Medications Management for People Living with Dementia

Abstract

Provision of dementia care has been evolving over the past number of years. The rise in person-centred approaches to care continues to flourish, particularly the enhancement of wellbeing and alleviation of distress through non-pharmacological interventions. While this is an important facet of dementia care, healthcare professionals must also have a good knowledge base about medications which are important for symptom management in dementia. This CPD article presents an overview of some of the most common medications which may be inappropriately prescribed and used within dementia care, such as antipsychotic, anxiolytic and sedative medications. Furthermore, this article will also consider some common medications which may be more appropriate for people living with dementia, such as cognitive enhancers and analgesia. This CPD article will aid healthcare professionals, who care for people living with dementia, in guiding shared decision-making about appropriate prescriptions of medications with people living with dementia, their family members and the extended multidisciplinary healthcare team.

Key Words

Dementia Care, Medications Management, Person-Centred Care, Holistic Care, Shared Decision-Making

Aims and Learning Outcomes

The aim of this article is to provide healthcare professionals, involved in caring for people living with dementia, with an overview of how to optimise medications management. After reading this article and completing the time out activities you should be able to:

- Understand the importance of pharmacological and non-pharmacological approaches in dementia care.
- Explain the principles behind good administration of medications.
- Outline the ethical dilemmas associated with covert administration of medication.
• Recognise the implications, for people living with dementia, who are receiving antipsychotic, anxiolytic and hypnotic medications.
• Discuss the benefits associated, for people living with dementia, who are being regularly assessed for pain, wellbeing and depression.
• Describe the possible benefits of analgesia, anti-depressant therapy and cognitive enhancers for people living with dementia.
• Consider medications that may be important for people living with vascular dementia.

Introduction

It is estimated that 46.8 million people live with dementia worldwide (Alzheimer Disease International, 2015). Conservative estimates suggest that the number of people living with dementia will continue to double every twenty years with most growth in low and middle income countries like China and India (Alzheimer Disease International, 2015). With these statistics in mind, it is hardly surprising that there has been much focus on improving the quality of life for people living with dementia (DH 2009; 2010; 2013; 2015).

Dementia is a medical term that is used to describe a number of cognitive diseases and includes Alzheimer disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Dening and Babu Sandilyan, 2015). The dementia syndromes each differ in terms of their aetiology, pathophysiology and clinical manifestations. Despite the uniqueness of dementia, there are some common symptoms which are common across the dementia diseases and these can include short-term memory loss, difficulties with communication, problems with spatial awareness and personality changes (Ballard et al. 2011). Importantly, these symptoms are caused by the dementia disease and are not a normal part of aging.

Time Out 1

In 2015 the Nursing Standard ran a series of over 30 articles that focused on dementia care. Read the first three papers of this series (Dening and Babu Sandilyan, 2015; Babu Sandilyan and Dening, 2015a; 2015b). Consider the four main types of dementia; Alzheimer disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. List how these
types of dementia are caused, what their specific impact is on the brain and what the common symptoms of these dementias are.

Background

There are a number of clinical manifestations, or symptoms, that are associated with the dementia diseases. These symptoms will depend on the type of dementia, the part of the brain affected and the stage of the dementia disease. Providing a full list of potential symptoms is difficult however table one outlines the main types over the course of early, middle and later stages of dementia. Knowledge of these symptoms is important when considering pharmacological treatments in dementia.

Table 1: Symptoms of Dementia (Adapted from Mitchell, 2016)

