

Advanced dementia practice model:

understanding and transforming advanced dementia and end of life care

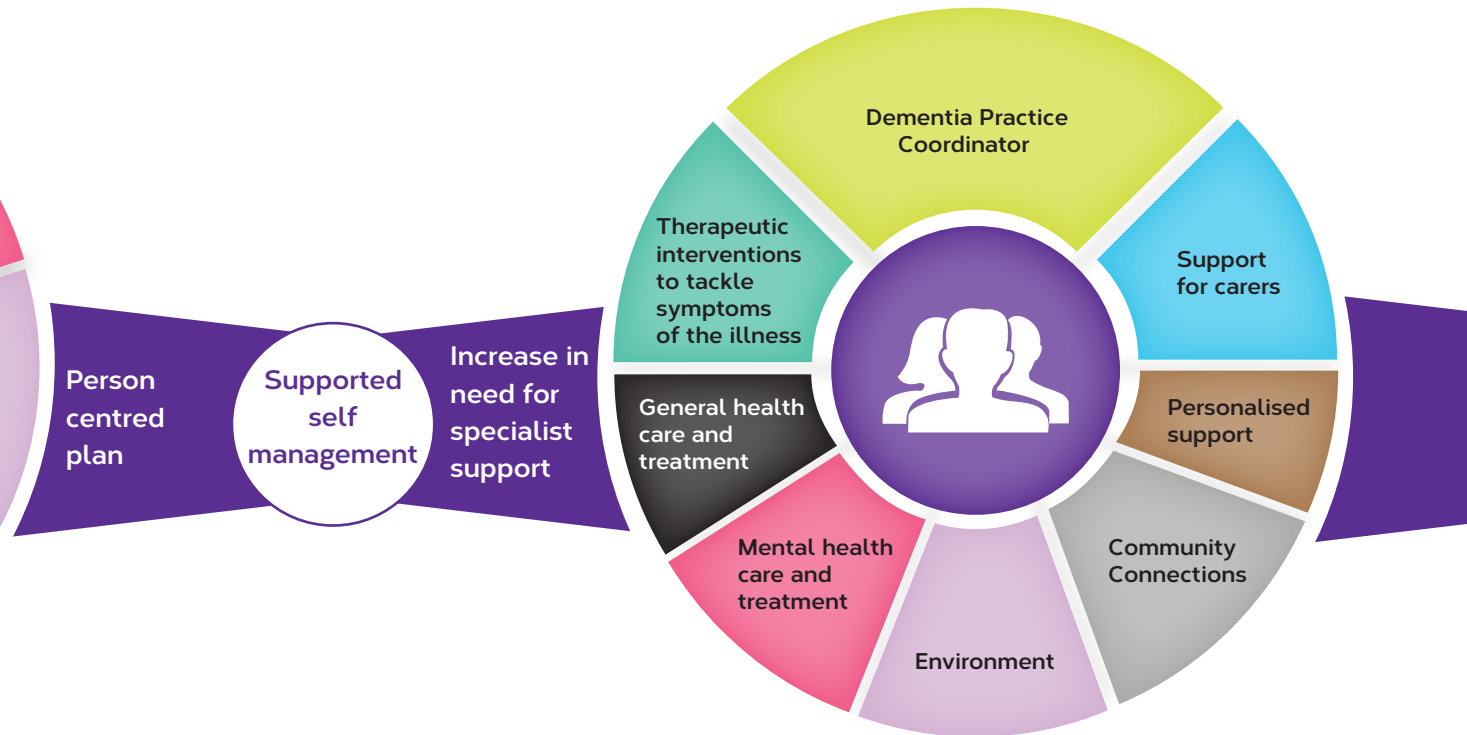


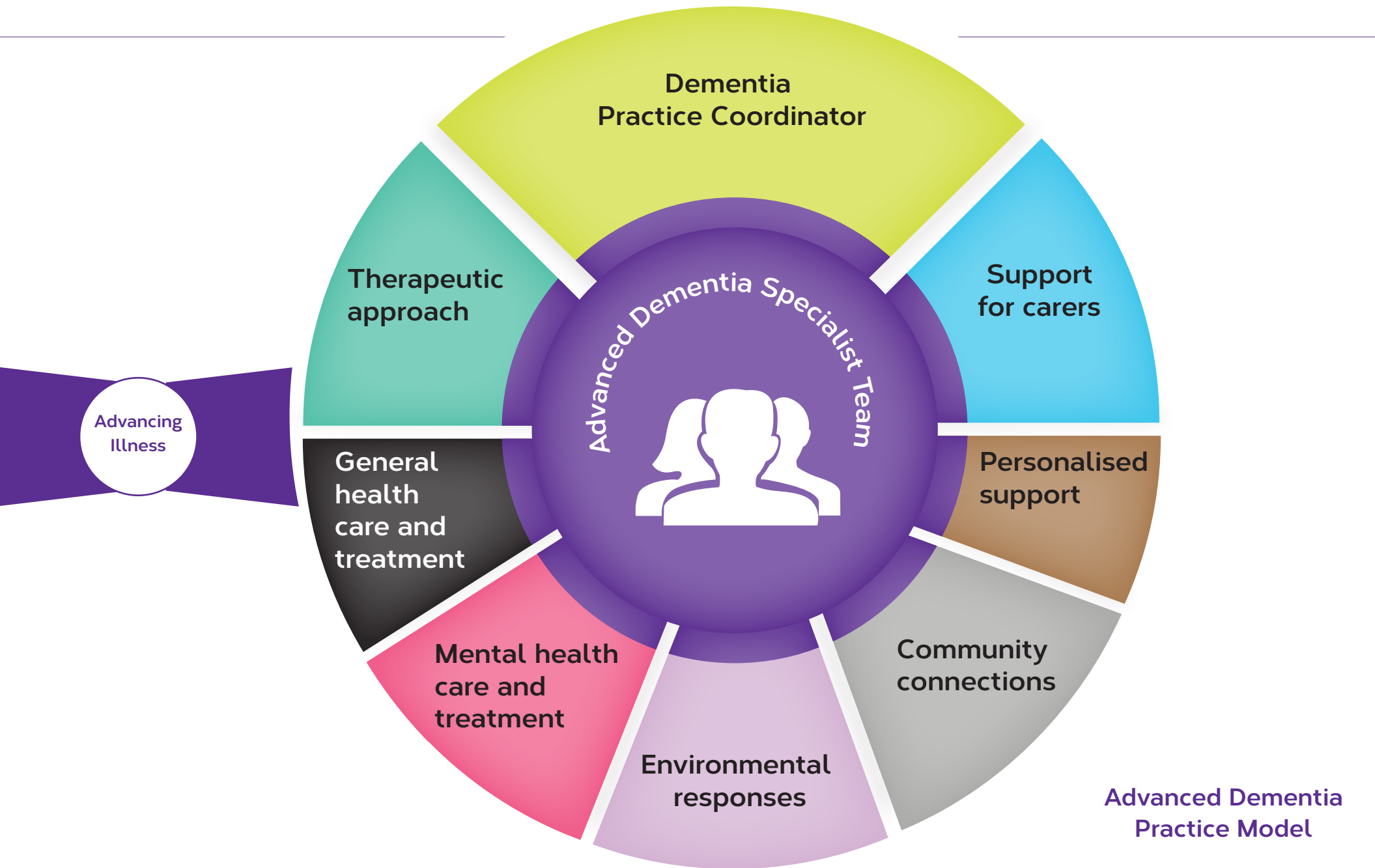


5 Pillar Model



8 Pillar Model





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Foreword

We have been working on this report for almost two years now. It has been developed through an extensive consultation and information gathering process, involving people with dementia, their family members and carers, individual professionals and partner organisations. We have researched best practice and explored in depth the available evidence of how best to understand and support people living with advanced dementia.

Despite the diverse range of stakeholders and information we have gathered, a remarkable number of common themes and clear principles have emerged. These themes include the need to understand the very physical and complex nature of the symptoms that develop in advanced dementia. The need for access to specialist support was also clearly highlighted, and crucially the need for there to be one person to support the person, their family and their carers to coordinate the complex array of care interventions that are required. A very striking core theme was how to deliver this care in such a way as to allow that person to reach the end of their life in a place of their choosing, supported by people who know them and their family well. Too many new faces, and having to move from one care setting to another, present significant challenges for people with dementia and those around them and does nothing to bring them the right care and support. We do not think it needs to be this way. We believe that the Advanced Dementia Practice Model that we propose here provides a deliverable and effective solution.

Our findings strengthen the need for the role of Dementia Practice Coordinator to be embedded in our health and social care system. This does not need a whole new workforce; it simply needs to be a clearly defined role and responsibility that a member of the health and social care team takes on for each person with dementia who requires social and health care services. We envisage that practising social workers, nurses or allied

health professionals would act as a Dementia Practice Coordinator for a small number of people as part of their overall work portfolio. We believe that this is a role requiring additional training to develop new skills and understanding in dementia practice to Enhanced level of the Promoting Excellence Framework. We hope that it will be viewed as a positive development opportunity for existing practitioners.

The Dementia Practice Coordinator is the key to unlocking the best quality of care for each person, but at the present time there is not much to unlock for those living with advanced dementia. Support for people living with advanced dementia is currently inconsistent in quality and availability. It is often based on a poor understanding of what people living with advanced dementia actually experience and need. Simply trying to pigeon-hole people at this stage of dementia into other pathways will not work. We need to define a new form of structured support that brings together expertise in dementia, palliative care, gerontology, psychiatry, psychology, nursing and the allied health professions.

We believe that this is best delivered in the form of an Advanced Dementia Specialist Team, a team that can be called upon by the Dementia Practice Coordinator when the person's needs change. This team will become a central cog in supporting the existing 8 Pillars team to continue to care for each individual wherever they might live. Providing expert support, advice and skills for the existing 8 Pillars team is vital to creating highly person-centred care plans that the Dementia Practice Coordinator will use to support the person and their carer throughout the advanced illness and at end of life, free from unnecessary stress and distress. Not only is this possible but it is necessary if we are to truly deliver the best dementia practice from the point of diagnosis to end of life.

In Scotland, we have led the way in the development of a human rights based and person centred approach to dementia practice. Our transformational approach to diagnosis, post diagnostic support, integrated care, general health care and dementia friendly communities is recognised internationally as an example of best practice. We believe that the Advanced Dementia Practice Model provides us with the next step in this transformation. It will also ensure that those individuals currently living with dementia who have not enjoyed the benefit of high quality post diagnostic support, or whose families are currently having to coordinate so many aspects of the care system on their own, will at the very least be relieved of this pressure and be provided with the highest standard of care throughout this crucially challenging and changing advanced stage of the illness.

From the point of diagnosis to the end of life every person with dementia and their family deserves nothing but the best care we have at our disposal. To truly deliver this we need to challenge our current thinking on how we care for and support people living with advanced dementia, change our current practice and transform our system. We believe that the Advanced Dementia Practice Model offers the key to delivering people with dementia and their families their right to the best possible life and the best possible end of life. We look forward to working alongside our many partners to test and refine the Model in the months ahead.



Henry Simmons

Henry Simmons,
Chief Executive,
Alzheimer Scotland

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1: Introduction

Increasing life expectancy means more of us will experience dementia and the proportion of people dying with dementia will grow. Current models of support for people with dementia do not respond to the needs created by the complex and intensive physical and psychological symptoms, and the difficult transitions in the advanced illness. This most complex phase of dementia requires a multi-disciplinary coordinated and planned approach to support those providing day-to-day care^a.

This report sets out an integrated and comprehensive, evidence-based approach to supporting people living with advanced dementia wherever they are^b. Advanced dementia presents a range of complex health issues in addition to the social and psychological impact of the illness. Whilst the distinctions between the different illnesses of dementia will diminish as a result of the progressed condition, experience of advanced illness will be influenced by a range of factors unique to each person. The Advanced Dementia Practice Model honours the human rights of those living with advanced dementia and provides a bio-psychosocial approach in responding to the individual experience.

In Scotland's National Dementia Strategies (2010, 2013) key target areas have included building resilience and support for self-management through post diagnostic support and then providing support in the community with the 8 Pillars Model. This report sets out a vision for how the care of people living in the community with advanced dementia can be similarly transformed in Scotland.

