# TABLE OF CONTENTS

## INTRODUCTION  
3

## HIGHLIGHTS  
4

## DISCUSSION  
5
- DEMENTIA AND PALLIATIVE CARE  
5
- QUALITY OF LIFE  
7
- QUALITY CARE  
9
- THE FAMILY  
14
- PROFESSIONAL SUPPORT  
16
- EDUCATION AND INFORMATION  
18

## STORIES  
20

---

**Respect, Dignity, Support**  
*Palliative Care for People with Dementia Conversations 2015*

Prepared by  
Phil Saunders  
Policy Officer  
Alzheimer’s Australia SA

Published by  
Alzheimer’s Australia SA  
27 Conyngham Street, Glenside SA 5065  
Telephone: 08 8372 2100  
www.alzheimers.org.au

© Alzheimer’s Australia SA  
ABN 36 236 331 877  
ISBN 978-0-9872055-7-5  
For information and advice contact the National Dementia Helpline  
1800 100 500  
(NDH is an Australian Government initiative)
INTRODUCTION

Consumer Forums

In September 2015 Alzheimer’s Australia SA held four forums across Adelaide for people living with dementia, their carers, families and service providers, to discuss palliative care for people with dementia.

Participants shared their experiences across the following questions:

- What are top challenges about palliative care?
- What does palliative care mean to you?
- What are the most important aspects in palliative care?
- What are top key actions that are required for palliative care?

Alzheimer’s Australia SA introduced the topic with presentations by Palliative Care Project Worker, Lyn Stone and SA&NT DTSC Educator, Helene Hipp who outlined two projects to be available in 2016. These projects are a palliative care assistance package for families and staff at aged care facilities and an End of Life/Dementia e-learning course for health professionals.

Themes from the Literature

Helene Hipp also reported on recurrent themes in the literature:

- There is a lack of knowledge, understanding and recognition by many health professionals and carers that dementia is a life limiting disease.
- Prognosis in advance dementia is difficult to predict due to age at diagnosis, presence of comorbidities and various other factors.
- People with dementia are subjected to more intrusive and burdensome interventions than other terminal groups.
- There are poorer diagnosis and treatments of pain for this group.
- The need for early advance care planning is very important. Many studies show that good advance care planning equates to less invasive interventions at end of life stage.
- There is a need to identify the latest research on the efficacy of the use of antibiotics and feeding tubes. There is not good evidence that these have any benefit. In some research outcomes have been shown to be worse.

- Undergraduate learning in health professions is very ad hoc and limited for both palliative care and dementia.

One hundred and four people attended the forums, with several carers unable to attend completing a questionnaire.

In addition the issue of palliative care was discussed at the Alzheimer’s Australia SA consumer reference groups – the Alzheimer’s Consumers Alliance SA, the Younger Onset Dementia Consumers Reference Group and the Residential Care Consumers Reference Group.

In total one hundred and forty three people participated, including ten people with dementia, seventy carers and sixty three service providers. A number of service providers also shared personal experiences of caring within their families.

Reports of discussions on palliative care and end of life by the Alzheimer’s Australia SA 2009 – 2010 Residential Care Reference Group were also noted.

The Forum Opportunity

People living with dementia, their families and carers are integral to informing the development of services that best meet their needs. Consumer forums provide a means for these people to share their experiences on particular topics and explore what could and should be done to support them.

The involvement of service providers in forums such as those on palliative care adds a further dimension.

Forum discussions are informal conversations based on open-ended questions within the core agenda. This results in a broad range of responses, extensive sharing of information and experiences and a large number of recommended actions. At the Palliative Care Consumer Forums Post-it Note exercises were used as an additional technique.

Comment Sheets give the participants an opportunity to add to the round-table conversations.

People unable to attend are invited to fill in a questionnaire based on the comment sheet.
HIGHLIGHTS

Dementia and Palliative Care

- Palliative care is understood as being care at the end of life.
- Palliative care could provide for a ‘good death’.
- There needs to be greater recognition in the community and by care professionals that dementia is a life limiting illness.
- A tailored, person specific palliative approach should begin at the diagnosis of dementia.

Quality of Life

- The aim of palliative care for people with dementia should be to provide the best quality of life possible.
- Respect and dignity for the person are cornerstone principles in maintaining the quality of life of people with dementia at end of life.

Quality Care

- The basis for providing quality care is to create a culture in which this takes place.
- An early assessment of approaching end of life enables appropriate symptom and care management.
- Meeting the person with dementia’s needs requires an individualised approach.
- Understanding and overcoming the limits of communicating by and with a person with dementia is a key factor in providing care.
- Advance care planning to outline the person with dementia’s wishes should be undertaken as early as possible.
- A person’s advance care plan needs to be observed in consultation with family.
- Recognition and management of pain is vital to ensuring the comfort of the person with dementia in palliative care.
- Care management is providing flexible treatment to enable the person with dementia to live well.
- Medical interventions should be appropriate to the care, not just prolonging life.

The Family

- Families play an important role in being with, supporting and advocating for the person with dementia in palliative care.
- Staff gain valuable insights into the person with dementia by listening to the family.
- Supporting families during the palliative care process enables them to care and deal with their own issues, in particular grief and loss.

Professional Support

- Consumers need easy access to information about available palliative services.
- Link workers would ensure consumers were connected to appropriate services.
- Residential care facilities are palliative care institutions.
- Residential care facilities should provide personalised, flexible care within a structured approach.
- Care staff at all levels and in all settings should be highly skilled in the palliative care of people with dementia.

Education and Information

- The ongoing education of the community and care professionals through a range of programs would result in the greater understanding of dementia and palliative care.
- Through education consumers become better prepared for end of life situations.
- Dementia care, complemented by palliative care with a dementia component, should be compulsory for aged care, health and community care professionals.
DISCUSSION

DEMENTIA AND PALLIATIVE CARE

- Palliative care is understood as being care at the end of life.
- Palliative care could provide for a ‘good death’.
- There needs to be greater recognition in the community and by care professionals that dementia is a life limiting illness.
- A tailored, person specific palliative approach should begin at the diagnosis of dementia.

