

## INTRODUCTION

Palliative care is a branch of healthcare that is concerned with life-threatening conditions, and is involved in the provision of end-of-life care and support to patients and their families by means of early diagnosis, identification of underlying problems, and pain management (Al-Mahrezi and Al-Mandhari, 2016).

The main objectives of palliative care are as follows:

1. Pain and distress management
2. Enhancement of disease prognosis and quality of life
3. Ensuring an active and independent life for the patient
4. Provision of support for families for grief management in the event of patient's death
5. Provision of emotional and spiritual care to the patient and family (Schroeder and Lorenz, 2018)

Death is an inevitable process, and therefore, palliative care is a very important branch of healthcare for patients suffering from terminal illnesses regardless of their age. The main objective is to provide support and comfort to people suffering from life-threatening conditions so that they can live their final days as positively as possible.

# PALLIATIVE CARE FOR PATIENTS WITH DEMENTIA



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## OUTCOME AND LEARNING OBJECTIVES:

The following are the objectives of this resource:

- (1) To understand the relevance and significance of palliative care for patients suffering from dementia
- (2) To understand the barriers in providing palliative care to patients suffering from dementia
- (3) To explore methods for overcoming these barriers to palliative care for dementia patients
- (4) To link best practices with National Palliative Care Standards
- (5) To list down the Principle Guidelines for providing palliative care to dementia patients

## TARGET AUDIENCE AND RATIONALE FOR RESOURCE

This resource will be useful to newly graduated Registered Nurses and third year undergraduate Nursing Students.

The rationale for creating this resource is:

1. To provide information so that the quality of palliative care provided to dementia patients can be improved
2. To provide best practice guidelines so that the main objective of palliative care can be achieved for dementia patients

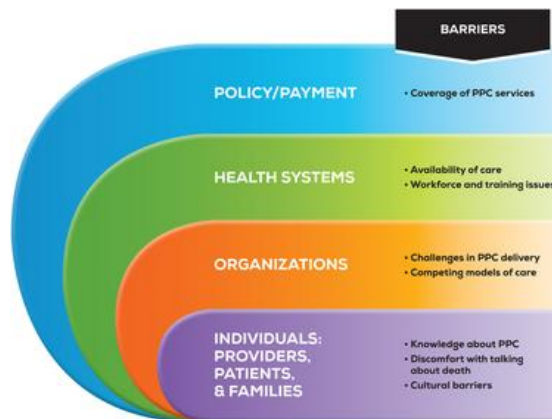
## WHY IS PALLIATIVE CARE IMPORTANT FOR DEMENTIA PATIENTS?

Dementia is a debilitating disorder in the older population, with a global prevalence, leading to significant dependency and disability among the affected. It is characterized by cognitive decline leading to loss of memory, impaired judgement, impact on orientation, and effects on the ability to perform simple everyday tasks (Duong et al., 2017). Statistics published by the World Health Organization (2020) indicate that currently there are around 50 million dementia patients worldwide, and the number increases by 10 million annually. Within the next decade, the number of dementia patients is projected to increase significantly, and therefore, palliative care for this group of patients will become very important. Palliative care for dementia patients ensures that each patient can be the decision-maker for their treatments and healthcare so that their journey can be made as comfortable as possible, especially since this disease affects cognitive function causing patients to lose their ability to take decisions. This places a significant responsibility on healthcare workers who need to keep in mind the different aspects of end-of-life care when providing palliative care for dementia patients.



## BARRIERS TO PALLIATIVE CARE IN DEMENTIA PATIENTS

1. Inappropriate end-of-life care
2. Inefficient planning for advanced care
3. Provision of culturally inappropriate care
4. Mismatch between cultural preferences in the dying process
5. Barrier to communication due to linguistic mismatch
6. Ineffective understanding of the behavioural characteristics of dementia
7. Unavailability of support and services for palliative care for dementia patients
8. Ineffective understanding of the significance of palliative care for dementia patients



## HOW TO OVERCOME THESE BARRIERS?

In a clinical setting, dementia patients who are hospitalized due to co-morbidities may have to go through medical interventions such as arterial blood gas testing and urinary catheters, which may cause pain and distress to dementia patients at the end of their lives. Therefore, healthcare workers need to be sensitive to this and tailor medical interventions such that appropriate end-of-life care is provided to dementia patients (Pandpazir and Tajari, 2019).

An important aspect of palliative care is advance care planning (ACP), which is useful for situations where healthcare workers are unaware of the patient's preferences and may need help from family members in providing appropriate end-of-life care. Dementia patients especially lose their capacity to decide and therefore, may not be able to object to a certain medical intervention that may be distressful for them (Denning et al., 2019). ACP allows people suffering from co-morbidities to inform family members of their end-of-life medical choices before they lose their decision-making ability, so that their wishes can be honoured appropriately.

