

# **Palliative Care and Dementia**

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## Abstract

An optimal approach to palliative care for people with dementia has been defined by the European Association for Palliative Care with eleven domains including, for example: Applicability of palliative care; Person-centred care, Communication and shared decision making; Setting care goals and advance care planning. Not all people with dementia will require specialist palliative care and all involved in dementia care, should be able to provide palliative care focussing on care and treatment which aims to increase the comfort and quality of life of the individual and supporting their family. There are many complications and symptoms which may arise for someone with dementia including: increased infections, shortness of breath, swallowing difficulties and pain which the individual may not be able to clearly express. These complications can lead to difficult decisions which need to be made by not only practitioners but also family caregivers as proxy. There should be a shared decision making approach to these complications and symptoms, with advance care planning performed where possible. Caring for someone with dementia is one of the most difficult caring roles support for family caregivers as part of a palliative approach is essential. Each person with dementia is different and needs should be assessed on an individual basis, adopting a person centred approach to care.

Keywords: Dementia, palliative care, end of life care, caregivers

## Introduction

With ageing populations across the world, the numbers of people with dementia continuing to increase and with no known disease modifying treatment, the delivery of high quality palliative care is becoming a high priority for health and social care services. Dementia is often not recognised or understood as a terminal illness which will ultimately lead to death, however research over the last decade has increased and attention paid to palliative care for people with dementia continues to be recognised. Through the use of a case study/vignette (Mrs S) in this chapter we provide a definition of optimal palliative care for older people with dementia through the domains of the European Association for Palliative Care (EAPC) (van der Steen et al., 2014b). Drawing on a case study we discuss common issues and symptoms for those with dementia including symptoms which may be experienced in the dying phase, and their associated treatments, considering the controversy of some of these treatments, such as artificial nutrition. The chapter considers the role of family caregivers in decision making and the difficult decisions which are often left to them to make as proxy. The importance of family caregivers in dementia palliative care is highlighted including their health and psychological needs. Throughout this chapter we highlight the person-centred approach which should be adopted and needs and support should be considered on an individual basis.

### 1. Defining palliative care for people with dementia

Palliative care has a great deal to offer for people with dementia. The trajectory of dementia usually involves multiple changes in condition and in the situation of people with dementia. What is needed is a care approach that is highly responsive to such changes, and which therefore explicitly incorporates and anticipates the future, to promote a feeling of being in control in a situation where people often feel loss of control. This does not mean that all people with dementia need specialist palliative care. Rather, with no cure of the disease available, the palliative approach may help as a reminder to focus care and treatment on

maintaining or improving quality of life of the patient and supporting the family caregiver in changing and often difficult roles. As the course of the disease is much less predictable than, for example, with cancer, it is more problematic to limit palliative care in dementia to the end of life: when should that be? In order to integrate a palliative approach in dementia care, and for specialist palliative care to appreciate what is specific about dementia, a common understanding of what is needed from palliative care in dementia.

A single sentence to define palliative care in dementia would not suffice. Therefore, in a Delphi study based on evidence and consensus among palliative care and dementia care experts, the European Association for Palliative Care (EAPC) sought to identify the important domains in palliative care in dementia to serve as a framework for development of practice, policy and research (van der Steen et al., 2014b). This Delphi study focussed on older people with dementia, as little is known about the specific issues of young onset dementia at the end of life. Within each domain, the most important recommendations were provided to optimize palliative care in dementia, backed up by an explanation and evidence where available.

Box 1. Domains of palliative care in older people with dementia European Association for Palliative Care (EAPC) (van der Steen et al., 2014b)

1. Applicability of palliative care
2. Person-centred care, communication and shared decision making
3. Setting care goals and advance care planning
4. Continuity of care
5. Prognostication and timely recognition of dying
6. Avoiding overly aggressive, burdensome or futile treatment
7. Optimal treatment of symptoms and providing comfort
8. Psychosocial and spiritual support
9. Family care and involvement
10. Education of the health care team
11. Societal and ethical issues

The first domain is Applicability of palliative care, because dementia is not always considered a terminal disease. It does shorten life expectancy (Rait et al., 2010), but perhaps more important is that dementia is a progressive disease and there needs to be continuous assessment of the needs of the individual, whether resulting in death with or from the dementia. Palliative care asserts that knowledge of and acceptance of the course of a disease, with no cure, is essential, even though this may be an emotionally charged area. In dementia there are indications that (on average) people die more comfortably and with better quality care when family and professional caregivers recognise dementia as a terminal disease before the dying phase (van der Steen et al., 2013). Also physicians perceived that patients suffered more in the final hours of life if their physician felt unprepared with an unexpected death (van der Steen et al., 2017). Studies of advance care planning also speak

to a general benefit of conceptualising dementia as a terminal disease and preparation for declining health.

The important question then arises when palliative care should begin. In principle, when diagnosed with a terminal illness, one may wish to start and prepare. However, and especially with an early diagnosis, the end of life may still be far away. One “solution” would be to label advanced dementia as a terminal disease – and therefore, moderate dementia not so (Mitchell et al., 2009). This is, however, difficult to maintain if half of people with dementia die before ever reaching this stage, and after having experiencing a number of complications, with pneumonia and dehydration of cachexia occurring in moderate dementia as well (Hendriks et al., 2016). Moreover, people with advanced dementia may survive for many years (Gill et al., 2010), often referred to as dwindling, with good care, they may even form a selected subgroup of “survivors”. The domain of Prognostication and timely recognition of dying (Box 1) acknowledges difficulties in prognostication and is therefore typical for palliative care in dementia, where it is not usually a domain in itself in palliative care more generally or for other diseases.

The EAPC work also acknowledges that it is not possible to state a uniform and good starting point for palliative care for all people with dementia. Instead, palliative care is conceptualised as most compatible with two of three major care goals: maintenance of function and maximization of comfort (Figure 1), which both relate strongly to quality of life. There may be a mixture of care goals, which can shift over time, with progressive dementia. Also, because this is a model, how exactly care goals may shift, differs between individuals. In principle, however, palliative care can start at diagnosis (such as with naming of a proxy decision maker, see advance care planning discussion section 2 in this chapter), even though the care goal that overwhelmingly takes priority at that point, may be life prolongation (Figure 1).

Understanding the applicability and mainstays of palliative care in dementia is not only important for practice, but also for policy making, given the benefits and slow uptake in, for example, national dementia strategies where, if included, palliative care is often regarded as care for the dying. Two other domains are relevant especially for policy makers, which are the final two domains (Education of the health care team, and Societal and ethical issues), however these are beyond the scope of this chapter and as such not discussed.

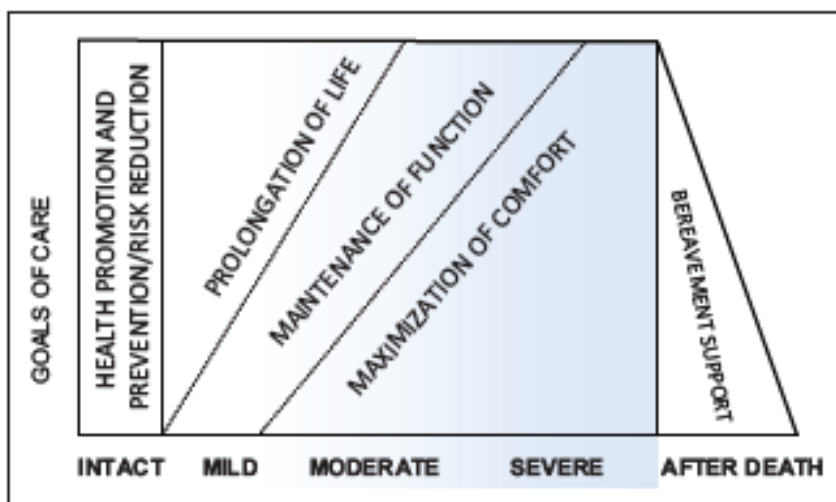


Figure 1. Dementia progression and suggested prioritising of care goals. The goals of maintenance of function and maximization of comfort are compatible with palliative care which aims to improve quality of life (van der Steen et al., 2014b).

van der Steen, J.T., et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine* 28(3), pp. 197-209. Copyright © 2014 by the Authors. Reprinted by permission of SAGE Publications, Ltd.