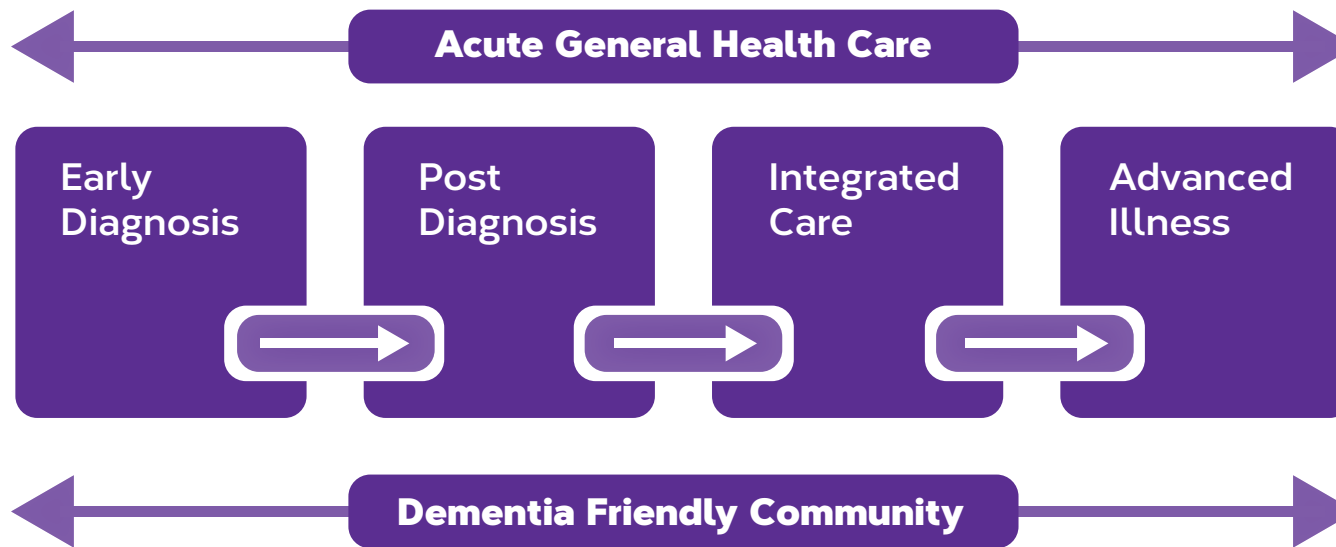
1.1 Alzheimer Scotland's vision for change

Alzheimer Scotland has a clear vision of the change required if people with dementia and their partners, families and carers are to be properly supported in Scotland and their human rights respected and upheld. Timely, skilled and coordinated support is essential throughout the illness to avoid the human, societal and financial costs of crisis driven care. Alongside that, we must continue to improve the care of people with dementia in hospital and enable our communities to become more supportive of people living with dementia.

Alzheimer Scotland is committed to developing system models to shape the highest quality of care, support and treatment for people with dementia from diagnosis to end of life. The Advanced Dementia Practice Model continues this commitment, providing a holistic approach to meeting needs at the most complex time of the illness.

^a This includes family carers, care homes, care at home service and day care.

^b Whilst the approach is focused on supporting people to remain where they wish to live, it applies to all people with advanced dementia and end of life with dementia. This includes people living in their own home, in a care home or spending time in a health care setting.



1.2 How Scotland can lead the way in dementia care

Scotland has made great strides in improving dementia care in recent times – most notably since dementia was made a priority in 2007. Alzheimer Scotland has worked alongside the Scottish Government and other key partners in developing, implementing and testing aspects of the dementia strategies. This progress has relied upon hard work and effective collaboration at every level and the contribution of both practitioners and policy-makers has been pivotal.

Improving standards of hospital care for people with dementia has been a key priority of the first and second dementia strategies. Alzheimer Scotland, in partnership with the Scottish Government, has funded Alzheimer Scotland Dementia Nurse Consultant posts to work as senior strategic leaders of change within NHS boards. Working alongside Allied Health Professional Dementia Consultants, these Nurse Consultants support more than 600 trained Dementia Champions.

The ground-breaking guarantee of a minimum of one year’s support after diagnosis for everyone diagnosed with dementia, underpinned by an NHS

HEAT^c target and Alzheimer Scotland’s Five Pillar Model of post diagnostic support, is a world first. A Link Worker provides a skilled approach to working with people and families living with dementia. They are not only helping to deliver better personal outcomes but are also contributing to reductions in expensive crisis interventions, such as unplanned hospital admissions and unnecessarily early moves to care homes.

The 8 Pillars Model of community support builds on the developments in post diagnostic support to enhance the resilience of people living with dementia during the moderate to severe illness. Central to the Model is a Dementia Practice Coordinator – a named, skilled practitioner to lead the care and treatment of the person across health and social care on an ongoing basis.

In addition to continuing to drive implementation of the commitments outlined above it is important we now focus on advanced dementia. The third dementia strategy provides the opportunity to make a commitment to people living with advanced illness and end of life with dementia.

^c Health Improvement, Efficiency, Access to Services and Treatment

1.3 Consultation on developing the Advanced Dementia Practice Model

Alzheimer Scotland conducted an open consultation from November 2014 to June 2015. The purpose of this process was to ensure that we developed a better understanding of advanced illness and built a consensus about the best approach to caring in advanced dementia and towards end of life.

The process included 1) a consultation paper on specific issues in advanced dementia and principles of approach, and 2) a summary consultation paper asking about experiences of advanced dementia and expectations for care. Over 50 responses were received to the consultation papers. The respondents were mostly individual or groups of practitioners with some responses from those caring for a family member with dementia.

The consultation process also involved a series of discussion groups and individual meetings with key informants. The discussion groups were conducted by Alzheimer Scotland staff members throughout Scotland. Over 30 group sessions were carried out involving a large number of people living with dementia and practitioners.

The contribution from practitioners provided their understanding of advanced dementia and guidance on specific subject matters. The participation from people living with dementia included aspirations for their future care and experience of living through advanced illness and end of life.

The consultation phase provided specialist expertise on key issues. The themes that emerged were:

- Theme 1 Advance planning and advocacy
- Theme 2 Personalised approach
- Theme 3 Support for carers
- Theme 4 Care services
- Theme 5 End of life

- Theme 6 Issues with current approaches
- Theme 7 Changes required
- Theme 8 8 Pillars Model

Theme 1: Advance planning and advocacy

It was felt that advance planning should happen early to allow the person to express their wishes and for these to be recorded. It was considered important to acknowledge that it is a dynamic process which should continue to be reviewed and updated, as what people want will change over time with experience and circumstances.

Respondents felt that anticipatory decision making required more open and honest conversations about the reality and what may happen. At the same time it requires understanding that this is a sensitive subject and should be appropriately timed.

It was considered important that all practitioners involved should understand the value of advance planning and have access to plans for those they are working with. Advance planning was highlighted as providing an opportunity for skilled practitioners to have meaningful conversations with families and build collaborative working.

Respondents felt that advance planning is currently not happening effectively. It was thought difficult to do with people who have multiple co-morbidities and often does not cover aspects of end of life scenarios.

There was considered to be a need for advocacy for people with dementia. Some people have little or no contact with family or there may be conflict. When the person is living in a care home they may have lost community connections and links to outside agencies.

Theme 2: Personalised approach

Knowing the person was considered to be essential, as well as understanding their individual cultural, spiritual and religious beliefs. Respondents highlighted the importance of providing additional time so that a person-centred care approach could be adopted.

There was concern that choice would not be offered and care and support would be shaped by available resources. There were anxieties that the person would not be treated as an individual, with activities imposed that are not relevant to them.

Respondents highlighted a need for broader approaches to communication such as music therapy, reminiscence and sensory touch.

Theme 3: Support for carers

It was felt those providing care required support and education ahead of advanced illness to understand what may happen. There was considered to be a need for a wide range of practical and emotional support in advanced dementia. More support is also required if the person is to remain at home, such as palliative care input and respite.

It was noted that people will have been caring for a long time at this stage and dealing with a wide range of complex issues. They may be at the point of exhaustion and likely to have become more isolated from family and social connections.

Changes were highlighted as often being incremental, so people may feel they are still coping. Assistance may be required in recognising that there is a need for support, that accepting help is not a sign of defeat, and that it is not the family member's responsibility alone to provide care.

It was considered important that those providing care should be recognised for their expertise in understanding the needs of the person. They should

be enabled to continue to be involved in care as much as possible when the person is no longer at home, as they will pick up changes and recognise the expression of distress.

Those providing care require support to understand and accept when the person is approaching end of life. The importance of bereavement support was also highlighted.

Theme 4: Care services

Care services can find it difficult to support people as their needs progress towards advanced dementia. This includes care homes, home care and day care.

Access to specialist knowledge and expertise was seen as crucial. There were good examples of this happening within care homes, enabling the person to remain in the home and avoid a move to hospital. However, this was highlighted as being piecemeal and reliant on local relationships.

Theme 5: End of life

It was thought to be important to know in advance what is important to the person. Ensuring the person's physical needs are attended to and responding to emotional, psychological and spiritual aspects were considered essential. It is important to recognise when the person is nearing end of life. It is also important to ensure those closest to the person know in advance what to expect and what may occur.

A range of issues were highlighted in relation to where the person should die. The person should die in their present location where possible and appropriate. The choice of where to die is not a reality for most. The appropriate place to die is dependent on the individual case – dying at home may be what a person wants, but may not be appropriate for those closest to them.

Theme 6: Issues with current approaches

Levels of support were highlighted as being inadequate and this was felt to relate to how we value older people in society.

Support was highlighted as happening at crisis points. Transitions for the person with dementia and carer were seen as key points and would create barriers if they were not responded to appropriately.

Care was considered not well coordinated and care at home not well joined up at the time of advanced dementia. Respondents highlighted a lack of consistency in how care is given and support offered.

There is also a lack of a pathway to, and availability of, palliative care for people living with dementia.

Theme 7: Changes required

As dementia progresses, time to care was highlighted as becoming key in delivering person-centred care and a focus on individual, as opposed to group, needs. It is also important to provide appropriate care where people are to prevent inappropriate admission to hospital.

There is a need for coordinated services with access to the range of skills and knowledge required in advanced dementia.

Theme 8: 8 Pillars Model

There was support from the consultation responses for basing the model of care for advanced dementia on the 8 Pillars Model. A number of issues were highlighted in relation to the development of this model for advanced illness and end of life:

- How all needs can be integrated and who can fulfil the Dementia Practice Coordinator role – needs are wide ranging and complex with the largest proportion of people in a care home.
- A requirement for more emphasis on physical health including co-morbidities which may be the primary driver of needs.
- Access to specialist input and knowledge e.g. responding to nutrition and hydration in advanced illness.
- Importance of a wide range of creative approaches to all forms of communication and a broader range of therapeutic interventions and non-verbal approaches.
- Recognition of the need for an increased focus on providing support to those close to the person who are providing care.
- The spiritual, emotional, grief and bereavement aspects of advanced illness and end of life should be included.

The consultation responses, together with the findings from the literature review, were taken forward to formulate a model of care for people living with advanced illness and end of life with dementia.

1.4 Outline of the report

Section 2: The nature and experience of advanced dementia

This section provides an understanding of advanced dementia and the complexity of needs at this time. It demonstrates why living with advanced dementia is a unique experience requiring a bio-psychosocial approach in responding to the individual circumstances.

It also highlights the support needs of those providing day-to-day care and why caring in advanced dementia requires a multi-disciplinary planned and coordinated approach.

Section 3: Advanced Dementia Practice Model

This section outlines the Advanced Dementia Practice Model following a bio-psychosocial understanding of the illness and focusing on:

- Advanced Dementia Specialist Team
- Pillar: Dementia Practice Coordinator
- Pillar: General health care and treatment
- Pillar: Mental health care and treatment
- Pillar: Personalised support
- Pillar: Therapeutic approach
- Pillar: Support for carers
- Pillar: Environmental responses
- Pillar: Community connections

Section 4: Conclusion and recommendations

The Advanced Dementia Practice Model provides an integrated and comprehensive approach to responding to the most complex phase of the illness. It honours the human rights and personhood of the person with dementia and also recognises the needs of carers.

Recommendations:

The Scottish Government accept and recognise that, on the basis of this report, there is clear evidence that once a person has reached the advanced stage of dementia, all their needs are health care needs.

Each Health and Social Care Partnership in Scotland provides a Dementia Practice Coordinator for every person with dementia as they progress to the point of requiring community and health care services.

The Dementia Practice Coordinator is confirmed as an additional Enhanced role delivered within the existing and established professional groups such as social workers, nurses and allied health professionals, with the appropriate authority to commission and coordinate the required level of care and support.

The Promoting Excellence Framework is used to ensure the Dementia Practice Coordinator meets the Enhanced practice level and that all staff within the 8 Pillars Team are operating at a minimum of Skilled level.

The Advanced Dementia Practice Model is tested as part of the objectives of the National Dementia Strategy 2016 and if successful, an Advanced Dementia Specialist Team is established in each Health and Social Care Partnership in Scotland by 2020.

2: The nature and experience of advanced dementia

Summary

The range of physical, psychological and social issues in advanced dementia requires a bio-psychosocial approach in understanding and responding to individual experience.

Health care practitioners have a key role in responding to the increasing physical nature of advanced dementia and the influence of co-morbid conditions.

Issues relating to nutrition and hydration are highly prevalent in advanced dementia and at end of life.

Psychological symptoms are common during the advanced illness and at end of life – increasing cognitive decline makes it more difficult to respond to these symptoms.

Communication changes in advanced dementia make the responses of others of key importance in ensuring the person remains socially connected.

Not everyone with advanced dementia will be in older age groups – in addition to early onset dementia, people with learning disabilities may develop dementia at a younger age.

It is important to recognise the particular needs of lesbian, gay, bisexual and transgender people and those from black and minority ethnic communities.

