharmacies are of questionable benefit in dementia, either for prevention or treatment, and the benefits should be weighed against the risks. The financial burden for the patient of purchasing these products should be considered, and pharmacy staff should have the knowledge to help the patient make an informed choice.

Section 3 Finding out it is dementia

Learning outcomes

At the end of this section you should be able to:

- » Describe the early symptoms of dementia and the effect they have on quality of life
- » Understand the importance of early diagnosis and the impact this has on patients, carers, health and social services and society as a whole
- » Understand how pharmacists and pharmacy technicians can act as stakeholders in promoting early diagnosis by recognising early signs of dementia and responding appropriately to requests for information and advice
- » Understand the referral process if worried that someone has possible signs of dementia
- » Describe common causes of memory impairment and have an understanding of common differential diagnoses
- » Have a basic understanding of the screening and diagnostic processes required before concluding diagnosis of dementia

3.1 Early signs of dementia

The early presentation of dementia varies depending on the type of dementia the person has, as illustrated by the examples in the following scenarios. Common early signs recognised by people with dementia, their friends, family or carers are as follows:

- » Struggling to remember recent events
- » Finding their concentration is poor e.g. finding it hard to follow programmes on TV or follow conversations
- » Forgetting names of friends or objects
- » Repeating things or forgetting what they were about to say
- » Having problems with thinking and reasoning
- » Feeling depressed, anxious or angry about being forgetful
- » Feeling confused even in familiar places e.g. getting lost, forgetting where the car is parked
- » People beginning to comment on the person's forgetfulness
- » Noticing a decline in ability to talk read or write.

Many people with dementia live with the condition without receiving a diagnosis. It is estimated that only around 40% receive a diagnosis in the mild/moderate stage of the illness. This has important implications as these people do not have access to the range of treatment options and post diagnostic support available. It has also been demonstrated that when people have an earlier diagnosis of dementia, they can be maintained in their own home for longer, resulting in reduced expenditure on in-patient care and maximising the quality of life for the individual.

The Scottish Government has produced a HEAT target to help support the early diagnosis and post-diagnostic support for people with dementia in Scotland. The HEAT target is as follows – ‘Maintain the proportion of people with a diagnosis of dementia on the Quality and Outcomes Framework (QOF) dementia register and other equivalent sources’. Encouraging GPs to maintain this register and carry out the associated monitoring for patients with dementia will improve recording of information about rates of diagnosis and improve follow-up monitoring of those on the register.

People may present at various stages of the illness and via different care settings. The main part of the initial assessment carried out by the GP or other referring service e.g. an acute hospital, is to exclude other explanations for the symptoms the patient is experiencing. For a diagnosis of dementia to be made, specialist mental health professionals must be involved in the process. Referral to these services can be made via various routes, and by various key stakeholders with the patient’s permission e.g. carers, primary care professionals, liaison services in acute hospitals, social workers, voluntary organisations caring for people in the community, and any NHS professional concerned about a person in the community including pharmacy staff. Referral will be made by highlighting concerns to the GP, who will then refer on to specialist services.

NHS Boards in Scotland have developed Integrated Care Pathways (ICPs) for dementia. (Examples can be readily found on the Internet by searching for “dementia ICP” or through your local intranet site). These have been developed locally taking account of how local services are set up but based on standards for dementia set out in the Scottish Dementia Strategy. People with dementia can expect a standard of treatment consistent with their local ICP standards.

The examples below illustrate how pharmacists and pharmacy technicians in various care settings can contribute to promoting early diagnosis and appropriate help for people experiencing difficulties which may raise suspicions of a diagnosis of dementia, but which may also be due to other conditions.

3.2 Illustrative cases

3.2.1 David



David is a 72 year old gentleman who lives in the housing estate across from the pharmacy. He is a regular visitor and is well known to staff as a polite and capable gentleman. He suffers from hypertension, and hyperlipidaemia and has been on ramipril and a statin for a number of years. He also has osteoarthritis in his hip and gets co-codamol 30/500 from his GP for this.

He normally manages his own repeat prescriptions and comes in to pick up his medication when he is passing on the way to the shops. He has brought in prescriptions for his three regular items today, but the pharmacy technician remembers dispensing them recently for him. When she checks the dispensing system she sees that he had received supplies of 2 month repeats for all three items twice in the last 3 weeks. When she goes to speak to him about it he becomes very distressed and says he can’t remember what happened to that medication. He has looked everywhere and can’t find it in the house so he thought he should order more. He hasn’t had his medication today and his hip is very painful.

Consider what the care issues here might be and what can be done to help David.

Pharmaceutical Care Issues	
Recent acute memory loss (potential untreated condition)	David’s memory problems appear to be quite acute – in recent weeks rather than months. This might indicate a delirium. It would be worth enquiring about whether he has been feeling physically unwell recently. If so, he should be referred urgently to his GP. He says he has been really tired recently but says ‘but I am an old man you know’.
Assess for drug induced/ related problems	High doses of codeine could result in confusion, or codeine could be a cause of constipation, which can cause delirium.

Poor concordance with medication	Because of David's memory problems he may have been poorly concordant with his medication and may have taken too much or too little. If the pharmacy provides this service, it may be worth checking his blood pressure. If it is high, referral to the GP would be appropriate. His blood pressure is 146/95mm/Hg, but you have no previous history for comparison and he cannot tell you what his usual reading is, so the GP would need to be contacted for this information.
Medication supply issues	David says he has no medication at home and has not taken today's dose of painkillers and ramipril. Before making a supply, it would be best to discuss the issue with the GP. On discussion with the GP, he agrees to a week's supply of medication for David and says to send him along to the surgery to be seen. David asks for a glass of water and takes his ramipril and two co-codamol in the shop, before leaving to go to the GP.
Improving concordance for the future	The pharmacy could help manage David's repeat prescriptions but this will only be helpful if he remembers where he has left the medication in the house and when he is supposed to take it. It is unlikely that a multi-compartment compliance aid would be helpful in David's current situation. It would be worth doing a detailed assessment of his needs but perhaps now is not the best time as he is distressed and may have an acute rather than chronic memory difficulty.
Locating missing medication	This is discussed with David as there is a significant amount of medication missing. He says his son visits him on a Saturday, and agrees to allow you to call his son to ask if he could try to find the medication.

David's GP phones you later to let you know that David has been admitted to hospital acutely confused (delirium) probably secondary to an infection. He has called his son to let him know, and has asked if he could have a look for the missing medication when he is in the house. He thanks the pharmacy technician for her vigilance in noticing the frequency of the repeats, as the surgery had not picked up on it. He says, although it is too early to say for sure he expects David to make a full recovery following appropriate treatment.

Discussion

In this case David's memory loss is acute, and is likely to resolve, however several issues arose here that pharmacy staff dealt with appropriately:

- » David's immediate physical health needs were dealt with appropriately, and timely communication with his doctor meant he received the help he needed quickly.
- » David was distressed and confused. The way he was communicated with, helped to ease his distress and reassure him that he was being listened to, and that his needs would be met. How this took place has not been illustrated in the example, but the way in which we communicate with people with memory impairment and confusion, and who may also be distressed is extremely important. Tips for communication effectively with people with dementia are discussed later in the pack.
- » A risk assessment was undertaken as David had significant amounts of medication at home. In this case the risks were dealt with through communication with a family member, but if this had not been possible there would have been a responsibility on pharmacy staff to inform an appropriate service of the risk under 'The Adult Support and Protection (Scotland) Act 2007'. This legislation is designed to protect people who may be at risk of harm or neglect, and who may be unable to protect themselves. People with a mental disorder such as dementia are more vulnerable to being harmed than people who are not affected by such an illness. People who have contact with those with disability, mental disorder, illness or physical or mental infirmity should be aware of this legislation, and how to access help if they feel that someone needs it. A useful resource giving more detailed information on the act, and how to contact services in your own health board area www.actagainstharm.org/what-the-act-does

3.2.2 Pauline



Pauline, a 67 year old retired school teacher comes into her local village pharmacy and speaks to the pharmacy technician at the counter, a girl she taught when she was at school. Pauline confides that she is a bit concerned that her memory is not as sharp as it used to be, and wonders if she should buy some Ginkgo biloba. She has read in one of the Sunday supplements that it is a natural, safe remedy for memory problems.

She says she is sure it is just her age, but she keeps putting things down and forgetting where she left them, and she is having real trouble remembering appointments. She got a letter in from her dentist yesterday because she forgot about her appointment, and she feels really guilty about wasting the dentist's time.

Consider how you would react to this request if you were the pharmacy technician or pharmacist asked this question.

Pharmaceutical Care Issues	
Provide Information and support	Clearly Pauline is worried enough about her failing memory to confide in someone and seek some help. It is worth re-assuring her that there can be many causes of memory problems apart from dementia, which is almost certainly what she is worried about. It is worth giving her a copy of the Alzheimer's Society – 'Worried about your memory?' booklet (www.alzheimers.org.uk/site/scripts/download_info.php?fileID=339) and talking through some of it with her. As the pharmacy technician knows the lady, she may be the most appropriate person to engage with her and talk to her initially, but it is worth referring her to the pharmacist so that a review of potential causes of memory problems, including any drug treatments Pauline may be taking can be undertaken. It is also important that Pauline is given enough information to make an informed decision about how to proceed. Alzheimer Scotland provides a confidential helpline to support anyone worried about dementia on 0808 808 3000 and Pauline may also find this helpful.
Assess for drug related causes of memory problems	Pauline is not currently on any medication, but it is always worth checking that something has not been recently prescribed or she has not purchased medication over the counter, which could be affecting memory. It is also worth bearing in mind that people may become more susceptible to the cognitive side-effects of medication as they get older, and even if they tolerated a drug when they were younger, it may need reviewed as they age.
Consider differential diagnosis – delirium	Acute memory problems, especially if they are moderately severe are more likely to be a result of a physical health problem, such as an infection, than an organic brain disorder such as dementia. It is important to exclude delirium as a cause of memory problems, although the symptoms would generally be much more extreme than those exhibited by Pauline and would include confusion and disorientation, rather than just impairment in short term memory. It is worth checking that she does not have physical symptoms such as a temperature, lethargy, pain when passing urine etc. to exclude a physical cause as the symptoms could worsen if they are not treated otherwise.

Consider differential diagnosis- depression	Lack of concentration and poor short-term memory are common symptoms of depression. It is worth asking questions about mood, concentration, sleep etc. to assess this as a possible cause. If Pauline's mood is low it is appropriate to refer her to her GP. Low mood and anxiety can also be symptoms in early dementia as people worry about the potential diagnosis and the long-term implications of it. It may not be possible for the pharmacist to determine what the primary problem is, but GP referral is appropriate.
Help Pauline to make an informed decision regarding the use of ginkgo biloba for her memory	As discussed in section 2 there is a lack of scientific evidence to support this treatment for memory problems. The financial implications of older people self-medicating with such products should also be taken into account when giving advice. It would be better for Pauline to seek a proper diagnosis than to self diagnose and self medicate. SIGN guideline 86 suggests that if she does wish to use this product, she should consult a qualified herbalist.
Promote positive lifestyle choices to decrease risks of developing / delay progression of dementia	Pauline is a non-smoker who has always maintained a healthy weight and has always enjoyed walking, although her opportunities are limited due to her husband's poor mobility now. She has good social contacts, and plays bridge with friends on Friday evenings and sings in the Church choir. She does not drink much but enjoys a social drink when out with friends. She does, however, find the demands of looking after her husband who is not physically well quite stressful. Apart from the stress, Pauline has a very healthy lifestyle and there is not much she could change to reduce her risks. It is worth suggesting to her that she mention to her GP that some help with the care of her husband might be beneficial as she is entitled to an assessment of her needs as a carer. At present Pauline won't hear of this, but is willing to consider some help around the house if that could be arranged.
Promote early diagnosis (taking into account Pauline's feelings)	Taking the step of going to her GP and voicing her concerns about her memory may be a frightening prospect for Pauline. It is important to emphasise the advantages of taking this step. Not only will her GP be able to treat or rule out other causes of memory loss but will also be able to support her with her problems and refer her for diagnostic testing if he/she feels the diagnosis may be dementia. It is important to re-assure Pauline that early diagnosis is the best outcome if she does have dementia as it gives her access to the full range of treatment and support options available at the earliest opportunity, and maximises her chances of managing to live independently for as long as possible.

Assist Pauline with the practicalities of making and remembering a GP appointment

Having been concerned enough to express worries about her memory in the pharmacy setting, it would seem reasonable for Pauline to go to see her GP about her concerns. It is very useful to prepare her for this visit by giving her a copy of the 'Worried about your memory?' booklet (www.alzheimers.org.uk/site/scripts/download_info.php?fileID=339). If the pharmacist did have any concerns that Pauline was suffering from an adverse drug reaction or a physical problem such as a urinary tract infection, it may be appropriate to speak to the GP to inform them of these concerns.

It is worth considering at this stage what Pauline's home situation is like. Pauline has a supportive husband at home, although she is his carer because he has physical health problems. If she had no one to accompany her to the GP or assist her in remembering the appointment, she may not go or she may not take in, or remember all the information she is given at the appointment.

Discussion

- » In this case pharmacy staff have empathised with Pauline and listened sympathetically to her worries. They have given her some information to take away, and have gone over this with her verbally as well. This is important as it should not be assumed that either verbal or written communications will be completely effective on their own if Pauline is in the early stages of dementia. She may have impairments in concentration, memory or reasoning which may mean she does not benefit fully from one or other means of communication.
- » The benefits of exploring her memory problems in more detail with her GP and seeking a diagnosis have been explained to Pauline in a sympathetic way so that she can make a decision about whether this is what she wants to do at this time.
- » The pros and cons of self-medicating with herbal products have been explained to Pauline so that she can make an informed decision about whether to purchase the product.
- » Ultimately, Pauline's decision regarding how best to proceed has been respected by the pharmacy team, but they have done their best to equip Pauline to make an informed decision.

3.2.3 Jenny



Jenny is a 74 year-old lady with a long history of recurrent depressive disorder. She lives alone in a one bedroom council flat two floors up, but usually manages out most days to pick up some shopping from the local convenience store. Her only relative is her son who lives in London. Her husband passed away two years ago after a long battle with cancer. She cared for him until he died. In recent weeks she has not been taking care of herself and has lost quite a bit of weight. Her neighbours, who usually keep an eye on her, became concerned that they had not seen her for a few days. When she did not answer her door they called the police who gained access to the flat and found her lying in bed in poor physical condition. On arrival at the Emergency Department (ED) she appeared confused and disorientated and could give no meaningful history of her condition. Her medication was confirmed with her Emergency Care Summary (ECS) as lofepramine 70mg twice daily, lithium carbonate 400mg daily and levothyroxine 100 micrograms daily. Jenny was transferred to the medical receiving unit. Her routine bloods were done, and her medication was prescribed on her in-patient prescription sheet as per ECS.

An emergency lithium level was taken and there was no lithium present in her blood, so she clearly had not been taking it at all. Her thyroid function test results showed that she was markedly hypothyroid. Her U&Es showed that she was dehydrated.

Pharmaceutical Care Issues	
<p>Confirm medication with at least two sources (patient unable to give history)</p>	<p>The ECS is a useful source of medication history, but the patient's consent should be sought before accessing it. As Jenny is unable to consent and her GP practice is closed, the ECS can be accessed as long as the lack of consent is recorded. In this case the patient is unable to say whether she has been taking her medication as prescribed, and where possible this should be checked. The ECS may also be incomplete if hospital only drugs are being prescribed, as these will not appear on the GP record. For these reasons, two sources should always be used in the medicines reconciliation process. If the patient is registered with a particular community pharmacy – the GP will be able to tell the hospital pharmacist which pharmacy this is.</p> <p>In this case Jenny had not been in to pick up her repeat prescription for the past 3 months. The community pharmacy had her on a managed repeat system so the repeat prescriptions had been ordered from the GP but 3 months supply was awaiting collection at the pharmacy. The community pharmacist said she had assumed that Jenny was probably in hospital as she had seemed quite 'wandered' the last few times she had seen her. She had phoned the practice one day and informed them that she had seen Jenny out at the shops in her nightdress in the morning and the receptionist said she would pass the information to the GP.</p> <p>On the basis of the blood results, Jenny's medication is discontinued at present, as she clearly had not been concordant recently.</p>
<p>Assess for drug related causes of memory problems</p>	<p>Lofepamine has anticholinergic effects, and can affect memory and cognition. Lithium, especially in toxicity can cause disorientation, confusion and memory problems, although these symptoms would normally be accompanied by ataxia, coarse tremor and gastro-intestinal upset. Hyper or hypothyroidism can result in a wide range of metabolic, physical and mental problems. Hypothyroidism has been linked to dementia, which may or may not be reversible when the thyroid function is normalised. Either taking too few or too many of her prescribed tablets could explain Jenny's current problems, although her blood results indicate the former.</p>

<p>Consider differential diagnosis – delirium</p>	<p>From the initial history delirium seemed a likely explanation for Jenny's symptoms, as she appeared to have been functioning normally until recently. The history from the community pharmacist suggests that there may have been some confusion and disorientation over the previous few months and this makes the diagnosis less clear. It should be borne in mind that depression, dementia, and delirium can co-exist. Dementia increases the risk of developing delirium five-fold, and the fact that Jenny is dehydrated further increases the risk. Jenny was initially treated for dehydration, and assessed for signs of infection. She was started back on her levothyroxine.</p>
<p>Consider differential diagnosis – depression / dementia</p>	<p>As Jenny has a history of depression, and has not been concordant with her medication for her depressive disorder it is possible that she is suffering from a severe recurrence of her depression which has led to her becoming so depressed that she has become very withdrawn and stopped eating and drinking. The assessment of her health from the point of view of diagnosing depression or dementia will require to be carried out by a mental health professional so referral to the liaison psychiatric service with a view to considering these diagnoses is appropriate.</p> <p>Following administration of intravenous fluids Jenny becomes more responsive, and is able to chat to the nurses. She can tell them a bit about herself, and knows her name, address and date of birth but has no recollection of the events leading up to the admission. When offered food and drink, she accepts it, but she admits her mood has been low of late. She keeps asking for her husband, and does not seem able to recall that he passed away 2 years ago. When asked about her son, she is not able to recall his name. She is unable to say what kind of place she is in just now, and keeps asking if someone would take her home because 'Stan needs her'.</p> <p>Jenny is considered medically fit for transfer to the acute mental health unit for assessment of her mental state.</p>

What happened to Jenny?

Following transfer to the acute mental health unit, Jenny is considered to be significantly depressed and is treated with a course of ECT. Her antidepressant is changed to sertraline, and lithium is re-instated. It is not considered entirely clear whether her cognitive function is within the normal range for her age at discharge, or not, as she is suffering the after effects of ECT making it is hard to assess properly. She is discharged with social work support and support from the Community Mental Health Nurse (CMHN) who will repeat her cognitive tests at 2 and 4 months post discharge. In the meantime, the care workers arranged by social services support Jenny by prompting her to take her medication as she is on lithium, which is considered high risk, and assist her to remember to visit her GP for her lithium monitoring.

At 4 months post-discharge Jenny's cognitive scores are within the normal range, and it becomes clear that her memory problems were related to a combination of delirium caused by dehydration due to self neglect, and a recurrence of her depressive disorder. Her mood disorder is well controlled and her mental state and functioning are good. Her CMHN will continue to see her and her consultant psychiatrist will see her six monthly for follow-up of her mood disorder, but she is told that she is not suffering from dementia.

Discussion

A large number of patients in acute hospitals at any time may be suffering from dementia. At present there is only one pharmacist who has qualified as a dementia champion in Scotland, and she is working with pharmacy staff in acute hospitals to try to raise awareness (through various road-shows and training initiatives) of the issues experienced by patients and carers. As part of the workplace evaluation carried out by the dementia champion, various issues were highlighted in relation to the training needs for pharmacy staff.

Some staff admitted that they were unsure of how to treat individuals with dementia, especially if they appeared distressed or agitated, and therefore tended to avoid engaging with them. Patients reported that staff in hospitals often talked about them in front of them without engaging them.

There was a lack of awareness of the signs and symptoms of dementia amongst pharmacy staff, and the fact that patients may have the diagnosis, but be at very many different stages in the dementia journey. Some staff tended to make assumptions that the person would not know what their medication was, and would be unable to manage it at home without the use of compliance aids or other memory prompts. Patients reported that decisions were sometimes made without consultation, such as arranging compliance aids, and this reduced their confidence and independence.

Patients reported that they needed people to be more understanding about their communication needs. People need to be patient with them and understand that they can have trouble finding the right word or organising their thoughts into a sentence. Some tips for communicating effectively with people with dementia are included later in this pack.

Pharmacy staff also require to have a good awareness of medication which can worsen cognitive function, or cause other physical health problems such as constipation or urinary retention, which can cause distress or pain. Pain should be adequately treated, preferably with the use of regular, rather than as required, medication if the patient is not able to adequately express their needs verbally.

The importance of environment in all settings to help people with dementia find their way around and feel comfortable has been recognised, and all acute hospitals are looking at ways of improving signage etc. This is discussed in some detail in section 5 of this pack.

This case illustrates the need to check more than one source before prescribing medication in a hospital setting, as it is not necessarily the case that the patient is concordant with all of their prescribed medication and the ECS may be incomplete or inaccurate. It is important not to discount the patient as one of the sources just because they have a diagnosis of dementia. Either they or their carer may be an excellent and reliable source of this information.

Unfortunately the managed repeat system has not been of benefit in this case as assumptions have been made about why Jenny has not been in to pick up her medication, and neither the GP practice nor the community pharmacy had investigated further. This should have been considered a warning sign, and steps should have been taken to ensure that the patient, carer and/or GP were contacted. The Scottish Government published a letter in July 2012 discouraging the use of managed repeat systems except in exceptional circumstances. Instead it would be preferable to assess the patient for suitability for the NHS Chronic Medication Service (CMS), and if appropriate use the serial prescribing/dispensing elements of this service. This leaves the control of the provision of the serial prescription under the control of the individual patient's GP, not the community pharmacy.

The community pharmacist did the right thing by highlighting when she thought a person she knew might be at risk in the community. Unfortunately this had not been followed through at the GP practice, and this highlights the importance of effective inter-agency communication when vulnerable adults are at risk in the community.

The hospital pharmacist can advise on whether the medication Jenny is on may be implicated in her current condition, on appropriate testing and serum levels for lithium, and how to safely re-instate medication if, and when this is appropriate.