The most important of the 11 domains (Box 1) of palliative care in people with dementia according to the experts - and perhaps for all patients with no dementia or palliative care needs - are: Optimal treatment of symptoms and providing comfort and Person-centred care, communication, and shared decision making. Nevertheless, how this is being achieved is different with dementia than with several other terminal diseases, this is discussed in sections 3.0, 5.0, and 6.0. Several of the domains listed in Box 1 are emphasized more in palliative care in dementia than with palliative care in other diseases. These are the domains of Setting care goals and advance care planning, because of missed opportunities when waiting for the patient to decline in cognitive functioning; and Family care and involvement because of the great burden placed on families through both the physical and cognitive decline of the person with dementia. It may be argued that in advanced dementia or at the end of life, continuity of care, avoiding transfer and change or adding of new staff in the last phase, is also of special importance in people with dementia. The same may be true for the two domains that relate to a historical development of palliative care in response to an overly aggressive unilateral medical approach until (almost) dying: avoiding overly aggressive, burdensome, or futile treatment, and psychosocial and spiritual support. Explicit attending to needs for spiritual care may fill a gap in dementia care practice, as spiritual care is nearly absent in most dementia guidelines and national dementia strategies (Durepos et al., 2017, Nakanishi et al., 2015).

Palliative care issues, however, may not be raised at all in the absence of a timely diagnosis of dementia which is shown in the case below.

#### Patient case/vignette part 1

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*Mrs. S. is an 82 year old lady who lives at home. She has two children, a daughter and a son, her husband died 6 years ago. Her daughter visits her at home as much as possible. Her son lives abroad.*

*She has a history of a hypertension and has had a hysterectomy. She visits the GP regularly to check her blood pressure. Over the past year she has visited her GP a few more times due to two urinary tract infections. She calls her daughter and son a couple of times a day and never remembers she has just called. Her daughter often finds mouldy food in the fridge and Mrs. S. has got lost on her way home several times.*

*One day Mrs. S. does not answer the phone, her daughter is worried and goes over to her mother. Mrs. S. is lying next to the toilet, she does not know how long she has been on the floor. She can't use her right leg because she is in too much pain. Her daughter calls an ambulance and in the hospital a hip fracture is diagnosed.*

*During her stay in the hospital Mrs. S. gets very disoriented and hallucinates and is diagnosed with delirium. The possibility of dementia is mentioned but at this point it is not*

*possible to run tests. Mrs. S.'s daughter agrees that her mother cannot go back home and they decide to transfer Mrs S. to a rehabilitation unit.*

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## 2. Advance care planning

As can be seen in the case of Mrs S there has been little planning for her future care or treatment as her cognitive decline progresses and as her ability and capacity to make her own health, care and welfare (including financial) diminishes. This stresses the importance of advance care planning.

### **2.1 Definition**

Advance Care Planning (ACP) has been defined as *'process of discussion that usually takes place in anticipation of a future deterioration of a person's condition, between that person and a care worker'* (Henry and Seymour, 2007). Advance care planning can include advance statements about wishes to inform subsequent treatment for example how one's religious beliefs should be reflected in care, or an advance decision to refuse treatment such as antibiotics to treat an infection. Included in the advance care plan are non-medical decisions such as decisions about who should manage the individual's finances. An advance decision may sometimes be referred to as a living will, advance directive, advance policy making or advance physician orders. It is important to highlight that ACP is a process of communication. It does not necessarily lead to a living will or nomination of a proxy decision maker, it may also simply be conversations which are not documented however this is not recommended and documentation of decisions should be made when possible.

### **2.2 Why is ACP important in dementia?**

A timely diagnosis of dementia can be vital to encourage the process of ACP. As discussed above as cognitive decline progresses, an individual's ability to consider their own health and care needs deteriorates, along with their ability to make informed decisions. At this point many decisions are left to families to make in a shared decision making process with practitioners, leaving families often unsure about their status and feeling guilty. ACP has demonstrated improved outcomes for both for people with dementia and their caregivers (Dixon and Knapp, Accepted), including; reduced depression, stress and anxiety in family caregivers (Dixon and Knapp, Accepted). As is in the case of Mrs. S. in patient case/vignette part 5 ongoing discussions around the future and complications, may have reduced the surprise for the family when she deteriorated. There is little evidence, however, if there are sub groups of people who benefit more, or less than others - for example, if there are people who would rather benefit from support in living one day at a time.

### Patient case/vignette part 2

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*Mrs. S. in the rehabilitation unit is dependent on nurses' care, and she becomes more disoriented in time and place as her cognitive decline progresses. She has more difficulty finding words to express herself. After a while Mrs. S. is diagnosed with dementia of*

*Alzheimer type. Her children and the multidisciplinary team do not think Mrs. S. can go back home and they want to transfer her to a nursing home with a special dementia care unit. Her children feel quite guilty about this even more so since Mrs. S. wants to go home.*

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### **2.3 What should they discuss and the approaches – who, how and when?**

The EAPC recommendations on optimal palliative care for people with dementia recognises ACP as a core domain (Box 1, domain 3) (van der Steen et al., 2014b). According to the EAPC, ACP should be considered early in the disease process shortly after diagnosis, continually reviewed as an ongoing process with the patient and family on a regular basis and following any significant change in health condition. As can be seen in Figure 1 the care goals will change and priorities may alter over time from life prolongation and maintenance of function in early dementia through to maximising comfort in the severe/advanced stages of dementia.

However, there is ambiguity about when to start advance care planning. Starting shortly after diagnosis may not be appropriate for everyone, and is currently not necessarily common practice in many countries. In recognition that the optimal timing of initiating the process is highly individual, the EAPC recommends a minimum as to what should be done at diagnosis, which is to name a (future) substitute decision maker. The health care team may also just “plant the seed”. Introducing planning and decision making as early as possible is encouraged in many countries. Decisions about when to start ACP should be considered on an individual patient by patient level and should include both the person with dementia and those close to them.

There are many national guidelines across many countries which provide example templates for ACP, including how to begin discussions and what the discussions should include. Initial discussions may include identifying the wishes and preferences of an individual, including; preference of where they would like to be cared for (e.g. hospital, nursing home or at home) but this often depends on the care that is needed, and how they may like their religious and spiritual beliefs incorporated in their care. Although, an individual with dementia may express their preference of place of care throughout their dementia, for example in the case of Mrs S in Patient case/vignette part 2. Often people with dementia want to remain at home, being a familiar environment and close to their relatives. Often, like in the case of Mrs S., people are admitted to a hospital and are afterwards transferred to a nursing home because they need more care and staying at home is not safe anymore or the partner or relatives can't deliver the amount of care or guidance that is needed.