<table>
<thead>
<tr>
<th>Early Stages of Dementia</th>
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<tbody>
<tr>
<td>Short-term memory loss</td>
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<td>Difficulty in finding the right words</td>
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<tr>
<td>Subtle personality and behavioural changes</td>
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<td>Short periods (lasting from minutes to hours) of confusion, disorientation and distress</td>
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<th>Middle Stages of Dementia</th>
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<tr>
<td>Severe memory dysfunction</td>
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<td>Disorientation to time and place</td>
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<tr>
<td>Difficulty in comprehension</td>
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<tr>
<td>Disinhibition</td>
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<tr>
<td>Major reduction in capacity</td>
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<tr>
<td>Deterioration in ability to self-care</td>
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<tr>
<td>Difficulties in taking long periods of sleep</td>
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<tr>
<td>Increasing periods of distress</td>
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<table>
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<tr>
<th>Later Stages of Dementia</th>
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<tbody>
<tr>
<td>Requirement for 24 hour care</td>
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<tr>
<td>Inability to recall even most recent events</td>
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In inaccurate recollection of past memories
- Higher levels of distraction
- Rapid loss of language skills
- Rapid loss of any ability to self-care
- Increased periods of inactivity and despondence
- Major decreases in appetite and eating
- Higher levels of distress

In dementia care, arguably the most challenging group of symptoms to treat are behavioural and psychological symptoms. These behavioural and psychological symptoms of dementia (BPSD) can often manifest as distress and this can occur in any of the dementia diseases and at any stage of a person’s journey. Indeed, these BPSD have been identified as some of the main reasons for fatigue and burnout amongst care partners, family members and healthcare givers (Baker, 2014). BPSD can denote a broad range of emotions which may include anxiety, anger, depression, fear or suspicion, excessive walking, uncooperative behaviour in relation to receiving personal assistance or repeated shouting. It has been estimated that BPSD occurs in up to 90% of people living with dementia (James et al, 2008).

Non-Pharmacological Interventions

While this article focuses on pharmacological interventions, healthcare professionals should also have an awareness of a number of evidence-based non-pharmacological interventions within dementia care which can enhance wellbeing, improve cognition and alleviate BPSD (Mitchell and Agnelli, 2015a; 2015b). Examples of non-pharmacological interventions currently utilised within dementia care include; reminiscence therapy, reality orientation, music therapy, horticultural therapy and doll therapy. It is beyond the scope of this article to consider non-pharmacological interventions in more depth, however Time Out 2 while provide readers with an opportunity to learn and reflect more on their importance in dementia care.

Time Out 2

Review Mitchell and Agnelli’s 2015 blog on non-pharmacological interventions in dementia
Discuss the benefits of implementing reminiscence therapy, reality orientation, validation therapy, music therapy, horticultural therapy and doll therapy within a unit which cares for people living with dementia. In addition to these benefits, consider the challenges that you may face during implementation. For further information, please see Mitchell and Agnelli (2015a) article that was published as part of the Nursing Standard’s Dementia series.

**Polypharmacy, Adherence and Covert Administration**

There are many medications that can be used in dementia for symptom management. Due to the increased incidence of dementia in older people, and the link between growing older and developing multiple comorbidities, it is likely that people living with dementia will also be taking medications for conditions other than their dementia.

The term ‘appropriate polypharmacy’ describes the situation where an individual is receiving multiple medications for their conditions and these medications are contributing to helping that person maintain good quality of life through optimum therapeutic effect. The term ‘problematic polypharmacy’ occurs when the person is prescribed a number of medications inappropriately and does not derive adequate therapeutic effect from their medication regimen (Duerden et al, 2013). As illustrated, people living with dementia will likely take a number of medications. It is the role of nurses and other healthcare professionals to ensure that people living with dementia fall into the category of appropriate polypharmacy when considering medication regimens.

Another important aspect of ensuring treatment is therapeutic relates to adherence of medications. In recent guidance by NICE (2015) it is estimated that as many as 50% of medications for longer-term conditions are not taken as prescribed. Within dementia care this might manifest as people refusing or forgetting to take their medications, taking the wrong dose of their medication or even chewing or crushing medications which are intended to be swallowed. As such it is important to ensure that, as far as possible, people living with dementia are supported to engage in shared decision-making about their medications so as
they are aware of how and when to take their medications and also of the therapeutic effect of their medications (Mitchell, 2014).