Transfer from one hospital to another, or between wards within a hospital is a risk if communication is poor. The medicines reconciliation process should be repeated on admission to the mental health unit to ensure that prescriptions are correct, appropriate and accurately transcribed.

Following discharge, the hospital and community pharmacies have successfully communicated and developed a care plan for Jenny which reduces the risks of her coming to harm in the same way in future. When it is clear that Jenny's medication has been stabilised again it would be worth considering her for CMS as she has long term conditions, and is on a high risk medication in the form of lithium. This would help ensure that appropriate blood monitoring tests take place and that her repeat prescriptions are managed appropriately.

The community pharmacy technician could take responsibility for ensuring that Jenny's needs continue to be met without the need for a compliance aid. It would also be worth making sure that everyone in the pharmacy knows who to contact if Jenny experiences any problems, or there are any concerns about her welfare. A contact sheet in her care plan would be very useful.

3.3 What happens when a patient presents to their GP with memory problems?

3.3.1 History taking and initial investigations

When a patient presents to their GP with symptoms consistent with a possible diagnosis of dementia, it is important that the following steps are taken:

- » A full history of the presentation is taken including the onset and duration of symptoms. Sudden onset of symptoms may raise a suspicion that there could be an explanation other than dementia. Wherever possible a second corroborative account should be sought from a family member or carer.
- » Psychological tests, such as Montreal Cognitive Assessment (MoCA) or Addenbrooke's Cognitive Examination III (ACE III), and assessments for depression should be performed as part of the differential diagnosis process. Note: the Mini Mental State Examination (MMSE) commonly used in the past is no longer being used in most areas now as it is subject to copyright restrictions.
- » An assessment of the person's social circumstances and any risks to determine whether there is a need for support services.
- » Provision of the 'Worried about your memory?' booklet if this is appropriate.

It may require more than one appointment for the full assessment to be undertaken by the GP. Some GPs may lack confidence in carrying out this assessment, but it is important that they at least try to exclude other common causes of memory loss before referring to specialist services.

3.3.2 Montreal cognitive assessment (MoCA)

This is a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations and orientation and takes about 10 minutes to administer. The score is out of a maximum of 30, with scores above 26 being considered normal. It is available from the MoCA website at www.mocatest.org/

Note – Executive functioning refers to the ability to carry out complex tasks such as planning ahead, setting goals and objectives, prioritising or sequencing tasks e.g. working out what order to add ingredients to a dish when cooking.

3.3.3 Mini-mental state examination (MMSE)

The MMSE is a brief, structured test of mental status that should take about 10 minutes to complete. It tests global cognitive function, with questions designed to assess orientation to time and place, word recall, attention and calculation, language abilities, and visuospatial ability (this is tested with a drawing task). The test is scored out of 30, with scores above 25 generally being considered normal. A score of 19-24 would indicate mild impairment, 10-19 would indicate moderate dementia and a score below 10 would indicate severe impairment.

The MMSE is a useful validated tool with reasonably good sensitivity (i.e. ability to identify those with the illness), and reasonably good specificity (i.e. ability to identify those who do not have the illness). It is also very useful to help track the course of cognitive impairment over time in an individual. Typically the MMSE score decreases by 3-4 points per year in an untreated patient with Alzheimer's disease. Response to treatment can be monitored and this can help guide future management.

One issue with widespread use of the MMSE is that it is no longer available free of charge, and has to be ordered from the copyright holder meaning that many health board areas have stopped using it routinely for initial screening and now use other tests instead.

3.3.4 Addenbrooke's cognitive examination (ACE III)

ACE-III is designed to operate in a similar style to the previous version, the ACE-R (this was withdrawn due to its similarity to the MMSE, which led to accusations of copyright infringement), scoring out of 100 and providing scores in five sub-domains. The main difference is in the language sub-domains. The test and scoring guides are available as follows – test available at [www.neura.edu.au/sites/neura.edu.au/files/page-downloads/ACE-III%20Administration%20\(UK\).pdf](http://www.neura.edu.au/sites/neura.edu.au/files/page-downloads/ACE-III%20Administration%20(UK).pdf)

Scoring guide available at [www.neura.edu.au/sites/neura.edu.au/files/page-downloads/ACE-III%20Scoring%20\(UK\)_0.pdf](http://www.neura.edu.au/sites/neura.edu.au/files/page-downloads/ACE-III%20Scoring%20(UK)_0.pdf)

This is now the most widely used cognitive assessment tool in elderly mental health services throughout Scotland. In recognition of this fact, a team from Glasgow University's Institute of Health and Wellbeing and supported by funding from NHS Education for Scotland, has developed an online training tool to aid consistent administration and interpretation of the ACE-III amongst health care staff. The tool is available at www.fom.gla.ac.uk/acelltrainer/

3.3.5 Alzheimer's disease assessment scale – cognitive (ADAS – Cog)

This is a more detailed assessment of cognitive decline, included here for completeness because it is often cited in research articles (ADAS-Cog was an important measure used in clinical trials of the cholinesterase inhibitor drugs) (AChEIs). It takes longer to administer than the other tests listed (around 45 minutes), and the interviewer requires specialist training. For this reason it is usually administered by a neuropsychologist or psychologist with specialist training, and is not often used in routine clinical practice.

3.3.6 Screening tests for reversible causes of symptoms

Reversible causes of memory problems include:

- » Depressive pseudo-dementia
- » Hypothyroidism
- » Seizure disorders
- » Normal pressure hydrocephalus, other space-occupying lesions in the brain
- » Vitamin deficiency for example B12 deficiency
- » Delirium (often described as an acute confusional state).

To screen for, and exclude these, blood tests including a full blood count (FBCs); urea and electrolytes (U&Es); glucose; liver function tests (LFTs); vitamin B12; folate; bone profile; thyroid function tests (TFTs); erythrocyte sedimentation rate (ESR); and lipid screen should be carried out. A mid-stream specimen of urine (MSSU) and chest x ray should also form part of the screen. The results of these tests will determine whether there is infection, give some indication of whether there may be a tumour, and screen for diabetes, thyroid problems, vitamin deficiencies or cardiovascular risk factors such as hypercholesterolaemia. More than one appointment may be required to carry out this screening, and make a provisional differential diagnosis. If there are treatable abnormalities in the blood screen such as vitamin deficiency, thyroid problems or cholesterol problems, treatments should be initiated as appropriate.

A GP may decide that it is appropriate to refer a patient for a CT scan at the same time as referring to the memory clinic, or they may decide to leave this decision to the Elderly Mental Health Team.

3.4 Differential diagnosis

It is important to differentiate between dementia, depression, delirium and mild cognitive impairment, as there is significant overlap in symptoms between them. There are also significant differences in presentation between the different types of dementia as explained in section 1. The priority at this point is to screen for, and exclude other causes in order to determine whether to refer the patient to a specialist for further investigation and confirmation of a diagnosis.

Below is a table which illustrates some of the differences between the features of the 3Ds i.e. depression, delirium and dementia which can aid in diagnosis, particularly if a detailed history of the progression of the illness is available. It should always be borne in mind, however, that one or more of these may co-exist at any time, and that dementia is a significant risk factor for development of delirium. It has been suggested that patients with dementia who develop delirium are more likely to develop the hypoactive form, presenting as very quiet and withdrawn.

The 3Ds, dementia, delirium and depression: a quick guide.

Table from NHS Education for Scotland Acute Care Dementia: Learning Resource www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources/publications-repository/acute-care-dementia.aspx

Domain	Dementia	Delirium	Depression
History	Slow onset weeks/ years	Sudden onset	Slow onset over weeks/months
Awareness	Usually unaffected	Distracted, reduced or changes rapidly	May have difficulty concentrating
Sleep Pattern	Stable over time	Significant change from usual pattern	Difficulty getting to sleep or waking early
Memory	Recent memory affected. Difficult learning new material	Immediate and recent memory difficulties	Person may say memory is worse
Thinking	Difficulty reasoning or understanding	Disorganised, jumping from one subject to another	Slowed. Feelings of hopelessness

3.4.1 Delirium

Delirium is a medical emergency and normally patients will present in the acute hospital setting. Precipitating factors may include any type of infection; trauma; surgery; withdrawal from alcohol or drugs such as benzodiazepines; some medications e.g. analgesics or drugs with anticholinergic side-effects; dehydration, malnourishment or constipation; or uncontrolled pain. The elderly are particularly at risk of developing delirium and those with dementia are at a five-fold increased risk.

There are a number of screening tools for delirium assessing the main features i.e. acute onset and fluctuating course, inattention, disorganised thinking and altered level of consciousness. In addition to these features, patients may have language difficulties, making communication challenging and they may be distressed by vivid hallucinations, illusions (e.g. seeing faces in the patterns on the curtains) or delusions (e.g. believing that people are stealing their belongings or mean them harm). In addition some patients become hyperactive, becoming physically and psychologically agitated. These symptoms can make treating those with delirium difficult in a busy acute ward setting. It is important that there are minimal changes to the patient's environment wherever possible, and they are disturbed and stimulated as little as possible to reduce distress.

Treatment of delirium should be targeted at the underlying cause e.g. treat infection, pain, dehydration or constipation. Environmental factors can contribute significantly to the patient's presentation and should be considered before drug therapy e.g. improving lighting, reducing sound stimulus, having someone sit with the patient, may all have a calming effect and reduce the need for sedative medication. Haloperidol and olanzapine are generally first line for treatment of delirium unless they are contra-indicated (e.g. in DLB or Parkinson's disease) in which case a short acting benzodiazepines can be used. It should be noted, however that benzodiazepines can worsen delirium. Benzodiazepines are first line in delirium tremens caused by alcohol misuse. If medication is needed, the minimal effective dose should be used and the patient carefully monitored for respiratory depression (with benzodiazepines) and extrapyramidal side-effects (with antipsychotics). Co-morbidities such as cardiac problems, and potential drug interactions should be taken into account before prescribing.

In recognition of the high incidence of delirium in acute hospitals, particularly among the older adults, Health Improvement Scotland (HIS) has developed a work stream focusing on identification and immediate management of delirium in acute care in Scotland as part of the Older People in Acute Care (OPAC) Improvement Programme www.healthcareimprovementscotland.org/our_work/patient_experience/opac_improvement_programme.aspx

3.4.2 Depression

There is a significant overlap between the symptoms of depression and dementia. Patients with low mood frequently complain of poor concentration and memory problems. In addition to these symptoms, however, they often have changes in their appetite, sleep and reduced interest in enjoyable activities and hobbies. These symptoms are not usually present in the early stages of dementia.

Various screening tools are available to GPs to assess for depressive symptoms. In acute hospitals elderly patients should be considered at high risk of developing depression, and it is a good idea to ask them about their mood during admission. The risk of suicide in the elderly, particularly those with chronic illness should not be overlooked, and if there is a concern that an elderly patient in hospital is depressed a referral should be made so that they can be assessed by a liaison psychiatrist during admission.

It is very common for people with dementia to develop depression, especially if they are not diagnosed early or given a good standard of post-diagnostic support. Often, therefore, the two conditions may co-exist and a person may present with symptoms of both conditions. If the diagnosis is unclear, it is appropriate to refer to mental health services for further screening.

3.4.3 Mild cognitive impairment (MCI)

Mild cognitive impairment is a measurable impairment in cognitive functioning which is severe enough to be noticed by the person and their friends and family, but not severe enough to meet the diagnostic criteria for dementia. It is a diagnosis based on clinical judgment and history from the patient, as there are no diagnostic tests for the condition. Some people with MCI go on to develop dementia, but some do not get worse, and some even get better over time.

There are two categories of the condition:

- » Amnesic MCI where memory is the main area of functioning affected and the person may have difficulty e.g. remembering appointments or recent conversations or events.
- » Non-amnesic MCI predominantly affects thinking skills such as judging time, sequencing tasks or visual perception.

It is recommended that those with MCI be re-evaluated every 6 months. There is no evidence that medications used in dementia will delay or prevent the progression of MCI to dementia. People with MCI should be encouraged to take part in mentally stimulating and socially engaging activities to try to maintain brain functioning, and reduce their cardiovascular risk factors as much as possible through lifestyle interventions such as exercise and healthy eating.

Although these people do not have a diagnosis of dementia, they have some of the impairments in functioning experienced by those who do. It is estimated that between 10-20% of those aged 65 or older may have MCI. This illustrates the need for those who interact regularly with older adults to be sensitive to the fact that they may have impairments in cognitive functioning and be aware of the resources and strategies available to help these people to lead full and active lives in their communities.

Activity

Revise the main differences in presentation between depression, delirium and dementia and make notes.



Note some practice points you could implement to help people with early dementia.

3.5 Referral to mental health services

GPs and medical staff in acute hospitals should be aware of how to refer patients to elderly mental health services in their local area for assessment. It is appropriate for anyone who is worried about a person to be a key stakeholder in the referral process including the patient, carer, primary care services, liaison services, social work, voluntary organisations and anyone who works for NHS services, including pharmacy staff. Usually, only urgent referrals are accepted by telephone. The patient and carer (if appropriate, as the patient has the right to refuse to allow this information to be given to the carer if they wish) should be made aware of the referral. Acute hospitals would generally refer via the liaison mental health service within the hospital and an initial assessment may be carried out in the acute ward before discharge if appropriate.

Referrals are screened for priority, and a key worker should be allocated to the patient. Unless the referral is urgent, a key worker will see the patient within 4 weeks of the referral being received. The key worker should complete a risk assessment and generic Integrated Care Pathway (ICP) assessment at this point. This will help identify whether there is a need for other members of the multi-disciplinary team to be involved in the care of the patient e.g. occupational therapists or social work. The key worker will then arrange follow-up appointments as often as required, will provide information and support pre diagnosis, at the point of diagnosis and post diagnosis.

The patient should be seen at a consultant led clinic within 18 weeks of receipt of the referral. Some memory clinics have specialist pharmacists involved, who may have a role in medicines reconciliation and compiling detailed medication reviews for some patients, and advising GPs or memory clinic doctors on adjusting medication to reduce the impact on memory function.

3.5.1 What happens at a memory clinic?

Not all clinics work in the same way. Some clinics prefer to perform a multidisciplinary assessment in one day, meaning that the patient will see several professionals at the clinic, including a psychologist and a psychiatrist. Other clinics may perform the same assessments over more than one visit. There are advantages and disadvantages to both systems. Doing all the assessments at once reduces the number of visits for patients and carers and allows a diagnosis and plan of care to be formulated more quickly. It can, however, be tiring for the individual to undergo such a lengthy and thorough assessment in one day. Essential elements of the assessment include:

An evaluation of all the test results carried out by the referring physician and an assessment of whether any have been missed or need repeated, or whether further tests are required.

Extensive assessment of functioning including a physical examination to assess for neurological signs and symptoms is carried out. The patient will also receive an extended memory test, usually the ACE III. Comprehensive neuropsychological evaluations for dementia and cognitive change include tests of multiple cognitive domains, typically including memory, attention, perceptual and motor skills, language, visuospatial abilities, reasoning, and executive functions. Measures of mood and personality may be relevant in many cases. This is why a multidisciplinary assessment, involving a psychologist if possible, is particularly useful. This type of testing can detect even very early AD and is superior to imaging tests such as CT and MRI scans in discriminating between those with AD and controls in studies. It also helps in distinguishing between the different types of dementia.

The patient and carer will be interviewed both separately and together in order to get as complete a history as possible. Carers often feel they can speak more freely and will give a more useful and accurate history of the difficulties and impairments the patient has, if they do not have to do so in front of their loved one. The carer may be asked to complete a questionnaire such as The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) to help with the history.

When interviewed by an experienced mental health professional, the patient's ability to relate a logical and complete account of their autobiography and current complaints gives an invaluable insight into their language, memory, and organisational abilities.

Neuro-imaging studies may be requested. Computed Tomography (CT) scans can distinguish between dementia and depression, but may be normal in early AD. They are not useful in differentiating between the different types of dementia, except where there is a clear vascular component. Magnetic Resonance Imaging (MRI) scans can be useful in distinguishing between AD and VaD. Single-Photon Emission Computed Tomography (SPECT) scans are useful where the diagnosis is in doubt, as they can be useful in distinguishing between the sub-types of dementia. According to SIGN 86, neuro-imaging should form part of the diagnostic work-up in patients with suspected dementia. SPECT scans may be used in combination with CT scans when the diagnosis is in doubt. It should be noted that structural imaging cannot be used on its own to determine the diagnosis but must be used in combination with all of the above.

The patient will be assigned a key-worker who will carry out a generic ICP assessment, which includes the needs of the carer, and an assessment of the function of the patient. This may require a home visit to complete in some cases, and the key worker will arrange whatever follow-up or support is identified from this assessment. They will also carry out a risk assessment, and arrange for any action needed to be taken. In extreme cases this may require a hospital admission, but in most cases risks can be identified and reduced in the home environment. The key worker will arrange any follow-up necessary. The key worker is responsible for supporting the patient and carer through the diagnostic process, the diagnosis and in the post diagnostic period. They could be a social worker or community mental health nurse (CMHN) depending on the needs identified.

The patient may be given a provisional diagnosis at this point or asked to return to the clinic when all the diagnostic screening test results are available. At this point diagnosis will be discussed.

Summary Box

What have you learned from this section?



- » What the common early signs of dementia are.
- » How to differentiate between dementia and other common causes of memory problems.
- » How pharmacists and pharmacy technicians can help identify people who may have early signs of dementia or other illnesses, which can cause memory problems.
- » How pharmacists and pharmacy technicians have a responsibility under adult support and protection legislation to help adults at risk in the community due to a mental disorder, to access the help they need.
- » How pharmacists and pharmacy technicians can promote early diagnosis of dementia and help people worried about their memory make informed choices about whether they wish to seek help.
- » The diagnostic process leading to confirming a diagnosis of dementia.
- » How a memory clinic works and an understanding of a key workers role in supporting a person newly diagnosed with dementia.

Section 4 Living well with dementia

Learning outcomes

At the end of this section you should be able to:

- » Describe how legislative frameworks are used to support the person with dementia to exercise their rights and choices (and if necessary protect them from harm) and be able to discuss options with individuals or other members of the multidisciplinary team, if and when necessary
- » Understand what a patient can expect to be told when they are given a diagnosis of dementia and what the follow up arrangements are likely to be
- » Describe how the acetyl cholinesterase inhibitor (AChEI) drugs or memory enhancers work and their licensed indications for use
- » Describe the differences between these drugs and how they should be used according to current national guidelines
- » Understand the pharmacology, side-effects, contra-indications, cautions, drug interactions and monitoring requirements for these drugs and discuss these with patients, carers and other members of the multidisciplinary team
- » Promote healthy lifestyle choices and appropriate drug therapies for those newly diagnosed with dementia.

4.1 Receiving a diagnosis

The patient will be invited back to the consultant led clinic to discuss their diagnosis and start a care plan with their key worker if they have a dementia. If the diagnosis is made at an early stage in the illness the patient should be able to fully participate in discussions about their treatment and planning for the future if they choose to be told their diagnosis. If diagnosis is at a later stage in the illness, issues regarding the ability to understand and consent to treatment and planning for the future become more complex. Wherever possible, the diagnosis, including the type of dementia should be discussed. It is important to gauge the feelings of the person with dementia regarding diagnosis. The information should be imparted sensitively in a suitable setting, and after exploring how much the person already knows, and how much they want to know. Advantages of receiving a diagnosis include reducing the uncertainty and worry surrounding the cause of their symptoms, and allowing them time to plan for the future. It also allows potential treatment options to be discussed openly, and means the person can discuss the resources available to people in their area with dementia, without the barriers to communication that are present if diagnosis cannot be mentioned. It is best if they share the diagnosis with loved ones, but this should only happen with the permission of the person with dementia. Written information should be provided to back up the discussions as the person may struggle to remember all the information they have been given later.

It is important that the key worker shares the appropriately coded diagnosis with the GP so that they are aware of the diagnosis and can provide post diagnostic support and help for the patient and family members. Selection of any medications for a person with dementia should include an analysis of its propensity to cause anticholinergic effects. Any of the following agents is likely to produce anticholinergic effects, which will interfere with memory and may exacerbate or cause confusion: hyoscine, oxybutynin, procyclidine, antipsychotics (including chlorpromazine, flupentixol, fluphenazine, zuclopentixol, clozapine, olanzapine), tricyclic antidepressants, furosemide, digoxin and cimetidine. A useful reference table indicating the relative cholinergic risks of different commonly used medication can be found at www.uea.ac.uk/mac/comm/media/press/2011/June/Anticholinergics+study+drug+list. The GP will be involved in assessing the ongoing need for medication which may have an adverse effect on memory, and should stop unnecessary drugs at the point of diagnosis. They will also have to continue to be vigilant about future prescribing to avoid the risk of drug interactions with newly prescribed drugs or worsening symptoms of dementia by prescribing drugs with an effect on cognition.

4.1.1 Driving and dementia

If a person is diagnosed with dementia and wishes to continue to drive they should be informed that the process to be followed is:

- » By law, they must inform the DVLA of their diagnosis straight away. In some cases their doctor may advise that they stop driving until further assessments can be carried out (which may take several weeks), and this advice should be followed.
- » They must also immediately inform their insurance company of their diagnosis. If they do not do so and they have an accident, they are likely to find that their insurance is invalid. Driving without insurance cover is against the law.

The DVLA will send the person a questionnaire seeking their permission to request medical reports from their GP or specialist. Based on the reports the DVLA will do one of the following:

1. Advise the person that they can no longer drive.
2. Request that the person undertakes a driving assessment or driving appraisal. These include an on road assessment with an advanced driving instructor, an assessment by an occupational therapist, and tests of reaction time and vision. Depending on the results of this the person will either be informed that they can no longer drive, or be issued with a new driving licence valid for a limited period only.
3. Notify the person that they may continue to drive and issue a new driving licence, which will be valid for a limited period, after which a reassessment will be carried out.

When giving a person newly diagnosed with dementia this information, it can be combined with information regarding welfare rights and income maximisation, which may help to alleviate fears about the costs of having to replace driving with use of public transport. Many patients fear being unable to drive because of the likely impact on their independence, and without support and understanding this can lead to them feeling low and isolated. It is important that they are supported to continue to have social contacts and play a role in their local community, and the key worker should provide advice on supports available to help achieve this, including the use of volunteer drivers or resources such as 'dial a bus' if they are available locally.