Figure 2 shows the different journeys for people with dementia, many live at home but with the increase in care dependency people are transferred to a hospital or a nursing home. Sometimes people are also admitted from home to a hospice, or from a hospital or nursing home to a hospice. The discussions may then gradually move on to consider more specific decisions, such as treatment and scenarios of future health. These may include treatment such as; artificial nutrition and hydration, the use of antibiotics for recurrent infections, and

cardio-pulmonary resuscitation. As with patient and families, physicians also differ in whether they feel comfortable with discussing future scenarios or rather focus on care goals and values with specific decisions postponed to when the situation occurs (van Soest-Poortvliet et al., 2015). There is a growing amount of literature surrounding planning with some placing high importance on what they regard as the necessity for people with dementia to complete advance care plans (Dixon and Knapp, Accepted).

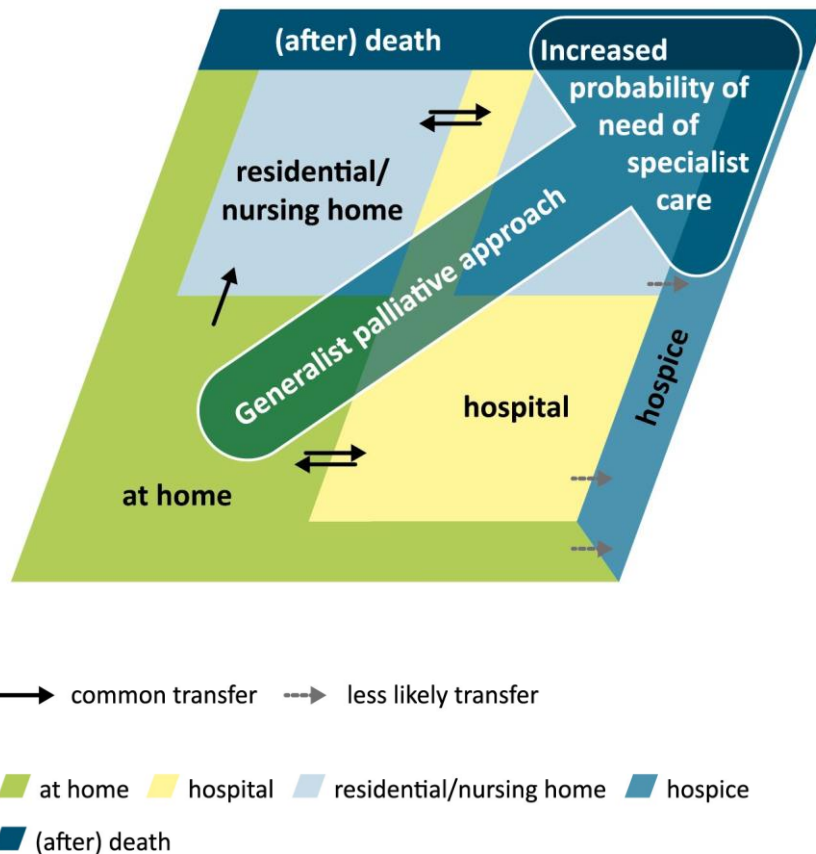


Figure 2. Possible journey for person with dementia and health care service transitions

#### 2.4 Barriers

Despite many efforts internationally to encourage ACP for people with dementia, they are often not consulted about their wishes. ACP is less well developed across Europe, with much more work in Australia, Canada, and USA. Several studies have identified a number of barriers why ACP does not occur including; a lack of knowledge of ACP, difficulty of talking about such sensitive topics, fear of facing one's own mortality, organisational context, discontinuity of care, lack of a relationship with practitioners as well as within families, lack of time, as well as being made more complex in dementia by it often not being acknowledged as a terminal illness (van der Steen et al., 2014c). Many health and social care professionals are reported to lack the confidence, feel inexperienced and need additional training and support in this area (Sampson et al., 2012). Health and social care staff in some countries believe that if they do not call emergency services in a crisis there will be repercussions for them (Harrison-Dening et al., 2012). This issue highlights the legal ambiguity that is often seen across countries of ACP (Jones et al., 2016). For example, in the UK, the legal document as part of ACP is the advance decision. The advance decision however is only legally binding if: it complies with the

Mental Capacity Act (2005); valid (for example it is signed by the individual and a witness and it specifies clearly the treatments the individual wishes to refuse); and applies to the situation. It is important to check the legal framework of decisions at the end of life in your country or region as this does differ.

### **2.5 Facilitators and benefits**

ACP potentially gives patients and families an opportunity to think about what is important for them and plan to try ensure these wishes are met. However, it may not always be possible for the individual's wishes to be met, for example as in the case of Mrs S's wish to go home in patient case/vignette part 2. To facilitate ACP, practitioners should be available to educate families, and in particular there should be a dedicated key facilitator to educate both practitioner and family. ACP can lead to reduced hospital admissions, unnecessary interventions, reduced costs (Robinson et al., 2012) and even reduced stress among family caregivers as discussed in section 7.2 of this chapter.

#### Patient case/vignette part 3

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*Finally Mrs. S. has been moved from the rehabilitation unit to a unit (wing) for people with dementia in a nursing home. At first she seems to experience problems with her new environment, later she seems to feel better in her new rhythm of the unit.*

*At one point she starts to frown sometimes and to behave in an agitated manner. She cannot verbally express what she is feeling at those moments. At first nothing is found which could explain this. One day a nurse hears Mrs S. moaning and sees her frowning. Physical examination and a urine test lead to a diagnosis of a urinary tract infection, which is then treated with antibiotics.*

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### 3. Symptom Management

At the beginning of the disease people with dementia live at home and are often still capable of expressing their feelings, for instance pain. But with the progression of the disease people often lose this ability to communicate verbally due to neuropathological changes. This is also reflected in functional and physical impairment and behavioural and psychological symptoms, for which people often have to be admitted to a nursing home. As the dementia progresses, the need for help rises and the last year of living with dementia is known for a high level of disability with a high need for assistance in activities for daily living. Symptoms that are often described in studies of people with dementia include: pain, shortness of breath, and agitation or other neuropsychiatric symptoms.

The clinical course of dementia shows that family or medical staff working with people with dementia should pay particular attention for symptoms of pain, shortness of breath or anxiety (Hendriks et al., 2015, Hendriks et al., 2016). Often with the progression of the disease people get urinary incontinence and later bowel incontinence, and are at high risk for swallowing problems and aspiration, weight loss, pressure ulcers, infections (pneumonia and urinary tract infections), and febrile episodes, as can be seen in the case of Mrs S (Patient case/vignette part 3) (Mitchell et al., 2009).



### **3.1 Pain**

The gold standard for the assessment of pain is self-report. This is often not possible in a later stage of dementia when people are often not capable of verbally expressing the experience of pain, or lose the capacity of pain memory. Pain can result in behaviour that challenges, for example agitation or aggression if left untreated. In the case of Mrs S. she can be seen to frown at times, and this is often coupled with agitation, this may be an indication that she is in pain. Pain can be experienced differently in people with different kinds of dementia or at different stages, related to the different neuropathological changes. Pain is however very common, 12%-76%, in people with dementia, in all stages (van der Steen, 2010).

Previous studies had suggested that people with dementia in nursing homes receive less pain medication compared to people without dementia, however newer evidence suggests that there is no difference with or without dementia (Haasum et al., 2011) or even higher in some studies among people with dementia (Lövheim et al., 2008). Studies have also expressed concern about the overuse of opioids in people with dementia. It is therefore vital to ensure pain is a central component of continual assessment with a person with dementia and an approach to maximising comfort and quality of life is taken.