Evidence points to the highest proportion of people with advanced dementia living in a care home, with a smaller number continuing to live at home. It also shows that hospitals are an important context for end of life care in dementia.

The demands of caring for a person with advanced dementia and at end of life means those closest to the person require an increasing amount of both practical and emotional support.

Health and social care support for paid carers is of key importance in the quality of care they are enabled to provide.

There is an issue of applicability and availability of current models of palliative care for people with dementia.

There is a need to bring together the expertise of dementia care practitioners and palliative care specialists in responding to advanced dementia.

2.1 Introduction

This section looks at the experience of advanced dementia. It outlines the issues that need to be addressed in responding to the most complex phase of the illness.

Dementia may have been experienced in a largely social way during the earlier stages, whereas in advanced illness the physical symptoms will also be to the fore. The distinctions between the different illnesses of dementia will also diminish as a result of the progressed condition.

The influence of social and psychological aspects will continue to be prominent. The experience will be unique to each individual and influenced by physical health, psychological responses, environment and social factors.

A bio-psychosocial approach is essential in responding to the needs of people living with advanced dementia and those approaching end of life.

2.2 Advancing dementia

The progression of dementia is often separated into mild, moderate and severe (corresponding to early, mid and late stage). A European collaborative review of the literature found that the evidence base was inclined to merge together advanced dementia and the end of life phase (Sandvide et al 2015). This fails to reflect the uniqueness of the individual experience and the fluctuations that may occur. It also does not recognise the potential for interventions that may enhance quality of life in advanced dementia.

Whilst there is no typical set of symptoms experienced and it is not inevitable people will experience certain symptoms, there is a pattern of physical decline with the loss of communication skills in many people. Some people can experience severe cognitive impairment ahead of physical decline. The picture in older people with dementia is increasingly likely to be complicated by the existence of other conditions commonly associated with ageing. In addition to this, not everyone with advanced dementia will be older and the particular needs of people with early onset dementia and learning disabilities must also be considered.

Kitwood (1990)^d provided a model to outline the factors that will influence the lived experience. This highlights how people will react differently to the symptoms of dementia according to their personal approach and social circumstances. An individual's personality, life experience, physical and psychological health and social context will have an influence on how they respond to the symptoms of dementia and in turn the approach to support required.

People can be supported to manage the symptoms and practicalities of their lives following a diagnosis of dementia. As the illness progresses, a coordinated approach to support can promote independence, citizenship and the ability to participate as fully as possible in society.

^d Social psychology + neurological impairment + physical health + biography + personality = the lived experience of dementia

2.2.1 Defining advanced dementia

The World Health Organization (2012) and Reisberg et al (1982) provide similar outlines of advanced dementia in Table 2.1.

Whilst these descriptions are helpful in providing a guide to the possible nature and intensity of symptoms, they do not convey the wide range of factors that can influence experience and determine when a person has reached advanced illness.

Advanced dementia will be unique to each individual and dependent on factors relating to underlying health, personality, biography and social context. Diagram 2.1 (page 24) outlines the frequently occurring symptoms and contributory factors in advanced dementia.

Defining the point at which a person can be said to have reached advanced dementia is complex. There is no particular set of symptoms that signify this and the pattern of declining cognitive and physical function is neither fixed nor predictable.

Given the unique nature of the individual experience and the influence of a wide range of factors it is more appropriate to consider the level and complexity of care needs in understanding when advanced illness is being experienced.

The point of advanced illness will be determined by the interplay of some combination of the factors outlined in Diagram 2.1 requiring substantial health care input in response to the physical and psychological symptoms of advanced dementia. Whilst the specific issues for each person will vary, there will be a point at which the person will experience complex needs resulting from the progressed medical disorder.

World Health Organization (2012)	Global Deterioration Rating Scale (1982)
<p>The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious:</p> <p>Usually unaware of time and place</p> <p>Have difficulty understanding what is happening around them</p> <p>Unable to recognize relatives, friends and familiar objects</p> <p>Unable to eat without assistance, may have difficulty in swallowing</p> <p>Increasing need for assisted self-care (bathing and toileting)</p> <p>May have bladder and bowel incontinence</p> <p>Change in mobility, may be unable to walk or be confined to a wheelchair or bed</p> <p>Behaviour changes, may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning)</p> <p>Unable to find his or her way around in the home</p>	<p>Severe cognitive decline (stage 6: moderately severe dementia):</p> <p>Awareness of people and surroundings will be diminished.</p> <p>More assistance will be required with activities of daily living such as bathing, eating and toileting.</p> <p>The person may begin to show increased anxiety and possibly develop delusions, hallucinations or obsessions.</p> <p>Daily rhythm is frequently disturbed, with sleep during the day and awake at night.</p> <p>Severe dementia (stage 7: severe dementia):</p> <p>The ability to speak will be very limited and may be lost completely.</p> <p>The person will require assistance to walk and to sit up.</p> <p>There will be loss of urinary and bowel control.</p>

Table 2.1

2.3 End of life with dementia

Age at the onset of dementia is the main predictor for life expectancy. Average life expectancy has been shown to be 4.5 years — this ranges from 10.7 years for those aged 65 to 69 years at onset of illness to 3.8 years for those aged 90 older (Xie et al 2008). Other factors contributing to life expectancy include level of disability, gender and the presence of psychotic symptoms (Russ et al 2012a, Xie et al 2008). Life expectancy for a person with Down’s syndrome remains significantly lower than the general population (Wilkinson & Watchman 2010).

Just as the lived experience of dementia varies considerably between individuals, so does the experience of dying with dementia. As many as one in three people over the age of 65 years may die with dementia (Brayne et al 2006). Not everyone reaching the end of life with dementia will be at an advanced phase of the illness. People can become terminally ill at any time during the course of dementia as a result of the presence of other illnesses.

People reaching advanced dementia become less able to cope with infections and other physical problems as a result of the progressed illness. People with dementia can be described as dying of (Cox & Cook 2002):“(1) some other identifiable condition at some point in the pathway through dementia (2) a complex mix of mental and physical problems but where the effect on the brain functioning is not as advanced and (3) the complications of dementia such as end stage dementia”.

There is a great deal of uncertainty in understanding when a person with dementia is actively dying (Murray et al 2005). A systematic review of assessment tools to predict six month life expectancy in people with advanced dementia found the presence of nutritional issues to be the most common indicator, followed by increased severity of dementia and the presence of co-morbidities (Brown et al 2012). This review demonstrated the need for more sensitive, reliable and specific indicators in order to more accurately predict life expectancy.

The complications that occur in advanced dementia are often considered to be the main cause of death, with dementia the underlying cause (Rexach 2012). Pneumonia causes significantly more deaths in people with dementia compared to the general population and is a frequently occurring condition in advanced dementia (Todd 2013). A study tracking the clinical course of care home residents with advanced dementia found the six month life expectancy rate for residents who had pneumonia was 47% — it was 53% for those with a fever episode and 39% for those with eating problems (Mitchell et al 2009).

A study of cause of death in care home residents with advanced dementia found the three most commonly reported immediate causes of death were cachexia^e /dehydration (35%), cardio-vascular disorders (20%) and acute pulmonary disease^f (20%) (Koopmans et al 2007). Cachexia/dehydration was a particularly common cause of death in those who had survived to end stage dementia (53%). Pneumonia occurs with greater frequency in Alzheimer’s disease, with heart failure and stroke more common in people with vascular dementia (Rexach 2012). Cancer is less likely to be an underlying cause of death in dementia (Todd 2013).

e Weakness and wasting of body due to chronic illness

f Mostly pneumonia

2.4 Numbers and location

It is difficult to estimate the number of people living with advanced illness and those approaching end of life with dementia. Prevalence rates provide estimated total numbers of people with dementia, but deterioration and life expectancy is highly variable, making it problematic to apply general assumptions to this overall number.

It is estimated that around two thirds of people with dementia live in private households and one third live in care homes. The proportion of people in care homes increases with age due to the severity of dementia and the decreasing likelihood of a family carer for people in the oldest age groups (Knapp et al 2007).

Official statistics show the proportion of residents with dementia in care homes for older people is 61%^g (53% medical diagnosis, 8% identified as having dementia with no formal diagnosis). The number of people with dementia within care homes has increased by 38%^h since 2005 according to official statistics (ISD 2014a). Dementia remains an underdiagnosed condition and these statistics may therefore be an under-representation. A study of nursing home residents found as many as 90% may have dementia (Lithgow et al 2012).

An estimated six per cent of people with dementia are inpatients in general hospital at any given point in timeⁱ (Russ et al 2012b). There are 1,886

NHS Old Age Psychiatry specialist care inpatient beds for people with dementia in Scotland^j. This number includes assessment beds and long stay beds. There are 4,713 Geriatric Medicine beds^k (ISD 2014b). It is likely a significant proportion of the patients in these beds have dementia along with a co-morbid condition that may have been the primary reason for admission.

A follow-up study of hospital patients found one in three had died a year later. This increased to one in two for the oldest age groups (Clark et al 2014). McCarthy et al (1997) found 67% of people with dementia had been in hospital during the last year of their life, with 26% staying for a period in excess of three months. Sleeman et al (2014) investigated the trend in hospital deaths for people with dementia in England and found two in every five people with dementia die in hospital. A trend towards increasing hospital deaths had reversed with a growth in care homes deaths — home and hospice deaths were rare (Sleeman et al 2014).

The evidence outlined above points to the highest proportion of people with advanced dementia living in a care home with a smaller number continuing to live at home. It also shows that hospitals are an important context for end of life care in dementia.

g Total of 19,376 people with 16,955 with a medical diagnosis and 2,421 with no formal diagnosis
h Adding together diagnosed and no formal diagnosis
i This compares with 0.6% of people aged over 65 without dementia

j Scottish Government audit of NHS Boards for National Dementia Strategy Commitment 11 Working Group (June 2014)
k 1,405 long stay beds and 3,308 in units other than long stay

2.5 Advanced dementia and equality

Whilst age is the greatest risk factor for dementia, not everyone with advanced illness will be in the older age groups. There are an estimated 3,200 people with dementia in Scotland under the age of 65. People with learning disabilities are also at increased risk of developing dementia at a younger age. The needs of LGBT¹ people and BME^m communities are also an important consideration in responding to advanced dementia.

2.5.1 Early onset dementia

Early onset dementia is a rare condition. Whilst the symptoms of dementia may be similar regardless of age, younger people will have different needs. People with early onset dementia are by definition at a different point in their life. They will be of working age when they show symptoms of dementia and may have a partner who continues to work and have dependent children. Younger people will typically be more physically fit and active than the older population.

Receiving an accurate diagnosis may have taken a long time and may have happened later in the illness. There can be a lack of specialist services and support for younger people. This will be a particular issue in advanced illness with a need for appropriate care responses for the younger age group.

2.5.2 Learning disabilities

Along with an increase in life expectancy for people with a learning disability, there will be an increase in those who develop dementia. Adults with Down's syndrome are at particular risk and are likely to be affected at a younger age. Dementia may progress more quickly towards the advanced stage among people with Down's syndromeⁿ. The illness may be beyond the early phase at the point of diagnosis — this makes it difficult to talk about the implications of dementia with the individual who has a learning disability (Watchman & Tuffrey-Wijne 2015).

¹ Lesbian, gay, bisexual and transgender
^m Black and minority ethnic

ⁿ This is complicated by difficulty in diagnosis and a lack of consistently applied diagnostic tools, with typical measures of assessment usually not suited to someone who has reduced capacity or cognitive impairment prior to suspicion of dementia (Strydom et al., 2007)

Wherever people live^o, increased support will be needed to accommodate changing physical, social and environmental needs on a 24 hour basis (McCallion et al 2010). Not everyone will be known to services at the point of diagnosis. However, learning disability services are more likely to have had contact pre-diagnosis and are best placed to coordinate ongoing care (Watchman 2014).

There will be a need for increased development of specialist training alongside the upskilling of staff in learning disability, palliative care and dementia services (Watchman 2014). Health and social care staff and families of people with a learning disability do not generally receive specific education that takes into account similarities and differences of living with advanced dementia among this population, or the potential for co-existing health issues such as epilepsy or gastrointestinal disorders in people with Down's Syndrome (British Psychological Society 2015). Similarly, dementia practitioners and palliative care professionals are often not familiar with the specific needs of people with a learning disability.

2.5.3 LGBT people

Lesbian, gay and bisexual people are estimated to represent five to seven per cent of the population, with the transgender population small but facing particular acute issues (Greenwood 2015). Older LGBT people experienced restricted legal and civil rights within their lifetime and may fear prejudice from the people around them, including professionals (LGBT Health & Wellbeing 2014a). There may be a reluctance to engage with services, concern about being treated with dignity, and apprehension about being open about sexuality or gender transition. People who do access services may hide their identity to protect themselves from discrimination (LGBT Health & Wellbeing 2014a).