4.1.2 Care planning

A care plan should be in place within 4 weeks, formulated by the key worker in consultation with the patient, carers and family members detailing care interventions depending on health and social care needs. The patient and carer should be reviewed and supported as needed by the key worker, who is also responsible for organising and managing a package of care involving other team members if necessary. Information regarding resources available in and around the local area should be provided, and the patient, family and carers should be signposted to useful resources such as the Dementia Helpline (Tel: 0300 222 1122) where they can receive independent advice on all aspects of care for people with dementia.

Being sensitive to the feelings of the patient and carer, the key worker should start discussions with the patient and their loved ones about their wishes for the future. These can include advance care planning for transitions between different care settings and allowing them an opportunity to think about, and discuss aspirations for end of life care in the context of their cultural and religious beliefs. Discussions about funeral plans can also be included if the person wishes this. Some of the following are options for the patient to consider so that their wishes are made clear to everyone involved in their care, and can be respected and adhered to, even when the person may no longer have the capacity to express them.

4.1.3 Power of Attorney

As part of the care plan, the key worker should facilitate discussions with regard to how a person with dementia can plan for the future when they may not be able to look after their financial affairs or make decisions about their welfare. The Adults with Incapacity (Scotland) Act 2000 is the key piece of legislation which can be used to help people to nominate individuals they wish to make decisions for them if they are unable to do so in future. By completing Power of Attorney documentation and lodging it with the Office of the Public Guardian, a person can nominate one or more individuals the power to look after some or all of their property and financial affairs and/or to make specified decisions about their personal welfare, including medical treatment in the event of them becoming unable to do this themselves. If this documentation is completed whilst the person is able to clearly express their wishes for the future, it can reduce the need for much more complex legal proceedings at a later stage in the illness. This legislation can be used by anyone, and does not require a current diagnosis of mental or physical ill health. Further information on how the Adults with Incapacity Act can be of benefit is available at: www.scotland.gov.uk/Resource/Doc/95555/0023122.pdf.

4.1.4 Advance directives

The patient may wish to express their wishes for future medical treatment through the use of an advance directive (sometimes known as a living will). This can specify medical treatments that the person may not wish to have in the future. The types of treatments people usually specify are treatments they may wish to refuse if they are dying such as cardiopulmonary resuscitation (CPR), life support etc. These documents can prevent loved ones from being placed in the difficult position of having to make this type of decision for someone. There are differences between Scottish legislation and the legislation in England and Wales regarding these, but a valid advance directive is recognised by the British Medical Association (although may not be legally enforceable in Scotland if challenged).

4.1.5 Advance statement

In Scotland an advance statement refers to a statement made under the Mental Health (Scotland) Act 2003. (Information about this can be accessed at www.scotland.gov.uk/Publications/2004/10/20017/44081). An advanced statement is a document, which the person draws up while they are mentally well, stating how they would like to be treated should their mental health deteriorate. If a decision is made which goes against the advance statement the patient must be given the reasons for this in writing. If they have nominated a 'named person' (someone to look after their interests if they are being treated against their will), or welfare attorney or guardian, a copy will also be given to them. A copy will also be sent to the Mental Welfare Commission (www.mwscot.org.uk/), an independent body set up to protect the interests of people who are vulnerable because of a mental disorder.

4.1.6 Guardianship orders

These apply where the person already lacks capacity to make decisions. Two independent medical practitioners must certify this to be the case. Where the incapacity is due to a mental disorder such as dementia, one of the medical practitioners must be a registered and licensed medical practitioner approved under Section 22 of the Mental Health (Care and Treatment) (Scotland) Act 2003. The two medical assessments must be carried out, where possible not more than 30 days before the application is lodged with the sheriff court. The Sheriff has discretion to accept medical reports older than 30 days. The medical reports must be accompanied by another report, the content of which will depend on the type of powers being sought, for example, welfare powers, financial powers or a combination. As these applications have to be lodged with the sheriff court, this is a much more rigorous and difficult legal process than seeking power of attorney whilst someone is able to express their wishes. Because of the legal complexities decisions affecting the person's welfare and health may be delayed. This is why it is important these matters are raised by the key worker as early as possible following diagnosis, and that the patient and their loved ones are guided through the processes so that their decisions are recorded in a valid way and will be respected when the time comes.

4.1.7 Risk assessment

Mental health services will have their own risk assessment tools, but according to the principles of the Scottish Dementia Strategy health professionals must balance their duty of care with the rights of people with dementia, who retain capacity to make decisions for themselves, to take risks in their own lives. People should be facilitated to continue to stay in their own home if that is what they wish, and adaptations and reasonable adjustments should be made to the physical environment to make this possible when necessary. In order that this can happen a multidisciplinary approach will be necessary, with effective communication between the members of health and social services.

When a person with dementia makes a choice to take part in an activity, the risk assessment and management process should include analysis, not only of the potential risks, but also of the potential benefit of the activity. Risk assessments will need to be repeated frequently as the risks will change as the illness progresses. Under the Adults with Incapacity Act it is the responsibility of anyone in contact with a person with dementia to raise concerns if they believe that a person is at risk of harm or neglect, and the pharmacy team should be active contributors to risk assessments. Where there are anticipated or predictable risks associated with medication, pharmacy staff should take all reasonable steps to minimise these. They should also ensure that there is appropriate and timely communication with other health and social services, as well as family and carers, to prevent harm coming to an individual.

4.2 Medication for cognitive symptoms of dementia where appropriate

There are two classes of medication licensed for the treatment of cognitive symptoms of AD in the UK:

Acetylcholinesterase inhibitors (AChEIs)

- » donepezil
- » rivastigmine
- » galantamine

N-Methyl-D-aspartic Acid (NMDA) receptor antagonist

- » memantine

4.2.1 Acetylcholinesterase inhibitors (AChEIs)

The three AChEIs are licensed for use in mild to moderate Alzheimer's disease, and despite some early controversy over their widespread use, are now approved by NICE Technology Appraisal TA217 (www.nice.org.uk/guidance/TA217) and endorsed by the Scottish Medicines Consortium for use in NHS Scotland as treatments for AD. NICE TA217 only recommends these drugs for treatment of cognitive decline in AD, and not in other dementia types. SIGN guideline 86 Management of Patients with Dementia (February 2006), (www.sign.ac.uk/pdf/sign86.pdf), however, endorsed the use of galantamine in treating cognitive decline in people with mixed dementias and the use of rivastigmine to treat cognitive decline and associated symptoms in those with a diagnosis of DLB. NHS Quality Improvement Scotland (QIS) now NHS Health Improvement Scotland (HIS) endorsed the NICE TA as valid for use in Scotland, superseding the recommendations in the older SIGN document.

There are two main types of central cholinesterase: acetylcholinesterase and butyrylcholinesterase. Acetylcholinesterase is the predominant form with butyrylcholinesterase being mainly present outside the central nervous system. The cholinesterase inhibitors exert their pharmacological activity by inhibiting the enzyme acetylcholinesterase (AChE) to increase the availability of acetylcholine (ACh) at sites of neurotransmission. Donepezil is highly specific for acetylcholinesterase whereas rivastigmine inhibits both acetyl and butyryl cholinesterase. Galantamine also enhances the action of ACh on nicotinic receptors, and thus may provide a different pattern of clinical activity to the other cholinesterase inhibitors. The clinical significance of the difference in receptor activity is not clear but since they all produce their pharmacological effect in a slightly different way, if a response to one agent is not seen, then it is justifiable to try another.

The main differences between the different drugs are summarised in the table below. The different side effect and interaction profiles of the different drugs in conjunction with the formulations available and the frequency of dosage schedules as well as the cost of therapy will determine which drug is best for an individual patient. In the absence of other factors, NICE suggests that the most cost effective treatment should be used in the first instance.

4.2.2 Differences between AChEIs

(Ref: NHS Education for Scotland. (2005, updated 2011). *Introduction to Pharmaceutical Care in Mental Health. Chapter 8 Dementias*)

AChEI	Donepezil	Rivastigmine	Galantamine
Dosing	5 – 10mg daily Available as tablets or orodispersible tablets	1.5 – 6mg twice daily Also available as patches: 4.6mg over 24 hours and 9.5mg over 24 hours	8-12mg twice daily, once daily with M/R formulation
Time to serum max	3 – 5 hours	0.5 – 2 hours	Tablet 0.5- 1 hr MR caps 4.4 hrs (lower Cmax associated with less nausea)
Effect of food on absorption	No	Yes	Yes
Serum t_{1/2}	70 – 80 hours	Oral -2 hours (8 hours activity) Patch – 8 hrs (less fluctuation between peak & trough than oral)	Tablet 5–7 hrs MR Cap 8-10 hrs
Protein binding	96%	40%	10 – 20%
Metabolism and excretion	Liver CYP450 (3A4 and 2D6), Renal excretion	No liver metabolism, Renal excretion	CI in severe hepatic and renal impairment
Interactions	Inhibitors of CYP 3A4 e.g. ketoconazole, erythromycin, ritonavir and CYP 2D6 e.g. paroxetine, fluoxetine, quinidine	Nil significant	Inhibitors of CYP 3A4 e.g. ketoconazole, erythromycin, ritonavir and CYP 2D6 e.g. paroxetine, fluoxetine, quinidine

4.2.3 Cautions with AChEIs

AChEIs should be prescribed with caution in the following patients: those with 'sick sinus syndrome' or other supraventricular conduction abnormalities; patients with concomitant asthma, obstructive pulmonary disease or those with, or at risk from, peptic ulcer disease. Rivastigmine and galantamine should be prescribed with caution in patients with renal impairment or mild to moderate hepatic impairment. Donepezil should be used with caution in hepatic impairment. All AChEIs can cause gastrointestinal effects such as diarrhoea, muscle cramps, nausea and vomiting. These side-effects are generally mild and transient, and often disappear within a few days of continued treatment. However in some patients these effects may be severe and result in significant weight loss. To reduce these effects, the medication can be taken after food and dose titrations should be over a four-week period (but remember that this may prolong the time to reach the maximum therapeutic dose). A trial of an anti-emetic may be prescribed (usually domperidone at 10–20 mg three or four times daily). Alternatively a different AChEI or formulation can be tried as patients sometimes tolerate one better than another, although it is difficult to predict whether this approach will be successful or not.

Care should be taken if co-prescribing drugs that can increase the risk of gastro-intestinal bleeding such as serotonergic antidepressants (e.g. fluoxetine, sertraline, paroxetine, citalopram), non-steroidal anti-inflammatory drugs (e.g. ibuprofen, diclofenac), aspirin, warfarin or oral steroids.

Combination of AChEIs with digoxin, amiodarone, verapamil, diltiazem or beta blockers may increase the potential for decreased heart rate. In the case of galantamine, caution is advised with drugs that have potential to cause torsades de pointes. In such cases an ECG should be considered.

Other side-effects of AChEIs include insomnia and dizziness, which also tend to be transient.

4.2.4 Monitoring procedures for AChEIs

AChEIs are not a cure for dementia but studies show that between 40-70 per cent of people with AD benefit from treatment. The benefits are symptomatic, and there is at present no compelling evidence that the drugs change the course of the disease. Not everyone benefits, and symptoms may only improve temporarily, between six and 12 months in most cases, although some people benefit for much longer. According to an Alzheimer's Society survey of 4,000 people, those using these treatments often experience improvements in motivation, anxiety levels and confidence, in addition to daily living, memory and thinking.

Although NICE recommended a wide range of treatment assessments before commencing a patient on an AChEI, many centres also use indicators important to the caregiver and/or the patient. Things such as being able to make a cup of tea; being able to enjoy an interactive game or complete a simple jigsaw; being able to take part in conversation; being able to wash, dress or eat for themselves. Monitoring is often a trade-off between ideal practice and what is realistically achievable within the framework of NHS budget and human resource. The results of cognitive, behavioural and functional assessments should be considered when deciding whether a drug has been of benefit in an individual case.

Often it is the behavioural changes that upset family and carers most. Continually being asked the same question or re-orientating people can be very tiresome. The results of trials looking at the effects of AChEIs in treating behavioural symptoms such as agitation or aggression are less clear, but some carers report benefits.

Activity

List the main points you would discuss with a patient about to start donepezil.



4.3 Illustrative cases

4.3.1. Peter



Peter, a 70-year-old gentleman has been referred to the memory clinic by his GP. He is a widower who lives alone, but has good family support, and his son is able to give a good history at the memory clinic. Peter's problems seemed to date back to when he had a fall about 10 months ago. Since then he has not been 'quite right'. He asks the same questions over and over again and his memory has been getting gradually worse.

He had another 'turn' about 4 months ago and has recently been having episodes of dizziness. His daughter-in-law has noticed him becoming quite suspicious of her and he has been hoarding things in his bedroom. His son has also noticed that he is less able to look after himself. He forgets to put in some of the ingredients when he is cooking, and has not been able to take care of his finances without help. He has also been forgetting his medication.

The GP referral indicates that he has hypertension, non-insulin dependent diabetes mellitus (NIDDM), coronary artery disease and osteoarthritis. His prescribed medication is as follows:

Metformin 500mg at breakfast, lunch and teatime, aspirin 75mg in the morning, bendroflumethiazide 2.5mg in the morning, simvastatin 10mg at night, co-codamol 30/500, 2 tablets up to 4 times daily as required for pain.

At the memory clinic Peter scored 21/30 on MoCA. A CT scan was done, and showed multiple lacunar infarcts in the right basal ganglia and left cerebellar region. This is consistent with vascular dementia. He is told that the memory enhancing drugs for dementia will not benefit his illness but there are some interventions his GP can make to reduce the risk of his dementia worsening, and that the consultant will write to his GP. The consultant does not intend to follow him up, but provides him with some information about his illness and help he can access via social services and Alzheimer's Scotland.

Peter comes into the community pharmacy with his son the next day. Peter's son explains what happened at the memory clinic and says he is worried about his Dad's ability to cope at home. He wonders if the pharmacy can offer help with his medication, as he does not always remember to take it consistently. He says he feels a bit let down by the specialists because it appears that his Dad does not have access to the same level of service as he would have had if he had AD and there is nothing much that can be done for him. What can the pharmacy service offer Peter and his son?

Pharmaceutical Care Issues	
Provide information and support	There are no licensed drug treatments for vascular dementia. The mainstay of treatment is to reduce the risk of further damage to the brain by reducing the risk of ischaemic attacks and stroke. Clopidogrel should be added as Peter has proven infarcts on CT. Further interventions to reduce cardiovascular risk factors by maximising control of hypertension and treating hypercholesterolaemia are also indicated. Peter is on a low dose of statin, and there is an option to increase this depending on his lipid profile, and if his hypertension and diabetes are not adequately controlled, his antihypertensive and diabetic medication may be reviewed by his GP. It is worth explaining how important this is to Peter's son as this will be what the consultant is writing to the GP about. The fact that Peter will not benefit from the AChEIs does not mean that he cannot positively influence the course of his illness and reduce the risk of progression – this is a positive message, and should be reinforced.
Signpost Peter and his son to useful resources	The Alzheimer's Society is a useful resource for anyone with dementia, and it is worth pointing out some of the helpful fact sheets available through the site. The helpline number may also be of use to Peter and his son as it provides confidential help and support 24 hours per day. The 'through our eyes DVD' may also help, as would the card available for people to carry to let people know about their memory problems. Peter may have already been told about these resources, but it is helpful to reinforce them. Alzheimer's Scotland is a Scottish charity with lots of information and support available to people living in Scotland, including carer support groups which Peter and his son may find useful. Both charities support people with a diagnosis of dementia regardless of the type of dementia.
Promote a healthy lifestyle	Peter is diabetic, and advice on maintaining a healthy diet and keeping his blood sugar under control is important to prevent end organ damage and reduce the cardiovascular risks associated with obesity.
Provide smoking cessation advice	Peter is a smoker, and now would be a good time to emphasise the positive health benefits of stopping smoking, and provide nicotine replacement therapy if he wishes to try to stop.

Promote the benefits of social interaction and activities which stimulate memory function	Emphasise to Peter the benefits of ensuring he does not become socially isolated and encourage stimulating activities depending on his preference and physical ability such as social groups, local choirs, sporting activities. Provide information on accessing local groups through Alzheimer's Scotland
Monitor medication to reduce the risk of cognitive impairment	It is worth monitoring Peter's medication now and in the future to ensure that he is not on medication which could have an effect on his memory, and that this is taken into account in future. At present Peter is taking co-codamol, so it is worth assessing how much he is taking, whether his pain is adequately controlled, and whether he is experiencing side-effects such as drowsiness, constipation or confusion. There may be an option to step down the dose or use a low dose regularly instead of as required dosing.
Promote concordance by providing support	An assessment of Peter's needs in terms of prompting him to order and take his medication at the correct times would be useful. He may need help ordering and collecting his prescriptions, and a compliance device or MAR chart may help. If Peter has care workers at home, his care provider could be contacted (with his permission) to ask if his care workers could prompt him with his medication and highlight any issues with his concordance so that these could be addressed. The best way to do this is through the "commissioning social care worker" usually the local authority so that this can be formally assessed and any issues recorded and fed back. This allows further action to be taken if a higher level of support is needed for Peter from care workers employed by the local authority.
Encourage Peter and his son to contact social work services	Peter should use this route to maximise the care he receives at home and ensure a risk assessment is undertaken as he lives alone. Social services should also be able to advise on income maximisation via any benefits Peter is entitled to.

Peter and his son express gratitude for the advice, and Peter says he feels a bit more positive about the diagnosis and agrees to come in again and discuss smoking cessation later in the week. Peter's son is going to contact social work services about getting him some help, and the pharmacist suggests that the CMS may be an appropriate way to monitor Peter's medication more closely.

It should be noted that Peter would now be entitled to one year of post-diagnostic support as recommended in the new dementia strategy, and this is a positive change for people who previously found themselves in the situation described in Peter's case.

4.3.2 Pauline (we met in section 3)



Pauline comes to the community pharmacy a few months later with a prescription for donepezil 5mg tablets. She explains to the pharmacy technician that she has been to the memory clinic on a couple of occasions, and it has now been confirmed that she has a diagnosis of AD 'in the early stages'. She has high hopes that the donepezil will prevent her memory from getting any worse.

Pharmaceutical Care Issues	
Cover the main counselling points for initiation of donepezil	<p>**See below for tips to aid successful communication with people with dementia.</p> <p>Donepezil treats the symptoms of dementia. Although it does not cure the illness it can improve symptoms and functioning. It is most effective when used early in the course of the disease as in Pauline's case. She will be followed up by her key worker to check her response to the treatment after a month. The dose will then be reviewed and increased to 10mg if tolerating it. As Pauline is not on any other prescribed medication drug interactions are not an issue, but she should be warned about the potential for increased risks of stomach problems if she uses aspirin or NSAIDs. If she is buying any medication she should do so in a pharmacy so that she can check it will not cause any problems. She should be warned about the most common side-effects i.e. GI problems – nausea, vomiting, diarrhoea (take with food), insomnia (take in the morning), dizziness. Usually side-effects are mild and transient but if they are severe she should let her doctor know. If this medication does not suit her, there are other options.</p>
Provide any support required to enable concordance	<p>Pauline's husband will help her remember to take her tablets, but if she lived alone the pharmacist could try to help her identify prompts which may improve her concordance such as a reminder chart for the medicine cupboard or an alarm set on her phone. Compliance devices are not always the answer for people who live alone, but may be beneficial for some especially if they have family or carers who pop in and can check that the daily dose has been taken. Remembering to order prescriptions may be an issue and it may be worth using the serial prescribing/dispensing elements of CMS to help.</p>

Reinforce information and enquire about tolerability and efficacy when seeing Pauline	Pauline will require ongoing support and may develop side-effects, new symptoms or co-morbidities as her illness progresses. It is important to continue to keep in touch, and be alert for any risks that come to light.
Be alert for addition of interacting drugs	If Pauline develops intercurrent illness it is important to ensure interacting drugs, particularly beta-blockers, aspirin, NSAIDs or calcium channel blockers are not added without consideration of the risks. Pauline should be advised not to purchase over the counter medicines without advice.

**Tips to aid successful communication with people with dementia or memory problems.

There is a great deal of skill involved in doing this well, and training courses are available through the Alzheimer Society, however we can all learn from the *Ten things to do to improve communication* recommended by Alzheimer Scotland as follows:

1. Believe that communication with the person is possible
2. Try to focus on the nonverbal signs as well as what is said
3. Avoid making assumptions: check things out with the person
4. Make your communication a two way process that engages the person with dementia
5. Avoid the use of jargon or complicated explanation. Keep your conversation as simple as possible without being patronising or sounding childish
6. Do not ask questions which have 'why' in them. The person with dementia may find the reasoning involved in giving an answer difficult and become annoyed with themselves
7. Be a good listener. Give the person your full attention and resist the temptation to finish their sentences and talk at the person.
8. Talk at a slower pace so that the person has an opportunity to grasp what is being said
9. Maintain a calm and unhurried approach
10. Discover the best time of day to spend time talking with the person.

It is also worthwhile encouraging people with dementia to carry a dementia help card, a card for people with dementia to use to help people who serve the public to understand their special needs. Copies are available from Alzheimer Scotland.

Follow-up – Pauline

At her review one month after the dose increase to 10mg, Pauline reports a good response to donepezil with improvement in her cognitive functioning and ability to take care of her affairs, including remembering appointments, coping with bills and dressing, washing and cooking for herself. She is a very independent lady, and her Community Mental Health Nurse (CMHN) has managed to help her develop strategies to cope at home. Her friends joke about the post-it notes all over the house, but they know that this helps her manage, including remembering to take her donepezil which she keeps in the same cupboard as her cereal and takes with breakfast every day. The post-it on the front of the cupboard reminds her. Pauline has great social support and a good network of friends and social contacts who look after her in the village and make sure that she is managing. She is reviewed 3 months later and her improvement has been maintained. Her reviews are therefore planned for 6 monthly at the memory clinic. Her CMHN sees her every 6-8 weeks and updates her cognitive test, needs assessment and risk assessments. Pauline can contact her if she needs her in between.

How would the care issues differ if Pauline:

Was on an SSRI?

Prescription of donepezil is not contra-indicated in a patient on an SSRI but fluoxetine could potentially inhibit the metabolism of donepezil theoretically increasing the risk of side-effects, and the recent warnings regarding prolongation of QTc interval with citalopram may make it a less favourable choice than e.g. sertraline. There is also an increased risk of bleeding with the combination of the two drugs, and this may be important if the patient has other medication or concomitant health problems increasing this risk e.g. co-prescription of NSAIDs or a history of gastro-intestinal problems. In practical terms, these would be cautions but would not prevent prescription of donepezil.