What is Palliative Care?

Participants understood palliative care as being care at the end of life, “during the final stages of life”: “someone caring for you”; “taking care of a loved one at the end of their life”.

“A help to an end.”

As one participant, mirroring the general understanding, explained, “At the end of life palliative care is preparing for death, preparing the family”.

They recognised that, “If one has palliative care, there is a better experience of death”.

“If “your mum has entered the terminal phase of life” how can we make that a good experience?”

As one participant explained, “If we take the palliative approach to care, end of life can be handled in a better way. End of life is every bit as important as the rest of our journey in our lives”.

One carer reported being traumatized because there was no palliative care for the person with dementia.

This care, “when there is no curative effect”, was about looking after the person’s needs with best care, using a holistic approach. As one participant explained, “Providing a comfortable symptom managed natural as possible death; supporting people and families respecting them through the process in a holistic manner”.

Providing a quality of life was central to the care, in particular relieving the symptoms experienced by the person toward the end of their life and making sure that the person was comfortable and free of pain.

Participants recognised that complementary to the care for the person with dementia was caring for the carer. “Being there for the family when needed” was a vital part of the process.

As a service provider explained, “(Palliative care) includes medical/clinical care as well as a range of therapies to provide support that helps make clients as comfortable as possible and carers function at optimal capacity”.

Participants were concerned that there was still a stigma attached to palliative care. They told of examples where people did not want to talk about dementia or palliative care because “this wouldn’t happen to me”.

“The term palliative care makes people nervous because of the experiences of people about palliative care.”

Issues for the process included an understanding of the palliative care process, what services could be accessed, making the decision to begin palliative care and having the difficult conversations with the person with dementia and across families regarding the onset of death and associated physical changes.
Dementia and Palliative Care

Participants were concerned that people with dementia were “overlooked in all areas: community, hospital, residential facilities, associated with a lack of understanding, education or advocacy for people with dementia”.

Participants observed that “the community needed to be aware of the importance of palliative care and dementia”.

They were concerned about the community’s lack of awareness and understanding of dementia as a life limiting illness, that people with dementia were “end of life”. They were particularly concerned that many professionals shared this lack of understanding.

Palliative services were more often geared toward malignant conditions such as cancer, rather than chronic conditions such as dementia.

“Recognition that dementia is a terminal illness. It is not always seen as palliative: it’s a long death.”

Participants wanted recognition that there was a need for palliative care for people with dementia. This recognition was to be complemented by the initiation of a palliative approach and pathways early in the palliative journey.

They were concerned that palliative care services were not often aware of dementia presentations and responses.

Participants wanted a tailored, person specific palliative approach for people with dementia. Palliative care should be taken “out of the nursing side of things to become care on its own”.

They spoke about the difficulties in deciding what to tell the person with dementia, in trying to explain things when the person with dementia was “still in denial after nearly nine years”.

Many argued for contact to be made with a palliative care team when a person was diagnosed with dementia, that this would assist in “determining what you want to do at the end of life: the role of palliative care”. Participants cited examples of ‘one stop shops’ catering for people living with dementia from diagnosis to the end of life.

Participants were concerned that palliative care services had a ‘physical’ focus. The issue was one of a “timeline associated with dementia” but palliative care was not limited to a specific age group. In addition the length of time a person with dementia was in palliative care varied widely.

Participants recognised the further complications with the existence of co-morbidities, whether they were mental health or physical health issues.
QUALITY OF LIFE

- The aim of palliative care for people with dementia should be to provide the best quality of life possible.
- Respect and dignity for the person are cornerstone principles in maintaining the quality of life of people with dementia at end of life.

Respect and Dignity

Respect and dignity for the person remained key principles in maintaining the quality of life of people with dementia during the palliative care processes, according to participants.

“End of life with respect, care and dignity.”

Central to respect and dignity was maintaining the rights of people with dementia, with the person with dementia being treated “as a participating human being”, being “respected as a person and ‘heard’”.

“The person with dementia is still a person.”

Respect meant treating each person as an individual, adapting the approach to the individual from day to day, accepting any changes in their behaviour.

Every person entering care, participants maintained, had a right to a ‘palliative approach’.

Respect included the knowledge of the wishes of the client/patient and that immediate relatives were kept informed and involved.

This palliative approach was a care that respected the individual’s desires and choices, that created opportunities for the person with dementia to have choices, was peaceful, minimised pain and suffering and provided best care with compassion. Participants wanted the focus to be on “their strengths not weaknesses”, “keeping them happy and feeling important” and providing them “with a sense of purpose/meaning”.

As one participant explained, this was “to maintain their dignity, and their independence safely with their consent on their needs as can reasonably be acquired, to endeavour to maintain a life, structured safely with contact with family and friends”.

Respect and dignity, as participants explained, was “the chance to look after someone in the last stage of their life in a holistic way”, with “love, seeing the inner spirit of the person” and having the person “surrounded with nice feelings and warmth”, and “care, touch, music, aromatherapy”.

One example of a respectful approach was for staff to “introduce themselves each time”.

It was important to respect the privacy of the person with dementia in their final stages. Recognising that many older facilities had double rooms, participants asked for the provision of single rooms. They observed that it was “uncomfortable for families at such intensive and emotional time to be in a room with other people”.

Quality of Life

Participants reported being challenged at seeing the person they loved “deteriorate and lose their dignity”, at being “very afraid of what was happening to them”, at their “increased confusion and distress”.

Carers told about partners, still at home, who “would rather die sooner as she knows what’s coming”; for whom it was “not a good life; I just feel so sorry for her”; that “they would not want to live like this” and for whom they just “wanted suffering to end”.

Participants wanted the best quality of life possible for themselves as people with dementia or for the person with dementia.

“To seize the day – while you have life; don’t die before your time. Live a good life but have a good death.”
Where, they asked, does saving a person “stop and change to letting them die”? When was “enough, enough”?