Sometimes, as a result of the symptoms of the dementia diseases, people living with dementia choose to not take their medications and healthcare professionals intervene to administer the treatment in a disguised form. This is usually when it is determined that the person does not have capacity to make the medical decision and it is in the person’s best interests to take a medication. This practice is known as ‘covert medication’ (NHS Trafford, 2011). As one would expect, there may be a place for covert medication within dementia care, however such a practice should be exercised with extreme caution, multidisciplinary involvement, agreement with care partners and consideration to deprivation of liberty and a person’s human rights (Tweddle, 2009). In particular, healthcare professionals should seek to understand why a person living with dementia is refusing their medication and ascertain if this can be remedied, for example a person with progressive dysphagia may find it uncomfortable to take their tablets but may be adherent with a liquid preparation of the medication.

**Time Out 3**

<table>
<thead>
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<th>Consider the following case study:</th>
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<tr>
<td>Rita is an 85 year old lady living with dementia. She was diagnosed with dementia four years ago and also lives with arthritis. Rita has recently been admitted to your care setting for an indefinite period of time. Within her medical file it is noted that Rita does not take her medications regularly and this can lead to periods of distress and discomfort</td>
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Discuss with a colleague what actions you would take to ensure that Rita can enjoy a good quality of life in your care setting.

The next section of this article will consider some of the main types of medications used within dementia care including; cognitive enhancers, analgesia, anti-depressant therapy, antipsychotics, anxiolytics, sedatives and medications for vascular dementia. An adequate knowledge of these common medications will help healthcare professionals, people living
with dementia and their family members, to come to shared decisions about their medications.

**Cognitive Enhancers**

At present there is no cure for dementia. However there are a number of recommended pharmacological treatments that are available which can help decelerate the progression of the most common form of dementia, Alzheimer’s Disease. According to NICE (2011) there are two types of cognitive enhancers that are recommended and these are cholinesterase inhibitors and antiglutamergic therapy (Mitchell, 2013).

Cholinesterase inhibitors, like Donepezil, Galantamine and Rivastigmine, are recommended for use in the early to middle stages of dementia. These classes of medication work by slowing the breakdown of certain chemicals (acetylcholine) in the nerves. This reduces the abnormal brain chemistry which causes irregular changes to the brain structure. While there have been reported benefits of cholinesterase inhibitor use in vascular dementia and dementia with Lewy bodies, evidence is not strong enough for them to be recommended outside of Alzheimer’s disease (Draper, 2013). It is important to note that, on average, about 1/3 of people living prescribed cholinesterase inhibitors will have a temporary improvement in their cognition for between 1 year and 18 months, 1/3 will stabilise for about the same period and the remaining 1/3 will derive no benefit from this class of medications (Draper, 2013). It should also be noted that there is no significant difference in the effectiveness of these 3 cholinesterase inhibitors (Mitchell, 2013).

There is currently only one medication that has been approved for antiglutamergic therapy and this is Memantine. Most therapeutic effects of Memantine are usually seen in the latter stages of Alzheimer’s disease, unlike cholinesterase inhibitors which work best earlier in the disease. Antiglutamergic therapy is only currently licenced for people living in the middle to late stages of Alzheimer’s disease (NICE, 2011). Memantine works by providing protection from glutamate which is a chemical that is released in excessive amounts during Alzheimer’s disease that alters normal brain chemistry (Mitchell, 2013).

The aim of these two classes of cognitive enhancing medications is to delay the progression of dementia and stabilise cognitive function. These two groups of medications are therefore
extremely important to consider for people living with Alzheimer’s disease throughout their journey because they can alleviate symptoms of the dementia disease and improve quality of life. It is also important that these medications are regularly assessed by healthcare professionals because, as noted, their therapeutic effects are only temporary.

**Analgesia**

Unfortunately a high proportion of people living with a dementia either have undiagnosed or unrecognised pain. It is estimated that over 50% of older adults living with dementia in nursing-home settings live with chronic pain but only half receive medicines for pain relief (Jones and Mitchell, 2015). One of the most common difficulties experienced by healthcare professionals, who practice within dementia care, is that the person living with dementia may not be able to clearly articulate when they feel pain. This difficulty in articulation of pain may present as distress and be misinterpreted by healthcare professionals as BPSD (Cohen-Mansfield, 2008).