Was prescribed an NSAID or aspirin?

As above, there is a potential increase in risk of gastro-intestinal ulceration, and the Summary of Product Characteristics (SPC) for donepezil (www.medicines.org.uk/) suggests that patients should be monitored for symptoms. However, the clinical studies with donepezil showed no increase, relative to placebo, in the incidence of either peptic ulcer disease or gastrointestinal bleeding.

Was on atenolol?

There is an increased risk of adverse drug reactions, including syncope, bradycardia, arrhythmia or cardiac arrest with the combination of a beta-blocker and centrally acting anticholinesterase drugs. This risk has been assessed as low, but it is important to assess heart rate before prescribing in patients on beta-blockers, and to be alert to development of bradycardia when starting either drug in combination with the other.

Had asthma or COPD?

Because they act to increase the availability of acetylcholine at receptors throughout the body the AChEs can have an adverse effect on COPD or asthma. They can also theoretically reduce the effect of ipratropium or tiotropium so should be avoided in combination with these drugs. Where a patient is reliant on anticholinergic inhalers to control their asthma or COPD, or has poorly controlled or advanced COPD, an AChEI may worsen their condition. The balance of risks vs. benefits has to be carefully weighed up in each individual case.

Was a 35 year old man with Down's syndrome (DS)?

People with DS are recognised to be at increased risk of developing dementia as they get older, but tend to have an early onset (30-49 years) compared to the rest of the population, where dementia is generally a disease of old age. The reasons for this are not entirely clear.

The challenge is in correctly diagnosing dementia in DS. Some people with DS have unsophisticated social skills, impaired communication skills, short attention span and a tendency to be suggestible, all of which make assessment particularly challenging. For this reason diagnosis of dementia in a person with Down's syndrome should only be made by consultant psychiatrists working within learning disability services, and only after a very thorough and comprehensive assessment. The way dementia affects people with Down's syndrome is similar to the general population, but they may be less able to express this, leading to late presentation. Symptoms include getting lost in previously familiar environments, memory problems, loss of previously learned skills, confusion, and increased dependency on carers. There can also be a relatively high prevalence of low mood, excessive overactivity/restlessness, disturbed sleep, excessive uncooperativeness and auditory hallucinations.

Some specific tests are available to aid diagnosis such as the Down's Syndrome Dementia Scale (DMR), the Down's Syndrome Mental State Examination, the Severe Impairment Battery or Test for Severe Impairment. Assessment should take place over a minimum of 4 weeks, and carers should be interviewed about changes they have noticed in the individual. The usual physical examinations should be carried out to exclude common differential diagnoses and tests for sensory impairment (which may mimic cognitive impairment in those with learning disabilities) should be undertaken. The diagnosis should differentiate between the different types of dementia. AD is the most common form of dementia diagnosed in Down's syndrome.

There is some evidence (mainly from case studies) to suggest that donepezil may help with memory, social function and behaviour in a proportion of people with AD associated with DS. An improvement in, or delay in decline in global cognitive functioning would be likely to improve quality of life and reduce carer burden (which is particularly important in this group of patients). The usual dose titration applies when starting donepezil, but as people with DS are particularly sensitive to side-effects of medication, a slower than normal titration may be considered. If the drug is tried, but is unhelpful, it should be stopped.

Did not tolerate, or did not respond to donepezil?

Side-effects related to the excess cholinergic stimulation of the AChEs are common during initiation and when the dose is increased. The typical early side-effects are nausea, vomiting, dizziness, and diarrhoea. These side-effects are very common, affecting as many as 1 in 10 individuals, but are usually transient. Reducing the dose or the speed of titration may help, but it is important that a therapeutic dose can be tolerated. Taking the medication with food can also reduce the gastro-intestinal (GI) side-effects. Another option is a short-term prescription of an anti-emetic such as domperidone. If the patient is really unable to tolerate donepezil in the early stages of therapy, it is best to stop the drug, and allow the symptoms to settle completely before trying a different drug. Although, in theory all the drugs should cause similar side-effects, there are some differences in their pharmacology and sometimes one drug is tolerated where another is not. It is preferable to titrate galantamine or rivastigmine at a slower than recommended rate in those who are particularly sensitive to GI side-effects. If rivastigmine is not tolerated orally, it may be worth trying the patches, which were better tolerated in trials with fewer discontinuations due to GI effects.

Side-effects experienced later in therapy tend to be of a different nature e.g. cardiovascular effects (particularly bradycardia), insomnia, weight loss, muscle cramps. If these are severe, it may be necessary to try a switch to a different drug. The benefits of treatment with AChEs are rapidly lost when the drug is discontinued, and may not be fully regained when re-instated. It therefore, may be worth considering cross-tapering two drugs if switching in a patient who has been on donepezil for a while with benefit. This would have to be weighed against the risk of additive side-effects, and should only be undertaken on the advice of a specialist.

Where donepezil is ineffective, it is reasonable to stop it. There have been some case reports of discontinuation reactions when donepezil was abruptly withdrawn, although the majority of patients tolerate this. The rationale for trying another drug, is again the subtle differences in the pharmacology of the three drugs.

Pharmacists should be aware of the risk of deterioration if a drug is withdrawn, and should recommend that a specialist is involved in advising on a suitable switching strategy for an individual patient.

Was unable to remember to take her donepezil?

There are a number of ways to help people who have difficulty remembering to take their medication. Pauline has already employed the use of “post-it” notes and making her medication part of her daily routine by leaving it beside her breakfast cereal in the cupboard. The use of medication charts can be helpful for some people, particularly if they have medication scheduled at different times throughout the day. The use of monitored dose systems may be beneficial for some people as they can see at a glance if they check the box whether they have taken that day’s dose, but only if they are orientated to the day and time. Mobile phones can be set to alarm at medication times. Boxes with alarms on them to remind people it is time for medication, are available, but patients usually have to purchase these themselves and having them filled by community pharmacies can be an issue. If these systems fail, it may be necessary to use telephone reminder systems (where a family member or care worker phones the person and talks them through taking their medication). Failing this, supervised administration may be necessary. This is easier and less intrusive for the patient if they are on once daily medication only, so the choice of drug and formulation may be important. If the patient has someone coming in to help with personal care they may agree that the appliance of a patch daily after their bath or shower would be easier. Note – this discussion relates to people who are unable to reliably remember to take medication, but are happy to agree to take it. The situation where someone refuses to take essential medication will be covered later in the pack.

Activity

List some interventions that can improve prognosis for people with a diagnosis of VaD.



Summary Box

What have you learned from this section?



- » A person has a right to decide whether to be told their diagnosis, and who to share this information with.
- » A person with a diagnosis of dementia must inform the DVLA and their insurance company of their diagnosis and accept the advice of their doctor and the DVLA regarding whether they can continue to drive or not.
- » The Adults with Incapacity Act (Scotland) 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003 are two key pieces of legislation which can be used to help people with dementia lay down plans for their future which will be respected in law.
- » How this legislation can be used in care planning to be able to discuss its use with patients, carers and other members of the multidisciplinary team.
- » How the pharmacy team can contribute to the risk assessment process for people with dementia.
- » How the AchEI drugs (memory enhancers) work and their licensed indications for use.
- » The differences between the three drugs, and how they should be used according to current national guidelines and the complexities of changing from one drug to another.
- » The pharmacology, side-effects, contra-indications, cautions, drug interactions and monitoring requirements for these drugs to be able to discuss them with patients, carers, and other members of the multidisciplinary team.
- » How to support people with a diagnosis of dementia to make healthy lifestyle choices to improve their quality of life.
- » The importance of effective communication with people with memory problems or distress associated with having difficulty communicating because of dementia.
- » The strategies available to help promote concordance in people with dementia who struggle to remember their medication.

Section 5 Living well with increasing help and support

Learning outcomes

At the end of this section you should be able to:

- » Describe the progression of dementia and how the increased impairment in cognitive and non-cognitive functioning impacts on the person, their family and carers
- » Describe the most common behavioural and psychiatric symptoms of dementia (BPSD) and the impact these have
- » Understand the risks and benefits of using psychoactive medication to treat BPSD
- » Discuss the role of pharmacists and pharmacy technicians in reducing inappropriate use of psychoactive drugs in this patient group
- » Understand the importance of excluding physical problems as a cause of BPSD (e.g. pain, constipation, infection) and be able to advise on appropriate management of these conditions
- » Utilise communication techniques that recognise individual needs and diversity
- » Appreciate the importance of interacting with the person in a person-centred way
- » Understanding the assessment tools available to help determine the underlying cause of distressed behaviour
- » Describe some of the evidence based psychological interventions in dementia and the stage of the illness they are relevant to.

As dementia progresses the early symptoms will progress, and new symptoms will emerge which can make caring for the person more difficult and distressing. Memory becomes more impaired to the point where the person will be unable to recognise people they have known, or perhaps even their own reflection. They will struggle to find their way around in what were previously familiar environments. Communication will become more difficult, and the person will struggle to find the right words or lose speech entirely, perhaps crying out or repeating the same sound over and over again. Mobility will also become increasingly impaired, and the ability to perform everyday tasks like washing and dressing will be lost. Gradually the person will become more dependent on others to take care of them, and may be at risk of falls or bumping into objects around the home if they do not have a carer with them.

It is likely that the person will become less interested in eating or drinking, and will need encouragement to take enough nourishment to keep them going. Swallowing difficulties may also become an issue. Losing too much weight weakens the immune system and makes people vulnerable to infection, and may also make them more liable to fall due to weakness. Continence can also become an issue for various reasons including losing the ability to recognise the need to go to the toilet or forgetting where the toilet is. It should not be taken for granted however, that a person with dementia is incontinent for these reasons, and medical causes such as urinary tract infection, constipation, prostate problems and side-effects of medication should all be excluded or treated appropriately before assuming that the person will require permanent interventions for incontinence.

Behavioural and Psychiatric Symptoms of Dementia (BPSD) are distressing non-cognitive symptoms which can occur at any stage of the illness (more commonly in some sub-types of dementia than others) but become more common in the later stages. The majority of patients with dementia will develop one or more of these symptoms, although severity can vary significantly. These symptoms are associated with higher caregiver stress, use of health care resources, and ultimately institutionalisation, than the cognitive symptoms of dementia. The most commonly reported BPSD are apathy, depression, irritability, aggression/agitation and delusions. Others include – anxiety, psychosis, hallucinations, repetitive vocalisation, cursing and swearing, sleep disturbance, shadowing (following the carer around), sundowning (behaviour worsens in the evening), sexually disinhibited behaviour, excessive hand activity (pulling at clothing etc.) and other non-specific behavioural disturbances e.g. hoarding.

The importance of treating BPSD appropriately cannot be over emphasised as these symptoms have a very high impact on patient and carer quality of life. Before deciding how best to manage these symptoms the following factors which could be influencing the symptoms, should be considered:

- » Whether there is a physical health problem such as infection, constipation or undetected pain or discomfort
- » Whether the person is suffering from depression
- » Side-effects of medication
- » Psychosocial factors e.g. other patients interfering with the person's belongings or invading their space, or the patient being under-occupied
- » Physical environmental factors e.g. the room is too hot or cold, the lighting too bright or too dim, the environment is alien or not 'homely'.

Although described as symptoms of dementia above, it is recognised that some of the behaviour displayed by patients may be an attempt to communicate distress. The term 'distressed behaviour' is preferred by psychologists to describe these behaviours. NICE uses the terms 'non-cognitive symptoms or behaviour that challenges' to describe them. As these symptoms may or may not be present as a biological consequence of the dementia, to help understand why this behaviour is being displayed by an individual, it is important that an experienced worker, in collaboration with carers and family members, should make a detailed functional and behavioural assessment. This should take account of the person's individual life story, spiritual, cultural and religious beliefs as these factors will strongly influence the way in which the person reacts in certain situations. Non-pharmacological approaches should be used in preference to drug therapy as discussed in section 5.2 wherever possible. Although drug therapies are discussed in detail here (as this is a resource for pharmacists and pharmacy technicians) it should be clearly understood that non-pharmacological therapies should always be tried first for behavioural symptoms.

5.1 Medication in moderate to severe dementia

5.1.1 Memantine

Memantine is the first NMDA-receptor antagonist to be licensed in the United Kingdom for the treatment of moderately severe to severe AD although NICE does not recommend its use in moderate AD unless the patient is intolerant of, or has a contra-indication to, an AChEI (Technology Appraisal 217 www.nice.org.uk/guidance/TA217). This position is endorsed in Scotland as discussed previously.

NMDA is involved in the regulation of glutamatergic transmission. Glutamate is released in excessive amounts when brain cells are damaged by AD. An excess of glutamate causes over stimulation of NMDA receptors, which allows free-flow of calcium into the cell. Sustained levels of excess glutamate lead to a chronic overexposure of calcium, which in turn leads to cell degeneration and ultimately cell death. Memantine binds to the NMDA receptors to block the glutamate-gated receptor channels. It allows the physiological activation of the receptors (which are involved in memory formation), but it blocks the pathological activation (which is involved in cell degeneration).

Dosing starts at 5 mg once daily, increasing to a maximum of 20mg daily (reduced in moderate renal impairment). The drug should be avoided in severe liver impairment. Caution is advised in patients with epilepsy, history of myocardial infarction, uncompensated congestive heart failure or uncontrolled hypertension. Concomitant prescribing of other NMDA antagonists should be avoided, for example amantadine, ketamine and dextromethorphan. Cimetidine, ranitidine, quinine, quinidine and nicotine may increase levels of memantine.

There have been isolated cases of increased INR with warfarin; effects of L-dopa, dopaminergic agonists and anticholinergics may be enhanced: effects of barbiturates and neuroleptics may be reduced: dose adjustments of baclofen, antispasmodics and dantrolene may be necessary.

The most common side-effects of memantine are dizziness, headache, constipation, tiredness, breathlessness and hypertension. Hallucinations and confusion have been reported rarely in patients with severe AD.

The Donepezil and Memantine for Moderate-to-Severe Alzheimer's Disease (DOMINO-AD) trial (www.nice.org.uk/guidance/TA217) investigated the role in therapy of memantine in community patients with moderate to severe and severe AD who were already established on an AChEI. 295 patients received the study treatment for the 52-week duration of the trial. The purpose of the trial was to try to help clarify whether the benefits of an AChEI are maintained as the illness progresses, or whether it is appropriate to make the difficult decision to withdraw the AChEI and start memantine, or continue the AChEI and add memantine in the hope of achieving additive benefits. The study demonstrated benefits on cognitive and functional outcomes of continuing donepezil. The benefits of starting memantine were smaller, and there was no demonstrable benefit on cognitive and functional scores of combining the two drugs, although all patients on memantine had better behavioural scores whether on donepezil or not. A previous six month study carried out in 2004 in New York demonstrated a significant difference in cognitive, functional and behavioural scores when the two drugs were combined. The DOMINO data, did, in fact, show this effect at 6 months, but it was lost by the 12-month follow-up. The failure of the trial to recruit the 800 patients originally sought means that some questions remain over the benefits of combining the two drugs in the end stages of the illness. Further research is necessary in this area to clarify the situation for clinicians, and some will attempt a trial of the combination of drugs in patients established on AChEIs as they progress to severe dementia or develop behavioural symptoms. NICE does not recommend the combination.

Evidence to support using memantine to treat the behavioural and psychological symptoms of dementia (BPSD) without having a negative effect on cognitive function is not robust. It has been suggested that there is a reduction in agitation and aggression, irritability, and appetite/eating disturbance, and a delay in emergence of agitation in those who were free of it at baseline. NICE TA217 (www.nice.org.uk/ta217) found that in people with AD, there is insufficient evidence to determine whether memantine produces clinically important improvements in neuropsychiatric symptoms. In the studies included in the review, there was no evidence of increased risk of adverse events. Further studies are required in this area.

5.1.2 AChEIs for BPSD

Recent research has suggested that AChEIs are beneficial in reducing behavioural and psychological symptoms of dementia (BPSD), but the evidence base is not robust. NICE published a technology appraisal in March 2011, available at: www.nice.org.uk/guidance/TA217, which reviewed the evidence for donepezil, galantamine and rivastigmine. This is the most up to date review available as the SIGN guideline is now several years old.

NICE concluded that:

- » In people with AD, there is moderate-quality evidence suggesting that donepezil produces benefits in terms of reduced neuropsychiatric symptoms and agitation/aggression that outweigh the risk of adverse events compared to placebo.
- » There was insufficient evidence to determine whether galantamine when compared with placebo, produces benefits in terms of neuropsychiatric symptoms that outweigh the risk of adverse events.
- » In people with VaD, there was insufficient evidence to determine whether acetylcholinesterase inhibitors when compared with placebo, produce benefits in terms of neuropsychiatric symptoms that outweigh the risk of adverse events.
- » In people with DLB, there was moderate-quality evidence to suggest that rivastigmine may produce benefits in terms of improved psychotic symptoms that outweigh the risk of adverse events.

The recommendations from NICE are to consider an AChEI for:

- » People with DLB who have non-cognitive symptoms causing significant distress or leading to behaviour that challenges.
- » People with mild, moderate or severe AD who have non-cognitive symptoms and/or behaviour that challenges causing significant distress or potential harm to the individual if:
 - a non-pharmacological approach is inappropriate or has been ineffective, and
 - antipsychotic drugs are inappropriate or have been ineffective.

Do not use acetylcholinesterase inhibitors for non-cognitive symptoms or behaviour that challenges in VaD except as part of properly constructed clinical studies.

There was also a recommendation from NICE that further research is required in this area as up to 75% of people with dementia will be affected by these symptoms, and they are a major source of distress for carers.

5.1.3 Role of antipsychotic drugs

Antipsychotic drugs are primarily used to treat psychotic illnesses (e.g. schizophrenia) and mood disorders (e.g. bipolar affective disorder).

They are sometimes referred to as 'psychotropics' but this term is less specific as it can be applied to any centrally acting drug i.e. any drug that crosses the blood brain barrier and acts on the brain. The term psychoactive is equivalent to this and is now the preferred term in Scotland when describing drugs which act on the brain.

Antipsychotics are classified into the older 'typical' drugs, which are prone to the classic movement disorder side-effects known as extra-pyramidal side-effects (EPSEs). Drugs in this category include haloperidol and chlorpromazine. Haloperidol has a license for restlessness and agitation in the elderly, mental and behavioural disorders such as aggression and hyperactivity in patients with organic brain injury and as an adjunct to short term management of severe psychomotor agitation, excitement, violent or dangerously impulsive behaviour.

The newer 'atypical' agents are associated with less of the movement disorder side-effects, and have been the preferred first line agents in recent years. Drugs in this category include risperidone, olanzapine, quetiapine, amisulpride and aripiprazole. Of these drugs only risperidone has a product license in AD. This is restricted to short term use (up to 6 weeks) for management of persistent aggression in moderate to severe AD.

In 2004, the Committee on Safety of Medicines (CSM) (predecessor of the **Medicines and Healthcare products Regulatory Agency (MHRA)**) highlighted the fact that in randomised placebo controlled clinical trials in the dementia population, a 3 fold increase in cerebrovascular adverse events had been demonstrated with some atypical antipsychotic drugs (specifically risperidone and olanzapine). The conclusion was that the risk outweighed any potential benefit of treating behavioural symptoms with these drugs, and prescribers were advised to review all prescriptions and consider alternative treatments. A year later, a Europe wide review concluded that the risk could not be excluded for other antipsychotics whether typical or atypical. There was also demonstrated to be a small increased risk of mortality in patients with dementia treated with certain antipsychotics compared to those on no treatment. The magnitude of the risk was estimated to be between 1-2%, with a slightly higher risk demonstrated if risperidone was combined with furosemide.

Because of the cerebro-vascular risks, these drugs should only be used after assessment of stroke risk. Those with mixed or vascular dementias should only be treated with these drugs if the potential benefits outweigh the risks (see below for conditions of use recommended by NICE). As the risk of mortality was found to be greater in patients on furosemide in trials, this should be specifically avoided in patients on risperidone. Dehydration is also a specific risk factor for increased mortality in patients with dementia, so hydration status should be carefully monitored in patients on these drugs.

In addition to these important risks, older adults with dementia can be particularly sensitive to some of the other side-effects of antipsychotic medication. These include:

- » Orthostatic hypotension due to alpha blockade. This can be particularly risky in frail older adults as it can lead to falls and fractures.
- » Tardive dyskinesia/extrapyramidal symptoms (TD/EPSEs) – although the movement disorder side-effects have been reported less frequently with the atypical antipsychotics than the typicals, the atypical drugs are a diverse group, and these side-effects are associated more with some drugs, including risperidone, than with others (e.g. quetiapine).
- » Neuroleptic malignant syndrome (NMS) – This is a rare but potentially life threatening side effect characterised by hyperthermia, muscle rigidity, autonomic instability, altered consciousness and elevated serum creatine phosphokinase. It can occur with any antipsychotic.
- » Parkinson's disease and dementia with Lewy bodies – Parkinson's Disease may be worsened with antipsychotics, and both of these groups may be at increased risk of Neuroleptic Malignant Syndrome as well as having an increased sensitivity to antipsychotics which may manifest itself as increased confusion, decreased level of consciousness, postural instability with frequent falls and extrapyramidal symptoms.
- » Hyperglycaemia and diabetes mellitus – These drugs may cause or exacerbate existing diabetes, and patients on them should be carefully monitored for symptoms of hyperglycaemia such as increased thirst or urine production or for worsening of glucose control.
- » Weight gain – Some of these drugs have been associated with increased appetite and weight gain which can sometimes be seen as an advantage in people with dementia, but this should be balanced against the other risks associated with the drugs.
- » Hyperprolactinaemia – these drugs can increase blood prolactin levels and can rarely stimulate milk production from the breasts in both males and females, which can be a distressing side effect.
- » QT prolongation – The antipsychotics should all be used with caution in those with known cardiovascular disease, family history of QT prolongation, bradycardia, or electrolyte disturbances (hypokalaemia, hypomagnesaemia), as they may increase the risk of cardiac arrhythmias. They should also be used with caution in patients on other drugs known to prolong the QT interval.
- » Seizures – all antipsychotics can lower the seizure threshold and should be used cautiously in patients with a history of seizures or other conditions that potentially lower the seizure threshold.