Dementia can present a range of particular issues for LGBT people. The person may be taken back to a time before they felt able to be open

^o Whether this is alone, with friends, a partner, with family or with the support of a social care provider

2.6 Advance planning and decision making

and when laws and attitudes were very different. They may forget they had been open about their sexual identity or the loss of inhibition may make the person more open than previously. A transgender person may forget they have transitioned (Greenwood 2015). Life-story work may present particular challenges for a transgender person and they may feel uncomfortable with younger images of themselves before their transition (LGBT Health & Wellbeing 2014b). Personal care may be particularly concerning if their body gives away their transgender status.

LGBT people may be detached from their family of origin and have created their own non-traditional families and forms of support (LGBT Health & Wellbeing 2014a). However, these support networks are likely to be made up of people of a similar age and LGBT people are more likely to live alone, be single as they age and not have children (Greenwood 2015).

2.5.4 BME communities

Around four per cent of the population identify themselves as from BME communities with people predominately located within the largest four cities (Scottish Government 2014a). People from BME communities are less likely to present to services or do so at a later stage of dementia (Mukadam N et al 2011).

A systematic review of pathways to care in dementia found significant barriers for minority ethnic groups (Mukadam N et al 2011). These included beliefs about dementia and it not being seen as an illness, caring being seen as a personal or family responsibility and feelings of shame and stigma in relation to dementia.

The particular needs of each BME group will differ and appropriate responses require particular consideration. English is likely to be a second language for many and may be lost as a result of advancing dementia.

2.6.1 Advance plans

Advance care planning provides an opportunity to make decisions based on an individual's values and preferences throughout the course of the illness and at the end of life. The principle is to act in an anticipatory way to prepare for future care and to enable the recorded wishes of the person with dementia to be known when they no longer have the ability to communicate these.

Conversations at a time when the person with dementia can assign Power of Attorney can be beneficial for future care to ensure those they entrust are in a position to be formally consulted by practitioners and make decisions.

Advance care planning also involves those closest to the person in discussing what is important and taking forward these wishes. The interests of the person with dementia can be seen as including the interests of those who are closest to them (Nuffield Council on Bioethics 2009). In this respect the person's family and social structure can be seen as an important context for understanding their wishes.

In order to be effective to inform future decision making an advance plan needs to have flexibility to cover as many eventualities as possible and provide guidance on what will be required for different care settings and in different scenarios. The advance plan should then become the starting point for continued engagement of the person as the condition progresses. It is important to empower those closest to the person to make decisions with education and support. The approach taken should then be supported decision making^p — with the person's present wishes, or former wishes where this is not possible, helping to guide decisions.

Anticipatory care planning is a sensitive issue that requires a considered approach. There is likely to be a period of adjustment following on from diagnosis before the person and those closest to them are able to respond

^p In contrast to "substitute" decision making

to the new circumstances (Bury 1982). However, some people may remain unwilling to contemplate the disease progression.

Health practitioners and other professionals working with the family have a role in encouraging a dialogue that allows hopes and concerns to be discussed (Trelaor & Crugel 2010). This can help to work through fears, clarify roles and dispel misconceptions and it also offers the potential to decrease futile or burdensome interventions (Hughes et al 2007).

The consultation process for the Advanced Dementia Practice Model highlighted a number of issues with the difficulties of creating an advanced plan. This included the emotional difficulty of contemplating the future for the person and the practical aspects of who takes responsibility for ensuring the opportunity is provided.

2.6.2 Decision making

In advanced dementia decision making is continuous and can be seen to be centred on quality of life, the benefit of a particular course of action (or inaction) and the impact on life expectancy. Decision making should be based on the individual and specific circumstances – this includes the severity of dementia, the presence of co-morbid conditions, nutritional status and the person’s response to an infection (Hughes et al 2007).

The General Medical Council (2010) highlight that the decisions to withdraw or not start treatment when there is potential to prolong life are the most challenging at end of life. The evidence of benefit and burden are not always clear – “overall benefit” is the ascribed approach to ethical decision making taking account of the full range of individual circumstances^q and consulting with those closest to the person.

Whilst legal frameworks set out the guiding principles for decision making, they need to be interpreted and cannot provide precise answers to particular questions. Nuffield (2009) provides a framework to guide ethical decision making outlined in Table 2.2 below.

Component 1:	Case based approach with three stages 1) identify relevant facts 2) interpret and apply appropriate ethical values to those facts and 3) compare with other similar situations to find ethically similar relevant similarities or differences.
Component 2:	Belief that dementia arises as a result of brain disorder and is harmful to the individual.
Component 3:	Belief that good quality of life can be achieved throughout the illness with appropriate care and support.
Component 4:	Importance of promoting the interest of the person with dementia and those who care for them.
Component 5:	Requirement to act with solidarity, recognising citizenship of the person with dementia and our mutual interdependence and responsibility.
Component 6:	Recognise personhood, identity and value of the person with dementia.
	Source: Nuffield Council on Bioethics (2009)

Table 2.2

^q “An assessment of appropriateness of treatment and care options that encompasses not only the potential clinical benefits, burdens and risks of those options, but also non-clinical factors such as the patient’s personal circumstances, wishes, beliefs and values” (General Medical Council 2010).

2.7 Physical nature of advanced dementia

One of the key impacts as dementia progresses is the increasingly physical nature of the experience. A person may no longer be able to walk unassisted and may even require help to make small movements when sitting or lying down^r. Advanced dementia also means the frequency and severity of ill health is likely to intensify. Whilst the initial symptoms of each of the diseases of dementia differ, the advanced phase of all illnesses presents similar problems and characteristics (Rabins & Black 2010, Rexach 2012).

Advanced dementia presents a range of potential symptoms that impact on mobility, bodily function, resilience and physical wellbeing^s. Many of the manifestations of advanced illness can be seen as resulting from a complex interplay of the increasing cognitive impairment and diminishing physical robustness. For example, skin integrity is compromised as a result of poor diet and lack of mobility (Hughes et al 2007).

In addition to this, older people are more likely to have sensory impairments such as reduction or loss of hearing and sight. Combined with dementia, these factors can result in a profound sense of disorientation and isolation.

2.7.1 Prevalence of symptoms and level of disability

A retrospective study found the most commonly reported symptoms in dementia in the final year of life were mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%) (McCarthy et al 1997). Mitchell et al (2009) tracked the clinical course of care home residents with advanced dementia – they found shortness of breath (46%), eating problems (86%), pain (40%), fever (53%) and pneumonia (47%) to be the most frequently occurring symptoms. The Lloyd-Williams (1996) case note audit of people who died with end-stage dementia found pain and shortness of breath (dyspnoea) had presented in most people.

A study of the trajectories of disability in the last year of life found that only advanced dementia followed a predictable pattern of disability^t – 70% of those with advanced dementia had severe disability (Gill et al 2010). A similar pattern was found in a study of the functional decline between different causes of death – frailty associated with advanced dementia was most likely to result in dependence in relation to activities of daily living and greater disability in the final year and months of life (Lunney et al 2003).

The impact of different (often co-morbid) diseases has been disentangled in a number of studies to show the independent contribution of each to disability. They demonstrate that among older people, cognitive impairment and dementia make the largest contribution to the need for care, much more than other types of impairment and chronic disease (Prince et al 2013).

r This will not be the case for all people with advanced dementia - some people will still be mobile and may continually walk about.

s See Diagram – 2.1

t Sudden death had a pattern of no disability

2.7.2 Inter-current and co-morbid health conditions

Inter-current infections^u are frequent in advanced dementia as a result of such factors as the person being unable to report symptoms, reduced immune response and swallowing difficulties (Hughes et al 2007).

Pneumonia is a common inter-current infection in advanced dementia.

In addition to the biological risk factors that influence progression, such as cardiovascular disease, older people are more likely to have co-morbid health conditions. The presence of additional chronic illness will combine with dementia in a complex way to shape the lived experience.

2.7.3 Delirium

Delirium is an acute condition resulting from a medical illness that has a profound impact on brain function. Dementia is the greatest underlying risk factor for delirium and, as dementia progresses, the risk of delirium increases (Vasilevskis et al 2012). Whilst the presence of delirium will be frightening and disorienting for the person and distressing for those providing care, it will also exacerbate the symptoms of dementia and present dangers such as the increased risk of falls. This can be a life threatening condition that can result in medical emergency and there is risk of it being overlooked in people with dementia.

2.7.4 Pain

Age is the highest risk factor for both dementia and pain. The presence of pain has been shown to be high in advanced dementia and increasing as death approaches (Lloyd-Williams 1996, McCarthy et al 1997, Mitchell et al 2009, van der Steen 2010). Evaluating the precise prevalence of pain is challenging because of the difficulties with communication and assessment (Hughes et al 2007). A review of pain in dementia considered there to be a high risk of under-treatment of pain and a need for even greater attention to proactive assessment in the presence of cognitive impairment (Scherder et al 2009).

What is revealed through behaviour and how this deviates from what is typical for the person provides important indications of the presence of pain and distress. People with advanced dementia can work around communication problems with the collaboration of others so their needs can be better understood. This relies upon the ability of those caring for the person to recognise and interpret the signs of distress such as facial expressions, movements, behaviours and vocalisations (Social Care Institute for Excellence 2015).

^u A disease that intervenes during the course of another disease and can alter the course of the underlying disease (dementia)

2.8 Nutrition and hydration

Issues relating to nutrition and hydration are of key importance in advanced dementia and at the end of life. Increasing cognitive and physical impairment can result in functional eating difficulties. Psychological factors such as depression and anxiety can influence the relationship with food, causing loss of appetite and withdrawal. Physical factors such as oral pain and constipation can present as a reluctance to eat and drink. Environmental factors such as lack of privacy, noise or unpleasant odours can also reduce appetite.

There are also a number of conditions caused by the symptoms of dementia such as difficulty swallowing (dysphagia), the loss of ability to coordinate tasks (dyspraxia) and the aspiration of food that may lead to pneumonia.

During advanced dementia, nutrition can be about maximising food intake and in turn maintaining nutritional status for a period of time. It may then be more appropriate to consider eating as a way of providing comfort and pleasure as the person nears end of life.

The wide range of potential factors outlined above calls for thorough assessment, specialist input and individualised responses in supporting those providing day-to-day care. It is also important that those closest to the person are supported in understanding issues relating to nutrition and hydration during advanced illness and at end of life.

2.8.1 Oral health

Maintaining the oral health^v of a person with advanced dementia is of key importance to their overall health and wellbeing. Poor oral health impacts on nutrition and hydration, quality of life and communication.

A person with advanced dementia will be reliant on others to perform their oral health care. Problems with oral health may be expressed by stressed and distressed behaviour. In addition to other potentially dangerous consequences, poor oral health is a risk factor for pneumonia and respiratory tract infections.

2.8.2 Artificial nutrition and hydration

There are two methods of artificial feeding: (1) food and fluids through a nasogastric tube^w and (2) a percutaneous endoscopic gastrostomy^x (PEG). Decisions to use these approaches are emotive and present ethically complex considerations. There is no evidence to support the increased survival, benefit to nutritional status or the alleviation of pressure ulcers in the use of artificial feeding in advanced dementia (Sampson et al 2009, Working Party Report 2010). There is also no evidence of the impact on quality of life and the insertion of a feeding tube carries a higher risk of mortality in advanced dementia (Sampson et al 2009, Working Party Report 2010).

Recommendations on artificial hydration and nutrition stop short at recommending a blanket ban^y, but present hand feeding as the preferred option, and state that gastrostomy should not be offered in advanced dementia (Working Party 2010). Hughes (2006) provides a similar conclusion in considering the ethical issues of artificial feeding, suggesting small amounts of appropriately prepared food should be continued for as long as possible with the understanding this may hasten death by causing aspiration (ethical commentary in Summersall & Wight 2006).

v This includes all areas of the mouth such as teeth and gums, soft tissue of the mouth and throat and tongue

w A tube that passes through the nose into the stomach

x Inserted into the stomach through an incision in the abdominal wall

y Expert group lead by Royal College of Physicians and British Society of Gastroenterology (Working Party 2010)

2.9 Psychological issues

2.8.3 End of life nutrition and hydration

Decisions on when to withdraw nutrition and hydration when a person is nearing end of life are complex^z. A person can continue to live for 60 days without feeding – whereas its withdrawal can result in nutritional problems such as pressure ulcers and prolonged discomfort (Rexach 2012). However, foregoing nutrition and hydration near death may provide greater comfort for the person and stop some physical problems associated with its continued intake, with thirst and dry mouth alleviated through good nursing care (Slomka 2003). The maintenance of comfort nearing end of life can be seen as dependent on ensuring that, if fluid and nutrition are withdrawn, it is at the appropriate time (Regnard & Huntley 2006).

Psychological issues continue to be prevalent during advanced dementia (Kverno et al 2008). Distress also occurs frequently towards the end of life and responding to it in ways that provide comfort to the person can be seen as a key purpose of caring at this time (Treloar & Crugel 2010). However, the diminishing cognitive function and the complexity of communication create difficulty in assessing the cause of psychological symptoms (Robinson et al 2005).