Despite this difficulty, self-reporting of pain should remain the “gold standard” for pain assessment and management (Horgas et al 2009). This traditionally takes the form of asking someone if they are in pain, how they experience their pain and how intense their pain is. Some guiding questions include:

- Are you in pain?
- Does the pain get worse when you move?
- Does the pain get worse when I touch you here?
- On a scale of 1-10 how severe is the pain?
- Is there any position when the pain is less intense or more intense?

For residents who live with a cognitive impairment or dementia, other approaches might be more useful due to difficulties in communicating pain. There are a number of validated pain assessment tools that are utilised in dementia care and the most popular are the Abbey Pain Scale, DOLOPLUS-2 and PAINAD. These are summarised in table two.

*Table Two: Key Validated Pain Assessment Tools in Dementia Care (Adapted from Carezzato et al. 2014)*
1. Abbey Pain Scale: Assesses vocalization, facial expression, changes in body language, behavioural changes, psychological changes and physical changes. Severity of pain is assessed individually for each of its 6 items.

2. DOLOPLUS-2: Consisting of 10 items, divided into three groups, namely, somatic reaction, psychometric reaction and psychosocial reaction. This instrument assesses the progression of the pain experience.

3. Pain Assessment in Advanced Dementia (PAINAD): Comprising 5 categories of behaviour: breathing, negative vocalization, facial expression, body language and consolability. Each is organized into three subcategories with behavioural descriptors allowing the recognition of the presence of pain or normality.

These observational tools provide healthcare professionals with critical information about pain which can guide prescription and administration of analgesia. Good regular pain assessment can guide the selection of interventions, help clinicians monitor the effectiveness of their treatments and be an effective source when communicating with multidisciplinary professionals. Therefore, the use of a validated pain assessment tool coupled with regularly prescribed analgesia, such as Paracetamol, are likely to safeguard against pain or reduce its impact for people living with dementia. Of course the form of pain relief will depend on the type of pain being experienced. For example, in the later stages of dementia, where the progression of the disease may lead to dysphagia, an analgesic patch (such as buprenorphine) can be applied to the body of the person to provide relief from pain when swallowing is difficult for the person. The importance of analgesia should never be underestimated because often pain this is the key reason as to why people living with dementia exhibit distress.

For healthcare professionals, it is best practice to follow the WHO (1997) pain ladder in relation to pain management. This means starting with the lowest strength of pain relief, re-assessment using validated pain tool, such as the Abbey Pain Scale, then moving up the ladder and continuing regular re-assessment until symptoms of pain decrease.
In summary, when a person living with dementia exhibits distress one should always consider the likelihood of pain, determine the likelihood of pain in that person, administer analgesia if appropriate and monitor wellbeing of that person to see if distress diminishes.

**Time Out 4**

Download and review the Abbey Pain Scale at the following link:
http://prc.coh.org/PainNOA/Abbey_Tool.pdf

Utilising the Abbey Pain Scale, consider what steps you would take if you came across a person living with dementia who was regularly receiving 4g of paracetamol per day but was still exhibiting significant levels of distress (in the form of shouting).

**Antidepressant Therapy**

The use of antidepressant medication (such as Sertraline, Citalopram, Mirtazepine and Fluoxetine) is utilised mostly for depression and anxiety. People living with dementia have a higher likelihood of being predisposed to depression. Symptoms of depression include;
feelings of low self-esteem, feelings of isolation, sleep disturbance and lethargy (Cipher and Clifford, 2004). While people living with dementia are more likely to have depression, there is caution against their use in dementia care. This is because antidepressant medication may actually be an underlying cause of dementia and that the medication can be ineffective for many people living with dementia anyway (Banerjee et al. 2013). This is because the brain damage already caused by dementia can often reduce the therapeutic effectiveness of the medication.