- » Venous thromboembolism – Cases of venous thromboembolism (VTE) have been reported with antipsychotic drugs, and this should be taken into account before prescribing in patients with risk factors for VTE.
- » There are additional concerns that antipsychotic use in people with dementia may worsen cognitive decline. As long ago as a decade ago, research demonstrated a statistically significant association between the rate of cognitive decline and the prescribing of antipsychotics. Many of these drugs can also cause drowsiness and anticholinergic side-effects, which also affect cognitive function.

Despite these risks, small doses of antipsychotic drugs can be very useful for treating some of the behavioural symptoms of dementia. In those who have psychotic symptoms such as delusions or hallucinations they can effectively target and treat the symptoms. These symptoms can represent a source of significant risk of harm to the patient or others, through risk of assault or risk of distress severely affecting quality of life. People with AD, VaD, mixed dementias or DLB with severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) may be offered treatment with an antipsychotic drug after the following conditions have been met:

- » Antipsychotics should only be used where alternative strategies including non drug therapies have been tried and failed.
- » Alternative medication should be considered if necessary, including considering pain management or treating any other potential underlying problems such as constipation or infection.
- » There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
- » Changes in cognition should be assessed and recorded at regular intervals.
- » Target symptoms should be identified, quantified and documented.
- » Changes in target symptoms should be assessed and recorded at regular intervals.
- » The effect of co-morbid conditions, such as depression, should be considered.
- » The choice of antipsychotic should be made after an individual risk–benefit analysis.
- » The dose should be low initially and then titrated upwards.
- » Treatment should be time limited and stopped when target symptoms resolve. It should be regularly reviewed (every 3 months or according to clinical need).

The principles of the Adults with Incapacity (Scotland) Act 2000 require to be adhered to if the patient is unable to consent to treatment, and the section 47 form and associated treatment plan should be completed documenting the fact that the risks have been discussed and the treatment agreed.

The Bannerjee project published in 2009 by the Department of Health <http://psychrights.org/research/digest/nlps/BanerjeeReportOnGeriatricNeurolepticUse.pdf> highlighted concerns regarding the over prescribing of antipsychotic drugs to people with dementia. These drugs are often prescribed to treat BPSD, but the report found that of 180,000 people with dementia prescribed these drugs, two thirds of the prescriptions were inappropriate. The report highlighted that 5.3% of people aged over 65 were prescribed one of these drugs, and that between 20-30% of people in care homes were on antipsychotic drugs.

Therapy should always be reviewed regularly and only continued in situations where:

- » Severe adverse consequences may occur (or have occurred) if therapy is withdrawn.
- » No alternative treatment approaches are suitable.

Otherwise it is appropriate to consider cautiously withdrawing drug therapy usually by gradually stepping down the dosage and monitoring the response and/or re-emergence of target symptoms.

Despite the launch of a toolkit following publication of *Dementia (the Right Prescription): Pharmacy and the Call to Action* (www.rpharms.com/dementia/dementia-pharmacy-and-call-to-action.asp) to encourage pharmacists to question all prescriptions for antipsychotic drugs in those over 65 or those with a diagnosis of dementia, progress with reduction in antipsychotic prescribing to date has been slow in Scotland. This is evidenced by the report – ‘Time trends in psychoactive prescribing to people with dementia in Scotland 2001-2011 www.scotland.gov.uk/Resource/0039/00393277.pdf. Following the CSM warning in 2004, where doctors were given clear instructions to review patients and discontinue or change treatment, there was a definite downward trend in prescribing of antipsychotics in older adults, although it then settled again to a stable and relatively high level. After the 2009 warning from the MHRA, where the advice was less specific about the action to be taken, there has been a significant decrease in the initiation of antipsychotics in older adults, but less specific targeting of patients already on antipsychotics than there was in 2004. This is perhaps because of less specific guidance on how to proceed for doctors, especially GPs. It is important to realise that the symptoms being treated with these drugs are a source of great distress for patients and carers, and alternative approaches have to be offered to allow prescribers to feel comfortable withdrawing medication (particularly if it has been effective). This is the main challenge associated with reducing antipsychotic prescribing in this group. To overcome this, everyone involved in the care of these patients (including pharmacists) have to be aware of the alternatives available (see psychological therapies in Sec. 5.3) and how to access them locally.

The report from the Dementia Expert Working Group commissioned to 'agree and recommend a national commitment on the prescribing of psychoactive medications (excluding cognitive enhancers), as part of ensuring that such medication is used only where there must be a likelihood of benefit to the person with dementia and where there is no appropriate alternative' is eagerly awaited to help clarify the situation in Scotland.

5.1.4 Role of antidepressants

Depression can be considered as both a cause (as it is a significant risk factor for the development of AD), and a consequence of dementia. The co-morbidity is estimated to be between 30-50% between the two conditions. Detecting depression in dementia can be challenging as the patient may be unable to express the way they are feeling and may just appear apathetic and unresponsive. Assessment by a doctor experienced in old age psychiatry is preferable before deciding to commence treatment for depression. Where the patient is considered likely to be suffering from depression, they should be treated with an antidepressant drug in accordance with depression guidelines (available from both NICE and SIGN). First line drugs would be SSRIs, and it should be noted that the starting dose of citalopram is now 10mg (escitalopram 5mg) in those over 65 years with the maximum dose now limited to 20mg daily (escitalopram 10mg) in older adults due to concerns over QTc prolongation. Both these drugs should be avoided if the patient is taking other drugs which can also prolong QTc e.g. antipsychotics, domperidone.

There is some evidence to suggest that some antidepressants are effective for treating BPSD. A Cochrane review of antidepressants for agitation and psychosis in dementia (www.summaries.cochrane.org/CD008191/antidepressants-for-agitation-and-psychosis-in-dementia) reported sertraline and citalopram to be helpful for reducing agitation in dementia. It also reported that these drugs and trazodone were comparatively well tolerated compared to antipsychotics for these symptoms. There is also evidence to suggest that some antidepressants help apathy, one of the most common BPSD.

The most commonly prescribed antidepressants in dementia are citalopram, trazodone, mirtazapine and amitriptyline. This tends to suggest that the drugs are being used for agitation and sedation as well as for depression, since they are being used more than less sedating alternatives. Citalopram and sertraline have low potential for drug interaction, so are useful choices in older adults where polypharmacy can be an issue. The tricyclic antidepressants are best avoided in dementia because of their anticholinergic side-effects including effects on cognition. Newer antidepressants such as mirtazapine and venlafaxine have good evidence to support their use in the treatment of depression, but have not been adequately studied specifically for BPSD to recommend their use for this purpose. They tend to have more side-effects than the SSRIs, and are probably best avoided unless the SSRIs have been ineffective or have been poorly tolerated.

5.1.5 Role of anti-epileptics

No anti-epileptics are licensed and there have been few studies of their use in BPSD, none of which give convincingly positive results. At present there is no evidence to suggest that the use of carbamazepine, valproate, lamotrigine, gabapentin or topiramate would be of benefit, and they cannot be recommended for this indication.

5.1.6 Role of hypnotics and anxiolytics

Despite limited evidence to support their use for BPSD benzodiazepines such as lorazepam, diazepam, nitrazepam and temazepam are still frequently prescribed in older adults to treat anxiety and insomnia in dementia. It has long been recognised that the use of these drugs in older people can be associated with adverse outcomes such as increased falls and fall related fractures, as well as effects on cognition. Some new evidence has come to light recently to suggest that use of these drugs in the elderly may also increase the risk of developing dementia www.bmj.com/content/345/bmj.e6231. For this reason it is very important to limit the use of these drugs to short term use for extreme anxiety, agitation or aggressive behaviour which is not able to be managed in any other way.

Where use is necessary in an emergency situation for rapid tranquillisation, the use of intramuscular benzodiazepines (lorazepam is the preferred agent) may be necessary. This should only be used as a last resort in hospital situations by those experienced in the use of the drugs for this indication, and strictly adhering to locally agreed protocols.

When treating sleep disturbance in dementia it is important to exclude drug related causes such as medication taken at night causing insomnia or vivid dreams. Ensuring that the person takes part in some form of stimulating activity during the day, and where possible limiting daytime napping may also help to ensure that sleep occurs when carers would like it to. It is also important to be realistic – many older people only require 5-6 hours sleep in 24 hours, so it is inappropriate to sedate them so that they will sleep for 8-10 hours at night. If night sedatives are considered necessary, the lowest effective dose should be used and the licensed dose not exceeded. Intermittent use is preferred to nightly use, as tolerance will otherwise develop rapidly. This should be explained to carers so that the use of medication can be reserved for nights when it is particularly important to both patient and carer to get a good sleep. Short acting, short half-life drugs such as zopiclone, zolpidem and temazepam are preferred to drugs with longer half-lives for most patients as they reduce the risk of hangover effects being experienced the next day.

Use of night sedation in care homes and hospital settings, where there are staff available to look after people who are unsettled during the night, is inappropriate.

Risks associated with using sedative agents include increasing the risks of falls during the night if the person awakens disorientated and sedated, and the risk of incontinence developing due to over-sedation. Some doctors prescribe other drugs such as sedative antipsychotics (e.g. quetiapine) or antidepressants (e.g. mirtazapine or amitriptyline) instead of licensed hypnotics for night sedation. Unless they are using the drugs for dual purposes (i.e. the patient is depressed or psychotic/has BPSD that meet the criteria for prescribing an antipsychotic) this is an inappropriate use of these drugs and should be challenged.

5.1.7 Role of analgesics

Pain can manifest itself in a number of ways. As well as the physical sensation of pain itself, there is also an emotional and functional impact on the individual, which can severely impair quality of life. It can be particularly difficult to assess pain in severe cognitive impairment or in those with communication or language difficulties. There are a variety of useful tools for the assessment of pain in those with varying abilities to express themselves. Verbal and numerical rating scales best quantify the intensity of pain, but, where the ability to use these has been lost pictorial rating scales can be used.

Examples of verbal or pictorial pain rating scales are – pain maps (where the person marks the location of their pain on a picture of a human body): A Numeric Graphic Rating Scale (where the person marks the severity of their pain on a scale from 0 to 10 on a diagram): Verbal descriptor rating scale where the person rates their pain as none, mild, moderate, severe, very severe): Verbal numerical rating scale where the person verbally ranks the pain from 0 to 10): Pain thermometer (the person indicates their pain level on a diagram of a thermometer with increasingly severe levels of pain marked).

Where cognitive impairment is very severe the patient may be completely unable to report pain, and clinicians may have to rely on behavioural responses. These can be very hard to interpret as some of the signs can be present as distressed behaviours which appear unrelated to pain. Examples of signs that a person may be in pain include:

- » Autonomic changes such as pallor, sweating altered breathing patterns or tachycardia.
- » Altered facial expressions e.g. grimacing, wincing, rapid blinking.
- » Body movements e.g. pacing, rocking, hand wringing.
- » Verbalisation/vocalisation – sighing, grunting, screaming, moaning.
- » Changes in interpersonal interactions such as withdrawing from contact or aggression.
- » Changes in activity patterns – wandering, altered sleep.
- » Mental status changes – confusion, crying, distress or irritability.

The Abbey Pain Rating Scale (readily available on the Internet) is a scale for assessing pain in people with dementia who are unable to verbalise, and it relies on the observation of the intensity of the above symptoms in an individual. Taking a history from family or carers about painful conditions the person may have suffered from in the past e.g. arthritis, osteoporosis can help to determine possible causes of pain, and a thorough physical examination should help the doctor decide whether there is an easily treatable cause such as constipation. The type of analgesics used will be determined by the type and intensity of the pain, but it is usually appropriate to initially assess the response to regular use of a simple analgesic such as paracetamol. The WHO organisation pain ladder is an internationally accepted step-wise approach to pain management irrespective of the cause described in detail at www.patient.co.uk/doctor/pain-and-pain-relief This should be used where pain is poorly controlled to determine which treatments should be added.

There is evidence to suggest that treating pain empirically in agitated patients with dementia can improve agitation and overall neuropsychiatric symptoms (study available at www.bmj.com/content/343/bmj.d4065) The majority of patients in this study did not require anything more potent than paracetamol, although some did receive low dose morphine, and some who were unable to swallow oral medication were treated with buprenorphine patches.

Opiates should be used with care in this population due to the risk of side-effects such as constipation, respiratory depression and drowsiness. Low doses should be prescribed initially and increased according to response. Fentanyl is a very high potency opiate, available in a patch formulation. However, fentanyl patches should not be prescribed in patients who are opiate naïve i.e. have not been on any other opiate. The MHRA reported in 2008 that they had received reports of serious adverse reactions and death with fentanyl patches some of which were attributable to dosing errors by health care professionals. Equivalent oral morphine to fentanyl patch dose information is listed in the current BNF and should always be consulted before prescribing fentanyl so that the correct dose is prescribed. If concordance is an issue or if a patch becomes detached, re-titration may be necessary as some tolerance may have been lost. Pharmacists may be asked for guidance in this situation and should familiarise themselves with the pharmacokinetics and relative potencies of the available products.

Buprenorphine patches are available in a number of strengths. The 5 microgram per hour patch (the lowest strength) is equivalent to 10mg of oral morphine per day. The lowest strength of fentanyl patch (12 micrograms) is equivalent to 45 mg of oral morphine per day. If an opiate naïve patient is unable to take oral medication and requires an opiate, the buprenorphine patches can be used to prevent the need for syringe drivers or injections. Buprenorphine also has the advantage that it is less likely to cause respiratory depression than other opiates. The Scottish Medicines Consortium has not recommended the use of buprenorphine patches in NHS Scotland to date so requests to use them need to be made on an individual case request basis.

5.2 Illustrative cases

5.2.1 Peter (we met in section 4)



For a few months Peter engaged well with smoking cessation advice and managed to cut down his smoking and finally stop. He was told at the memory clinic that the diagnosis of dementia meant he was no longer able to drive. He found this difficult to accept, and was still using his car from time to time as this was his main means of independence. His son found out about this and was annoyed with him and insisted that he sold the car. Since then Peter has become socially isolated and his mood has become low. He has also had a few 'turns' recently and has fallen a couple of times so a home care worker was organised through social work services to go in daily to check on him.

Today when, he arrives at the pharmacy with his neighbour who has taken him out for a walk, the pharmacist asks how the smoking cessation is going. Peter says he has gone back to smoking, as he doesn't see any point in 'denying myself my last pleasure – life is hardly worth living anyway'. His neighbour volunteers that Peter has been a bit 'maudlin' recently and he had trouble persuading him to come out with him today although he used to enjoy getting out once a week with him. You notice Peter seems to have lost weight and he looks quite unkempt.

Pharmaceutical Care Issues	
Consider depression	Depression is common in dementia, especially if post-diagnostic support is not provided and/or the person has poor social or family supports. It is worth asking Peter if his mood has been low recently and asking about his appetite, sleep pattern and interest in things he previously enjoyed (e.g. does he still enjoy reading, watching TV, can he concentrate and follow a story line on TV or in a book). His neighbour may be able to add some information about how his self-care has been, and whether he is managing to take care of shopping, bills etc. (but should only be included in the conversation with Peter's permission). Many people shy away from asking whether someone has considered harming himself or herself but the risk of suicide in the elderly should not be under-estimated. As Peter has already said he feels life is hardly worth living, it is worth exploring whether he had thoughts of ending his life. If he answers yes to this it is worth also asking him whether he has made any plans to do so, and if so what is the nature of these plans.

On questioning Peter says he has not been sleeping well – he lies in bed worrying and has trouble getting over to sleep. He can't be bothered socialising and has no appetite – if it was up to him he would not bother making anything. He only bothers when the carers come round and encourage him. When asked if he really feels life is not worth living he says – 'yes I have nothing to look forward to – I just want to end it all'. When asked if he has plans to do this he says he has been saving his pills up.

The pharmacist wants Peter to go round and see his GP and offers to arrange this. He gets angry about this and storms out of the shop, leaving his neighbour standing there.

Activity



What should happen now? Choose from the following:

- A Peter has said he does not want the GP contacted. This is his right and so he should be left alone.
- B The GP or another agency should be contacted urgently as he may be a risk to himself if he is left alone.
- C Peter's home care workers should notice there is a problem and deal with – it is their responsibility as they are employed to look after him.

Research the following link to help you decide what your responsibility is under Adult Support and Protection legislation www.actagainstharm.org/what-the-act-does

Discussion

Peter has expressed suicidal thoughts and intention to act on them. He also has the means to do so as he has been saving his medication with the intention to overdose on it. He has biological symptoms of depression (e.g. low mood, poor appetite, lack of interest in things he used to enjoy, altered sleep pattern) and although he has expressed a wish to be left alone, may not be well enough to have the capacity to make this decision. He may meet the definition for detention (being admitted to hospital without his consent) under the terms of the Mental Health (Scotland) Act 2000, as he is a significant risk to himself. Urgent assessment by a doctor is required. Under the Adult Support and Protection Act (2007) as discussed in David's case (sec 3.1), it is not an option to do nothing when you know an adult is at risk in the community. During GP practice hours Peter's GP could be contacted urgently and apprised of the situation or Adult Protection can be contacted through the local council. Out of hours numbers are also available for the Adult Protection services via the local council (numbers available via the above link or on individual council websites).

The home care worker will be employed by social work, and may have links with the Community Mental Health Team (CMHT) and line managers who should know what action to take, but they may not have had much training in this area. Given that there is likely to be a delay since the care worker is not due in again until the next day, and there are urgent concerns, it would be better if the pharmacist dealt with the situation as detailed above.

Outcome

The pharmacist phones and speaks to Peter's GP, explaining why she is so concerned about Peter and informing him that she believes he has both suicidal thoughts and the intention to act on them. He also has the means to do so as he has been saving up medication for this purpose. Peter's GP goes to see him at home. Peter initially refuses to let him in, but with persuasion agrees to speak to him. On further persuasion he accepts that he is depressed and agrees to come into hospital for a while to see what can be done to help (as he has agreed to admission he does not require to be detained under Mental Health Act legislation).

5.2.2 Jane



Jane is a 76-year-old lady. She was admitted to hospital via ED after being found walking in the street in a state of confusion. She described having 'visions' at home. She saw flowers and bread on her table, which she had no recollection of putting there. She was not terribly distressed by these hallucinations but was quite confused and unable to give a clear history. Her husband was contacted and was able to say that she has a six month history of Parkinson's Disease and was started on co-careldopa for this 5 months ago. The dose was recently increased to 200/50 four times daily, although he does not feel it has made much difference to her Parkinsonian symptoms. He feels that other symptoms have also been present over the same period. He has noticed her becoming more forgetful and she has also been complaining of these visual hallucination symptoms. During the day she is intermittently really sleepy, sometimes seeming alert and aware and at other times not. She also has some beliefs that the neighbours are spying on her and that they can communicate with each other telepathically about what she is up to. Her neurologist had explained that these were side-effects of her levodopa (but her husband is not so sure as he thinks these symptoms were present before she started on the levodopa, but were just not as extreme) and had prescribed some quetiapine 100mg at night. Despite this, she still complained of hallucinations intermittently and the beliefs about the neighbours are still present. She had also had a lot more falls since she started on the quetiapine, and he thinks she is worse on it.

Jane was referred to liaison psychiatry. Her MoCA was carried out on two occasions and fluctuated between 18/30 and 22/30, but she had consistent problems with the clock-drawing element of the test. Her history raised a suspicion of DLB and/or dementia associated with PD and further investigations were ordered to exclude delirium and other reversible causes of dementia. Following these investigations the working diagnosis was DLB and it was decided to review her medication on this basis.

Pharmaceutical Care Issues	
Review antipsychotic use in the light of diagnosis	Diagnosis of DLB can only be confirmed at post mortem and there is considerable overlap in symptoms between PDD and AD. One of the most striking features of DLB is the tendency for sensitivity to neuroleptics, which can cause rigidity, altered consciousness, pyrexia and collapse. Although quetiapine is one of the lower risk antipsychotics in PD, it is likely to lead to side-effects in a person with DLB. This is an unlicensed use of the drug. Clearance of quetiapine is significantly reduced in the elderly and dose titration should be slow, keeping the dose as low as possible. As there are significant risks in using antipsychotics in those with DLB, it would be best to gradually decrease and stop (if possible) the quetiapine, and see whether there is any worsening of symptoms.
Review levodopa dose	Despite parkinsonian features, many patients with DLB exhibit limited clinical response to levodopa. It can also cause or exacerbate visual hallucinations, and often the risks out-weigh the benefits in these patients. The plan was to gradually decrease the levodopa and monitor the response.
Consider whether prescribing an AChEI is appropriate	<p>None of the AChEIs are licensed for treatment of DLB. Rivastigmine, does have a licence for ‘symptomatic treatment of mild to moderately severe dementia in patients with idiopathic Parkinson’s disease’. NICE guidelines suggest that AChEIs can be used where non-cognitive symptoms of dementia are causing significant distress or leading to behaviour that challenges.</p> <p>In Jane’s case an AChEI is prescribed because her non-cognitive symptoms worsened when the levodopa was reduced, and the quetiapine discontinued. The least expensive drug i.e. donepezil is prescribed as there is no reason to justify using one drug over another. Jane’s motor symptoms should be monitored as AChEIs can worsen rigidity in PD.</p>
Ensure information is shared with the neurologist and GP regarding the revised diagnosis.	It is important to raise awareness about the risks of prescribing antipsychotics for Jane. If hallucinations and delusions cannot be managed in any other way in future, drug therapy should be prescribed cautiously, titrating slowly and using the lowest effective dosage. If necessary Jane should come in to hospital to facilitate dose titration.

Pass on medication changes to Community Pharmacist	Ensure repeat prescriptions of quetiapine and levodopa are stopped and the community pharmacist and GP are aware of donepezil prescription and the diagnosis of DLB.
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What happened to Jane?

Jane’s levodopa and quetiapine were gradually withdrawn over a three-week period. Her mobility and cognition improved as a result of this, but her hallucinations became much more prominent and her delusions more intrusive, to the point where her husband was saying he was finding it difficult to care for her. She had started acting on the delusions by shouting and swearing whenever she saw the neighbours and he found this very distressing. She became aggressive, and could not be persuaded that her hallucinations and delusions were part of her illness. She was started on donepezil 5mg daily, which she responded well to, and tolerated. 8 weeks after starting donepezil, there was a decrease in the frequency and duration of hallucinations and the delusions, although still present, were impacting less on daily life. Jane’s MoCA score had also increased by 3 to 4 points. She was able to be discharged home with her husband who was very pleased with her progress and reported that she had not been so talkative and interactive for about 6 months.