2.9.1 The expression of stress and distress

The expression of psychological distress was traditionally thought of as relating to the symptoms of dementia. Responses were based on a medical model resulting in the use of medication for different behaviours (British Psychological Society 2013). The bio-psychosocial nature of behaviour is now better understood, with appropriate approaches based on a holistic understanding of the person (Stokes 2010).

Behaviour is a communication and a natural part of the human condition. It is an attempt to fulfil needs – these needs can relate to a desire for attention, occupation or social stimulation. An appropriate therapeutic response can be viewed as attempting to understand what the need is and to address it.

Distress can also be caused by both mental distress and physical pain – it is important that the causes of mental distress are considered in an equally broad manner as with the causes of physical pain (Treloar & Crugel 2010). A person-centred stepped care model of behavioural support^{aa} is recommended in understanding the likely cause of distress and to consider the appropriate treatment (British Psychological Society 2013, Regnard & Huntley 2006).

A person with advanced dementia can become more restless or disorientated at particular times, such as in the late afternoon or early

^z The person may decide to stop eating and drinking

^{aa} This approach requires the working through of individual timed steps with the least invasive and least intensive intervention being attempted first.

evening. This may be as a result of tiredness or the expression of an unmet need such as hunger. The person may be responding to the reduced sensory stimulation of evening and be searching for an environment that feels secure.

It is also important to consider the possibility of delirium^{bb} ahead of assuming that changes in behaviour are symptoms of the person's dementia. Whilst it is difficult to distinguish between acute and chronic confusional states, the onset of acute episodes is more rapid and may also fluctuate (Regnard & Huntley 2006).

For people with advanced dementia behaviour may be the only way of communicating their emotions and needs. When the person is seen by others through the filter of dementia this will be the basis for the interpretation of all of their actions (Sabat 2010). This presents a danger of inappropriate treatment and fails to recognise personhood. In advanced dementia it is important that people are responded to in a person-centred way with an understanding of their biography, who they were in healthier times and what they are currently experiencing.

2.9.2 Psychological conditions

The three main neuropsychiatric syndromes in dementia are (1) agitation: including symptoms of irritability, restlessness and pacing (2) psychotic symptoms: including symptoms of visual hallucinations, auditory hallucinations and delusions and (3) mood disorder: including depression, anxiety and apathy (Ballard & Aarsland 2010). Psychological conditions can also be present as a result of a co-morbid illness.

A non-pharmacological therapeutic approach is advocated for the treatment of behavioural and psychological symptoms in dementia (Scottish Government 2010). However, medication may be required at times in responding to the presentation of psychological conditions such as clinical depression and psychotic symptoms. It is recommended that this should follow from a person-centred stepped care model of behavioural support (British Psychological Society 2013). Despite this, antipsychotic medications continue to be routinely used to treat behavioural symptoms such as agitation in people with dementia despite limited evidence of clinically meaningful benefit and severe side effects^{cc} (Corbett et al 2014).

There have been ongoing efforts within policy and practice to reduce the use of antipsychotic medication and promote more person-centred responses since the Care Commission and Mental Welfare Commission published "Remember I'm still me" (Care Commission & Mental Welfare Commission 2009). A multi-disciplinary, coordinated and planned approach to care is required in order to make access to evidence-based alternatives to antipsychotic medication widespread, and support those providing day-to-day care for people with advanced dementia.

bb Delirium is an acute confusional state related to medical illness

cc The potential harms such as increased cerebrovascular events and mortality outweigh the benefits

2.10 Communication, personhood and social relationships

Communication through speech dominates our social world. As dementia progresses, the ability to communicate in this way will diminish – the person may only retain the use of a few words or may no longer be able to speak at all. The increasing cognitive impairment that accompanies advanced illness can have a devastating impact on human interaction. Our responses are of key importance in understanding broader approaches to communication to honour personhood, recognise the needs of the person and ensure they remain in the shared social world.

The responses of others can result in the person being discounted and excluded. Kitwood (1997) provided the term “malignant social psychology” to describe a set of 17 behaviours and actions by others that fail to treat the person with dementia as fully human. These include (1) “ignoring – carrying on (in conversation or action) in the presence of the person as if they were not there” (2) “withholding – refusing to give asked-for attention, or to meet an evident need” and (3) “disempowerment – not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated” (Kitwood 1997). Whilst people with advanced dementia can be inadvertently socially excluded in these ways, through changing the nature of the interaction, ways of recognising and honouring the person can be found.

Ward et al (2008) found people with dementia living in care homes invested great effort in attempting to engage the people around them.

Their study of interactions between care staff and residents^{dd} found these were characterised by the conducting of tasks in a standardised manner, as opposed to engaging more socially with the person. Whilst individual resident social interactions varied, dependent on their level of engagement with visitors and other residents, direct contact with care workers accounted for less than three per cent of the day, with little variation.

People with advanced dementia continue to express their sense of self and make attempts to understand their environment and experiences (Clare 2008, Edvardsson & Nordvall 2007, Sabat 2010). Whilst the person may no longer be able to use words to communicate, other forms of expression will be found and this calls on the resourcefulness and creativity of those around the individual to tune into these messages (Allan & Killick 2010, Kitwood 1997).

An inclusive approach is required in considering and responding to what may represent attempts at communication by the person. Physical movements, sounds and other embodied gestures can be seen as attempts at communication and expressions of selfhood in people with advanced dementia (Allan & Killick 2010, Kontos 2004, 2012). It is important to find ways that work for the individual – making a meaningful connection with the person will provide social connection and may have wide ranging benefits in relation to overall wellbeing and quality of life.

dd 4.5 days of researcher observation and video recording over 12 daytime hours in communal areas

2.11 Bio-psychosocial approach

A bio-psychosocial lens provides a holistic approach in considering the potential influence of a wide range of factors on the lived experience of dementia for an individual. Biological, social and psychological factors in advanced dementia are outlined in the Diagram 2.1 below. Each of these factors of the illness influences every other factor, and impacts on the overall health and wellbeing of the person.

Spector and Orrell (2010) provide a model for understanding the impact of the different biological, psychological and social factors for an individual and to consider appropriate responses. These factors may be “considered fixed (not amenable to change)” or “tractable (may be amenable to change)” (Spector & Orrell 2010). It is important to see the potential to improve the lives of people with advanced dementia and bring comfort to those who are approaching end of life.

PHYSICAL

Difficulty coordinating movements (apraxia)
Difficulty coordinating tasks (dyspraxia)
Sudden involuntary muscle/s spasms/jerking movements and seizures (myoclonus)
Muscle tone stiffness leading to awkward movements (general spasticity and rigidity)
Reduced mobility and increased vulnerability to falls
Physical problems and ill health stemming from feeding and hydration (e.g. aspiration of food leading to pneumonia)
Skin integrity compromised
Swallowing difficulties (dysphagia)
Breathing difficulties (dyspnoea)
Pain
Risk of delirium
Likelihood of co-morbid and pre-existing conditions
Increased vulnerability and occurrence of infections
Likelihood of sensory impairment
Risks of poor oral health
Problems with bladder and bowel function: urinary incontinence, bowel incontinence, constipation, impaction and overflow incontinence.

PSYCHOLOGICAL & SOCIAL

Communication difficulties
Emotional responses (grief, fear, anger, sadness, frustration)
Distress
Agitation (irritability, restlessness and pacing)
Mood disorder (depression, anxiety and apathy)
Psychotic symptoms
(visual hallucinations, auditory hallucinations and delusions)

Diagram 2.1^{ee}

ee This diagram is intended to provide a representative range of potential symptoms rather than exhaustive list of possible issues.

2.12 Carers in advanced dementia

When a person continues to live at home during advanced illness much of their care may be provided by those closest to the person^{ff} – if the person is living in a care home their day-to-day caring will be provided by care workers. Those providing care require support to understand and respond to the changing and challenging needs of the person and their condition. They also need to be appropriately supported in providing care and for their own wellbeing to be recognised and addressed. We therefore need to consider the needs of both those who provide care informally due to a close relationship with the person, and paid care staff to ensure that they are adequately supported, trained and resourced to provide quality care.

2.12.1 Caring relationships

Those providing care are important in their own right and the wellbeing of the person with dementia can be seen as closely aligned to the wellbeing of those around them (Nuffield Council on Bioethics 2009). The recognition, working conditions and support provided to paid carers are key factors in the quality of care they are enabled to provide. The interests of those closest to the person are of equal importance to those of the person with dementia – their own physical health and emotional needs should be considered independently of the person with dementia.

A relationship understanding of caring emphasises the interpersonal processes and experiences involved in providing care (Nolan et al 2004). Good care requires all those involved in the caring relationship^{gg} to “(1) to feel safe within relationships (2) to feel part of things (3) to experience links with consistency (4) to have personally valuable goals (5) to make progress towards a desired goal and (6) to feel they matter” (Nolan et al 2004).

Those closest to the person are likely to have neglected their own interests, focusing instead on the interests of the person with dementia. At the time of advanced illness they will have been caring for a long period – they will have been required to make continuous adjustment and adaptations

as the illness progressed. Given these changes are typically incremental, they may not realise the detrimental impact this may have on their own health and wellbeing. The intensive nature of supporting a person with advanced dementia means it is difficult for them to hold on to their own identity and continue to pursue their own interests. This underlines a need for practitioners to give attention to the interests and wellbeing of those providing care.

2.12.2 Understanding experience and needs

Understanding the experience of those closest to the person with dementia who are providing a key component of caring is crucial. The responsibility of caring is often accepted for emotional reasons, not because the person feels expert or comfortable with the type of caring required. It is determined by the relationship to the person with dementia – it is therefore important to recognise the basis of this relationship and shared biography. The continued acknowledgement of this underlying reciprocal caring relationship is important so their personhood is understood and they are not thought of as assuming the identity of “the carer”.

The duration of dementia is typically long and the level and type of care demanding – this strain may be intensified by the advanced age and frailty of the person providing care (Prigerson 2003). In addition to dealing with communication and psychological issues, caring also requires “extraordinary vigilance” towards the person with dementia (Schultz et al 2003). This can be compounded by sleep disturbance, exhaustion, behavioural issues and dealing with incontinence issues. Whilst carers generally report a great number of physical health problems and worse overall health, those caring in dementia are also at increased risk of psychological ill health (Brodaty & Donkin 2009).

When the person with dementia continues to live at home, close family member/s are likely to be coordinating a range of health and social care

^{ff} This is often the spouse, partner, adult children or other close relationship

^{gg} Person with dementia, those closest to the person and paid or voluntary carers

needs of the person, with a number of practitioners coming into the home. Where the person has moved into a care home the level and type of support these family members wish to continue to provide will vary. Irrespective of this, it is important their continued engagement in care is supported so their concerns are understood and any problems with care rectified with their input.

The experience of caring is subjective and people will respond differently – this means the support needs of those providing care will depend on a number of factors including personal circumstances and relationship to the cared for person (Brodaty & Donkin 2009).

Those providing care require practical input, emotional support and consistent information to prepare for the changes that accompany advancing illness and the issues that may arise as the person is approaching death. In addition to the complex care required, advanced illness brings a range of difficult decisions in response to the person's ongoing care and treatment. They will require the support and knowledge of practitioners involved in the care of the person in making decisions.

2.12.3 Loss, grief and bereavement

Those providing care will experience losses throughout the course of the illness as a result of the progressive nature of the illness, their changing relationship with the person and possible move to a care home (Prigerson 2003). In the case of a caring spouse (or partner) these losses relate to the person who is likely to have been their primary life companion and source of emotional support.

It is suggested the adjustment and adaptation that occurs during the course of the illness – referred to as anticipatory grief – influences the experience of bereavement. However, the extent to which anticipatory grief impacts upon the experience once the person dies is disputed (Collins et al 1993).

Burke et al (1992) suggest carers experience “chronic sorrow” whilst remaining “highly focused and functioning in the presence of ongoing loss...performing new tasks, making far-reaching decisions and modifying lifestyles”.

To assume that some of this grieving has taken place before the person has died discounts experience and may result in a prolonged bereavement process (Sammut 2005). Marwit and Meuser (2001) suggest a dual grief once the person with dementia has died, for the loss of the person and the loss of focus and activity when the caring role has ceased.

It is clear there is both an ongoing experience of loss during the illness and a bereavement process once the person has died – both emotional responses require recognition and appropriate support. The death of the person represents a major transition and should be viewed as part of the caring experience and not separate from it (Sammut 2005).

2.13 Where we are now

Palliative care is the key model of care in responding to non-curable chronic disease. Whilst palliative care is often referred to as occurring from the point of diagnosis, end of life care is related to the final phase of life^{hh}. End of life care can therefore be viewed as an integral part of palliative care. Scottish policy guidance provides “palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living and dying from an advanced, progressive or incurable condition” (Scottish Government 2008).

A national statement on caring for people in the last few days of life provides the principles of the approach that should be taken, whilst acknowledging that what is appropriate in individual circumstances will differ (Scottish Government 2014b).