While antidepressant medications can make a positive difference to some people living with dementia there can be a risk of side-effects which include nausea, vomiting, diarrhoea, increased risk of falls and sodium imbalance (which can lead to confusion). As such, the use of antidepressant medications should be used with caution and regularly reviewed with input from the person living with dementia, their care partner and/or a validated assessment tool. While antidepressant therapy may not always be effective, it is important that healthcare professionals can recognise when someone living with dementia is depressed so as they can employ appropriate support, both in the form of pharmacological and non-pharmacological interventions (Mitchell and Agnelli, 2015a).

**Time Out 5**

Review the Alzheimer’s Society guidance on treating depression on dementia.

[https://www.alzheimers.org.uk/info/20064/symptoms/264/apathy_anxiety_and_depression/6](https://www.alzheimers.org.uk/info/20064/symptoms/264/apathy_anxiety_and_depression/6)

In a small group, consider how you guide or support people living with dementia to engage in guided self-help activities such as talking therapies or cognitive behavioural therapies.

**Anxiolytic and Hypnotic Medication**

People living with dementia may feel anxious from time to time due the clinical manifestations of their disease. These clinical manifestations can cause people living to become disorientated or to be less able to carry out activities they used to be able to do (Mitchell et al. 2016a; 2016b). As a consequence, people living with dementia may become anxious. Anxiety can take many forms including; feeling worried, feeling tired, feeling
restless, feeling uneasy and having difficulty concentrating. In addition anxiety can cause the person to have physical symptoms like; shortness of breath, high blood pressure, headache, insomnia or dizziness (Draper, 2013).

The use of anxiolytic medications (such as Diazepam and Lorazepam) and hypnotic medications (such as Temazepam and Zopiclone) are frequently prescribed to alleviate against potential episodes of distress associated with anxiety in dementia care. As the name suggests, anxiolytic medications are used to reduce anxiety which can lead to episodes of distress in dementia care, while hypnotic medications mainly used for sleep disturbances, also associated with anxiety and depression. While these medications can be beneficial in reducing distress in dementia care they should be used with caution as there a strong chance that they will cause over-sedation. Over-sedation can cause higher levels of disengagement, drowsiness, falls, weight-loss and pressure ulceration (Mitchell and Agnelli, 2015b).

Healthcare professionals should consider non-pharmacological interventions when supporting people living with dementia to live well. While anxiolytic and hypnotic medications may help some people living with dementia there is a danger that these are overprescribed. It is also important to highlight that these medications are usually only recommended for short-term use. The long term use of these types of medications is associated with intolerance, dependency and reduced therapeutic effect.

**Time Out 6**

Review the guidance published by the Royal College of Nursing on Restraint (RCN, 2008), available here: [https://my.rcn.org.uk/__data/assets/pdf_file/0007/157723/003208.pdf](https://my.rcn.org.uk/__data/assets/pdf_file/0007/157723/003208.pdf)

Consider how the prescription of anxiolytic and sedative medications may be perceived as a form of chemical restraint.

**Antipsychotic Medication**

Antipsychotic medications (such as Risperidone, Quetiapine, Olanzapine and Haloperidol) were originally designed for use in some types of mental health conditions like schizophrenia...
or bipolar disorder. The psychotic symptoms that these antipsychotic medications target are feelings of suspiciousness, delusions, paranoia and hallucinations. While dementia is not the same as schizophrenia or bipolar disorder (due to its progressive clinical features that are evident in brain tissue), antipsychotic medications are frequently prescribed to people living with dementia who experience significant distress as a result of their illness (Sturdy et al, 2012).

While antipsychotic medications are extremely beneficial to some people living with dementia, the evidence suggests that these medications are significantly over-prescribed. In fact, a report for the Department of Health in the United Kingdom estimated that of 180,000 people in the UK who are prescribed antipsychotic medications approximately only 36,000 of these people will derive any therapeutic benefit (Banerjee, 2009). This means, on average, only 20% of people living with dementia (or 1 in 5 people) who are prescribed antipsychotic medications actually benefit from this form of medication. Sustained administration of antipsychotic medications can be associated with adverse effects which include accelerated cognitive decline, increased fall risk, over-sedation, Parkinsonian symptoms and increase risk of developing cardiac problems (James et al, 2008).