5.3 Role of non-drug therapies in dementia

As discussed at the beginning of section 5, the term BPSD is not preferred by psychologists as it tends to reinforce the common belief that dementia is the direct cause of ‘challenging behaviour’, and therefore the behaviour requires treatment. In fact, the behaviours exhibited by many people with advanced dementia are often (but not always) driven by feelings of distress, leading inevitably to distress in those who care for them. Behaviours such as aggression, resisting personal care, sexual disinhibition and nocturnal disturbance are best described as ‘distressed behaviours’, with symptoms such as apathy, depression, hallucinations and anxiety, better seen as causes of behaviour. It is important for carers to realise that the behaviours they find difficult to cope with and distressing, leading them to seek help from clinicians, are in themselves an attempt by the person with dementia to communicate distress. What is required is therefore an investigation of what unmet need or needs lie behind the distress.

The way that we communicate with people with dementia can impact significantly on the way the person reacts to us i.e. on their behaviour. We may come across as bossy or controlling, our tone or volume of speech may inadvertently come across as threatening and we may be tempted to talk down to a person with dementia (treating them like a child), or to speak about them as if they are not present. We may also be tempted to constantly challenge the persons beliefs e.g. when someone is repeatedly asking to see a member of their family who has passed away, it is more helpful to spend time talking to them about the person, using old photographs if they are available than to say ‘you can’t see your husband dear, he died last year remember’.

We should not assume that frightening experiences such as being physically assisted into the shower, or being physically given medications such as enemas are forgotten. Explicit memories may decline but many people with dementia will implicitly remember situations, places or people with whom experiences that have distressed or frightened them have occurred. Because of these memories they may misinterpret what is likely to happen in a similar situation again, and may become aggressive or upset.

Sometimes our failure to really listen to the person with dementia – not just to their verbal cues, but also to the non-verbal cues, is the problem. When someone is crying out repeatedly, could it be that they are in pain? When a person with dementia is agitated and pacing – could they be looking for a toilet? When someone is aggressive, are they just frightened because the last time they saw you, you had to do something to them that they found unpleasant?

People with dementia have the same needs as the rest of us for safety and security, affection, privacy, comfort and refreshment. Before we consider interventions for 'distressed behaviour', we should consider whether all these basic needs have been met.

The Dementia Skilled – Improving Practice Learning Resource, jointly produced by NES and The Scottish Social Services Council gives some excellent practical advice to improve understanding and management of some of the most commonly reported 'challenging behaviours'. It is available at www.nes.scot.nhs.uk/media/857092/dementia_skilled_final.pdf.

Where the person is exhibiting distressed behaviour the above resource suggests the use of an ABC chart to assess the pattern of the behaviour, and the reasons behind why it occurs. (A sample chart is available in the resource). The chart should be completed over a 1-2 week period every time the behaviour being studied occurs. Anyone who observes the behaviour can, and should, complete the chart, although some guidance on how to do this from a person trained in use of the charts is helpful. The chart provides a factual record of events, not an opinion on what may or may not have caused the behaviour.

ABC stands for:

A – Antecedents: This means what was happening just prior to the person becoming distressed.

B – Behaviours: This is simply a description of the behaviour(s) witnessed by you/staff/carers.

C – Consequences: These are the responses or outcomes to the distressed behaviour, either from others or the person in distress. This helps to determine the things that have been successful in dealing with distress.

Analysis of the ABC chart may help to identify patterns e.g. the behaviour always occurs just before lunch time (may indicate hunger) or a certain carer always manages to calm the person using distraction techniques such as music. The results can be incorporated into a person centred care plan. This should then be tested to see whether there is a reduction in the frequency or severity of the behaviour.



Activity

If you work with people with dementia e.g. in a hospital or care home setting – observe the way care workers interact with the person. Seek out people who have good relationships with people with dementia, and people who do not – what is the difference in the way they interact?

Consider people you know with moderate to severe dementia. Consider how much time they spend each day in social contact with others? Is most of this time during personal care only?

Consider the way you communicate with people with dementia. After observing someone who does this well, practice it yourself. (Before you start, think about sensory impairments – can the person see and hear you? If they need their glasses or hearing aid make sure they are wearing it). At first you will find this difficult, as many of us automatically start conversations with questions, and this is unhelpful in advanced dementia. Having some knowledge of the person's life story is important in order to start a conversation. Use the person's name to demonstrate that you know them, and are not a stranger (respect their preference if they would rather be addressed as Mr. or Mrs.). Speak slowly and calmly, using a gentle tone, keep sentences short and avoid jargon. Remember to give the person time to respond to you, and listen carefully to what they have to say. Use non-verbal cues such as smiling and nodding to show that you are listening and understanding.

5.3.1 Evidence based psychological interventions in dementia

Promoting Psychological Wellbeing for People with Dementia and Their Carers : An Enhanced Practice Resource available at www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/multiprofessional-psychology/psychology-and-psychological-interventions-in-dementia/enhanced-practice-resource.aspx goes into more detail about the evidence based psychological approaches available to help people with dementia. It is not necessary for pharmacy staff to have detailed knowledge of these therapies as they would be unlikely to be delivering them, but knowing that they are available means that staff are aware of the alternative to psychoactive medication. Below is an outline of the therapies available.

Cognitive stimulation therapy (CST)

CST is currently recommended in SIGN and NICE guidelines for the management of dementia, as an evidence based intervention. It consists of a programme of cognitively stimulating activities carried out in a social group of 4-5 people, facilitated by one or two staff. It is mainly useful for people with mild to moderate dementia who retain some ability to communicate verbally. A manual is available to help people deliver the 14 sessions over 7 weeks covering different topics, including creative activities, quizzes and memory games. No specific qualifications are required to deliver the sessions.

Trials have demonstrated improvements in cognitive function of the same magnitude as is achieved with cognitive enhancing medication. In those already on medication, these benefits are additive. People with dementia also report benefits in their quality of life and social skills of attending CST sessions.

Reminiscence approaches – group and individual including life story work

Reminiscence work can be carried out in a group, with or without family or carers present, or on an individual basis. This type of therapy helps stimulate the person's memory of their own personal life experiences, thereby helping them to maintain a sense of their own identity and improve their self-esteem and wellbeing. When therapy is carried out in the presence of family or carers (e.g. remembering yesterday, caring today (RYCT) groups) relationships with family can be enhanced by sharing the activity and the memories. Although these activities are mainly useful for those with mild to moderate dementia, the development of life story books or DVDs, and memory boxes can be helpful in the later stages for staff communicating with the person and understanding their life story. No particular qualifications are required to work on a life storybook or to lead a reminiscence group, but sensitivity is required to the way in which the person with dementia is responding to the activity. If there are any signs of distress, the activity should cease.

Cognitive rehabilitation

This is an individualised approach to setting goals for the person with dementia, according to their individual strengths and difficulties. Examples include learning to use a diary or memory aid. This therapy is for people with mild dementia and is usually delivered by an occupational therapist or clinical psychologist.

Cognitive behavioural therapy (CBT) for anxiety and depression

CBT works by influencing cognitions to be more realistic and less negative or hopeless and changing unhelpful behaviour such as avoidance or inactivity. It is useful for people with mild dementia who also suffer from anxiety or depression. It can only be delivered by therapists with accredited training, although family members can be taught to help the person to engage in more stimulating activities as part of the therapy.

Multisensory stimulation

This approach is for people with severe dementia. It involves using a variety of methods to stimulate the senses e.g. lava lamps, aromatherapy burners, tactile materials, rummage boxes containing different materials, hand massage etc. This approach focuses on sensori-motor abilities, and can help the person relax by reducing arousal or helping focus attention on external stimuli rather than internal needs. Reviews of this approach have so far failed to prove that it is beneficial on behaviour, mood or interactions of those with dementia. However difficulties in comparing the studies and populations make interpretation of the results difficult.

Formulation led interventions to distressed behaviour

This is an individualised approach to distressed behaviour based on an understanding of the person and not simply on providing a standard intervention. The approach involves first excluding the influence of medical or physical factors such as pain, constipation, infection etc. If the distress continues, and taking account of the carers views / level of distress, a theory (or formulation) is developed as to why the person is experiencing distress. A formulation-led model that can be used is the Newcastle Clinical Model. The model includes information on physical and mental health, the social environment, medication, cognitive abilities and the life story and personality of the person, to assist in understanding the thoughts, emotions, and beliefs underlying the person's stress or distress. The functional analysis includes analysis of when and where the distressed behaviour occurs, but goes beyond the ABC chart approach above, in the sense that it recognises the fact that the trigger may be an internal thought or experience. The formulation provides working solutions (not final answers), from which an intervention plan is drawn up.

NES has begun to train health and social care staff working with people with dementia, in the formulation led approach used by specialists working in Newcastle. The NES training has utilised the "Training for Trainers" model whereby staff are trained to roll out training to colleagues within their local area. The approach is complex and multi-disciplinary, and pharmacists are involved as part of the team in assessing the influence of medication, the need for review of existing medication or appropriate use of new medication to target symptoms. Liaison and other specialist teams have begun using this approach with individuals in care homes in some areas.

Training in this approach also trains staff in some stand-alone techniques which can be used with staff and carers to improve understanding of dementia and reduce their distress.

5.4 Cases revisited

5.4.1 Pauline (we met in sections 3 and 4)



Pauline's husband comes into the pharmacy with a prescription for Pauline for risperidone tablets 500 micrograms twice daily and temazepam 10mg at night. He explains that he has been to speak to the doctor today about Pauline because he is finding it increasingly difficult to cope with her 'behaviour'. She gets very agitated and asks the same questions over and over again, she also has a tendency to pace up and down and follow him around the house. On two occasions she decided to leave the house unaccompanied. He doesn't get much sleep because she is up and down during the night. He worries that she might leave the house during the night and he is so tired that he might not waken, so he asked the GP if Pauline could have a sleeping tablet. He explains that he is an old man himself, and that he doesn't really keep well and is finding the lack of sleep difficult. His GP has given him an emergency number for social work services and he is going to phone them when he gets home.

He wonders if you could hurry up with the prescription because he has called his daughter away from her work to sit with Pauline while he nipped out.

Pharmaceutical Care Issues

Criteria for prescribing an antipsychotic – are they met in this case?

- » Risperidone can be used in persistent aggression in patients with moderate to severe AD – Pauline has not been aggressive, just agitated, and the reasons for her agitation need to be investigated.
- » The recommended starting dose of risperidone is 0.25mg twice daily adjusted according to response by increments of 0.25mg twice daily, not more frequently than every other day. The optimum dose is 0.5 mg twice daily for most patients. Some patients, however, may benefit from doses up to 1 mg twice daily. The GP has started Pauline on a higher than recommended dose.
- » General recommendations for antipsychotics is that they should only be used where other strategies have been tried and failed, including non drug treatments.
- » Other reasons for the behavioural problems, including physical problems need investigated before prescribing antipsychotics.

It would be worth exploring with Pauline's husband.

Has the doctor been to see Pauline to assess whether she has any physical problems, which might be causing her distress?

Have non-pharmacological options been tried? Have the risks of medication been explained to him?

How have the benefits of the medication to be assessed?

How will any negative effects of the medication be assessed?

When does the doctor plan to review Pauline again?

On exploring these points it seems that the doctor has not been to review Pauline, and physical causes for the recent change in her condition have not been explored. The doctor had mentioned to him that there was a risk of stroke with these medications in people with dementia, but had assured him that this would be very small as Pauline had never had any blood pressure or heart problems. He had been told to try the medication for 2 weeks and let the doctor know if it had helped.

<p>Appropriateness of temazepam? Consider alternatives</p>	<p>The doctor has decided to prescribe a night sedative for Pauline because her husband is worried that she may leave the house unattended during the night. If Pauline did manage to do this she could be at risk of getting lost, falling or developing hypothermia.</p> <p>On questioning, Pauline's husband admits that she has never attempted to leave the house during the night. The two occasions when she did leave were during the day. At night she just gets out of bed and walks around the room. When he tells her to go back to bed she does so, but he does not sleep because of this.</p>
<p>Discussion with GP</p>	<p>The pharmacist contacts the GP and explains that she has reservations about dispensing this medication for Pauline as it goes against the guidelines on psychactive prescribing in people with dementia. One of the issues is that two drugs are to be commenced at the same time, both of which are sedative. The additive effect could lead to excessive drowsiness, risk of falls and potential for worsening of cognitive function. Even if the medication is thought to be beneficial, it will be hard to assess which medication is helping. The pharmacist is also concerned that there could be a physical cause for Pauline's recent change in presentation and is worried that this could be worsened by medication. The proposed starting dose of risperidone is also higher than recommended, the target symptoms have not been identified, and no follow up is planned within the first two weeks of treatment.</p> <p>The GP is not particularly happy to be questioned in this way by the pharmacist, and asks 'what do you expect me to do, the poor old man is at the end of his tether?'</p>

Discussion

Often medication is prescribed for a person with dementia because their behaviour is distressing a carer. Certain types of behaviour are better tolerated in some care settings than in others and what one carer finds difficult to cope with, may not be a problem for someone else. The most important factor is to identify when the person with dementia, is them self distressed, and to try to identify what might be the reason for the problem.

It is important that Pauline's physical health is assessed by the GP before he makes a decision to prescribe medication for her behaviour. Pauline could have an infection, be constipated or be in pain. It may be impossible to get any history from Pauline, but a physical examination would reveal obvious issues and should be carried out. It would then be appropriate to make an urgent referral to the Community Mental Health Team (CMHT) and social work services. A CMHN will have the skills to discuss Pauline's presentation in detail with her husband and take a good initial history of how and when Pauline's distressed behaviours present. Social work services may be able to put in an emergency care package to help take some of the pressure off Pauline's husband, and care workers would be able to help by keeping a diary of Pauline's distressed behaviours and any strategies that can be employed to help. It may help Pauline's husband to see how care workers deal with Pauline's behaviour, as this may help him to view it as less difficult to cope with.

Outcome

The CMHN visited Pauline and her husband the following day, and carried out an assessment. Pauline's repetitive questioning seemed to focus on where the house keys were. Traditionally the keys had always hung on a hook by the front door. Recently, whenever Pauline found the house keys she would try to leave the house. Because of this her husband had taken to hiding the house keys from her. Not knowing where the keys have gone, now seems to be a source of great distress. Putting a key back on the hook by the door where the keys have always been, seems to relieve Pauline's distress. Because of the risk of her leaving the house a key that does not fit the lock is placed there. This addresses Pauline's unmet need i.e. to have access to her house keys, without placing her at risk. If Pauline then tries to use the key to leave the house, a distraction technique can be used to persuade her that it is not time to go out just now, but this would only be necessary if she became distressed. When the couple do go out, Pauline's husband is encouraged to give her the key and let her lock the door as this makes her feel independent.

Because Pauline has a history of arthritis in her neck, and is not currently prescribed any analgesics it is decided to try some ibuprofen at night to see if she is more settled (the prescription of ibuprofen has to be balanced with the risk of side-effects, especially bleeding). This has excellent benefit, and her husband is delighted because he is able to get a nights' sleep again.

The need for medication to treat Pauline's agitation and sleep disturbance is avoided.

5.4.2 Peter (6 weeks on)



Peter is admitted to the elderly acute psychiatric unit and treated with sertraline for depression. His diabetes, hypertension and lipids are poorly controlled on admission and it is clear that he has not been taking his medication as he confided to the community pharmacist before admission. His medication is reinstated and sertraline 50mg daily is started. After 3 weeks his mood begins to respond, but it becomes clear that he is having frequent transient ischaemic attacks (TIAs). His ability to care for himself is significantly impaired, and he is quite paranoid and suspicious about the other patients. He takes to hoarding food in his locker, and hides his personal items. He then forgets where he put them and accuses other patients of taking them. He also seems to be responding to hallucinations at times, shouting out when there is no one there, particularly at night time. This disturbs other patients. His ability to find his way about gradually starts to deteriorate and he gets confused about which locker and bed are his. Because of this, he often interferes with other people's property or lies down on their bed. Toileting is also an issue. He starts to become incontinent and even if he does manage to make it to the bathroom, either misses the toilet, or wipes himself with a towel rather than paper, or just uses his hands.

It is felt that Peter's needs would be better met in a care home that specialises in the care of patient's with dementia. In the meantime the plan is to treat his behavioural and psychiatric symptoms with some medication.

Role of the pharmacy team during Peter's admission to the mental health unit

When Peter arrives in the mental health ward, the admitting doctor should start his medicines reconciliation form. The doctor should use at least two sources to confirm Peter's medication and ensure that it is correctly prescribed on admission. The pharmacist is responsible for checking that the documentation has been completed properly, that appropriate medication has been prescribed on the in-patient prescription sheet (taking account of any contra-indications to previously prescribed medication that have arisen since admission), and that both documents are signed and verified as accurate.

The pharmacy technicians are involved in ward top-up services, ensuring that prescribed medications are available on the ward for administration.

Pharmacists are part of the multi-disciplinary team involved in making decisions about appropriate drug choices in the mental health setting. They will be involved in multi-disciplinary team discussions; meetings with patients and carers; patient, staff and carer education, and discharge planning. They are also involved in ensuring that patient's rights are protected by ensuring Mental Health Act, and Adults with Incapacity Act, legislation is adhered to. Where a patient's history is particularly complex, a pharmacist may be asked to compile a detailed medication history, and advise on treatment options for future treatment.

Some patients may be tried on supervised self-medication in the ward setting to assess their ability to take their medication independently once they leave hospital. In some areas care workers have been trained to administer medication without the need for compliance devices, reducing the need for these to be supplied by community pharmacists when the patient is not self-administering, and allowing them to be reserved for those most in need of them. Original pack dispensing is preferred, with provision of MAR charts to facilitate recording of administered doses. Care plans include details of action to be taken to feed back any problems or issues encountered with medication. Local protocols are in place in areas where this service is available.

Liaison with GPs and community pharmacy colleagues is an important part of the role of mental health pharmacists to ensure continuity of supply and appropriate review of medication post discharge. Liaison with CMHT and social work colleagues is also important to ensure that care workers are aware of any issues regarding medication that may crop up or need resolved.

Mental health pharmacists also provide a specialist medicines information service within their own area.

Pharmacy technicians support the pharmacists to provide these enhanced services by taking the lead in dispensing and ward stock services, supporting clinical audit activities and having specialist knowledge of the needs of patients with mental health problems.

Pharmaceutical care issues related to treatment of Peter's BPSD

Pharmaceutical Care Issues	
Exclude physical causes of distressed behaviour	Exclude the influence of infection, pain, constipation etc. before considering any treatment.
Advise on appropriate treatment of BPSD	<p>It is important to be clear about what symptoms are to be targeted with any medication to be used. Potentially problematic symptoms are as follows:</p> <p>Paranoia, suspicion, hoarding, hiding personal items, accusing others of stealing, increased disorientation, responding to hallucinations, disturbing other patients especially at night, interfering with other people's property and continence and toileting issues.</p> <p>The majority of these problems are not directly treatable with medication, and would be unlikely to respond. The symptoms which might respond to drug treatment would be the psychotic symptoms i.e. paranoia and hallucinations. Some of the other problems such as hoarding and accusing others of stealing are happening as a result of the psychotic symptoms. If medication is to be used at all it should be very clear that these are the symptoms being targeted. Medication should only be used where these symptoms are causing Peter severe distress or putting him or others at risk. The risks of using antipsychotic medication are very high in this case as Peter is experiencing TIAs as it is. There is no evidence for use of AChEIs to treat these symptoms in vascular dementia, and the NICE guideline does not recommend this. There are also no studies to suggest that memantine will work. In this case options are extremely limited, and medication should only be used if there is no other option. One option would be the use of low doses of short acting benzodiazepines (e.g. lorazepam 0.5mg – 1mg) for periods of acute distress if Peter cannot be calmed by other means such as talking to him, taking him somewhere quiet, distracting him etc.</p> <p>The use of antipsychotics would be reserved for consideration only if behavioural approaches had failed and Peter's symptoms were causing him extreme distress or putting him or others at risk. A multi-disciplinary decision would be required and his family / welfare proxy would need to be fully informed of the risks involved. Dosage would be the lowest available dose for the chosen drug. Target symptoms and cognitive functions would be monitored, and the drug stopped if it was ineffective.</p>

Discuss options other than drug treatment with the MDT	<p>Some of Peter's problems would be likely to respond to non drug strategies as follows:</p> <p>The reason that Peter lies on other people's beds or goes through their belongings is because he is unable to identify his own bed area. Helping Peter to know which bed space is his e.g. by using bedding that he will recognise (e.g. football colours if he has a favourite team) may help.</p> <p>Orientation around ward areas can be helped by making it more obvious what the purpose of each room is e.g. by putting a picture on the door. This might help Peter find the toilet more easily. Many people with dementia also have visuo-spatial difficulties making it hard for them to distinguish objects if the background is the same colour as the object. This can result in them bumping into objects around a room, or finding it difficult to aim accurately when using a white toilet in a white bathroom with a white seat. The use of contrasting colours can be helpful.</p> <p>Peter's continence issues could be as a result of a physical problem such as constipation, an inability to locate the bathroom on time and/or an inability to identify the toilet in the bathroom or remember what to do. Before it is decided that Peter is now incontinent these issues need to be investigated.</p>
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Activity



The University of Stirling website includes a 'virtual care home' available at: www.dementia.stir.ac.uk/virtualhome that illustrates design features suitable for people with dementia. Look at the features highlighted in the different rooms. Think about whether any of these design features could be applied in the setting you work in to make it more accessible to people with dementia (if appropriate).

Barnton Pharmacy in Edinburgh has been working closely with the charity Alzheimer Scotland (who have provided training for the staff) to look at ways of making the pharmacy more dementia-friendly. The pharmacist has produced a dementia check-list which includes – making dementia resources available in the pharmacy; ensuring the pharmacy is accessible with clear signs and layout; and using services like the CMS to help people with dementia. Could you implement this in your setting to make your pharmacy more dementia-friendly?

It is important to know about other networks available to help people with dementia in your local area, and know how to help people access them. Such services include hospital and intermediate care teams, falls services, community mental health teams, home-care service providers and community groups. Could you compile a contact list for these services in your area and find out what the referral processes are?