There are a number of instruments (pain scales) which can be used to assist staff identify pain in people with dementia if they are not able to verbally express this pain, such as the case with Mrs. S. the team is alerted by the moaning and frowning suggesting she is in pain. The involvement of family and caregivers may be a very good way of assessing the patient, especially at home or just after admission in a nursing home, as they are familiar with changes in behaviour or expression that may indicate distress. There are a large number of available instruments which have shown different reliability and validity, currently over 30, but for clinical practice the Pain Assessment in Advanced Dementia (PAINAD) and Pain Assessment Checklist for Seniors With Limited Ability to Communicate (PACSLAC) are often recommended (Ellis-Smith et al., 2016). Research continues to look for an instrument that is reliable, valid and which can identify expressions specifically indicative for pain. In clinical settings it is important to evaluate the possibility of pain regularly and sometimes try the effect of analgesics, as well as assessment of current pain medication being received; is it still adequate, is it still necessary?

### **3.2 Shortness of breath**

Shortness of breath is often reported in studies of people with dementia with a range of 16% to 26% (Hendriks et al., 2015, Mitchell et al., 2009). Shortness of breath can be caused by different problems, common causes include pulmonary infection such as pneumonia, or cardiac problems. Pneumonia may also be related to aspiration. Angina and pulmonary embolism are very difficult to recognise in people with dementia in cases where there are difficulties verbally expressing pain (chest) or shortness of breath.

### **3.3 Unmet need/challenging behaviour**

Many feelings, for instance pain as mentioned above, are the result of a sensation that is unpleasant and they can lead to a change in the individual's behaviour, which may be considered challenging. Many neuropsychiatric symptoms are seen in people with dementia and can have a great impact on the quality of life of that person and those surrounding them; family and caregivers.

Neuropsychiatric symptoms (NPS) (or behavioural and psychological symptoms of dementia BPSD) include delusions, hallucinations, depressive mood, anxiety, irritability/lability, apathy,

euphoria, disinhibition, agitation/aggression, aberrant motor activity, sleep or appetite changes (Cerejeira et al., 2012). The range of NPS prevalence in community-dwelling people with dementia is generally more than half of people (Borsje et al., 2015). These different types of behaviour, often called challenging behaviour, can also be frequently seen in nursing homes. Family or a regular staff member that know the person with dementia can often provide extra information on the cause of the behaviour or have useful information on how to diminish this.

Infections such as a urinary tract infection, are known to be a frequent cause of challenging behaviour or even cause an episode of delirium, this is often the cause of admission to hospital for many people with dementia. The prevalence and incidence of delirium can be high in people with dementia, ranging from 8% in nursing homes to 89% in hospital and community populations (Boorsma et al., 2012, Fick et al., 2002). Many tools have been developed to assess delirium, including tools that are also used for people with dementia to ensure early recognition (Morandi et al., 2012), including the Richmond Agitation and Sedation Scale (RASS) and modified-RASS (m-RASS) (Morandi et al., 2016).

Agitation is often reported as one of the biggest behavioural challenges in people with dementia and numbers ranging from 57% to 71% were found (Hendriks et al., 2015). However for many families are more concerned with pain, breathing problems and memory problems than agitation (Shega et al., 2008). Pain and agitation are often reported simultaneously but a strong association was not found (van Dalen-Kok et al., 2015). Anxiety is also frequently reported in people with dementia but this is also complex and difficult to test, due to an overlap with depression (Seignourel et al., 2008).

As can be seen in the case of Mrs. S, these symptoms and challenges often result in family caregivers acting as proxy, making decisions about the person with dementia's care when there is no advance care plan or in case of an advance care plan to check if the decision is in accordance with the ideas/wishes of the person with dementia. These are very difficult decisions for families as discussed in section 5. One of the most difficult decisions is whether to move the person with dementia into a nursing home, in the case of Mrs S the family believe this is in the best interest of Mrs S, however they feel guilty about this decision as Mrs S would like to return home (Patient case/vignette part 2).

#### Patient case/vignette part 4

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*After a few months in the nursing home, Mrs. S gets a fever, is short of breath, coughs and the amounts of fluids and food she takes are less than normal according to the nursing staff. The visiting physician diagnoses pneumonia and wants to talk to the family to discuss if Mrs. S should be sent to a hospital or not.*

*Mrs. S recovers from the pneumonia, but she eats and drinks less every week. She can still walk but she is less stable and has a high risk of falling. She sometimes coughs during the meals. Her son asks if his mother should receive artificial hydration and feeding.*

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#### 4. Treatment options of common complications

In this section we refer to pharmacological and non-pharmacological treatment options for a variety of complications/symptoms which may arise before the person with dementia is in the dying phase. Later in this chapter (section 8.2) we will discuss treatment in the dying phase.

##### **4.1 Non-Pharmacological treatment options (including spiritual care)**

In recent years person centred care has been introduced in the care for people with dementia and more evidence is showing the benefits of non-drug treatment, particularly for behavioural and psychological symptoms in relation to pain. Person centred care is discussed in more detail later in this chapter in section 6. The care for people with dementia should be multidisciplinary and include spiritual care. Studies show an effect of therapies like music therapy, massage and aromatherapy and these should be considered and need to be prioritized in clinical and research settings (Winblad et al., 2016). For example, music therapy has shown a reduction in the short term of depressive symptoms following at least five sessions, but there was little to no effect on agitation or aggression and the long term effects are yet to be studied (van der Steen et al., 2017).

Every time when behaviour changes, one has to pay attention to the possibility of medical conditions causing this change, for instance infections, constipation, bladder retention, pressure sores, pressure sores or infections in the mouth, side effect of medication, but also for instance changes in environment. Regular evaluation in a multidisciplinary team including the nursing staff, psychologist, physiotherapist, social care practitioner, occupational therapist, spiritual care counsellor, dietitian and a physician with evaluation on among others; behaviour, pain, medication, mobility, swallowing, weight change and incontinence can help improve the quality of care for a person with dementia.

There are several environmental factors which should be considered when caring for someone with dementia. These may range from consideration about the aesthetics of the individuals' room and environment, through to consistency of staff. In the home or nursing home small alterations may help with orientation such as using different coloured doors or pictures to help identify different rooms. It is important to ensure continuity of care when delivering palliative care for someone with dementia (van der Steen et al., 2014b). Continuity encompasses; ensuring the individual is able to remain in their preferred place of care with minimal disruption and minimising the need for transfers between settings, continuity of the provision of care even if there is a transfer, and continuity of staff caring for the individual.

##### **4.2 Pharmacological treatment options**

Infections in persons with dementia are usually treated following national or regional antibiotic guidelines, like Mrs. S in the Patient case/vignette part 3. As the dementia progresses there should be a process of on-going discussions as to what to expect from treatment (this may be part of ACP), for instance antibiotics, and the likelihood of response to treatment. In some cases, a patient may not respond to treatment when they are too sick and are not capable of drinking and eating anymore. The use of antibiotics should be discussed with the family or advocate and include the person with dementia if possible, it is viewed differently in different countries. In some countries the families have more influence on treatment decisions and the practitioner may simply provide choices, whereas in others this may be a medical decision, in discussion with the wider multidisciplinary team and family. Antibiotics can prolong life but sometimes just for several days (van der Steen et al., 2012). See section 5 on controversies and decision making in this chapter.

When people with dementia are transferred to a hospital they often receive intravenous treatment with antibiotics or fluid, or even tube feeding. This treatment increases at the end of life but practice in different countries varies (Klapwijk et al., 2014, Mitchell et al., 2009), and they also vary over time; for example there is a decline in feeding tubes used in USA (Mitchell et al., 2016).