Dignity included “not driving to extend life”, but rather helping “in deciding when best to assist in allowing death”. It provided for an “acceptance of death, giving the person and family the chance to talk about it, giving them permission to die, to go in peace”.

The dying, then, would be “with dignity and a high level of care and support for carers”.

“The right of every human, regardless of diagnosis to have a ‘good death’.”

Participants wanted palliative care to be about “supporting that person to live the best possible quality of life”.

For the participants quality of life considerations included “keeping the person with dementia occupied in a meaningful way”, taking the time to spend with the person “so they felt valued and cared for”, maintaining good health through diet and exercise and tapping into “the faith/spiritual heart of the person”.

As one participant explained, quality of life was, “An approach that incorporates a holistic approach, person centred care focussed on the person with the life limiting illness, and their family/carers/significant others. It provides impeccable assessment of symptoms and management of symptoms including pain, weakness, fatigue, nausea, vomiting and shortness of breath to maintain the best quality of life.”

Care workers spoke about the importance of a “peaceful environment” and allowing the resident in care “to remain in their familiar room with their own things when care becomes palliative”.

The most important aspects for one care worker were “understanding dementia, being patient, probably firm and being well, strong and caring”.

QUALITY CARE

• The basis for providing quality care is to create a culture in which this takes place.
• An early assessment of approaching end of life enables appropriate symptom and care management.
• Meeting the person with dementia’s needs requires an individualised approach.
• Understanding and overcoming the limits of communicating by and with a person with dementia is a key factor in providing care.
• Advance care planning to outline the person with dementia’s wishes should be undertaken as early as possible.
• A person’s advance care plan needs to be observed in consultation with family.
• Recognition and management of pain is vital to ensuring the comfort of the person with dementia in palliative care.
• Care management is providing flexible treatment to enable the person with dementia to live well.
• Medical interventions should be appropriate to the care, not just prolonging life.

A Culture of Quality Care

Participants described the aspects of a quality care culture as an individualized, one on one, holistic, multidisciplinary approach, maintaining trust and dignity and “keeping them safe” within the appropriate environment, whether that be at home or within a residential facility or hospital setting. There would be “caring people all the time with the person with dementia”.

“Appropriate, timely, best practice care.”

The people with dementia would be “treated with kindness”, “shown lots of love, surrounded by family and friends”. There would be “time appropriate, accessible, meaningful care” within a “peaceful environment for patient and relatives”. Carers and care workers would offer “reassurance – constant” with patience and “soothing tones”.

Service providers and carers would endeavor to understand the needs of the person with dementia, and communicate to the person to help them understand what was going on regarding any changes of care, so that they would “know that I’m accommodating to their needs”.

Accommodating needs included providing an “emotional balance between the medical and the personal”, supporting a person’s emotional, spiritual and cultural needs as required.

“Providing really good care to one when (generally) one is dying.”

There would be recognition of early changes in the person with dementia, facilitating an early start along the palliative pathway.

Carers were encouraged to “set aside time during the day to interact with the loved one (providing full attention) if necessary organize structured activity of the loved one’s choice”.

---

Palliative Care for People with Dementia Report of Conversations 2015

9
Participants were concerned that staff in residential care did not have enough time to give the residents one on one time. They observed a lack of adequate community support, respite and hospice care. More funds were required to improve the availability of one on one time, respite and hospice care. Participants wanted a consistent approach within facilities and across the sector. Such care was “important in our society”.

**Assessment and Diagnosis**

Participants regarded getting a “timely and appropriate” diagnosis of dementia as key to accessing services for the person with dementia, including appropriate palliative care, professional information and “ready access to an ACAT assessment”.

They sought an understanding by professionals and the community that dementia was “a physical degenerative disease”.

They expressed concern that palliative care was not mentioned at any time by health care professionals at diagnosis or afterwards. This resulted in carers asking, “Where do we go, what do we do, what care is available?”

Participants sought the inclusion of palliative care as a concept at diagnosis and a following discussion about advance care directives.

They wanted assistance with early recognition that the person with dementia had reached the palliative stage, in particular to enable “correct/accurate assessment and symptom management”. They sought a recognition that a diagnosis of dementia did not limit palliative care services.

**Meeting Needs**

Participants shared their desire to meet the needs of the people with dementia in palliative care. They wanted to make sure that the needs of the person were understood, that “all their needs were met”, their “wishes enacted”. They wanted “accurate assessment and symptoms management”.

They were concerned at comments such as, “When I needed help I couldn’t get it”.

Informal support and formal organisational support included “being aware of a person’s background likes/dislikes”, knowing “the person’s individual needs”.

Finding the person’s wishes was seen as part of the definition of palliative care, to “ask people what their wants were, not just focussing on treatments”, for people “to have a choice in their care”. Participants wanted an individualised approach in care delivery towards the end of life.

“Palliative care means that my husband can carry on living safely with as much independence that is supported and structured to his needs.”

Participants expressed concern at the difficulties in “trying to fulfill the wishes of your partner, interpreting them”. New issues got “ignored or overlooked because of existing care”. People with dementia got “overlooked in any environment, community or facility”.

Service providers expressed their concern at the lack of “adequate funding and supply of equipment to meet the needs of the palliative client group”.

“Getting the help I need” included trying to “continue to provide meaningful activities for as long as they are able to engage in them”, “encouraging cultural and spiritual needs for the person and family as required and requested”, offering support groups and “forever trying new things to see what works”.

Family members wanted professionals to talk to the families and include them in processes and decisions and provide more responsive answers and services when families were requiring help.

**Communication**

Participants shared their concerns at the “decreased ability to communicate” by people with dementia as they approached the end of life as a major barrier to people with dementia receiving the quality care they needed. The “loss of communication and interaction with a loved one” was keenly felt.

Early conversations about future care could be hard “because the person of concern loses their sense of reality; they have their own reality”.
People with dementia were unable, participants reported, to verbally communicate exactly how they felt, their wants, needs and desires, their wishes for end of life care to maintain their comfort if there was no advance directive, to communicate to their GP what they wanted, or ask for assistance with toileting or pain. In some cases they were not able to let others help them.