Another important aspect of providing palliative care is cultural awareness, and the specific knowledge of the concept of death in the patient's culture. Patients with dementia should be paired with healthcare providers from the same cultural background so that religious ceremonies such as confession, holy mass, and pastoral support can be provided appropriately at the end of the patient's life (Fox et al., 2018). Also, all cultures have very stringent end-of-life beliefs, and healthcare workers need to be aware of the patient's cultural preferences regarding end-of-life care so that these preferences can be honoured.

In Australia, several support services and guidelines for palliative care exist that are completely patient-centered. These services should be accessed by palliative care nurses who provide end-of-life care to dementia patients (Elliot et al., 2021).

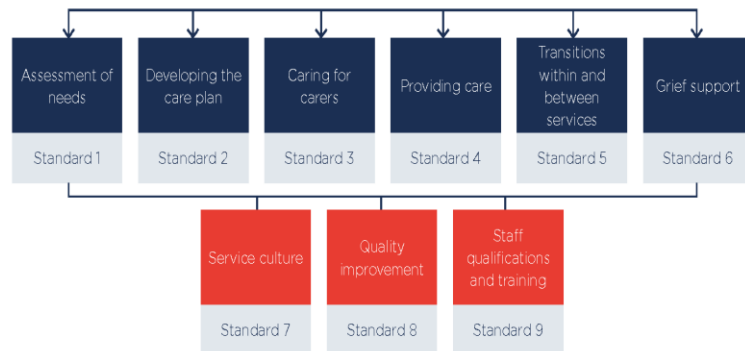
Palliative care nurses should be provided with the appropriate training for understanding the needs of dementia patients. This can be achieved through workshops and training sessions designed for nurses to enhance their skills in providing patient-centered palliative care services. Most cultures consider that a peaceful death is a blessing,

and it is a palliative care nurse's duty to ensure that the patient experiences a peaceful death (Lee et al., 2017).

An important barrier to be considered is communication barrier in the elderly population. In instances when the patient may be a migrant or the healthcare worker may be a foreigner, there may be miscommunication between the staff and the patient leading to dire consequences. Some ways in which this barrier can be overcome are using interpreters, communicating in simple words, using visual cues, listening carefully to the patient, keeping eye contact at all times, and repeating important information to make sure the patient has understood. Body language is another important method to overcome the language barrier as it can signal the level of pain and other needs of the patient (Erel et al., 2017).



Figure 1: The National Palliative Care Standards



## LINKING WITH NATIONAL PALLIATIVE CARE NURSING STANDARDS

The National Palliative Care Standards is a theoretical framework that promotes the importance and implementation of palliative care. This framework signifies the need for providing optimum care and attention to the elderly, recognizing them as a high-risk and vulnerable section of the society. All healthcare workers need to adhere to these standards so that they can provide quality care and enhance the palliative care provided to dementia patients. The framework comprises of 9 standards which provide best practice guidelines, improved patient outcomes, and risk management (Miranda et al., 2019). These standards also require critical thinking and innovation in healthcare workers so that the best palliative care can be provided to dementia patients. They have been created to reinforce the need to provide appropriate end-of-life care to dementia patients and they stress the importance of providing the best palliative care services to these patients.

### STANDARD 1

Assessing the needs: The first step to appropriate patient management is to measure the vital signs and to carry out a comprehensive head-to-toe assessment of the patient. For example, if a routine checkup reveals a low oxygen saturation level, the healthcare worker can administer oxygen therapy and use the semi-Fowlers position to immediately raise the oxygen saturation level of the patient (Eisenmann et al., 2020). If immediate action is not taken, the symptoms may become worse causing the patient to suffer unnecessarily, and therefore, healthcare providers can link to Standard 1 to carry out appropriate assessment of the patient.

### STANDARD 2

Developing a care plan: According to this standard, healthcare workers need to actively collaborate with the patient in developing an end-of-life care plan. This care plan should include the types of medications that may be administered, hygiene-related actions such as oral hygiene,

genital hygiene, and sponge baths, food and fluid intake, and religious ceremonies and observances. This care plan should be developed in a standard format so that if the palliative care nurse changes, the next nurse can have a perfect framework for providing appropriate palliative care to the patient (Huang et al., 2020).

### STANDARD 9

Staff qualification and training: According to this standard, all palliative care staff members should regularly undergo training to enhance their knowledge base regarding evidence-based clinical practice and current guidelines. This training may take place in the form of workshops, print media such as brochures and booklets, and pop-up sections so that palliative care training for providing end-of-life care to dementia patients may take place at an internationally accepted standard.

### PRINCIPLES OF PALLIATIVE CARE

There are 6 principles of palliative care that form the pillars of end-of-life care based on the requirements of these patients. The implementation of these principles helps achieve the objectives in providing optimum palliative care to terminally ill patients.

The first and the most important principle of palliative care is patient-centered care, wherein the patient's decisions and requirements are always placed on the top in all services provided. In order to uphold this principle, it is important that all aspects of the patient's decisions are always considered while providing care. Therefore, the patient

should always be the primary decision-maker and all other family members and care staff should merely be supporters of the patient's choices in delivering palliative care services (Bokberg et al., 2019).



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