As pain medication, acetaminophen (Paracetamol) is often used as a first line treatment (Hendriks et al., 2015, Sandvik et al., 2016a), followed by the use of opioids to treat more severe pain which is non-reactive to acetaminophen (commonly used; up to 24%) (Hendriks et al., 2015, Pieper et al., 2017, Sandvik et al., 2016a, Griffioen et al., 2017). Antipsychotic drugs are frequently used to treat challenging behaviour in dementia, often with no positive result and many adverse effects, like extrapyramidal symptoms, stroke or death. Research and the EAPC white paper recommend that non-pharmacological treatment (see above) should be tried first for behaviour which challenges (van der Steen et al., 2014b). Several other types of medication besides (typical and atypical) antipsychotic drugs are also used to treat neuropsychiatric symptoms; anxiolytics, sedatives, antidepressants and anti-dementia drugs. More research is needed to gain a better understanding of how and when to start and stop these pharmacological treatments to optimize prescription in people with dementia, including for cases of delirium (Agar et al., 2016) (Agar et al., 2016). Bronchodilators are often used in the treatment of shortness of breath, studies show different prevalence, ranging from 29% to 67% (Hendriks et al., 2015).

## 5. Controversies and decisions

### **5.1 End-of-life decisions**

The decisions which need to be made towards the end of life are often medically focussed, relating to the complex symptoms which pose a dilemma for practitioners. However many other non-medical factors are also important and need to be considered, for example spiritual care. As discussed in the previous section, difficult decisions both medical and non-medical can include: spiritual care, place of care, cardiopulmonary resuscitation, treatment of infections, management of eating and drinking problems, pain, shortness of breath, behavioural problems and hospitalisation, as well as any co-morbid conditions. In the case of Mrs. S, as she begins to eat and drink less, the son wishes to discuss the potential use of artificial hydration and feeding (patient case/vignette part 4).

In some countries, many are raising the option of euthanasia for people with dementia. This is legal in a small number of countries including the Netherlands when strict criteria are met but many physicians are reluctant to fulfil such a preference in the absence of clear communication with the patient.

### **5.2 Who should make the decisions?**

Ultimately, health and care based decisions should be made by the individual/patient themselves. However, in many cases, by the time dilemmas such as difficulty with eating and swallowing arise it is not possible due to a diminished capacity. Hence, the individual does not have the ability to make informed decisions. Despite efforts to increase advance care planning (ACP) with people with dementia many people reach the end of life without one (see section 2 earlier in this chapter). Some are not ready to have conversations about death and face their own mortality, and decision making is left to families (Davies et al., 2014). Practitioners rely on families to know the wishes of the individual and to relay these with confidence and accuracy when making end of life decisions. However, caution should

be taken by practitioners as family caregivers/proxies have been shown to have a low to moderate agreement with the person with dementia about preferences for end of life treatments (Harrison Denning et al., 2016). Practitioners should engage closely with families to understand the individuals previous wishes, and work with the family through a shared decision making process.

### ***5.3 What gets in the way of making decisions?***

Many barriers have been identified by family caregivers/proxies which prevent them from making decisions about end of life care, including; a lack of information, poor communication, difficult dynamics/conflict within families, limited emotional and practical support, and dynamic care systems (Davies et al., 2014, Lamahewa et al., In press). Practitioners should provide clear information which is communicated in a sensitive and supportive manner, helping to facilitate the decision making process. Social care practitioners can also act as mediators in family conflict to encourage supportive family relationships and aid decision making.

It is not just family caregivers/proxies who have difficulties in making decisions; many practitioners lack the confidence to hold such difficult conversations and shy away from these discussions (Davies et al., 2013, Lamahewa et al., In press). These difficult conversations require a high level of skill and a vast amount of experience to be conducted sensitively, many practitioners, and even experienced practitioners, dread such conversations. This leaves family caregivers often not knowing how to approach such conversations, being left to make difficult decisions and care plans, with many feeling doubts about their status.

### ***5.4 Approaching challenging decisions/dilemmas***

There are relatively few professional guidelines which address end-of-life care for people with dementia. Until recently, many palliative care guidelines have focussed on cancer such as the National Institute for Health and Care Excellence (NICE) (England and Wales). Practitioners should consult their national guidelines for both dementia and palliative care (see EAPC Atlas of Palliative Care in Europe), Alzheimer's Europe, and consult the EAPC white paper on optimal palliative care for people with dementia (van der Steen et al., 2014b) as discussed in the symptom management section 3.3.

A recent practical toolkit for making decisions specific for end-of-life care of people with dementia used in conjunction with available guidance (Davies et al., 2016a), consists of a series of heuristics (schematic patterns that can be applied in complex situations and function as prompts to initiate thinking and action) which offer a clinically familiar approach, are brief, easy to remember and lead to action). The toolkit covers key decisions including: eating and swallowing difficulties, agitation/restlessness, reviewing treatment and interventions at the end of life (for example routine medication), and providing routine care at the end of life (for example changing dry bed sheets in the final days to hours of life). Examples of the heuristics are given in Figures 3 and 4 and are discussed below with reference to common dilemmas and controversies.

### ***5.5 Common decision making dilemmas and controversies***

A number of challenges and controversies around providing end-of-life care for people with dementia have been identified:

### *5.5.1 Hospitalisation*

In the process of attempting to manage symptoms and maintain quality of life, many people at the end of life often experience what are termed as avoidable hospital admissions (van der Steen, 2010). This description of 'avoidable' may be for a number of reasons including the nature and consequences of the condition, such as an infection (van der Steen, 2010). These admissions often cause more pain and distress to both the individual and their family than remaining in their normal place of care. It is important, as in the example of Mrs S (Patient case/vignette part 4), to discuss the possibility of hospitalisation with the relatives, discuss expectations and make this decision together. Individuals can go to hospitals which have a focus on cure as opposed to care, and may receive what is described as unnecessary tests or aggressive and invasive procedures. Cardiopulmonary resuscitation should be avoided in people with dementia, as it is less likely to be successful in people with dementia compared to those without. CPR can be very distressing for all those involved including both the person with dementia and the families, with those who are successfully resuscitated often being transferred to intensive care and dying a short while later.

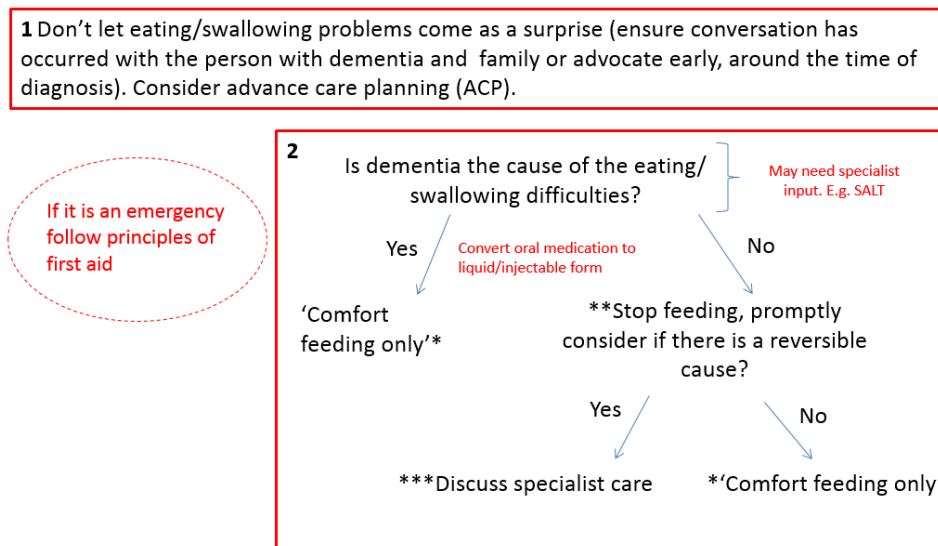
### *5.5.2 Artificial nutrition and hydration*