People with dementia became afraid from the lack of comprehension due to their inability to communicate their wishes and needs. For people from culturally and linguistically diverse backgrounds reverting back to an original language made it even more difficult to communicate.

This “communication deficit” as one participant described it, led to “lots of misunderstanding, confusion”. Family members and care workers were dealing with the confusion, anxiety, stress and different behaviours of the person with dementia that resulted from their inability to communicate.

Care workers reported on their own concerns about “not knowing how to talk to people with dementia”, on the “miscommunications” and the “misinterpretation of client’s needs”. The importance of communication was not appreciated in a culture that was “very task focussed, not care focussed”.

Participants described focussing on non-verbal communication, in particular “human facial expression” and senses as central to overcoming communication barriers.

They sought the education of care workers and open discussions with families about the person with dementia’s nonverbal clues. Communicating with the person with dementia would be assisted through “being a good listener and being aware of triggers if the person is unable to speak”, by “talking slowly, speaking with smooth speech” and by “re-explaining something carefully”.

It was important not to “over-see things in palliative care in relation to the resident with dementia because they can’t express themselves”.

Clear and essential communication with all parties involved such as the family and the GP was required.

Advance Care Planning

In meeting the needs and wishes of the person with dementia in palliative care, participants recognised the value of advance care planning, in particular the completion of advance care directives, outlining an “end of life pathway”.

“In having my wishes, needs met in my last stage of life and that I am as pain free as possible and able to have my friends and family to understand what I am going through and to be treated with respect as directed in my care plan.”

Participants were concerned that the person’s wishes could not be fulfilled if advance directives were not in place. They recommended that advance care planning take place as soon as possible following a diagnosis of dementia to “have discussion about what is wanted”, to, for example, outline “what medical treatments they wished to receive”.

Completed plans would “set things in place while people have capacity”.

As participants with dementia explained, “Don’t leave it until the last minute to tell family. Aged care facilities and others do not know what to do. You need time to work everything out, to get things off the ground.”

“Along with other documents about end of life care it matters about stating what you want.”

Participants raised the question, “Who makes decisions when palliative care comes into play, including guardianship or the person with the Power of Attorney?”

They recognised that advance care directives in particular gave the people recognised as the person with dementia’s guardian “permission to implement decisions, permission to make hard choices”.

From a caring point of view professionals would be “gaining an understanding of how the person wishes to die, at home, at a hospital, with family and the key people”.

“Being understood and responded to appropriately.”
Participants were concerned, that even with advance care directives in place that the wishes of the person with dementia were not always respected and followed. As one participant explained, “Due to historical services and education to me, following the plan doesn’t always happen. Health service providers need better education and attendance at annual updates”.

Participants wanted everyone who had any contact with people with dementia to be aware of the decisions made by the person with dementia and to treat/look after them accordingly so that all their needs should be met, to help them “keep their independence and rights”.

They wanted people to ensure that when the advance care directives were known that they would be understood and obtainable. The issues of advance care directives and consent should be discussed with families and clients.

They urged carers to insist on an adherence to the person’s wishes, ideas and requests as outlined in advance care directives, because many had experienced care staff and GPs overriding the wishes outlined in advance care directives. Informed consent and decision making meant keeping the individual involved.

Participants sought improved and regulated communication between residential age care facilities and hospitals regarding end of life care wishes. They wanted the legal enforcement of a person’s end of life wishes in acute care.

Participants recommended that hospitals provide for a “dedicated provider of advance care planning in the acute care setting”. People were to be encouraged to complete an advance care directive on arrival at a facility should one not exist.

They recommended a campaign to promote advance care directives, to encourage and advocate regarding the importance of advance directives for all clients/carers. The campaign would include “designated programs with workshops to discuss advance care directives” and “positive media increasingly talking about advance care directives”.

Participants observed that advance care planning was decision making about death that should be done “before dementia”.

“Everyone should discuss advance care direction.”

Pain Management and Comfort

Participants regarded pain management as vital to ensuring the comfort of the person with dementia in palliative care, “maintaining a pain free end of life with dignity, respect and support”.

“I would like to have good care and be kept as comfortable as possible.”

They spoke about “helping make people who are approaching the end of life comfortable”, “comfort care specially focussed on that person” and having “comfort care measures instituted when the quality of life deteriorates beyond an acceptable level”.

Participants recognised that a major concern for the people caring for the person with dementia was their recognition of the person’s pain. They understood that pain perception by people with dementia varied and experienced the limited ability of the person with dementia to voice their needs and the changes to their pain levels as perhaps pain increased.

Participants asked, “How do we know if they are in pain?” if they “can’t tell you if they are in pain”, can’t “express how they feel with physical and emotional pain”.

Carers relayed their experiences of “trying to get or read signs from a partner regarding pain”.

“Pain: as a carer or nurse or family member know the person, try to understand the signs, the nonverbal communication.”

The challenge in this situation was to overcome a lack of knowledge of the person’s pain, to recognise when they were in pain and unhappy and uncomfortable, to avoid a poor diagnosis of pain and to manage pain appropriately and effectively.

Participants sought care regimes where there was “an understanding of the process involved with treatments ensuring the people with dementia were comfortable”, where staff “showed compassion and dignity”.

Participants wanted a culture of “gentle pain reducing treatment”, “ensuring practices were pain free, taking note of facial expressions, providing meaningful activities”, in which “families and friends were supported”.

“Everyone should discuss advance care direction.”
Recognising that the issue “was identifying what was pain, and what was not” and that it was “difficult to know what was causing behaviours but the person with dementia can’t communicate”, participants wanted treatments of the pain, separating out pain from Behavioural and Psychological Symptoms of Dementia (BPSD) behaviours.

Pain/symptom management, “sometimes underutilised” according to one participant, included regular pain medications, rotating the person in bed, using meth swabs, keeping up with hygiene, pulling out S/C lines and removing oxygen.

One family carer urged other carers to “speak up if you think someone is in pain and keep speaking up until it is addressed”.