Despite these risk factors coupled with issues around over-prescription, it is somewhat surprising that Risperidone is actually the only licenced antipsychotic medication for use in people living with dementia if they have psychosis (delusions or hallucinations) that developed before their condition and have been exacerbated by dementia (Banerjee, 2009). Other antipsychotic medications that may be prescribed for people with dementia are done so on an ‘off-label’ basis, meaning that medical practitioners can prescribe these if they believe they have strong evidence to do so. Indeed many practice development programmes over the past number of years have focused on nurse-led interventions which seek to reduce the amount of antipsychotic medications which are administered to people living with dementia in their units (Royston et al. 2016, Royston et al. 2017). In short, antipsychotic medication should be an absolutely last resort for people living with dementia.

Time Out 7

Individually, or in a small group, consider how you might go about introducing an
intervention to reduce to administration of antipsychotic medications to people living with dementia on your unit.

You should consider who would be involved in the discussions, how you would monitor antipsychotic medication reduction/removal to ensure that the intervention was both safe and therapeutic, how you would support other healthcare professionals to be involved and what sorts of interventions (both pharmacological and non-pharmacological) you would supplement in the place of antipsychotics.

Medications for Vascular Dementia

Vascular dementia is one of the most common types of dementia and it occurs when blood supply to the brain is disrupted due to arterial disease. This results in reduced neuronal function and eventually the death of brain cells (Dening and Babu, 2015). As vascular dementia is associated with disrupted blood supply people with co-morbidities such as stroke, hyperlipidaemia, heart disease and hypertension are at an increased risk of developing vascular dementia. It has been suggested that efforts to reduce blood pressure and complications of cerebrovascular disease may reduce the incidence of vascular dementia (Emdin et al. 2006).

For people living with vascular dementia, it is advised that acetylcholinesterase inhibitors and Memantine should not be prescribed for the treatment of cognitive decline, except as part of properly constructed clinical studies (NICE, 2006). There are no effective approved pharmacological treatments available and this then creates a difficult situation for those living with the disease, their caregivers, and healthcare providers (Baskys and Hou, 2007).

Assessment and Review of Medications

Healthcare professionals have a duty of care to ensure that the medications that they administer to people living with dementia are both appropriate and therapeutic (NICE, 2014; 2015). Good communication between healthcare professionals, people living with dementia, their care partners/family members and the extended multidisciplinary team is therefore an important aspect to consider. Due to the aforementioned clinical manifestations of the
dementia diseases, which includes cognitive impairment and memory loss, healthcare professionals should be supported in their practice by a range of validated assessment tools which have already been illuminated in this article, for example assessment tools to ascertain whether a person living with dementia is in pain or is depressed.

Regular patient assessment should therefore take the form of both regular communications with all involved in the care of the person living with dementia and the use of validated assessment tools where appropriate. While NICE guidance (2014; 2015) advise that all patient medications should have their medications assessed between every 6 to 12 months, this is not advisable for the medications noted in this article. Medications for cognitive enhancement, pain relief and symptom management in dementia should be reviewed a minimum of once per month, or sooner if the medications do not derive the intended therapeutic effect. In short, NICE (2014) guidance about optimising medications asserts the goal of helping clinicians to adopt:

“A person-centred approach to safe and effective medicines use and to ensure people obtain the best possible outcomes from their medicines”.

**Time Out 8**

Individually, or in a small group, discuss the steps you would take in organising a comprehensive medication review for a patient living with dementia.

**Conclusion**

The dementia diseases are a group of neurological conditions which affect people in different ways. In addition, the clinical manifestations, or symptoms, of the dementia diseases are unique to people living with the condition. Healthcare professionals have a duty of care to people living with dementia to ensure that symptom management is personalised to meet the unique needs of that person living with dementia. While provision of non-pharmacological interventions is important, healthcare professionals must too be cognisant about how appropriate pharmacological prescription and administration can enhance quality of life for people living with dementia. Equally, it is important for healthcare professionals to be aware
about how to recognise when medications are therapeutic or indeed dangerous for people living with dementia for which they care.
References