A common medical decision, towards the end of life (like in the Patient case/vignette part 4) is the introduction of artificial feeding when the individual is no longer able to swallow food, liquid or medication. Many people, families and professional caring teams, believe that they cannot allow the individual to "starve to death" and they feel that the use of artificial feeding will extend life and prevent discomfort or further complications such as aspiration, potentially leading to an improvement in quality of life (Mitchell and Lawson, 1999). In the UK, the Netherlands and many other countries the adoption of artificial nutrition and hydration has been a controversial topic for some time and remains so. The EAPC recommends that hydration (preferably subcutaneous) should only be provided if appropriate in the management of potentially reversible causes, such as infection, but not should not be used in the dying phase when an individual loses their ability to swallow (van der Steen et al., 2014b). However, the EAPC white paper was unable to reach a consensus on this topic with the professionals they consulted, acting only to further highlight the controversy within this topic. It is unclear if rehydration therapy affects discomfort or indeed survival. A study of Italian nursing home patients with advanced dementia demonstrated that for almost all patients treated with intravenous rehydration therapy, the goal of treatment was to reduce symptoms and suffering. Despite this goal, discomfort was high overall, but symptom relief may be improved (van der Steen et al., In press). More work to explore the effects of rehydration therapy and discomfort is needed.

The EAPC also recommends that permanent artificial feeding, using a gastrostomy or a nasogastric tube should be avoided (van der Steen et al., 2014b). Careful and skilful hand feeding or comfort feeding should be provided. Comfort feeding refers to the process of eating for pleasure, providing small amounts of food, even though there may be associated risks such as aspiration. Practitioners together with families must balance the risks of feeding with the potential comfort and pleasure that eating may provide for the individual - figure 3 illustrates a heuristic which conveys a practical approach to how these decisions can be considered in the case of Mrs S.

Currently there are no studies which show an association that artificial feeding offers benefits to the individual. On the contrary some studies have demonstrated they increase the chance of infection, aspiration, further complications (Palecek et al., 2010) and potentially mortality (Ticinesi et al., 2016). As with the limited understanding of pain in dementia we similarly have a limited understanding around feelings of hunger and thirst in people with dementia.

Data in the USA indicates a reduction in the use of feeding tubes in people with dementia (Mitchell et al., 2016).



*\*comfort feeding may carry associated risks of aspiration*

*\*\*Closely observe all intake particularly if changes to swallow function are suspected*

*\*\*\* Consider appropriateness on individual basis*

Figure 3. Heuristic for eating/swallowing difficulties

### 5.5.3 Medication: Antimicrobial treatment

The ability of antimicrobial treatment for recurrent infections in people with dementia to extend life or improve comfort is not well understood, however, some studies have demonstrated increased survival following antimicrobial treatment compared to no treatment or a palliative approach (van der Steen et al., 2012). The use of antimicrobials including oral, intramuscular, and intravenous for pneumonia, has increased survival but were also associated with more symptoms reported in retrospect in the period from before to after the pneumonia in a nursing home population with advanced dementia (Givens et al., 2010). However, this was in the US, where people with dementia and pneumonia with fewer symptoms were more likely not to be treated with antibiotics (van der Steen, 2011). Another study used discomfort observed by independent, blinded observers measured with validated tools after antibiotic treatment and discomfort levels were lower after antibiotic treatment (van der Steen, 2011). A more recent study with the same strong methods, showed that, with more symptom-relieving-treatment provided, antibiotics were no longer associated with discomfort. (van der Maaden et al., 2016) Antimicrobial use might be more beneficial for people in the earlier stages of dementia compared to the later stages, with no difference in mortality at in more advanced dementia between those receiving antimicrobial treatment and palliation and those not (Fabiszewski et al., 1990). Some studies have shown that increased survival after antibiotic treatment, but this may only last for a few days in some cases (van der Steen et al., 2012), which may be simply prolonging the dying process (van der Steen et al., 2012). Antimicrobial treatment is associated with renal failure, diarrhoea, use of intravenous lines, and skin rashes. After nearly 25 years of research investigating the effectiveness of antimicrobial treatment for people with dementia, the effects (benefits and adverse effects) are still unclear.

It is important to identify the source of the infection which may be causing symptoms such as fever and balance the benefits of treatment with the potential side effects and

consequences. The EAPC recommends that antibiotics are appropriate for treating infections which have a goal of increasing comfort, but life prolonging effects should be considered carefully (van der Steen et al., 2014b). This can be demonstrated through the heuristic in Figure 4.

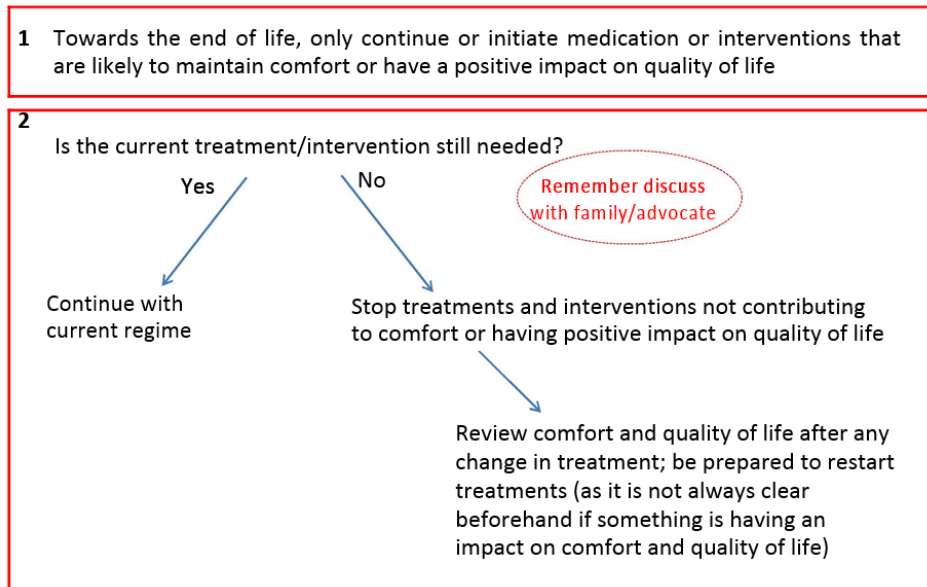


Figure 4. Heuristic for initiating medication and interventions

#### 5.5.4 Other medication

Treatments with other medication for preventive or symptomatic use can cause dilemmas too. Acetylcholinesterase inhibitors, HMG-CoA reductase inhibitors (statins), antihypertensive drugs, antihyperglycaemic drugs, anticoagulants are prescribed often in people with advanced dementia but many medical guidelines provide an understanding of initiating such treatments but often do not include when and how to stop them. Discontinuation should be considered but it can be difficult to determine what the effect can be and if stopping will contribute to a better quality of life (see Figure 4), however it can reduce the risks of side effects and drug interaction. Multidisciplinary meetings, medication review and educational programs can help to improve appropriate medication use for people with advanced dementia in nursing homes.