Care Management

Participants offered a range of care activity to provide comfort or ease the symptoms of people in the last stages of disease, emotional or physical pain.

“Symptom management without disease cure.”

They wanted “flexible treatment not non-care” to enable the person with dementia to “live well”. “What was the point of ‘ticking the boxes’ for example taking blood pressure?” asked one participant.

They understood the importance of providing symptom control. They wanted the appropriate management of pain, nausea, vomiting, swallowing, feeding, oral care, hygiene, pressure areas, nutrition and hydration. They wanted the person with dementia to be “kept warm because often people with dementia feel the cold”.

Appropriate activity, memory books, “bright music”, and “getting them into the sun, into the garden” were other recommendations to overcome negative aspects such as depression.

Service providers sought education on “reading the person’s signs, emotions, pain and responding appropriately”. They wanted to know “what to do on refusal to eat or take medication”. They were concerned to understand that the person with dementia was not “resisting because they lashed out and became violent”. They wanted to be able to manage deteriorating behaviours without the use of medication.

Intervention

Participants sought clarification about end of life pathways, in particular when to stop “unnecessary life extending medical intervention”. There were too many “grey areas about what ‘interventions’ could be done”.

They wanted better palliative care supports in the community and in residential care facilities to avoid unnecessary hospital admissions which “often were quite threatening and meant invasive burdensome assessments/medications which did little to improve quality of life”.

They wanted close liaison with medical professionals on necessary treatments, on limiting the number of unnecessary presentations to Emergency Departments.

“Don’t prolong the dying process.”

Rather, they wanted “medical interventions that were truly and appropriate to the person with dementia and their family” that did not include “extraordinary means of life extending treatment”. They wanted medical professionals who could go into residential facilities to treat and care to avoid hospital “intrusive/burdensome” interventions.

They wanted choice about “living and dying ‘in place’”.

A number of participants sought further discussion on assisted end of life. As one participant explained, “I am an advocate for assisted end of life but how does a person with dementia let you know they are ready?”
THE FAMILY

- Families play an important role in being with, supporting and advocating for the person with dementia in palliative care.
- Staff gain valuable insights into the person with dementia by listening to the family.
- Supporting families during the palliative care process enables them to care and deal with their own issues, in particular grief and loss.

Participants reported the vital role of families in preparing the person with dementia for their experience of the palliative stage and in supporting them and advocating for them at that time.

Palliative care was recognised as an intimate experience for families and the staff of the community or residential organisation. It was important to consider the knowledge, experiences and expectations of all parties.

Involvement and Inclusion of Families

Participants reported that interaction with the family included understanding their potential involvement in the terminal phase.

They recognised the value of staff “taking time to sit down with the resident and family to recognize problems like pain, discomfort”, of staff talking with families, listening to them and discussing with them the person with dementia’s wishes, including when to follow medical comfort measures only, what they enjoyed and what worked when ‘problematic behaviours’ occurred.

“For a person with no insight; listen to the family member. ”

Participants wanted “quality engagement between staff, resident, family”. They encouraged others to “have family, friends, carers, someone with the patient”.

Carers thought that staff should “listen to the carer, responding as though they were important and acting upon their understanding of the physical and emotional needs of the person with dementia, with, for example, exercise, physiotherapy, pain relief”.

Service providers recognised the value of discussions “with all the family”, “being much more informed about the complexities and sharing with family” but acknowledged that that was “a long way off”. They acknowledged the need to “cater to family as well as the individual who was ill”, to “support the family and include them in decisions” “at all times”.

This would avoid such examples as one reported by a participant,

“In residential care the last twenty four to forty eight hours were particularly poor. The family was really involved over the last two to three weeks but not one person asked the carer how she thought her mother was feeling or how the carer was doing.”

Carers were encouraged to “make sure you know all the details from the doctor and that the nursing home is giving pain relief”.

One recommendation was for people to consider case conferencing “involving everyone, GP, family RN etc. include a palliative care consultant if necessary to interpret and explain” when necessary.

Supporting Families

Complementary to the acknowledgement of the important role of families, participants recognized the need to support carers and other family members.

“For a person with no insight; listen to the family member. ”

Participants wanted “quality engagement between staff, resident, family”. They encouraged others to “have family, friends, carers, someone with the patient”.

Carers thought that staff should “listen to the carer, responding as though they were important and acting upon their understanding of the physical and emotional needs of the person with dementia, with, for example, exercise, physiotherapy, pain relief”.

Service providers recognised the value of discussions “with all the family”, “being much more informed about the complexities and sharing with family” but acknowledged that that was “a long way off”. They acknowledged the need to “cater to family as well as the individual who was ill”, to “support the family and include them in decisions” “at all times”.

This would avoid such examples as one reported by a participant,

“In residential care the last twenty four to forty eight hours were particularly poor. The family was really involved over the last two to three weeks but not one person asked the carer how she thought her mother was feeling or how the carer was doing.”

Carers were encouraged to “make sure you know all the details from the doctor and that the nursing home is giving pain relief”.

One recommendation was for people to consider case conferencing “involving everyone, GP, family RN etc. include a palliative care consultant if necessary to interpret and explain” when necessary.

Supporting Families

Complementary to the acknowledgement of the important role of families, participants recognized the need to support carers and other family members.

“Concern for spouses/family member surviving without drowning.”

This support was being provided “through a difficult time, listening to family needs and expectations, in particular to provide support after the family member has passed.”
Carers reported watching a loved one feel lost/confused and at the “changes in the relationship dynamics” as the dementia progressed. As one participant observed, “long relationships, such as being married for fifty eight years, makes a big difference to how to approach the situation”.

As another participant outlined: “Palliative care to me as his carer means I can continue to maintain as healthy and engaging a life and relationship meeting my husband’s need, with my husband and my other loved ones, and continue to maintain my independent living.”

Support for the family included consideration for the mental state of carers and family, helping the family cope with the frustrations of the decisions they had to make, to focus on the family and friends as they began the process of grieving, in particular caring for the carer if their partner had died.

“For family members who cannot accept they have ‘lost’ their parent they are losing them again.”