There is currently no planned and coordinated approach to providing the care required to support people living with advanced dementia in the community. This can result in crisis interventions in response to medical emergency and the breakdown of the caring relationship. The recent “Dying without Dignity” report outlined the key problems in end of life care in England (Parliamentary & Health Service Ombudsman 2015). Issues highlighted included a need for better identification of those requiring palliative care and care planning. The progress report on Scottish policy guidance also highlights these areas for targeted improvement and, crucially, palliative care support for care homes (Scottish Government 2012).

Palliative care was developed as a response to cancer when active treatment was no longer applicable – care models and access routes reflect these origins. A palliative care approach would seem highly relevant in dementia with its focus including (1) the management of pain and other distressing symptoms (2) support for the emotional, practical and spiritual issues in serious illness and (3) involving and supporting the family through illness and bereavement.

^{hh} There is no defined time period for this final phase.

The effectiveness of palliative care in dementia is not currently well researched and there is much less evidence on effective treatments compared to cancer (Hughes et al 2007, van der Steen 2010). This means that dementia specific palliative treatment guidelines are mostly consensus based (Gove et al 2010, Holmes et al 2008, Lloyd-Williams & Payne 2002, Lorenz et al 2007, van der Steen et al 2014, van der Steen et al 2000, Volicer et al 2005).

The presence of communication and psychological issues are a significant consideration in responding appropriately to advanced dementia. It is suggested that communication issues, alongside ethical and legal concerns, can make practitioners reluctant to take a palliative care approach when faced with difficult decisions (Dixon et al 2015). Extending a palliative care approach to dementia also raises concerns about the level of need this will create and whether practitioners have the appropriate skills (Hospice UK 2015).

Review of evidence in palliative care has shown the symptoms of dementia are not effectively addressed and the dying phase can often go unrecognised (Birch & Draper 2008, Rowlands & Rowlands 2012). A study of primary care identification of palliative care needs found only 20% of non-cancer patients received palliative care before dying compared to 75% of cancer patients (Zheng et al 2013). People with dementia who received palliative care typically did not begin receiving it until around two weeks before death (Zheng et al 2013). A study of those who had died in an acute ward found people with dementia were considerably less likely to be referred to palliative care teams and were prescribed fewer palliative medicines than those who were cognitively intact (Sampson et al 2006).

Despite the difficulties outlined above, there is potential for a palliative care approach to be an important aspect of supporting people living with advanced dementia. However, the extension of palliative care in itself cannot be considered a ready-made response to advanced dementia.

2.14 Next steps

Rather, it has an important supporting role for those already providing care in dementia, alongside the other specialists required in responding to the most complex phase of the illness.

Palliative care specialists are skilled in assessing and managing pain and other distressing symptoms. Dementia care practitioners have key skills in responding to communication difficulties and psychological symptoms of dementia. A planned and coordinated approach is required to harness the contribution of both specialities in responding to the complexity of advanced dementia.

A European collaborative literature review identified the need for a range of educational strategies to equip dementia practitioners in responding to the advanced illness (Sandvide et al 2015). The Promoting Excellence framework (2011) provides an important tool to developing the skills and knowledge of dementia practitioners in responding to advanced dementia and end of life care.

The following chapter outlines a model of care in supporting people living with advanced dementia in response to the key issues outlined in this section.

It addresses the need for a key role for health care and a bio-psychosocial approach in responding to the range of physical, psychological and social factors that interplay to determine the individual experience of advanced dementia.

The importance of understanding a person's way of being and acting in a way that honours personhood is recognised as an important aspect of providing appropriate care and support.

It also sets out the support required for those providing day-to-day care and how the needs of those closest to the person should be addressed.

3. Advanced Dementia Practice Model

3.1 Introduction

The evidence outlined in the previous section and the consultation responses demonstrated the complexity and intensity of advanced dementia. It identified the key factors that must be responded to in caring for people living with advanced dementia and ensuring those providing day-to-day care are appropriately supported.

The Advanced Dementia Practice Model provides the response to this most complex phase of dementia. The set of needs outlined in the previous chapter can be met by an approach which ensures that each person with dementia can continue to be supported in their community, with the input of specialist practitioners.

Our proposition is that each Health and Social Care Partnership should establish an Advanced Dementia Specialist Team, as well as providing a Dementia Practice Coordinator for every person with dementia as they progress to the point of requiring community and health care services. When these needs reach the complexity and intensity of advanced dementia and expert input is required, the Dementia Practice Coordinator will facilitate the Advanced Dementia Specialist Team to enhance the care provided by the 8 Pillars Teamⁱⁱ. This will enable a planned and coordinated approach that tackles the full range of factors in advanced dementia and end of life with dementia.

3.2 Advanced Dementia Practice Model

3.2.1 Advanced Dementia Specialist Team

Practitioners will be located within this team on a full, part time or consultancy basis as required. There will be shared learning across the group of practitioners with a focus on training to Expertise in Dementia Practice Level (Scottish Government 2011). Care pathways, team lead and structure will be determined by what is appropriate within the local context.

Health Practitioner	Description
Consultant Geriatrician	Specialist overview in care of elderly. Whilst the involvement of other consultants will also be relevant – e.g. for younger people and for psychological conditions – the vast majority of people receiving the Advanced Dementia Practice Model will be in the older age groups
Mental Health	Psychiatrist, psychology and community psychiatric nurse for promotion of psychological wellbeing and responses to stress/distress and psychological conditions
District Nurse	Management and guidance on physical health conditions such as bowel and bladder function and skin integrity
Allied Health Professions	Occupational therapy for engagement, occupation and environment Physiotherapy for pain management and movement Speech and language therapy for communication and nutrition/hydration issues Dietitian for nutrition and hydration
Palliative care specialists	Approaches to the management of pain and other distressing symptoms and end of life care

ii 8 Pillars Team includes all those providing care and support: care homes, care at home, family carers, General Practitioner (GP) and specialist practitioners involved in the person's care before transition to the Advanced Dementia Practice Model



3.2.2 Developing the 8 Pillars approach

The consultation we undertook to inform the development of the Advanced Dementia Practice Model indicated clear support for the 8 Pillars approach – providing care and support in the community that tackles the full range of factors that influence the experience of dementia, coordinated by a Dementia Practice Coordinator.

The consultation and evidence also point to the value of supporting people with dementia where they are. Consistency is important, so existing care staff and teams should remain in place as far as possible.

The Advanced Dementia Practice Model therefore describes an approach which enables people with dementia to remain where they are, supported by the people they are familiar with. It adds an Advanced Dementia Specialist Team to the existing 8 Pillars team^{jj} to act as an extra cog in the wheel, to provide expert input to existing care and support providers so that they are able to respond to the increasing complexity and intensity of needs as dementia advances.

jj 8 Pillars Team includes all those providing care and support: care homes, care at home, family carers, General Practitioner (GP) and specialist practitioners involved in the person's care before transition to the Advanced Dementia Practice Model



3.2.3 Why we need an Advanced Dementia Practice Model

Section 2 outlined the complex health conditions associated with advanced dementia resulting from increasing cognitive impairment and diminishing physical robustness. Alongside this, the frequency and severity of ill health is likely to intensify as a result of people being unable to report symptoms, reduced immune response and swallowing difficulties. Advanced dementia presents the greatest risk factor for delirium.

In addition to the biological factors that determine the progression of dementia there is also the influence of co-morbid illness. There is an increased likelihood of a range of complicating factors in the older age groups including pre-existing health conditions, sensory impairment and pain.

The complexity of both the cause and effect of issues relating to nutrition and hydration is a key factor in responding to advancing dementia. These issues have implications for physical health and emotional wellbeing — they require specialist assessment and individualised responses.

The management of pain and other distressing symptoms and end of life care calls for the knowledge and experience of palliative care specialists in supporting dementia practitioners.

Whilst the physical aspects of advanced dementia are critical, the social stimulation and activity of the person are also of key importance to their wellbeing and quality of life. Those providing day-to-day care require support from skilled practitioners such as allied health professionals in social connection and purposeful activity.

A person's emotional responses to advancing illness must be understood within the context of their personality and biography. Promoting

psychological wellbeing in advanced dementia requires a stepped care approach with specialist support for those providing day-to-day care.

Symptoms of stress and distress occur frequently and there is great risk of escalation if the underlying problem causing the behaviour is not responded to appropriately. The presence of psychological conditions requires specialist assessment from mental health practitioners.

The responsibility of responding to the complex health care needs of people living with advanced dementia in the community currently falls on general practitioners and primary health care. They require access to the resources that will be needed to deliver the necessary specialist care.

Whilst some care homes have good links with key health practitioners such as palliative care specialists and allied health professionals this is not universally available.

Those closest to the person and care workers^{kk} provide the greatest proportion of day-to-day care for people with advanced dementia. Care homes are increasingly dealing with highly complex care and dying. They require the specialist support of key health care practitioners.

The Advanced Dementia Specialist Team is pivotal in providing essential health care input and supporting those providing day-to-day care. This new coordinated and planned approach to tackle the most intensive phase of the illness will enable the delivery of optimum care through responding to complex conditions. It will also provide essential advice and guidance on caring in advanced dementia and end of life to the 8 Pillars Team and support the reduction of unnecessary hospital admissions.

kk This includes the family carer who is a key part of the caring partnership

3.2.4 Transition to an Advanced Dementia Practice Model

The needs of people with dementia will fluctuate and extra support will be required at different times for particular problems. The Dementia Practice Coordinator will bring in additional specialist support at different times in response to particular issues. However, it is not until there is a substantive change that there will be a move to the Advanced Dementia Practice Model.

When a person requires the Advanced Dementia Practice Model there will be a range of people already involved in their care and support – this is the 8 Pillars Team¹¹. They will be coordinated by the Dementia Practice Coordinator and determined by the person's experience of dementia and underlying health. For younger people with dementia there may be continued involvement from the neurology team. People with learning disabilities are likely to continue to be supported by specialist services. There should also be close links between the Dementia Practice Coordinator and medical disciplines related to the person's co-morbid conditions.

The decision to refer the person for assessment by the Advanced Dementia Specialist Team will be initiated by the Dementia Practice Coordinator. This will follow from discussion and agreement between the Dementia Practice Coordinator and the 8 Pillars Team.

The entry point to the Advanced Dementia Practice Model is determined by the level of complexity of need requiring substantive health care as assessed by the Advanced Dementia Specialist Team. The range of factors necessitating this approach will be specific to each individual but likely to be determined by the progressed physical experience of dementia and inter-play of co-morbid illness. Access to this approach is based on the principle of equality and determined by need as opposed to prognosis.

Once the person has been assessed as requiring the Advanced Dementia Practice Model the Advanced Dementia Specialist Team will review their current care and identify gaps. A care plan will be created outlining the responses to the person's physical, psychological and social care needs. Diagram 3.1 outlines the operation of the Advanced Dementia Practice Model.

The care plan will build a strategy to support the person through advanced dementia and end of life. It will identify the practitioners required to support the person's care – bringing in specialist support where this is not already being provided by the 8 Pillars Team. The Advanced Dementia Specialist Team will enhance the support provided by the 8 Pillars Team and provide advice through the Dementia Practice Coordinator.

The care plan will be held by the Dementia Practice Coordinator and 8 Pillars Team. Crucially, there will be regular review of the care plan and ongoing input from the Advanced Dementia Specialist Team.

People may experience the advanced dementia phase for months or years. The intensity of health care input required is likely to fluctuate along with the level of involvement from the Dementia Practice Coordinator. The input from the Dementia Practice Coordinator and the Advanced Dementia Specialist Team may be less intensive for periods if the person has relatively stable needs and support is in place to meet these.

Whilst the entry point to this Model is determined by the level and complexity of health care needs, responding to the social and emotional experience of advanced illness and end of life is of equal importance.