### 6. Person-centred care

For many, being viewed as a person and treated with respect and dignity is, in addition to good symptom management, fundamental to a good death. This is consistent with what experts regard as the most important domains in palliative care with dementia: optimal treatment of symptoms and providing comfort and person-centred care, communication, and shared decision making (van der Steen et al., 2014b). It can be argued that person-centred care is always important, but it may help to emphasize its importance in patients at risk of not being seen as a person anymore, which is the case with advanced dementia or when patients are not very responsive due to illness or at the end of life. Indeed, with admission to a nursing home for example as is the case with Mrs. S, family caregivers may be concerned that staff do not know the patient well enough to provide person-centred care, and as they



live in a nursing home continue to lose their identity and may struggle to maintain this identity which is so important to person centred care (Davies et al., 2016b).

## 7. Family caregivers of people with dementia

### **7.1 Importance of family caregivers**

An estimated 46.8 million people are living with dementia worldwide (Alzheimer's Disease International, 2015), many of whom will be cared for by family caregivers and can be referred to as lay carers, untrained carers, informal carers, caregivers, or proxies. In the United Kingdom the Alzheimer's Society has insisted that without the help and support of family caregivers the formal care system would collapse. Traditionally there are distinct boundaries between caregivers and the cared for. Caring in palliative care however may differ from caring for someone with a non-terminal physical or intellectual impairment. The boundary between the 'caregiver' and the 'cared for' is said to be somewhat blurred, because of the increasing need for support for the individual from the caregiver in palliative care. The caregiving career involves a variety of tasks in addition to meeting the physical and mental needs of the person with dementia. These include: interaction with health and social care professionals, doing daily house hold chores, and escorting the person with dementia to various medical, dental, optical and hairdressing appointments.

### **7.2 Effects of caring for someone with dementia**

It is well known that caring in general can be a stressful role and that the burden placed on the individual caregiver is often great, with limited opportunity to have breaks, socialise and have whatever one may classify as a 'normal' life. However, caring for an older person or a relative with dementia is thought to be one of the most stressful and difficult forms of caring. Caregivers as described in the portraits by Sanders and colleagues, face the difficulty of coming to terms with the diagnosis and the loss of the person they once knew (Sanders et al., 2009). They may find difficulties with the individual's behavioural and cognitive decline, the loss of their own 'normal' life, the role of caring, and finally the eventual death of the person. Uncertainty of death and the treatment options for people with dementia can lead to feelings of guilt among family caregivers, this is illustrated in patient case/vignette part 2. Caregivers of people with dementia have higher rates of various health problems, both physical and psychological, including; depression and cardiovascular problems, resulting in increased doctor visits and an economical burden on health care services, with a higher risk of mortality (Brodaty and Donkin, 2009).

### **7.3 Supporting caregivers**

The lack of definitive split between the person with dementia and the caregiver can be conceptualised as what Twigg termed as carers as co-clients (Twigg, 1989). Despite caregivers being seen as having a caring 'career', the experience is not the same for all. Something which is often forgotten or not considered is that not all caregivers are loved by their relatives and conversely, can be mistakenly labelled as "loved ones". The caregiver may endure a trajectory of caring from the encounter stage, where they are coming to terms with both the diagnosis of dementia and also their new role; moving onto an enduring stage at which point the caring intensity increases; through to the exit stage where they face the death of the individual and adapting to their new life (Lindgren, 1993). As we discussed in

section 1.0 of this chapter, palliative care may cover all stages of this 'caregiving career' and each individual caregiver may require more or less support at various stages (Davies et al., 2014). A thorough caregiver's assessment should be completed with the family caregiver of the person with dementia, to identify their needs and levels of support required. This should be a holistic assessment considering, medical as well as psycho-social aspects of care and support.

#### **7.4 Grief, loss and bereavement**

Grief and loss when someone dies is to be expected with most people, and is considered a normal response to death. Grief has been defined as 'the reaction to the perception of loss with symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings and a variety of physical symptoms unique to the individual' (Rando, 2000).

Throughout the course of dementia family caregivers may be experiencing a series of multiple losses, for example; loss of intimacy, companionship, control, personal freedom and well-being among them (Chan et al., 2013). These losses can be described as part of anticipatory grief, that is grief which occurs before the death of the individual (Rando, 2000). Anticipatory grief occurs in 47-71% of family caregivers of people with dementia (Chan et al., 2013). The sometimes long projected course of dementia means that anticipating the death of the individual and ambiguity of what the future holds, can be common among family caregivers. Anticipatory grief has been shown to have an association with depression, and depression is increased with anticipatory grief (Sanders and Adams, 2005). However some studies have suggested that what appears as clinical depression may actually be a grief reaction (Sanders and Adams, 2005). Other factors which appear positively associated with increasing anticipatory grief include burden, non-English primary language in English speaking countries, living with the person with dementia prior to being placed in a care home, and less satisfaction with care (Chan et al., 2013).

Grief appears to be more severe during the moderate to severe stages of dementia (Chan et al., 2013). However, as suggested, the needs of individual caregivers may differ and this may also relate to their response to grief and loss. Individual caregivers may experience grief at different stages and this should be carefully considered when supporting family caregivers. In particular, there may be a marked difference between spouses and adult children responding differently at different stages. Adult children appear to experience minimal grief in the early stages of dementia, most intense at the moderate stage, and the grief lessens towards the advanced stages with feelings of relief when the individual moves into a nursing home for example. For spouses, grief appears to reflect a linear pattern increasing as dementia progresses, however other work has suggested grief remains stable in advanced dementia and therefore may not continue to increase for all (Givens et al., 2011). It is important to reassure caregivers that relief after death is common and they should not feel guilty about this feeling, it can be part of the post-death grieving process (Chan et al., 2013). For some, grief may continue for some time after death, termed complicated grief if more than six months, this is termed as *persistent complex bereavement disorder* in the DSM-5, marked by an individual 'incapacitated' by grief affecting their daily life.

Particular consideration and attention may be needed towards male caregivers who can find it difficult to openly accept their feelings of grief, strain and distress (Sanders et al., 2003). Grief in some may be expressed in different ways or using different language, for example

portraying emotional dissociation from the person with dementia (Sanders et al., 2003). Males often have less stable social support networks and are less likely to seek assistance in dealing with their grief than. This may be particularly pertinent in spouse male caregivers, who may be older and for whom grief may be particularly challenging, as they come to deal with the emotions associated with being alone at a time when their own social networks will be dwindling (Sanders et al., 2003).

In addition to regular caregiver assessments and reviews as mentioned, post bereavement support should be offered to families (van der Steen et al., 2014b), including helping them adjust to a life of post-caring when much of this previous world will have disappeared. This may include as in the case of Mrs. S. patient case/vignette part 5 a meeting at the nursing home with the family after their relative has died. Practitioners should identify caregivers who are at increased risk of grief (anticipatory, normal and complicated grief), such as those with high levels of burden and depression, offering caregiver support at an early stage.

### **7.5 What do caregivers want from care?**

The individuality of caregivers is not only reflected in the needs of them as a caregiver, but also in their views of how palliative and end-of-life care should be provided for someone with dementia. Caregivers' views regarding the appropriate treatment in particular referring to the dilemmas discussed in section 5 of this chapter lie on a spectrum of beliefs from provision of care purely aimed at comfort by relieving symptoms, through to active/invasive/aggressive treatment which is aimed at "cure" (Davies et al., 2014). It is important to reflect on the stage of the dementia and provide information and education to family caregivers as to the progression of dementia (see Figure 1) and appropriate treatment options (van der Steen et al., 2014b). However, it is also important to acknowledge that there is a great deal of diversity of when families want to receive the information (individual and between countries). When considering families' views there should be a recognition that they may not have the complex medical knowledge that many practitioners have and this may be their first experience caring for someone who is dying. Caregivers, may focus on the psycho-social aspects of care as their main priorities (Davies et al., 2016b). This is important to emphasise as we discussed previously, that not all decisions are medically focussed.