Residential care providers were urged to “have a comfortable environment for the family to be able to be with the person with dementia, plus having the emotional support through that time, with an opportunity in the palliative care situation to stay by the side of/spend time with the person with dementia”.

A number of providers reported that they had “a trolley and space for the family”, but continued to ask, “but what can I do, things I can improve on”.

Support also included education for people and their families early in the process, for example at diagnosis, to help carers “understand what is happening to their loved ones”, on what to do and how to access information, on their rights and to provide a ‘go to’ person when issues arose.

Participants reported on the challenges of providing support for the carers to look after their loved one at home, of teaching carers effective hands on care techniques, for example transfers, of the difficulties if children lived interstate and other relatives, friends or service providers were providing the care.

Grief and Loss

Participants observed that dealing with grief, loss and the fear of the person with dementia and people around them was of major concern.

They were particularly concerned at the “gaps in understanding of the grief and loss during the time of supporting the person with dementia and the level of support required”.

You could not “show you were upset”. Australians were “hopeless at grief. They don’t like it if you cry. Even other members of the family didn’t understand what the carer did and went through”.

“People don’t understand the grief the carers and family feel. It is like the person has died twice.”

As one participant explained, “It seemed that no-one cared for the person’s quality of life. They did not understand the ambiguity of the grief nor the impact of the grief”.

Participants were also concerned at the “hidden grief” in culturally and linguistically diverse communities where it was observed, “people get to a crisis because there is no support from other people”.

One participant observed a funeral industry connection. Funeral parlours were “often the first to realise and assess the status of families, particularly with a new widow or widower”.

Participants observed that dealing with grief, loss and the fear of the person with dementia and people around them was of major concern.

They were particularly concerned at the “gaps in understanding of the grief and loss during the time of supporting the person with dementia and the level of support required”.

You could not “show you were upset”. Australians were “hopeless at grief. They don’t like it if you cry. Even other members of the family didn’t understand what the carer did and went through”.

“People don’t understand the grief the carers and family feel. It is like the person has died twice.”

As one participant explained, “It seemed that no-one cared for the person’s quality of life. They did not understand the ambiguity of the grief nor the impact of the grief”.

Participants were also concerned at the “hidden grief” in culturally and linguistically diverse communities where it was observed, “people get to a crisis because there is no support from other people”.

One participant observed a funeral industry connection. Funeral parlours were “often the first to realise and assess the status of families, particularly with a new widow or widower”.

Participants reported on the challenges of providing support for the carers to look after their loved one at home, of teaching carers effective hands on care techniques, for example transfers, of the difficulties if children lived interstate and other relatives, friends or service providers were providing the care.
PROFESSIONAL SUPPORT

- Consumers need easy access to information about available palliative services.
- Link workers would ensure consumers were connected to appropriate services.
- Residential care facilities are palliative care institutions.
- Residential care facilities should provide personalised, flexible care within a structured approach.
- Care staff at all levels and in all settings should be highly skilled in the palliative care of people with dementia.

Links to Services

Knowledge of Services

Participants observed the need of consumers for improved knowledge of the available palliative care services.

They wanted to see links between service providers and peak agencies such as Alzheimer’s Australia SA and Palliative Care Australia.

They wanted to “look at who was doing what and not ‘reinvent the wheel’”.

Participants sought training and education regarding services that were available at palliative care time, not only for consumers but also for nursing home staff and GPs.

They wanted information packs for professionals and families that included the palliative care process and clarified how to access relevant information to assist in finding appropriate services for them.

One action explored was for service providers to look at options for employing qualified care managers to be the face who recognise when clients with dementia, whether at home or in a residential care facility, were approaching the palliative care stage so that appropriate palliative care could be provided to the clients.

Links to Services

Consumers expressed their need for “someone to turn to for advice”.

“Any help as a carer is helpful. It is a minefield out there.”

Coordination of the help that was available was a requirement to better access respite care, palliative care and medical and nursing assistance.

When a consumer was deemed as palliative, by a GP or a palliative care service, they should be able to have access to palliative care services in the community.

Concerns outlined by participants included “premature placement in residential care” if people needed services after 9.00pm or overnight. There were problems accessing the My Aged Care Gateway, particularly for people without computers. People were getting referrals to specialists “after twelve weeks of actively trying”.

People with younger onset dementia who could not get an ACAT assessment were being “sent off to disability” with mixed outcomes.

Link nurses and case managers to coordinate services were two suggestions from participants to link consumers with the services they required. They were to be “key workers with a palliative care background who have experience in dementia understanding”.

Aged Care Facilities

“Residential care facilities are really palliative care institutions”.

Participants acknowledged the central role of palliative care in aged care facilities. Their observations ranged from “one third of nursing home care is palliative care mainly for pain relief”, through “residential care facilities are doing quite a lot with palliative care at various levels” to “residential care facilities are really palliative care institutions”.

Staff should, therefore, “be educated that they are nursing terminal patients”.

They understood that the decision about when to go to a nursing home where the nursing home would decide the degree of palliative care was a difficult one.

Participants also acknowledged that there was “much up-skilling of aged care facility staff, with different facilities having different practices”.

They noticed that “in residential settings there were lots of procedures for staff to follow but it was the ‘little things’ that made a difference”.

Participants asked whether palliative care programs were mandatory for every care facility and if not why it wasn’t part of licensing.

They urged residential care facilities to have a structured approach to palliative care. Within this structure the consumers were looking for flexibility because “everyone is different and everyone’s needs were different”.

They wanted facilities to recognise that palliative care was people oriented. It was OK to “let people know it was fine to hold their hand”. They wanted support for the people involved, the care workers, nurses, allied health, hospitality staff and the person affected and their family and friends.

They wanted residential care facilities to have someone to explain what was happening at the palliative care stage.

It was important for carers to know the person with dementia would not be left alone in their dying stage, even if this meant the cost of extra staff and beds for the family.

Service Provider Staff

Participants observed the importance that people who work in the field, whether that be in the home, in an aged care facility or in a hospital setting, “understand and know how to deal with dementia”.