¹¹ 8 Pillars Team includes all those providing care and support: care homes, care at home, family carers, GP and specialist practitioners involved in the person's care before transition to the Advanced Dementia Practice Model

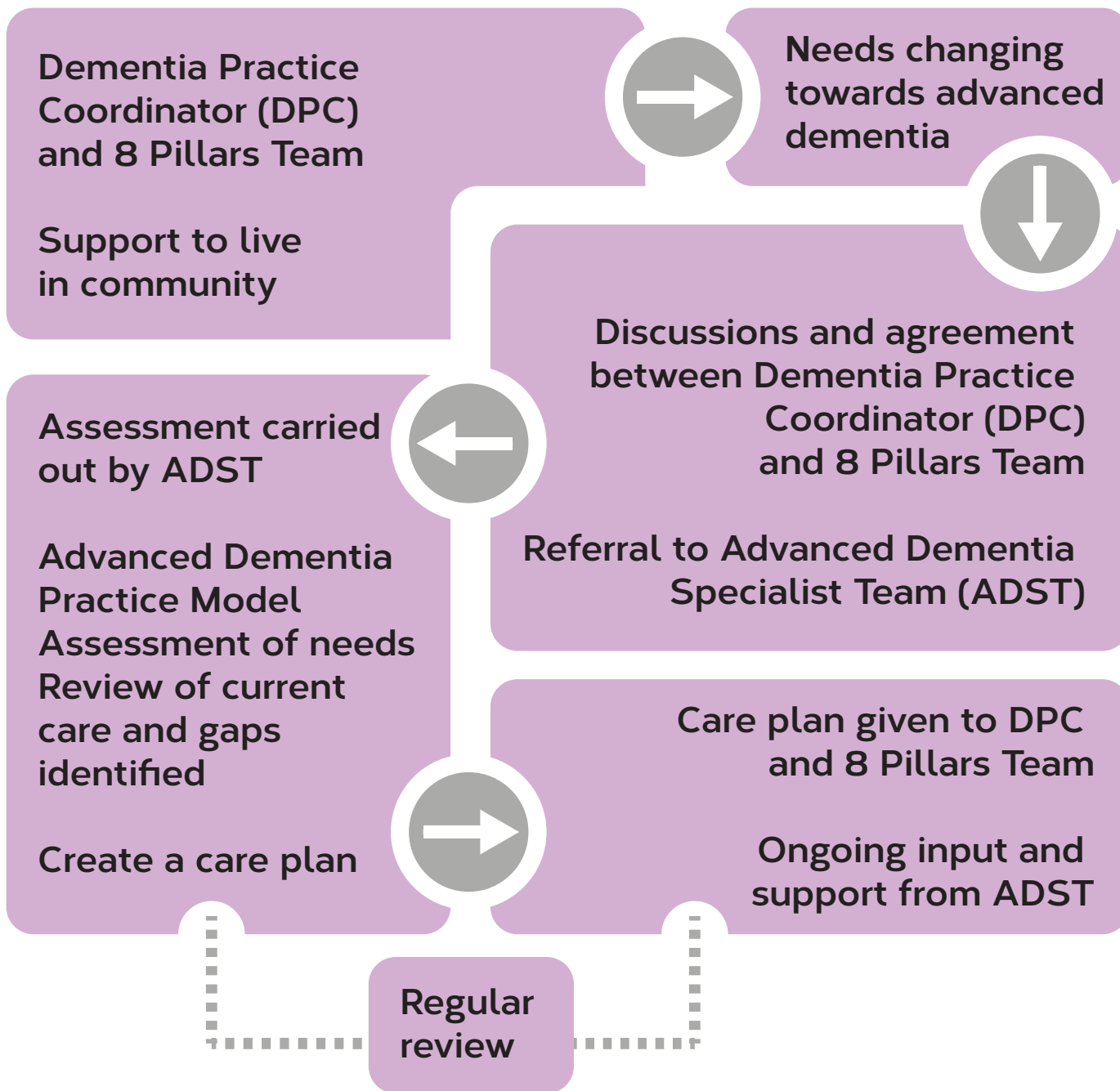


Diagram 3.1

3.2.5 Pillar: Dementia Practice Coordinator



The Dementia Practice Coordinator provides the essential component to ensure a planned and coordinated approach to care from the moderate phase of dementia. Their role is pivotal to the successful operation of the 8 Pillars Model of community support and Advanced Dementia Practice Model. An outline of the Dementia Practice Coordinator role is provided in Appendix 1.

Dementia Practice Coordinators are named and skilled practitioners operating at the Enhanced Level of the Promoting Excellence Framework (Scottish Government 2011). Their role relies upon the authority and status to commission and control interventions and harness the contribution of a wide range of practitioners.

Dementia Practice Coordinators come from among existing skilled practitioners working within health and social care^{mm}. They coordinate the contribution of and provide effective communication between the 8 Pillars Team, Advanced Dementia Specialist Team and GP.

Bringing together the 8 Pillars Team and the Advanced Dementia Practice Team

The Dementia Practice Coordinator leads the care, treatment and support for the person and their carer from the point of the 8 Pillars Model of community support. They bring together the contribution of the 8 Pillars Teamⁿⁿ to support the quality of life and independence of the person with dementia and their carer. They coordinate the collective impact of all pillars to build the resilience of the family unit and supporting full citizenship and optimum participation in society.

The Dementia Practice Coordinator identifies critical points when the person and their carer require alternative or additional interventions. Crucially they identify the point at which the Advanced Dementia Specialist Team should become involved in the person's care.

The Dementia Practice Coordinator initiates the assessment by the Advanced Dementia Specialist Team when they consider that the person is experiencing advanced dementia. They will then continue to accompany the person and their carer throughout advanced illness and end of life.

The Dementia Practice Coordinator provides the planning and coordination for the Advanced Dementia Practice Model. They combine the expertise and understanding of the 8 Pillars Team and Advanced Dementia Specialist Team. They provide a structured approach to integrate specific supports to respond to the symptoms of advanced dementia, enhance coping and prevent crisis. They coordinate delivery of the care plan, monitor its effectiveness and ensure its timely review. Working with the 8 Pillars Team, they identify critical points when the person and their carer require alternative or additional interventions and facilitate the contribution of the Advanced Dementia Specialist Team.

During advanced dementia the Dementia Practice Coordinator brings together the care and support required to enhance quality of life and provide comfort to the person with dementia and their carer. They work to build the resilience of the family unit and support those providing day-to-day care (8 Pillars Team) through the contribution of specialist practitioners (Advanced Dementia Specialist Team). The Dementia Practice Coordinator supports the person with dementia dying in their place of choice. They also support those closest to the person through the bereavement process.

^{mm} Community psychiatric nurses, district nurses, social workers and allied health professionals all have strong relevant skill sets in their own right. These can be built on to ensure a full understanding of all approaches required to tackle the full range of symptoms.

ⁿⁿ 8 Pillars Team includes all those providing care and support: care homes, care at home, family carers, GP and specialist practitioners involved in the person's care before transition to the Advanced Dementia Practice Model

3.2.6 Pillar: General health care and treatment



What it will deliver

The Advanced Dementia Specialist Team will provide advice, assessment and treatment in responding to complex symptoms of advanced dementia, underlying health conditions and complications that arise such as infection.

The Advanced Dementia Specialist Team will provide specialist input where this does not already form part

of the 8 Pillars Team. They will support complex clinical considerations and specialist assessment in consultation with the Dementia Practice Coordinator and 8 Pillars Team.

The Dementia Practice Coordinator and 8 Pillars Team will identify the point at which additional support is required from the Advanced Dementia Specialist Team. The Dementia Practice Coordinator will then bring in the appropriate practitioner(s).

The particular set of issues will vary between individuals and be dependent on personal circumstances and underlying health of the person. The intensive nature of advanced dementia means that additional complications are likely to present. The Advanced Dementia Practice Model provides a comprehensive and integrated response to provide holistic care for the person with dementia and support those providing day-to-day care.

The practitioners required to support physical health conditions include GP, Consultant Geriatrician, District Nurse and Allied Health Professionals^{oo}. Palliative care specialists will provide guidance on pain and other distressing symptoms and dying.

Impact and outcome

The Advanced Dementia Practice Model will provide care and treatment for the person with dementia in their current location to avoid unnecessary hospital admission. It will provide timely responses to physical health conditions to promote quality of life and comfort.

It will also support family carers and others providing day-to-day care by giving guidance on appropriate approaches to care and responding to the complex physical complications that arise.

^{oo} Such as Speech and Language Therapists and Dietitians

3.2.7 Pillar: Mental health care and treatment



What it will deliver

The psychological wellbeing of the person will be supported through the contribution of the Advanced Dementia Specialist Team to enhance the care provided by the 8 Pillars Team.

A range of people working with the person have a role in responding to moment-to-moment distress. The

Dementia Practice Coordinator and 8 Pillars Team will identify the point at which additional support is required from the Advanced Dementia Specialist Team. The Dementia Practice Coordinator will then bring in the appropriate practitioner(s).

The possible reasons for stressed and distressed behaviour are multifaceted. A range of specialist practitioners are therefore required to support those providing day-to-day care to respond with a person-centred approach that reduces the use of inappropriate medication.

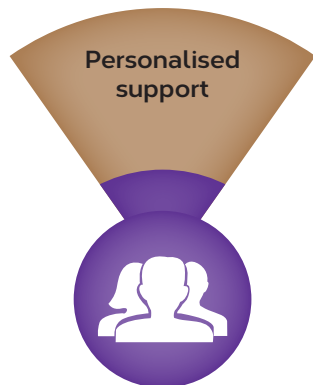
Physical or psychological assessment may be required dependant on the suspected cause of distress. Mental Health Practitioners and Allied Health Professionals have a key role in supporting the responses to more intensive experiences of stress and distress.

Impact and outcome

The Advanced Dementia Practice Model ensures that the person with dementia and their carers have access, through the Advanced Dementia Specialist Team, to psychiatric and psychological expertise and appropriate Allied Health Professionals. The combined expertise and knowledge of the Advanced Dementia Specialist Team allows the team to explore the full range of factors which can result in stress and distress and impact on the psychological wellbeing of the person with dementia.

The Advanced Dementia Specialist Team's expertise will enable the use of person-centred approaches, such as the stepped care approach, recommended by the British Psychological Society (2013) in understanding the unique biological, psychosocial and social factors which may be causing stress and distress for the person with dementia. This will help identify the most appropriate and least intensive solutions which respond to the practical, physical, emotional and spiritual needs of the person with dementia to minimise or prevent escalation of stress and distress for them and those closest to them, and reduce the inappropriate use of medication.

3.2.8 Pillar: Personalised support



What it will deliver

The increasing cognitive impairment that accompanies advanced dementia can have a devastating impact on human interaction. This may also make it difficult for the person with dementia to interpret surroundings and care interventions, which may lead to distressed or resistive behaviour.

Communication is important to understand a person's experience and to assist in responding appropriately to their needs. People with dementia also need attention and the opportunity for self-expression. The Advanced Dementia Specialist Team will bring knowledge and expertise in equipping the 8 Pillars Team with person-centred approaches to promote communication, care-giving and social connection.

The Dementia Practice Coordinator will facilitate the contribution of the Advanced Dementia Specialist Team in maintaining and enhancing the existing caring relationships provided by the 8 Pillars Team.

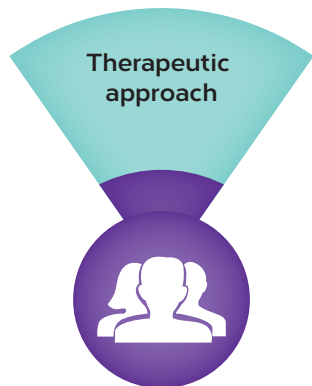
The Advanced Dementia Specialist Team will support care staff and family carers in delivering care around complex physical, emotional and psychological needs. This will include the allied health professionals and mental health practitioners whose expertise will provide a valuable resource in interpreting needs and identifying appropriate person-centred approaches.

Impact and outcome

The Advanced Dementia Practice Model will equip those providing day-to-day care to develop skills and coping strategies that sustain and enhance their involvement in the person's care. The Advanced Dementia Specialist Team will bring a high level of expertise to challenging care situations. This will support the 8 Pillars Team to further develop their approaches and techniques that achieve the best care for the person with dementia. It will support approaches to care that promote dignity and honour personhood.

It will promote the social connection and stimulation of the person with dementia in ways that are meaningful to them, which will have a range of potential benefits that contribute to overall wellbeing. It will support care that recognises and responds to the individual within the context of their biography, relationships, cultural background, sexual identity and spirituality. It will also support the person to express their emotional and spiritual responses to advancing dementia and dying.

3.2.9 Pillar: Therapeutic approach



What it will deliver

People with advanced dementia have a continued need for meaningful occupation and social stimulation. Whilst communication through speech may be limited by advanced dementia, other approaches will be found including sounds, gestures, movements and touch that bring the person into our shared social world.

The Advanced Dementia Specialist Team will support the 8 Pillars Team in providing therapeutic approaches and interventions that facilitate communication, support social connection and provide meaningful occupation. This contribution will be facilitated by the Dementia Practice Coordinator.

Allied health professionals^{pp} will work directly with the person with dementia to provide a highly skilled approach in providing occupation and working with non-verbal responses, behaviours and communication. They will also support the 8 Pillars Team to understand and apply different techniques to support communication and connection with the person with dementia.

Impact and outcome

The Advanced Dementia Practice Model will equip family carers and care workers with approaches that foster connection and shared experience with the person with dementia. It will develop the 8 Pillars Team's, understanding of the cues and prompts coming from the person with dementia and how to respond to these in providing communication and engagement. It will promote a wide range of potential benefits for the person with dementia that enhances self-esteem, quality of life and wellbeing.

Moment-to-moment experiences are an important component of wellbeing for people with advanced dementia. Approaches such as reminiscence therapy, life story work, Enhanced Sensory Day Care^{qq}, Adaptive Interaction^{rr}, Talking Mats and Playlist for Life were highlighted through the consultation process on developing the Advanced Dementia Practice Model. These techniques and approaches were used by dementia practitioners in understanding who the person is and identifying appropriate approaches to social connection and occupation.

3.2.10 Pillar: Support for carers



What it will deliver

The complex and intensive care of people with advanced dementia relies upon the contribution of those closest to the person^{ss}. There is an ethical rationale and a public interest to provide proactive support to carers. This support should respond to race, cultural background, sexual identity, religion and spirituality. It should recognise those closest to the person will not necessarily be their family of origin^{tt}.