#### Patient case/vignette part 5

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*Mrs. S. gets weaker and is not able to walk any more. She has lost a lot of weight in the past few months. She gets another case of pneumonia, is in bed all day, and doesn't eat or drink anything anymore, the nurses think that Mrs. S. is going to die this time. For the daughter of Mrs. S. this comes as a surprise. The physician and the nursing staff make all sorts of arrangements, for example on pain relief, treatment in case of shortness of breath and prevention of pressure ulcers and constipation. A spiritual counsellor is asked by the nursing home to visit Mrs. S. Mrs. S's daughter stays with her mother all the time. She frequently asks when her mother is going to die. After 3 days and nights Mrs. S. dies in the presence of her daughter.*

*A few weeks after the death of Mrs. S. the family is invited to attend a meeting with the nursing staff and the physician. They talk about the stay of their mother in the nursing home and the final days to death.*

\*\*\*\*\*

## 8. Dying with dementia

A prognosis is very difficult to provide to a person with dementia (Brown et al., 2013). With the disease comes a decline in cognitive functioning but it is very difficult to predict if a person with dementia is in the last months of life whereas with cancer patients, end of life seems more predictable. People do not always reach the last phase of dementia and about half of people with dementia may die before the advanced stages (Hendriks et al., 2016). In people with cancer and dementia, a high number of symptoms are found while dying in various settings, such as a hospice and nursing home. In the USA hospice generally refers to hospice care as a service. In many other countries across the world, such as the UK, a hospice is a physical building which delivers palliative care (see Figure 2), however few people with dementia will receive care here (Reyniers et al., 2015).

The 6-month mortality rate in nursing homes is high, and often higher than anticipated (van der Steen et al., 2007). The most frequent causes of death are respiratory infections or cardiovascular disorders and in later stages people are often more dehydrated and cachectic due to eating/swallowing difficulties like Mrs. S in the patient case/vignette part 5 (Hendriks et al., 2014). Also in the earlier stages of dementia there is an association between eating and drinking less and mortality (Hendriks et al., 2016).

Many people with dementia die in a nursing home, but the numbers differ between countries related to the available system of care for people with dementia. In some countries a large proportion of people will still die in a hospital (Reyniers et al., 2015). The different journeys from home to sometimes hospital, nursing home or hospice to death and the increased need for palliative specialist care are shown in Figure 2.

Prognosis for someone with dementia is difficult, however the prediction of short-term mortality, for example, one week is much more accurate (Casarett et al., 2012, Klapwijk et al., 2014). Even when death is expected within days it is not possible to predict when exactly someone is going to die such as in the case of Mrs.S (patient case/vignette part 5). Many studies on the last days of life of dementia show often burdensome symptoms like pain or shortness of breath and this is also indicated by relatives, who in many cases experience death as a struggle. Only 50% of the relatives perceive death as peaceful in a Dutch study (De Roo et al., 2014).

In the literature a minority of nursing home residents with advanced dementia enter or are transferred to a hospice (Reyniers et al., 2015), but this also depends on available care system and the care that is required, not all people with dementia will require a hospice placement (see figure 2). Hospice care is often more for symptomatic treatment, often scheduled treatment of pain and shortness of breath. All people with dementia should get good quality of care at the end of life, not only in a hospice.

### **8.1 Symptoms in the dying phase**

Several studies on the last days of life with dementia show high percentages of pain in the days before death, ranging from 15% to 78%, however there are differences among studies, possibly also due to different measurement scales or methods (Hendriks et al., 2014, Hendriks et al., 2015, Klapwijk et al., 2014, Sandvik et al., 2016b). There is a high prevalence of shortness of breath in people with dementia increasing in the period to death sometimes even to 80% of people (Hendriks et al., 2015, Klapwijk et al., 2014, van der Steen, 2010). Different behaviour is seen in the days before death. People are often in bed and can be unconscious. Restless behaviour, anxiety and agitation is seen in several studies

and also delirium has been reported (Hendriks et al., 2014, Vandervoort et al., 2013, Hendriks et al., 2015, Mitchell et al., 2009).

## **8.2 Treatment options**

### *8.2.1 Non-Pharmacological treatment options (including spiritual care)*

Many of the non-pharmacological treatment options as described in section 4.2 can also be used in the last days before death. The Namaste care program, offering meaningful activities by a trained nursing assistant in nursing homes for people with advanced dementia, specifically describes the use of the program for the dying phase (Volicer and Simard, 2015).

When a person with dementia reaches the dying phase nursing staff and medical team should pay close attention to prevent: constipation, bladder retention and pressure sores. Regular mouth care should be started. People should be offered drinks and food but it should not be forced upon them. The medication should be evaluated and if oral medication can't be swallowed it should be stopped. Regular evaluation of pain, shortness of breath or discomfort is needed, observational instruments for pain or discomfort can be used in this phase, for example the Discomfort Scale-Dementia of Alzheimer Type (DS-DAT) (Hurley et al., 1992). The presence of a pacemaker or Implantable Cardioverter Defibrillator (ICD) should be checked and in case one of these is present it should be explained what to do to nursing staff and family.

It is important to highlight the needs of people are individual and some people have personal needs and may want spiritual counselling. Spiritual counselling is often overlooked, a study from a UK hospital showed that the religious beliefs of people with dementia were documented less than those without dementia (Sampson et al., 2006). Spiritual care has been associated with an improved perception of quality of care from families at the end of life (Daaleman et al., 2008), and families' satisfaction with physicians' communication shortly after admission to a nursing home (van der Steen et al., 2014a).

It is very important for the nursing staff and medical team to explain the course of symptoms and possible treatment options to the family (including presence of Cheyne stokes, rattle and time of death) and to make a clear description of medication with explanation what to give when, and also if necessary extra medication which can be given. It is vital to include families as much as possible and to ask for the wishes of the family, when the team should contact the family and who. An end-of life-care plan can help to improve communication and care in the last days of life (Detering et al., 2010).

### *8.2.2 Pharmacological treatment options*

Pain and shortness of breath are often treated with opioids, a high percentage of people use opioids on the last day before death, often requiring an increase on the last day (Hendriks et al., 2014, Klapwijk et al., 2014, Hendriks et al., 2015, Sandvik et al., 2016b). Agitation is treated with anxiolytics, but also palliative sedation may be initiated, with a Dutch study demonstrating palliative sedation was started in around 21% of cases (Hendriks et al., 2014, Hendriks et al., 2015).

Response to opioids should be closely monitored when prescribed for pain or shortness of breath to ensure effective response without excessive side effects. Special caution should be taken when prescribing for patients with renal failure as there is a risk of accumulation of renally excreted opioids.

Death rattle is sometimes treated with hyoscine (also known as scopolamine) subcutaneously however evidence is limited with a lack of consensus on the best approach (van der Maaden et al., 2015).

### Conclusion

As this chapter demonstrates, palliative care for people with dementia shows similarities to palliative care for people with other conditions such as cancer in particular with relation to symptoms. However, there are also differences which make palliative care for people with dementia unique, including; communication difficulties with the individual, recognition of dementia as a terminal illness and large elements of uncertainty in several areas including patient wishes and prognosis. Advance care planning is important for people with dementia. Person centred care should be adopted throughout the care journey, but in this chapter we have also highlighted the importance of family caregivers. Families should be involved in care decisions and processes but also we highlight their need for care themselves, as such palliative care for people with dementia is not a dyad relationship of health and care team, and the person with dementia but a triad of the person with dementia, family, and the health and care team.

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