Consumers were concerned that there were not enough staff trained in palliative care, that they lacked an understanding and training in dementia.

They were concerned that there were not enough staff to implement ideas to keep residents stimulated.

Participants wanted residential care facilities and hospital settings to have highly skilled staff who were supported in understanding the specialised care needs of people with dementia and in making the appropriate responses to their needs and behaviours.

They wanted residential care facilities to make sure that all staff were “on the same page with care”, that they had the skills “in managing confusion and behaviours”.

They wanted staff to be “palliative care advocates” for the person with dementia to ensure “smooth process”.

Service provider staff participating in the forums indicated a desire to be better educated about dementia, including, “I wanted to improve my skills and learn more on palliative care.” “I was wanting training about meshing dementia and palliative care together.” “We wanted to be able to gain more training and more knowledge, to be able to improve our skills to give the residents the best care possible”.

Service Provider Staff
EDUCATION AND INFORMATION

- The ongoing education of the community and care professionals through a range of programs would result in the greater understanding of dementia and palliative care.
- Through education consumers become better prepared for end of life situations.
- Dementia care, complemented by palliative care with a dementia component, should be compulsory for aged care, health and community care professionals.

Participants outlined the importance to them of increasing the awareness across the community that dementia is a terminal illness.

They wanted across community, across sector education specific to the progression of dementia and palliative care at end stages, in particular the role of advance care planning.

**People Living With Dementia**

Participants outlined the value of developing palliative care packages for consumers when it was appropriate. A fact sheet on palliative care, for example, “would validate people living with dementia asking for palliative care”.

People “needed to know what the end stages looked like”, for example if the person was bed ridden and unable to speak.

**The Community**

Participants underscored the importance of communicating to the general public to raise the understanding of the level of dementia and the stages of dementia.

“Continue being ‘out there’ in the community.”

They wanted to see ongoing education for providers and the general public through education programs, training sessions, workshops in schools and general promotion to recognize the issues of dementia and palliative care so that early planning could be implemented.

By service providers spreading the words and information about their organisations “more and more people would become aware of whom to contact for support”.

“Education! Education! Keep making people aware about the disease.”

**The Family**

Participants wanted to know “how much education do you give people without causing undue anxiety?”

They were concerned that providers did not “reinvent the wheel” but rather offered “more for carers, education and discussion and support groups” regardless of whether the partner was in residential care.

They wanted greater access to information for consumers at all stages, ongoing education for families on the supports available for their changing circumstances and how to make the most of the remaining life. It “could be hard to come to terms with changes”.

“I see palliative care as a requirement for the future and would like to understand it better.”
Service Providers

In observing the limits of the knowledge about dementia and palliative care by professionals working with people with dementia, the participants outlined their requirements.

Training for aged care, health, community care and other professionals needed to include dementia care as a speciality that was a compulsory subject, not an optional one.

Professionals needed to know that dementia was a disease oriented process that was not a passing phase but a life limiting disease. As such the inclusion of a palliative approach was a necessity, not an option.

The interaction of dementia and palliative care demanded training in appropriate responses, in the home and in residential care and hospital settings.

The professionals needed to know about dementia as a disease, observing the state of the person with dementia and their needs and the need to involve significant others as substitute decision makers in decisions involving their care.

Consumers wanted the service providers, whether GPs, other doctors, nurses, clinical staff, residential or community care workers, or ‘behind the scenes’ staff, to be able to recognize the stages of dementia and therefore be able to communicate their observations to family, friends and other services, to be able to refer the consumers to other services.

They wanted the professionals to be able to understand and implement strategies to support and empower the consumers.
**STORIES**

**WHAT IS YOUR PALLIATIVE CARE FOR PEOPLE WITH DEMENIA STORY?**

**Consumers**

My husband aged sixty nine was diagnosed with frontal lobe dementia in December 2013. I cared for him at home with the support of an Alzheimer’s Australia SA key worker and after hours behaviour unit phone support.

I needed to fly to the UK for two weeks in May 2014 and he needed respite care; so he was admitted to BUPA. While at home I enrolled him in three days of day care activities, which did help him to adjust to nursing home.

I returned from my trip to find my husband’s condition had deteriorated. He couldn’t walk, talk or move but he seemed to know I was ‘special’ to him.

I spent most of every day with him singing old time songs etc. His mum and sister flew from Melbourne to visit once a month.

I gave our GP written instructions regarding no antibiotics, tube feeding etc. She organised for QEH palliative care team visit.

The day my husband died his mum and sister flew in to visit. He seemed OK when we left him. I had a call from the nursing home that he was having breathing problems. They gave him oxygen. I and his sister went in to see him. He died peacefully 15 minutes later.

“People with dementia with no support need advocacy.”

A woman with dementia was a widow, having many falls. Her daughter was stressed as she lived three hours away. The widow was proud and did not want to move. The daughter asked, “What do I do?”

Disappointment: that staff are not well educated: that staff bring their own beliefs into play when caring for the person: MOs don’t understand pain management: advance planning is not attended early enough so that the person can determine their end of life pathway.

My husband was diagnosed with frontotemporal dementia at the end of November 1996. He was cared for at home until February 2008 when he went into residential care. He died in May 2015. He was in a palliative situation for many years.

My father was diagnosed with frontotemporal dementia. He was told the disease was terminal, aggressive in progression, with no treatment, no cure. No palliative care input/direction was given.

My aunt was in a nursing home and survived until the very end with her body shutting down. A friend had a fall and broke her hip and was given pain relief and music and touch until death.

“Night shift staff can be special as you can spend time with the person with dementia.”

My partner died in a nursing home and had a very good care. My partner had been a care worker in a nursing home for many years and was very fearful of going into a facility. He became aggressive toward a care worker. How to manage that? I had knowledge of dementia but when it was applied to your loved one it was emotionally hard. There was an impact on the carer when the person with dementia was aggressive. There was communication from the nursing home to the carer about deterioration.