Outcome

Peter was moved from the acute mental health admission unit into the dementia rehabilitation unit so that a full multi-disciplinary needs assessment could be undertaken prior to social work identifying a suitable placement for him. The environment was more suited to Peter's needs, and the staff more relaxed about his behaviour in this unit. After an initially unsettled period, he began to become more relaxed and orientated around the ward. The team carried out an assessment of his behaviours, taking into account results from ABC charts and other observations. A formulation led intervention plan was devised by the psychologist, including some strategies for helping to calm him when he became distressed. His continence improved by implementing regular visits to the toilet, but he required help to clean himself. He had his own bedroom, so interfering with other people's property became less of an issue, and although he still shouted out at night (seemingly in response to auditory hallucinations) this did not unduly distress him, and had less impact on others. As a result of the positive environmental changes, attitude of experienced staff and some behavioural interventions such as being taken to the toilet regularly, the need for medication to treat Peter's behaviour was avoided.

5.4.3 Jane (1 year on)



Jane did well on donepezil, which had been increased to 10mg daily after 8 weeks, for some time. Recently, however, her delusions had become more intrusive, and now involved her husband as well. She was becoming quite aggressive towards him, and had also become quite sexually disinhibited. Her husband found this very embarrassing, especially when they had young male visitors as she behaved quite amorously towards them, and on one occasion had taken her top off. Mobility was also becoming more of an issue and Jane had had a number of falls around the house. Her personal hygiene was also a problem now as she could not get in and out of the bath, and would not let her husband wash her.

Jane's GP had organised an emergency social work assessment, and an occupational therapist had been round to the house to see what could be done to help with Jane's mobility and bathing. A bath chair had been fitted and Jane was given a stick for around the house, but over a period of a few weeks she became difficult for the care workers to look after because she was very aggressive when they tried to bathe her. On one occasion she hit one of the care workers with her stick when she suggested it was time for her bath. The team psychologist's opinion was sought but despite behavioural strategies Jane remained very difficult to care for to the extent that her personal care was so poor that it was presenting a risk of infection and breakdown of her skin. The pharmacist involved with the team was asked for suggestions.

Pharmaceutical Care Issues	
Advise on appropriate treatment of BPSD in DLB	<p>Whilst aggression can be viewed as a distressed behaviour (perhaps due to fear pain etc), and the reasons why it is happening should be investigated, it can also occur as a direct result of the biological changes in the brain in dementia, and as such medication may be beneficial.</p> <p>As Jane had DLB, the use of antipsychotics is high risk, and should only be used for severe non-cognitive symptoms where other strategies have been tried and failed.</p> <p>An alternative would be to add memantine. There is some evidence that memantine can reduce the impact of some non-cognitive symptoms in DLB including aggression and disinhibition. This intervention is not supported by NICE.</p> <p>As quetiapine is the antipsychotic least likely to adversely affect mobility, a very small dose could be initiated and carefully monitored (25mg initially).</p>
Formulate a multidisciplinary treatment plan	<p>When starting the quetiapine the target symptoms should be clearly identified. A baseline assessment of the frequency and severity of these symptoms should have been undertaken prior to starting medication and charts should be continued to assess for change in the pattern post prescription.</p> <p>NICE recommends monitoring for neuroleptic sensitivity reactions (severe extrapyramidal reactions or acute and severe physical deterioration following prescription of antipsychotic drugs for which there is no other apparent cause).</p> <p>Assessment of cognitive changes should also be undertaken. If the drug is ineffective, it should be withdrawn.</p>

Ensure risks/benefits of treatment are explained to patient/family members (taking into account capacity issues) and legal issues are addressed.	Where the patient is unable to consent to treatment and there is a welfare proxy (i.e. a person with Power of Attorney or a Welfare Guardian) they should be consulted and the risks/benefits of medication explained. The discussion should be documented in case notes.
Ensure discussions are documented and information shared with relevant people e.g. GP	A clear multidisciplinary care plan should be developed so that everyone looking after Jane is aware of the monitoring to be undertaken, and the plan for review of the antipsychotic. Information should be shared with the GP.
Arrange reviews of plan at regular intervals	The dates for review of the care plan and medication should be planned in advance and clearly documented.

Outcome

Jane initially responds to the quetiapine 25mg at bedtime and becomes less aggressive and difficult to care for, however after a few weeks she starts to become aggressive again. The reasons for this are not clear until her husband drops something on the bedroom floor one morning. When he bends down, he finds a number of half chewed quetiapine tablets under the bed. Her husband discusses this with the GP who suggests that the care workers try observing Jane taking the medication more closely at night. This becomes a major problem at night time, leading to verbal, and sometimes physical aggression as Jane point blank refuses to accept the medication. It is not clear what is driving this – whether it is suspicion driven by psychosis or just a reaction to feeling forced to take the medication. No matter how hard the carers try, they cannot get Jane to accept the medication, and her physical health begins to deteriorate due to poor self care again. It is clear that she can no longer be looked after at home due to the risks to her and her husband, and a care home placement is found for her locally.

Role of the pharmacist working with the care home

The first task for the pharmacist working with the care home is to ensure that Jane's medication is accurately prescribed, and a supply is made. Unfortunately, in this case, the problem is that Jane is not taking her prescribed medication. The need for this will need to be re-assessed in her new environment, and if it still required, a plan made to ensure that the medication is able to be given. Jane is still prescribed donepezil 10mg in the morning (which she takes) and her quetiapine 25mg at night, which she refuses. One of the staff in the home asks the pharmacist if it would be acceptable to crush the tablet and put in yoghurt to give it to Jane. Pharmacists working with care homes may be community pharmacists involved in supply of medication, prescribing support pharmacists working with GP practices or pharmacists employed by the health board to provide a service to care homes. The level of knowledge of the legal and ethical issues raised by this question will therefore be variable. If unsure how to proceed, it would be worth consulting the medicines information department in the local hospital, who can advise on any local contacts and any local guidelines and procedures specifically related to administration of medication to people who lack capacity to consent.

In the first instance it is important to understand why Jane accepts one tablet and not the other. If Jane is unable to explain, it is important to explore why this is the case:

- » Is she used to the routine of taking donepezil, so does not question it?
- » Is it because she is more approachable in the morning than at night?
- » Is it because of the colour, shape or taste of the tablets?
- » Does she dislike certain members of staff?
- » Does she believe that the quetiapine is poisonous/dangerous?

These issues need to be explored before any changes are made. Giving the quetiapine in the morning could be tried. Different members of staff could offer the tablet to Jane to see if this makes a difference (although all members of staff should make it clear that what they are offering is medication). If Jane still continues to refuse quetiapine, a different antipsychotic available in different formulations could be tried e.g. risperidone which is available as a liquid and orodispersible tablet, which she may find more palatable. This is more likely to affect Jane's movement, but may be unavoidable if she will not accept quetiapine.

Covertly administering (hiding the fact that medication is being given) can be used as an absolute last resort where a patient would be at significant risk without the medication, and where this constitutes the least invasive option. Clear guidelines on the process for decision making in this situation is available on the Mental Welfare Commission website www.mwscot.org.uk/search/?keyword=covert+administration The decision should be multi-disciplinary, and always involve a pharmacist. All other avenues such as using different formulations should have been explored. In this case, injectable antipsychotic formulations are available, but these may expose Jane to higher equivalent doses and therefore greater risk of side-effects, and would be more invasive and lead to more distress as it may require restraint to administer an injection. In this case covert administration might be less intrusive, however the method of administration is also important, and compatibility issues have to be taken into account when mixing drugs with food and drinks, as well as the possibility that incomplete dosing will occur because the patient may not consume all of the food or drink offered. Whenever the formulation of a medicine is changed, it is being used out-with the product license, and this should also be understood by staff administering the drug. Specialist advice can be sought from hospital medicines information departments when considering covert use of medication. Specialist mental health and learning disabilities pharmacists are also useful contacts for advice on this issue.

Mental Health Act and Adults with Incapacity Act documentation should be complete and pharmacists can be involved in multidisciplinary audits of adherence to legislation. Pharmacy staff will be involved in ensuring continuity of supply of medication for Jane, and it would be good practice to ensure that review dates are documented and adhered to, and that any changes to the plan are communicated between the care home, pharmacy and the GP practice. Original pack dispensing should be used with no more than 28 days supply per individual at a time.

Patients in care homes on antipsychotics or other psychoactive medication may be identified for review through projects carried out by prescribing support pharmacists in GP practices. They may use reviews to identify reasons why prescriptions were initiated and help identify patients who could appropriately be tried without medication.

Summary Box

What have you learned from this section?



- » The place of memantine in the treatment of dementia, and the common side-effects and limitations of its use.
- » The importance of assessing and treating underlying causes of distressed behaviour such as pain, constipation or infection before using any psychotropic medication.
- » Antipsychotics and other psychoactive medication can have a role in the treatment of specific symptoms in some individual patients with dementia, but are frequently used inappropriately for treating BPSD or distressed behaviour, without proper consideration of the causes of the symptoms.
- » The importance of the findings of the Bannerjee report and how it has influenced the recommendation of the Scottish Government to set up a working group to improve the prescribing and monitoring of psychoactive medication in older adults, especially those with dementia.
- » The importance of carrying out a thorough assessment of the circumstances leading up to the occurrence of BPSD, the nature of the behaviour, and any factors which help reduce the impact of the behaviour. Some understanding of tools available to help this process.
- » The psychological treatments available for distressed behaviour and when they can be used. Recognition of the importance of knowing how to access these therapies to avoid inappropriate use of medication in individual patients.
- » Awareness of some of the common pharmaceutical care issues encountered in different care settings, and the different roles of pharmacy staff depending on the care setting.

Section 6 End of life and dying well

Learning outcomes

At the end of this section you should be able to:

- » Understand the importance of providing high quality end of life care for people with dementia in the context of the Scottish Government's commitment to ensure that this is provided for the people of Scotland regardless of diagnosis
- » Discuss the Gold Standards Framework (GSF) and how it should be applied to ensure best practice in end of life care
- » Understand how the electronic palliative care summary (ePCS) should be used to improve communication between agencies and avoid unnecessary and unwanted hospital admissions
- » Understand the role of care pathways such as the Liverpool Care Pathway (LCP) in the last days and hours of life. Be aware of recent controversy surrounding this, the plan to phase out its use in England, and the current position in Scotland
- » Anticipate and advise on treatment of, commonly encountered symptoms at the end of life in dementia.

Dementia is not always recognised as a terminal illness or documented as an actual cause of death. This is because increasing frailty at the end of life in people with dementia exposes them to the risk of death from other causes such as infection, heart failure, etc. There can also be other co-existing illness such as cancer or cardio-vascular disease. Dementia, is, however a life limiting illness. People with a diagnosis of dementia should be given opportunities to express their wishes about the type of care they would and would not like to receive, and where they would like to receive end of life care, while they still have the ability to do so. When the time comes for decisions to be made about these issues, it is very helpful for family and carers to know that they are respecting the wishes of their loved one.

The Scottish Government action plan for health and wellbeing 'Better Health, Better Care', published in December 2007, stated a commitment to the delivery of high quality palliative care to everyone in Scotland who needs it, regardless of diagnosis. Following on from this document, the Scottish Government published 'Living and Dying Well: a national action plan for palliative and end of life care in Scotland' in 2008, introducing for the first time a single comprehensive approach to the provision of palliative care across Scotland. The document is available at: www.scotland.gov.uk/Publications/2008/10/01091608/11 In order to take the work forward a national clinical lead for palliative care and executive leads within each NHS board area were appointed.

One of the issues identified in the 'Living and Dying Well' document was the fact that many of the dedicated palliative care resources in Scotland had tended to be targeted at those with a diagnosis of cancer, whereas the main causes of death in the UK – organ failure, cancer, dementia and/or, frailty – are fairly evenly distributed. This document recognises the need to 'ensure that all patients and carers with palliative and end of life care needs are identified and their physical, social emotional and spiritual needs are appropriately assessed and reviewed'. It recognises that in dementia, triggers for considering assessing these needs might include significant deterioration in function, increased need for carer support, referral for specialist advice or admission to a care home

6.1 Gold standards framework (GSF)

It is now considered good practice to follow the Gold Standards Framework (GSF) model in community settings to identify when a person with a life limiting illness is nearing the end of their life. It is available at: www.goldstandardsframework.org.uk/. The framework is an anticipatory pro-active approach. It provides a framework for a planned system of care in consultation with the patient and their family. It helps promote better communication between different agencies involved in care, optimise out of hours care, and prevent crisis and unnecessary or unwanted hospital admissions.

The GSF includes Clinical Prognostic Indicators for different illnesses which help inform clinicians of some of the signs of disease advancement, which may suggest that the patient is in the last year or so of life, so that appropriate care planning can be undertaken. When these triggers are present it is appropriate to put the patient on the GSF supportive / palliative care register so that they will receive the input they require from the primary care teams, and any out of hours issues can be dealt with appropriately and according to the wishes of the patient and carer.

Although it is recognised that it is very difficult to assess at what stage to discuss end of life care in dementia, the following specific clinical indicators of advanced disease for dementia have been identified in the framework:

- » Unable to walk without assistance, and
- » Urinary and faecal incontinence, and
- » No consistently meaningful verbal communication, and
- » Unable to dress without assistance
- » Barthel score < 3*
- » Reduced ability to perform activities of daily living

Plus any one of the following:

- » 10% weight loss in previous six months without other causes.
- » Pyelonephritis or UTI.
- » Serum albumin 25 g/l.
- » Severe pressure scores e.g. stage III / IV.
- » Recurrent fevers.
- » Reduced oral intake / weight loss.
- » Aspiration pneumonia.

(*The Barthel score relates to a scoring system for activities of daily living which scores urinary and faecal continence, ability to dress, wash, eat and bathe independently, and assessment of mobility. The rating is 0-20 with lower scores indicating increased disability).

The Scottish Government acknowledged the progress made since publication of 'Living and Dying Well in Palliative and End of Life Care in Scotland' CEL2 2011, 27 Jan. 2011 available at www.scotland.gov.uk/Resource/0040/00400709.pdf In order to fully realise the necessary improvements, however, NHS boards were asked to consider further improvements in the following areas:

Early identification of patients who need palliative care – the GSF Clinical Prognostic Indicators were designed to assist with this.

Advance/anticipatory care planning – A survey by Dying Matters* found that 35% of GPs had never initiated a conversation with a patient about death and dying. The National End of Life Care Programme provides resources for professionals and the public to help promote better end of life care, including a booklet specific for dementia entitled 'difficult conversations', to help those caring for people with dementia to open conversations about this issue. Their website is available at www.endoflifecare.nhs.uk/

*Dying matters – In 2009, the National Council for Palliative Care (NCPC) set up the Dying Matters Coalition to promote public awareness of dying, death and bereavement. The work of the Coalition is supported by NCPC's Board of Trustees. More information on the work of the coalition can be found on their website at www.dyingmatters.org/

Palliative and end of life care in acute hospitals – although over 70% of people would prefer to die at home, over 50% of people actually die in hospital. 40% of people who die in hospital have no medical need to be there. People who are dying, many of whom neither need nor want to be there, occupy 20% of hospital beds. (Statistics from the National Council for Palliative Care document, 'Dying Matters' available at www.ncpc.org.uk/sites/default/files/Dying_Doing_It_Better.pdf

Recent Care Quality Commission reports from England have highlighted shortfalls in standards of care, and have found that dignity, privacy, and nutritional needs of older adults in hospital are not always being met.

Electronic palliative care summary (ePCS). This was introduced in 2010 to allow GPs to summarise important information about patients with palliative care needs and make this available (with the patient or carer's permission) to services out of hours including the ambulance service and acute hospitals. In order for data transfer to be able to work the patient must have a read code which places them on the palliative care register, and have a palliative care review date. Data can be updated twice daily so that even patients with rapidly changing care needs can have up to date records. The majority of GP practices are now using this system.

Do not attempt cardiopulmonary resuscitation (DNACPR) – Guidance has been produced by the Scottish Government to help promote discussion between patients, their families and health professionals about whether or not they would wish CPR to be attempted in the event of a cardiopulmonary arrest. The guidance is to help prevent inappropriate, futile and/or unwanted attempts at CPR, which may cause significant distress to patients and families. Advice for clinicians on when to attempt to resuscitate, and when it is appropriate not to do so, is available. The relevant joint statement in Scotland is from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (October 2007); Integrated policy on Do Not Attempt Cardio-pulmonary Resuscitation (2010) NHS Scotland.

6.2 Liverpool care pathway for the dying patient (LCP)

The LCP was developed to transfer the hospice model of care into other care settings. It is a multi-professional document, which provides an evidence based framework for end-of-life care. The LCP provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included.

There has been criticism in the press of the LCP mainly due to lack of understanding of what the pathway is designed to do. When it is clear that a person is dying, and this has been explained to the patient (if possible), and to relatives, the LCP is used to ensure that the best possible care and support is provided during the last days and hours of life, allowing the patient a comfortable and dignified death. It has been adopted as a model of best practice throughout the UK (and in another 18 countries) because, when a patient is on the LCP, regardless of the care setting, the staff looking after the person are clear about what they are trying to achieve and the decisions, communication and documentation required.

There has been criticism by patient and carer groups, and in the press, of the LCP. Criticisms have focused on:

- » *The assumption that putting someone on the pathway is a medical decision, which does not involve carers.* The General Medical Council (GMC) in its guidance 'Treatment and care towards the end of life: good practice in decision making' published in 2010 has made it clear that there should never be an occasion when the relative or carer named as the first contact or next of kin, is unaware of the diagnosis of dying or the decision to start the LCP. A second opinion can be sought if the relatives disagree with the decision.
- » Concern that the LCP will be commenced too early, when a patient has a reversible cause of deterioration such as hypercalcaemia, opioid toxicity, renal failure or infection. The LCP specifically includes assessment of this issue, however, there may be times when a dying patient lives longer than expected, or appears to recover a little before deteriorating.

NHS Forth Valley and the Managed Clinical Network for palliative care have addressed this concern by developing a checklist for embarking on end of life treatment (CELT®). This decision making framework is designed to facilitate the transition from active treatment to end of life care. The purpose is to link the Gold Standard Framework and the Liverpool Care Pathway. The CELT framework was developed to reduce the risk of missing reversible causes of deterioration. It can be reused in the event of a further deterioration in the patient's condition.

- » Concerns have been raised that when a patient is put on the LCP, all active treatments such as fluids will be withdrawn, thereby hastening the person's death. In fact, the LCP promotes assessment of the need for interventions such as the need for intravenous / subcutaneous fluids, and does not preclude their use. Being on the LCP neither hastens nor delays the person's death.
- » The idea that the LCP recommends continuous deep sedation has been suggested. The LCP recommends review of all prescribed medication, with withdrawal of unnecessary medication and prescription of medication for specific symptoms, including pain if necessary. Medication will only be given in response to a specific symptom, at the right time, and in sufficient dosage to control the symptom.

Recent controversy around the use of the LCP led to a review, and ultimately the withdrawal of its use in England recently. The review was entitled 'More care, less pathway: a review of the Liverpool Care Pathway' and is available at www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients. The associated press releases are also available on this site. The devolved governments in Scotland and Wales have yet to declare their positions on this, but the Scottish Government has published a letter on its website clarifying the current situation regarding use of the pathway whilst the Scottish Government undertakes its own review. This letter is available at www.scotland.gov.uk/Resource/0042/00428023.doc.

Activity



Review the references above, and think about what you have heard reported in the press recently about the LCP. Form your own opinion on whether the use of the LCP should also be phased out in Scotland.

6.3 Experiences of end of life care in dementia

'My life until the end – Dying well with dementia' was launched by the Alzheimer's Society on 25 October 2012. 38 people with dementia, their carers and former carers were interviewed and recommendations for change made based on the interviews. The full report is available at www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537

The report found that the wishes of many people with dementia were unknown because advance care planning had not taken place due to lack of discussion around death and dying. There were also issues around dignity and treatment of pain, hunger, thirst etc. at the end of life, for people with dementia, as they were unable to express their needs. Also, despite the fact that many people would have preferred to die at home, many died in hospital instead.

The report recommended that there should be greater recognition of dementia as a terminal illness, and more opportunities made available for people to discuss their wishes for the future. It suggested training was needed for health professionals so that they were better equipped to have these discussions with patients, family and carers. It also suggested that more research was needed into the detection of pain in those with advanced dementia, and that people should be supported in different models of care and different settings where they have chosen to die.

The experiences reported by the people who contributed to this study suggest that there is still some way to go in supporting people with dementia to die in the way, and in the place they would have chosen.

A Scottish resource called 'Essential Conversations: Talking about death and dementia' which is a programme initiated by Alzheimer Scotland, managed by the National Carer Organisations and funded by the Scottish Government is available at www.essentialconversations.org.uk/ This is a useful resource for anyone who works with people with dementia and may have to discuss these issues with them. It is also a very thought provoking and helpful resource for anyone who has a family member with dementia. It is divided into chapters to allow people to work through it at a pace they feel comfortable with.

6.4 Anticipated issues in advanced dementia

Although these issues can emerge at any point in dementia (and if they do the same treatment principles apply), in the final months of life, people with dementia have particular needs in relation to:

- » **Constipation** – This is common as fluid intake and dietary intake of foods which promote gut motility, may be inadequate. Constipation can cause discomfort and pain, and may present as agitation in end stage dementia as the patient is unable to express their discomfort. Medication which can slow bowel transit time should be stopped unless it is absolutely necessary at this stage. Oral medication is preferred for treating constipation, but if it is severe, more invasive treatments such as enemas may be required. This is likely to cause distress for the patient so it is better to anticipate the problem and treat it early, rather than allow the problem to develop to a more severe stage.
- » **Continence problems** – As dementia progresses, the person is likely to become incontinent as they lose the ability to translate the urge to go to the toilet into the action of doing so in an appropriate place at an appropriate time. This can be for many reasons including mobility problems or not remembering where the toilet is. If there are mobility issues, an occupational therapist may be able to advise e.g. a raised toilet seat or other simple measure may help. The involvement of a continence nurse can also be helpful. Continence issues can lead to other problems such as risk of infection e.g. urinary tract infection due to poor hygiene, and risk of skin tissue breakdown leading to ulcers or infection. Urinary tract infections can be particularly difficult to diagnose in people with dementia as they are unable to describe their symptoms, and managing to get an uncontaminated urine sample can be challenging. Often empirical treatment is started.

The Scottish Antimicrobial Prescribing Group (SAPG) has published a decision aid for diagnosis and management of suspected urinary tract infection (UTI) in older people available at www.scottishmedicines.org.uk/SAPG/Older_People.