Understanding the subjective experience is crucial in responding appropriately to needs. Carers require practical and emotional support throughout advanced dementia, during the end of life phase and at the time of bereavement. They also require their own health and wellbeing to be considered independently of the person with dementia.

The Dementia Practice Coordinator and 8 Pillars Team will identify where additional input is required from the Advanced Dementia Specialist Team in supporting the carer. The Advanced Dementia Specialist Team will then support the carer directly or provide guidance through the Dementia Practice Coordinator and 8 Pillars Team as appropriate to each particular issue that arises.

The Advanced Dementia Specialist Team will build on the support provided by the 8 Pillars Team in maintaining the health and wellbeing of the carer. They will support responses to particular challenges and introduce techniques to enhance coping. They will equip the carer with practical skills and strategies to care and optimise their opportunities for a good quality of life.

The practitioners required to support the carer will be dependent on individual circumstances and needs. Allied health professionals will be important in supporting the care provided to the person with dementia. Mental health specialists and physical health care practitioners will be important to supporting the carer's own health and wellbeing.

^{ss} Those providing informal care as a result of their relationship with the person with dementia – this can be a family member, partner or friend.

^{tt} Whilst this can be true of any person, LGBT people often create their own non-traditional families and forms of support (LGBT Health & Wellbeing 2014a). These close relationships should be recognised and respected within the caring partnership

3.2.10 Pillar: Support for carers (continued)

Impact and outcome

Advanced dementia brings a range of difficult decisions in response to the person with dementia's ongoing care and treatment. The family carer is a key part of the 8 Pillars Team and a partner in care alongside the Dementia Practice Coordinator and Advanced Dementia Specialist Team^{uu}.

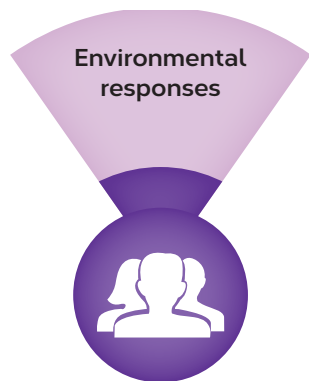
When the person remains at home during advanced illness the Advanced Dementia Practice Model will ensure the appropriate level and quality of practical support is provided around the carer. It will also provide specialist support in relation to communication, psychological and behavioural issues.

When the person has moved into a care home it will support the carer to remain part of the 8 Pillars Team and continue to make the contribution to care that is important to them and of which they are capable.

The Advanced Dementia Practice Model recognises the carer as an individual in their own right and responds to their personal need for emotional and practical support. The carer will have gone through loss and change throughout the course of dementia – their physical and psychological health may have deteriorated. The 8 Pillars Team and Advanced Dementia Specialist Team – as planned and coordinated by the Dementia Practice Coordinator – will have an important role in helping the carer to recognise and respond to their own needs.

The death of the person with dementia is both the loss of a central relationship and a major transition from the activity of caring. Moving forward and re-engaging with activities is likely to be difficult to contemplate. Being able to talk about the caring experience may be an important factor in enabling a sense of acceptance to be found. The Dementia Practice Coordinator will facilitate access to counselling and support for bereavement.

3.2.11 Pillar: Environmental responses



What it will deliver

Environmental considerations are a key component of supporting people living with advanced dementia. They can address some of the challenges caused by the symptoms of advanced illness and co-existing conditions. Attention to environmental factors may also promote psychological wellbeing and help to alleviate or prevent stress and distress in the person with dementia.

The Dementia Practice Coordinator and 8 Pillars Team will identify when additional support is required from the Advanced Dementia Specialist Team. This will enable individual assessment to be carried out by an appropriately skilled practitioner to determine what is required in the particular circumstances. This can include occupational therapists, physiotherapists, nurses, podiatrists and housing practitioners.

Impact and outcome

The Advanced Dementia Practice Model will deliver specialist advice and support to those providing day-to-day care. It will provide support and responses in assessing the impact of the environment on the person with dementia.

When the person with dementia is living at home it will offer consideration of housing issues – adaptations and equipment will be an important component of providing appropriate care. When the person is living in a care home it will support consideration of the impact of environmental aspects, culture, routine and structure for individual needs and wellbeing.

It will support therapeutic movement for people who are more sedentary. It will also provide assessment in relation to appropriate seating to promote comfort, health and enabling the person to see and engage with those around them^{vv}.

It will support consideration of layout of space, dementia design and individual assessment to minimise risk of falls and maximise mobility. Attention to the environment such as trip hazards and the provision of stopping places is important for people who continue to be mobile and walk about. Ensuring foot care and access to appropriate aids such as walking sticks, well fitted shoes and spectacles is essential.

^{vv} The supply of specialist seating should then be based on need and not location of the person. Consultation responses suggested issues about equality of access to specialist seating – care homes may be expected to fund specialist seating which may be a barrier to a person being supplied with appropriate seating.

3.2.12 Pillar: Community connections



What it will deliver

A recent public attitude survey demonstrated an overwhelming readiness within the community to help people living with advanced dementia^{ww} (Reid et al 2015). These findings link to the concept of “solidarity” and “the need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and

responsibility to support people with dementia, both within families and in society as a whole” (Nuffield Council on Bioethics 2009).

The Dementia Practice Coordinator will work with those closest to the person in identifying opportunities to link with natural supports within the community to support caring activity and provide peer support. They will support the carer in maintaining or re-engaging with wider community connections and activities.

The Dementia Practice Coordinator and 8 Pillars Team will also engage with community development partners and other relevant organisations or groups to facilitate provision of purposeful community activity and social connections for the person with dementia.

The Dementia Practice Coordinator and 8 Pillars Team will identify where additional support is required from the Advanced Dementia Specialist Team in supporting community connections for both the person with dementia and their carer.

Impact and outcome

Peer support can provide the opportunity for those caring in advanced dementia to gain companionship and learn from those experiencing similar challenges. It can facilitate the development of coping strategies and shared understanding. Peer support networks can provide an important source of social connection and support at the time of bereavement. These community connections can help to reduce the sense of isolation and support the caring relationship through providing practical support.

Social relationships, activities that are meaningful to the individual and connections to the wider community can keep the person with dementia socially connected and honour our shared humanity. This will be of particular importance when the person does not have informal supports such as family and friends to provide social stimulation and activity.

^{ww} 80% of respondents would be prepared to assist a neighbour with severe dementia

4. Conclusion and Recommendations

4.1 Conclusion

The Advanced Dementia Practice Model provides an integrated and comprehensive approach to respond to the most complex phase of the illness. It aims to improve the quality of life for people living with advanced illness and provide holistic care at end of life. It develops the 8 Pillars Model of community support to respond to the complexity of advanced illness and end of life with dementia. The multiplicity of health care issues is addressed by the Advanced Dementia Specialist Team. At a time of demographic change, the Advanced Dementia Practice Model delivers a coherent approach in responding to the increasing number of people dying with dementia.

The Model builds on key developments in post diagnostic and community support provided by the 5 and 8 Pillars Models. It presents a structured joint health and social care practice approach led by a Dementia Practice Coordinator working with the 8 Pillars Team. It promotes the wellbeing and quality of life of both the person with advanced dementia and those closest to them. It also provides the essential support to care homes and those providing day-to-day care in this complex illness.

Human rights are a fundamental aspect of understanding the citizenship and rights of people living with advanced dementia. The Advanced Dementia Practice Model honours the right to personhood, full citizenship and optimum participation in society for people living with advanced illness and at end of life with dementia.

Care needs in dementia are often classed as ‘social’ despite stemming from illness – this places people living with dementia at a great disadvantage. The highly complex care needs in advanced dementia are a result of progressive damage to the brain and are therefore health care needs.

This Model delivers the final essential component in supporting people throughout the illness. The interconnected approach responds to the subjective experience of dementia and honours the personhood and citizenship of those living with advanced dementia. This has provided a blueprint for optimum integrated dementia care to support people living with dementia from diagnosis to end of life.

The research and consultation process undertaken to develop this Model identified several areas requiring further work. Therefore, Alzheimer Scotland will work in partnership to investigate the development of a replicable model of delivery of a stepped care approach to minimising and managing stress and distress for people with dementia.

In addition, there was a strong view, from both practitioners and people with lived experience of advanced dementia, that there are difficulties in achieving advance planning in dementia. We therefore suggest further investigation of what is required to support the facilitation of advance planning in dementia.

4.2 Recommendations

Recommendations

The Scottish Government accept and recognise that on the basis of this report, there is clear evidence that once a person has reached the advanced stage of dementia, all their needs are health care needs.

Each Health and Social Care Partnership in Scotland provides a Dementia Practice Coordinator for every person with dementia as they progress to the point of requiring community and health care services.

The Dementia Practice Coordinator is confirmed as an additional Enhanced role delivered within the existing and established professional groups such as social workers, nurses and allied health professionals, with the appropriate authority to commission and coordinate the required level of care and support.

The Promoting Excellence Framework is used to ensure the Dementia Practice Coordinator meets the Enhanced practice level and that all staff within the 8 Pillars Team are operating at a minimum of Skilled level.

The Advanced Dementia Practice Model is tested as part of the objectives of the National Dementia Strategy 2016 and if successful, an Advanced Dementia Specialist Team is established in each Health and Social Care Partnership in Scotland by 2020.

Appendix 1: Role of the Dementia Practice Coordinator

The Dementia Practice Coordinator role is pivotal to the successful operation of the 8 Pillars Model of community support and the Advanced Dementia Practice Model. Working at the Enhanced level of the Promoting Excellence Framework (Scottish Government 2011) they provide the key component to ensure a planned and coordinated approach to care, treatment and support from the moderate phase of dementia to end of life.

It is crucial, therefore, that the Dementia Practice Coordinator has the authority and status to commission and control interventions, and facilitate the contribution of the practitioners from the 8 Pillars Team and the Advanced Dementia Specialist Team. This section sets out the authority required by the Dementia Practice Coordinator as well as the key responsibilities of the role in coordinating the interventions of the 8 Pillars Team and Advanced Dementia Specialist Teams.

The authority of the Dementia Practice Coordinator

The authority to:

- Monitor the individual's care plan
- Evaluate the input from the members of the 8 Pillars Team and the Advanced Dementia Specialist Team
- Negotiate and coordinate the delivery of the care plan
- Access appropriate resources
- Facilitate and arrange effective reviews

Primary responsibilities of the Dementia Practice Coordinator

- To establish and maintain a professional relationship with the person with dementia, and those who care for them, based on appropriate regular contact.
- To coordinate and monitor the planning and delivery of the care, treatment and support delivered by the 8 Pillars and Advanced Dementia Specialist Teams.
- To ensure that the person with dementia and those who care for them are able to participate fully in the decisions which affect them, taking account of past wishes, including those expressed in any existing advanced plan.

The 8 Pillars Model

The Dementia Practice Coordinator will;

Lead the care, treatment and support for the person and their carer

Coordinate access to all Pillars to support independence, wellbeing and quality of life as appropriate to each individual

Coordinate between all the practitioners delivering care, treatment and support

Provide an individualised approach to lead the care, treatment and support of the person and their carer

Provide a structured approach to integrate specific supports that will tackle the symptoms of the illness, delay deterioration, enhance coping and prevent crisis

Identify the critical points when the person and their carer require alternative or additional interventions and harness the contribution of a wide range of practitioners

Link support together, and have an overview of each individual's care and treatment

Advanced Dementia Practice Model

The Dementia Practice Coordinator will;

Along with 8 Pillars Team, identify the point at which a referral should be made to the Advanced Dementia Specialist Team

Initiate referral to the Advanced Dementia Specialist Team

Coordinate and plan the input of the Advanced Dementia Specialist Team in supporting the 8 Pillars Team to deliver optimum care and treatment in response to the complexity of advanced illness and end of life

Continue to accompany the person and their carer throughout advanced illness and end of life

Provide the planning and coordination for the Advanced Dementia Practice Model

Provide a structured approach to integrate specific supports to respond to the symptoms of advanced dementia, enhance coping and prevent crisis

Coordinate delivery of the care plan, monitor its effectiveness and ensure its timely review

Support the person with dementia dying in their place of choice and support those closest to the person through the bereavement process

Working with the 8 Pillars Team, identify critical points when the person and their carer require alternative or additional interventions and facilitate the contribution of the Advanced Dementia Specialist Team

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Advanced dementia practice model: understanding and transforming advanced dementia and end of life care

Increasing life expectancy means more of us will experience dementia and the proportion of people dying with dementia will grow. Advanced dementia presents the most complex phase of the illness and calls for a coordinated and planned approach to care.

This report sets out an integrated and comprehensive approach to supporting people through the advanced phase of illness and at end of life. The Advanced Dementia Practice Model combines the skill and understanding of the 8 Pillars Team and the Advanced Dementia Specialist Team in providing optimum care.

Building on developments in post diagnostic support and community support, the Model will enhance the quality of life, resilience and comfort of people living with advanced dementia. The Advanced Dementia Practice Model provides Health and Social Care Partnerships with a blueprint for delivering integrated dementia care.

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