People with dementia with no support need advocacy. There are difficulties with inappropriate care in hospital particularly with single people on their own. There needs to be a buddy service introduced earlier so familiarity builds.
My mother has Alzheimer’s but lives in the UK. I have been back this year and set in place good care at home. I also chose a care home if needed. I talk to her everyday even though she thinks I am with her anyway. My mother-in-law is also in early dementia and she lives close by so all this has been good.

My mother had frontotemporal dementia but in my opinion despite being in a residential facility was never really given a palliative care approach. She only lasted three months.

Stayed with my grandfather overnight, the last night he was alive. He was very uncomfortable, making noises, irregular breathing. I felt unheard although I was pushing the call button every thirty minutes.

My partner had younger onset dementia, diagnosed twenty four years ago. He died four years later. He was the first in the family with genetic dementia. Five out of six siblings have been affected. It was horrific at first.

Now my aunty has been diagnosed. I made a memory book, went to her church, found friends. Her sister in law flew over with her twin. We all visited as a group and individually. I sang to her, read to her, showed pictures, rubbed her hand or held it, gave her drinks, advocated for her and turned her because of pressure sores.

I have this Aged Care Directive in place for my husband who is in a care facility. If he has any illness there will be no prolonging of life by medication. Only painkillers.

My partner came back from hospital much worse, confused, frightened. You need to direct responsibility and care back to the nursing home to work with a professional palliative care team to work towards a good ‘outcome’.

The GP was not listening to my wishes about no interventions. He was not believing that dementia was terminal under sixty five. He needed education in this area. Carers are being manipulated. The nursing home experience is to send people with dementia to hospital so they don’t have to deal with it.

My husband and I have been married twenty six years, together thirty plus years. We share family and two sons. We had a SIDS daughter. My husband had a cardiac history and prostate cancer. He worked thirty plus years in mental health. He had Alzheimer’s diagnosed in 2014. I work in mental health and I am my husband’s carer/wife/partner in life.

Service Providers

Experienced palliative care with a person who did not want intervention. Discussion needs to be had early: guilt.

Working in an aged care facility especially at night it is about best possible practice.

“My aim is to treat all the people with the dignity they deserve at their end of life care, whether they have dementia or not.”

One lady who had dementia, her son is a doctor but he did not want his mother to get opioids for the pain.

One lady had dementia and fractures after a fall. Her family did not let her get an X-ray or get any treatment, so she was in pain (severe pain) in the end of her life.

These two cases conflicted with medical staff’s decision and care. It was hard to care for them during the end of their life.

The doctor was not recognising when palliative care can be ‘commenced/initiated’. It is embedded into doctors to save life.

I was not wanting to transport my partner with dementia to hospital from the nursing home but wanting to have someone go to the nursing home.

My partner came back from hospital much worse, confused, frightened. You need to direct responsibility and care back to the nursing home to work with a professional palliative care team to work towards a good ‘outcome’.

The GP was not listening to my wishes about no interventions. He was not believing that dementia was terminal under sixty five. He needed education in this area. Carers are being manipulated.

The nursing home experience is to send people with dementia to hospital so they don’t have to deal with it.

My husband and I have been married twenty six years, together thirty plus years. We share family and two sons. We had a SIDS daughter. My husband had a cardiac history and prostate cancer. He worked thirty plus years in mental health. He had Alzheimer’s diagnosed in 2014. I work in mental health and I am my husband’s carer/wife/partner in life.
From a caregiving organisation, experiences in providing care for palliative patients in conjunction with health providers/family etc. Found palliative teams very helpful.

I am a care worker in a facility ensuring the personal needs of individuals are met, maintaining hygiene, reducing pain.

I am a personal care worker in residential care. I have looked after many people with dementia at end stage of their life. I want to provide quality of care for my resident and their family. It can be a challenging and difficult time for their loved ones and try to provide tender loving care for them.

"Identifying the resident’s care needs so their end of life can be as pain free as possible, and as respectful as possible. It is a privilege to be able to look after them."

I work in aged care primarily with people with dementia. It can be a challenge sometimes. I work to provide the best care for my palliative residents and listen to family members making the end of life as comfortable as possible. I feel blessed that the resident’s family trust me to be helping their loved one in such a difficult time.

Being able to care for the person with dementia is a privilege for me. Making sure they are comfortable, have no discomfort. Knowing that I am the person that needs to look for signs that they may be in pain, provide mouth care, skin care. Making sure all their needs are met. Being there for their family, friends and also work colleagues to support each other.

Recurrent hospital admission for infections with a client who had advance dementia. She had no advance directive and family could not come to agreement about treatment. The lady endured ongoing suffering via futile treatment.

As a personal care worker then EN in aged care for 16 years I have watched possibly hundreds of people with dementia go through palliative care. Their families, loved ones, friends and other staff. A lot of people struggle with death. It’s been a privilege to look after each of them.

Diversional therapist: part of the palliative care team; being involved with providing resources and care to those in the home on palliative care. So emotional support to families, providing a nice room environment with flowers, music, aromatherapy and liaising with care and nursing staff.

I worked as a social worker student for four months in Mary Potter Hospice.

"I found that it was equally important to provide support to family/carers as for the person who is dying."

I visit a nursing home weekly where dementia patients are being looked after.

I am dealing with residents in end stage of life but advance directive planning is not discussed by family or the paperwork about resuscitation is not completed or not well documented.

I work in an aged care facility with a secure dementia section. I want to learn more with regards to care.

I have worked previously with people in a palliative care setting in a major hospital. I now work in aged care and have ensured that residents have adequate palliative care where able.

Not able to full understand and meet needs of a person who has not expressed wishes, ideas, prior to health decline. If advance care directives in place ensure that these are followed through.

It is quite difficult to decide when to begin palliative care. It is a focus on quality of life. The person with dementia was not respected in hospital. The carer was there to advocate. If the carer was not there needs would not have been met. The hygiene was poor. The physio said that there was nowhere for people with dementia, even though the person had private cover. At one place the OT did not want to work with the person with dementia.

"Working with dementia in aged care: some days are very hard but most days are so special; challenging but special."