- » **Swallowing problems, lack of interest in eating and drinking** – Difficulty with swallowing can expose the person to the risk of aspiration pneumonia due to food or drink being inhaled into the lungs rather than swallowed. The pharmacist can give advice about medicines administration when swallowing is a problem. It may be appropriate to change to liquid medication, or to alternative formulations such as patches or suppositories. A speech and language therapist may be asked for advice as it is often necessary to thicken fluids to reduce the risk of aspiration. The person will also gradually lose interest in food and drink, and will need encouragement to take anything orally. If the patient is becoming dehydrated, a decision may be made, in consultation with their family, to commence intravenous or subcutaneous fluids. Using subcutaneous rather than intravenous fluids may prevent the need to transfer the person to an acute hospital as they can be used in other environments such as care homes and mental health wards. There is no evidence for the benefit of enteral feeding in advanced dementia.
- » **Infection** – Patients with end stage dementia are at risk of infection from a number of causes. Immunity to infection is reduced due to poor nutritional status, and they are exposed to extra risk for some of the reasons described above. Infection is often the recorded cause of death for people in advanced dementia. The use of antibiotics for the treatment of infection and fever in end stage dementia is somewhat controversial, and needs to be judged in individual specific circumstances taking into account the severity of the dementia, co-morbidity, immobility, nutritional status and the person's response to the infection. If the benefits of treatment outweigh the risks, it should be used. Where the antibiotic is likely to make the person more comfortable e.g. in pneumonia where breathlessness can cause distress, it should be used. Family members (especially the welfare proxy) should be consulted, and should be actively involved in any treatment decisions. The SAPG has also published good practice recommendations for antimicrobial use in frail elderly patients in NHS Scotland available at www.scottishmedicines.org.uk/SAPG/Older_People.
- » **Pain** – There is considerable concern that people with advanced dementia experiencing pain may not receive adequate treatment. There is some evidence to suggest that people who are unable to report their pain receive less analgesia, even after severe trauma such as hip fracture. Often analgesics have to be added empirically and the response assessed in terms of level of agitation, distress, or observed signs of discomfort. In end stage dementia the oral route may not be an option, and the availability of syringe drivers and staff trained in their use, when needed, regardless of the care setting is important.
- » **Breathlessness** – This is a common symptom in the last days or hours of life. It can be distressing for family members and can be treated with small doses of opiates. Oxygen therapy is not usually of benefit unless underlying pulmonary disease such as asthma or COPD is the cause of the breathlessness.

- » **Pressure sores** – As a person becomes less active, they become vulnerable to developing pressure sores. Particularly vulnerable areas are the heels, buttocks, elbows, shoulder blades and the back of the head, but any area where there is friction can be affected. Carers should particularly look out for red areas of skin when helping bathe, dress or change the person. If caught early, pressure can be relieved through simple measures such as pressure relieving pads, special cushions or pressure relieving mattresses. If untreated, painful sores can develop which may become infected and be difficult to treat. In bed-bound individuals it is important that they are gently turned regularly, any incontinence pads are changed regularly, and that their skin is kept clean and dry. Bedding should be smooth, made from natural fibres, and clothing should be free from rough seams which could cause friction. Where there are sores present, a district nurse or specialist tissue viability nurse should be involved in assessing and treating the patient.

- » **Family and carer support** – The duration of illness in dementia means that the period of adjustment for family and carers is quite different from e.g. cancer. This has led to the notion of ‘anticipatory grief’. The gradual loss of personal attributes and cherished interactions has been labelled ‘social death’ and adds to the experience of significant grief before the death of a loved one with dementia, such that death can actually come as a relief. For this reason carers benefit significantly from increased help and support during the moderate to severe stages of the illness.

- » **Psychological, social and spiritual needs** – It should not be assumed that a person in the advanced stages of dementia would not benefit from any psychological interventions. It is often assumed that the ‘person’ has died before their biological death. The possibility of lucid moments should not be discounted and active attempts at communication and understanding should be continued even when dementia is severe. Even when patients cannot speak or smile, their need for companionship remains and they will still get comfort from touch or hearing a soothing voice. Surrounding them with pictures and mementos, reading aloud from treasured books, playing music, reminiscing, and recalling life stories promote dignity and comfort. From a social perspective, there should be a greater willingness to try to accommodate an earlier expressed desire by a person with dementia to die at home. This may not always be possible e.g. if they are living with a frail or ill partner, but too many people currently die in acute hospitals or care homes when it could have been possible for them to die in their own home. Spirituality and religious beliefs are part of our identity as human beings. In dementia, a person’s religious beliefs can have a positive impact on their experience of dementia, and carers can benefit from spiritual and religious support. The palliative care approach to end of life care tends to support awareness and respect for these issues.

6.5 Cases revisited

6.5.1 Pauline (we met in sections 3, 4 & 5)



Pauline had been living at home with support from her husband, who has his own health problems but managed to look after her most of the time. Care workers had been coming in twice weekly to help with Pauline’s bathing but her husband was not keen for more support than this as he felt he could look after her other needs. He still managed to take her out most days for a quick trip to the shops in the car to pick up a paper and something for their tea. Because she is on donepezil, Pauline has annual follow-up by the Community Mental Health Team, but otherwise has little input, as her husband does not request help.

Pauline and her husband never discussed what her wishes might be at the end of her life. Recently her husband had requested an alert system because he was worried that if something happened to him Pauline would not be able to help, and if something happened to Pauline he might not manage on his own. One evening, for no apparent reason, Pauline refused to walk. Her husband could not persuade her to get up out of the chair to go to the toilet or get ready for bed. She was unable to express why she suddenly felt unable to do these things. By the time social work services had sent some care workers round to help, Pauline had been incontinent of urine in the chair, and was upset and agitated. Because her lack of mobility created a crisis situation, NHS 24 was called and the doctor who visited arranged an emergency admission to hospital.

Following assessment and insertion of a venflon to facilitate commencing intravenous fluids in the ED, Pauline was admitted to the acute medical receiving ward. During an eight-day admission to the ward, Pauline’s mobility did not significantly improve despite input from physiotherapists, she developed faecal and urinary incontinence, she was reluctant to be touched or fed by staff (although she would eat if the food was left close to her), and her fluid intake was poor. She developed dehydration and constipation and required intravenous fluids and several enemas. No obvious cause of the deterioration which led to the admission was found. On the eighth day of the admission Pauline developed a chest infection, and was treated with intravenous antibiotics.

6.5.2 Jane (we met in Section 5)



Jane is cared for in a care home. Jane's initial diagnosis had been of Parkinson's disease (PD), which was later changed to DLB. When she was diagnosed with PD by a neurologist she was advised to consider her wishes for her future care, and had discussed some issues with her husband. They had put in place Financial and Welfare Power of Attorney, and discussed the fact that Jane would prefer not to have invasive treatments at the end of her life if they were only likely to prolong things. She would prefer to let nature take its course, but would like to be kept comfortable and pain free. She said she trusted her husband to make decisions for her when the time came. She had a strong Christian faith, and had been a choir member in the church before her illness. She wanted her favourite readings and hymns for her funeral, and she had spent time planning this with her husband. She and her husband had also made financial provisions for their funerals. With regards to place of death, Jane had been realistic about the fact that she may not be able to die at home, and might end up in a care home, but had specifically asked her husband not to let her die in the local acute hospital where she had watched both her parents die. When she went into the care home, her husband had explained these wishes clearly to staff, and they were documented in her care plan.

Over the course of the few months since Jane's move into the care home, the staff had noticed a gradual deterioration in her condition. When she completely lost her ability to self care, lost most of her ability to communicate verbally, became incontinent and chair or bed bound, they spoke to the GP about initiating the Gold Standard Framework, ensuring that Jane was on the palliative care register, had regular multi-disciplinary reviews of her care, and that an advance/anticipatory care plan was in place and an electronic palliative care summary was available so that it was accessible out of hours.

When Jane developed a high temperature one Friday evening, an on-call GP was called out. He had access to the ePCS. He was aware of Jane's wishes and the fact that her husband had Power of Attorney and called her husband to check that he was happy for Jane to be managed conservatively in the care home and not transferred to the acute hospital. Her husband was in agreement with this approach.

The GP prescribed some paracetamol to treat Jane's fever and help with any aches and pains. She was also prescribed some amoxicillin liquid empirically to treat infection. The doctor did not think she has a chest infection, but thought she may have a urinary tract infection. Because of her incontinence, it was not practical to get a urine sample. The GP did not take blood as he felt it would cause Jane unnecessary distress. He left clear instructions for staff to call out a GP again if Jane's condition deteriorated as he considers it too early for anticipatory prescribing because Jane was still able to take oral medication, and may recover with oral treatment for her infection.

Activity



1. Reflect on the difference in management of these two cases and the likely impact of the decisions made on the patient and their family.
2. Do you think it would have been distressing or comforting for someone to have discussed end of life issues with Pauline's husband before a crisis arose, and how do you think this would have changed the management of the situation?

Discussion

In Jane's case, the fact that she and her husband had spoken about her wishes, meant that her husband could convey them to professionals responsible for her care and feel empowered to assertively carry out her wishes without guilt about not pursuing active treatment for her. Although he would have felt sad that her condition was worsening and she was nearing the end of her life, he would feel that they had prepared for this together and he could take comfort from knowing that he was doing what she wanted.

1. In contrast, Pauline's husband has no control over the situation he is in. A crisis situation, which could have been predicted, has arisen. Because no advance provision for a situation where Pauline would be unable to manage the stairs in the house has been made, there is no alternative but to admit her to an acute hospital as an emergency. This leads to the inevitable scenario of an ambulance journey at night, when she would normally be in bed, the distress of triage and admission through A&E, including the invasive procedure of having blood taken and a venflon inserted. The bright lights and noise, plus Pauline's lack of understanding of what is going and the necessity to undress her, examine her and move her around are extremely distressing for her and her husband. Her husband then has to go away and leave her in an unfamiliar environment where the routine is completely different from her quiet life at home.

Her husband will feel distraught and guilty and will worry about the standard of her care in the busy ward where her needs could easily be forgotten. Pauline's mental and physical health predictably rapidly deteriorate in this environment, which often happens when the care setting is changed, and she develops problems she has never had before. These lead to the need for more invasive interventions, leading to more distress for Pauline and her husband, and further deterioration in her mental health. Exposure to the infection risk in the acute medical unit, coupled with increasing frailty then leads to a crisis in her physical health. Treatment decisions are not discussed with her husband, and he does not feel empowered to make a fuss because he does not understand his rights.

2. Often discussions about end of life care are not initiated because it can be uncomfortable for the staff involved, or because they feel they do not have the necessary skills. Communication does have to be carried out sensitively, and the professional involved has to demonstrate empathy and compassion. In dementia, it is best to raise end of life issues as early as possible to allow the person a chance to plan for the future whilst they have the capacity to make their wishes known. If a doctor or nurse opens a conversation about end of life issues, the subject can become less of a taboo, and family members often find it easier to continue the conversation on their own. If Pauline's husband had had any idea of the consequences of the lack of planning for her future, he would undoubtedly have been keen to participate in discussions. Even if discussions had been started when he contacted social work requesting extra help in the form of the alert system, the hospital admission may have been avoidable by looking at provision of a bed downstairs and a commode in case they were required. This would have enabled Pauline to stay at home, at least until a suitable alternative placement could have been found for her.

6.6 Cases followed-up, last days

6.6.1 What happened to Pauline?

As active treatment was initiated early for Pauline's chest infection, she recovered after a few days, but her cognitive function and activity levels were noticeably more impaired. She completely lost her verbal communication skills after the infection, and lost all interest in food although she would take some sips of fluid. She had no ability to self-care and was virtually bed bound. She also had faecal and urinary incontinence. She was not fit to return to her home situation as her bedroom and toilet were upstairs in the house and her husband was unable to cope. She was therefore transferred to the dementia continuing care unit.

In this unit dedicated to the care of people with dementia, the staff made an appointment with Pauline's husband and discussed end of life issues. They explained that it would not be in Pauline's best interest to attempt to resuscitate her if she had a cardio-pulmonary arrest, and discussed with him what to expect over the next few weeks to months. Because Pauline was not eating, and not taking much fluid intake, it was decided to give her some intravenous fluids to prevent dehydration and constipation and prevent discomfort. All other medication was withdrawn, but it was explained that frequent reviews would be undertaken, and that if Pauline needed medication for new symptoms or to make her more comfortable, it would be prescribed. Pauline's husband seemed very relieved that these discussions had finally taken

place and he knew what to expect.

Gradually Pauline became more and more frail, until the point where she was bedbound and unresponsive and she was placed on the LCP in consultation with her husband. Her spiritual needs were discussed. Her husband explained that because of her religion, Pauline's funeral required taking place as soon as possible after her death, and he was very worried about this as he had heard that there could be a delay if the person died in hospital. This information was added to Pauline's care plan so that there would be no delay in provision of a death certificate. This was a great source of relief to her husband as he knew that this would have been very important to Pauline.

6.6.2 What happened to Jane?

The next day an out-of-hours doctor is called as Jane has deteriorated. She is now unable to take medication or fluids orally and is not responding to staff. Her husband is contacted, and comes in to speak to the doctor who explains that he feels that Jane should be placed on the LCP. He contacts a palliative care specialist nurse and arranges for her to pick up anticipatory prescriptions from the local palliative care network pharmacy and to visit the care home to advise staff on management of the patient, and set up a syringe driver if needs be. He also sets up some subcutaneous fluids for Jane.

6.6.3 Pharmaceutical care Issues at end of life for Pauline and Jane

(Once a patient is on the LCP, the care issues are the same regardless of the care setting).

Further information can be found on the NHS Scotland Palliative Care Guidelines website at www.palliativecareguidelines.scot.nhs.uk/default.asp

Ideally, if a patient is no longer able to take medication orally, syringe drivers should be available, and staff trained in their use should be available 24 hours a day to respond to new symptoms regardless of the care setting (including if the patient is in their own home). This does not infer that all patients will require a syringe driver, but some symptoms described below are difficult to treat without using invasive procedures such as intramuscular injections otherwise, so a syringe driver may represent the least invasive method of treating these symptoms and improving patient comfort by reducing the impact of such symptoms. Examples include pain or myoclonus (sudden brief jerky, shock like involuntary movements).

Pharmaceutical Care Issues	
Assess need for intravenous fluids	Intravenous or subcutaneous fluids can be prescribed to prevent discomfort caused by dehydration. They should be withdrawn if they are contributing to excess secretions.
Assess need for prescribed medication and discontinue if no longer needed	Unnecessary medication, medication which can only be given by the oral route or medication which could contribute to side-effects should be withdrawn at this stage. In Pauline's case donepezil can be withdrawn, and ibuprofen stopped (but the need for an alternative analgesic should be assessed). In Jane's case donepezil and her antipsychotic can be discontinued.
Assess need for pain relief/ palliation for breathlessness if it is causing distress	Small doses of opiates by injection e.g. 2mg of morphine subcutaneously (sc) can be given to relieve these symptoms if necessary
Nausea	Where opiates are prescribed, an antiemetic should be co-prescribed. Levomepromazine can be given sc
Treat excess secretions if needed	Hyoscine butylbromide can be used for this purpose sc if necessary. If artificial hydration via intravenous or subcutaneous fluids is contributing, the fluids should be stopped.
Anxiety / distress / myoclonus	Midazolam can be used by subcutaneous injection or via a syringe driver for these indications. The lowest dose to control symptoms should be used.
Mouth care	An oral gel should be applied frequently to the mouth and lips if oral fluids can no longer be taken.
Skin care	Incontinence pads should be changed frequently and the skin cleaned carefully. Appropriate pressure relieving equipment should be used, the patient should be turned frequently to avoid pressure sores, and all broken skin should be treated appropriately according to tissue viability guidelines.

6.6.4 Other care issues in the last days and hours

It is important to allow family members access to sit with their loved one whenever they want to in the last days. One of the most important aspects of a 'good death' is having those we love around us when we die, regardless of the surroundings. Ideally it is best if the environment is quiet, and peaceful, allowing the family some privacy and the patient dignity and privacy. Hospices are ideally suited to providing this type of environment. It is not possible to replicate this standard of care in a hospital setting, but best efforts should be made to provide some privacy. A high standard of nursing and medical care should be provided, ensuring that the patient, their clothing and their bedding are kept clean, and that the person is warm and comfortable. Privacy and dignity should be respected whenever the patient is being washed or changed.

It is helpful for family members to be prepared for some of the changes that happen when a person is nearing death. A leaflet entitled 'what happens when someone is dying' is available on the Palliative Care Guidelines website.

It is also helpful to discuss spiritual needs and wishes such as whether the family would like a minister or chaplain to visit their loved one. If the person has had strong spiritual beliefs throughout their life, knowing that these needs are being met can be a source of great comfort to the family.

Some family members will ask questions about the practicalities of obtaining a death certificate and arranging removal of their loved one's body to a funeral home if they do not die in their own home. It is important that they are given the answers they seek at the time they would like the information.

Family members may be grateful for some information about bereavement support, or they may feel that they have enough support from family, friends or a faith community.

Summary Box

What have you learned from this section?



- » It is possible to support people with dementia to have a “good death” by initiating conversations about their wishes early, and promoting the appropriate and timely use of the Gold Standards Framework, the ePCS and care pathways such as the LCP (which is under review in Scotland and may be replaced by individualised care plans).
- » Pharmacists can make an active contribution to the pharmaceutical care of people with late stage dementia to promote early recognition and management of predictable issues such as swallowing difficulties, bowel and bladder dysfunction, agitation, anxiety and pain control.
- » Pharmacy team members in all care settings can contribute to educating people with dementia, their family and carers about the benefits of actively planning for their future so that their wishes are known and respected when they no longer have the ability to express them.

Section 7 Summary of practice points in dementia for pharmacists and pharmacy technicians

- » Help promote healthy lifestyle advice to help prevent dementia by keeping the mind and body healthy and engaging in activities and social networks for older people in the community.
- » Give expert advice on the evidence and cost effectiveness of herbal remedies and food supplements promoted for their benefits on memory
- » Help identify people at risk of dementia – Think about those who may be showing signs of memory problems and help to promote early diagnosis and support from health and social services and the local community.
- » Offer advice and support – signpost to relevant services and be aware of what is available in the local area for people with dementia. Make contact with local dementia experts and social services.
- » Help promote dementia friendly environments in hospitals, community pharmacies, care homes and the patient's own home. Promote use of dementia friendly signage, appropriate lighting, use of contrasting colours and availability of dementia resources.
- » Be able to undertake detailed medication reviews, and advise on whether any currently prescribed medications may be implicated as a cause of memory problems.
- » Educate patients, families and carers about the medicines they are prescribed, and promote concordance using a variety of appropriate methods which encourage independence and keep the patient engaged with services for as long as possible.
- » Check for drug or disease interactions whenever a new medicine is prescribed, to ensure that if the patient's physical or mental state has changed, appropriateness of medicines already prescribed is re-assessed.
- » Monitor for side-effects of medication and advise on strategies to reduce side-effects or medication changes if necessary.
- » Ensure that guidelines are followed when psychoactive medicines are prescribed in patients with dementia, and information is passed between care providers so that everyone is aware of their responsibility to assess and review the use of these medicines.
- » Help promote the patients right to make choices in the present and for the future. Be able to discuss the relevant legislation with patients, their family and carers, and ensure that information is shared with relevant agencies so that the person's wishes are known when decisions are being made about care.
- » Ensure that when medicines are started, stopped or altered, information is passed efficiently between care providers, particularly when there have been hospital admissions and discharges, to ensure seamless and safe care.
- » Advocate for excellent care of patient's physical health needs – ensure vaccinations, eye checks, dental checks, and any other age appropriate or disease specific health checks are being offered to the patient. Also ensure pain assessments are carried out, bowel, bladder and infection problems are investigated and skin and soft tissues are adequately cared for.
- » Advocate for excellent care of the patient and carer's mental health needs – ensure proper assessment of BPSD and appropriate assessment and treatment of anxiety and depression in both patients and their carers if required.
- » Advise on appropriate formulations or alternative medication for patients who develop swallowing difficulties.
- » Ensure medication is prescribed and administered to people who lack capacity to give informed consent within the legal frameworks of the Adults with Incapacity and Mental Health (Scotland) Acts.
- » Advocate for the appropriate and timely use of end of life pathways, taking account of the wishes of the patient, their family and carers.
- » Help promote excellent end of life care regardless of the care setting by advising on palliative treatments which help reduce pain, distress and suffering and take account of the patient's and families expressed wishes.
- » Carers are likely to have regular contact with the pharmacy team. Help to link them with community support networks, and provide information, support and guidance throughout the dementia journey and beyond.

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Section 9 Resources

9.1 Educational resources for professionals, patients and carers

Alzheimer Scotland. *Through our Eyes, A Life With Dementia*. DVD. Available to order at www.alzscot.org/store/pages/Training%20materials

Alzheimer Scotland. 2009 *The Charter of Rights for People with Dementia and their Carers' in Scotland*. www.dementiarights.org/charter-of-rights/

Alzheimer's Society Factsheets. www.alzheimers.org.uk/factsheets

Alzheimer's Society. *Worried About Your Memory?*
www.alzheimers.org.uk/site/scripts/download_info.php?fileID=339

Alzheimer's Society.(2012). My life until the end: dying well with dementia.
www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537

Care Comission / Mental Welfare Comission. (2009) *Remember I'm Still Me*.
www.mwscot.org.uk/search/?keyword=standards+of+care+dementia

9.2 For pharmacy staff

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Mental Welfare Commission for Scotland website www.scie.org.uk/publications/dementia/index.asp

Dementia resources available at The Royal College of Psychiatrists website www.rcpsych.ac.uk/

Dementia resources available at the NHS Education for Scotland website:
www.nice.org.uk/guidance/TA217

Dying Matters Coalition/National Council for Palliative Care (2011). *Difficult Conversations – Making it easier to talk to people with dementia about the end of life*. Available to purchase from www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/difficult-conversations.aspx

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Dementia strategy and other publications relevant to dementia available at Scottish Government website www.scotland.gov.uk

Scottish Intercollegiate Guidelines Network/ NHSQIS (2006) *Management of Patients with Dementia*. www.sign.ac.uk/pdf/sign86.pdf

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Congratulations

You have now made it to the end of the pack! We hope that you found the learning both interesting and challenging. However we now require one more task from you... to complete the online multiple choice questions via your Portal account at www.portal.scot.nhs.uk If you don't already have a Portal account, you can register at the above address.

The questions are designed to test your knowledge and understanding of the contents of this learning pack. Please take a few minutes of your time to add your comments about all aspects of this learning pack. Your feedback will allow us to improve future learning resources.



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