​**Palliative care & End of Life Care**

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**What is Palliative care?**

Palliative care (pronounced pal-lee-uh-tiv) is inter-disciplinary care aimed to relieve suffering and imp​​rove quality of life for patients with advanced disease and for their families. It involves a multi-disciplinary team approach, with attention to relief of physical symptoms and provision of social, psychological, spiritual and family support.

It is appropriate along the entire course of an illness, regardless of whether treatment is focused on cure or making someone comfortable at the end of the life.

**General principles of palliative care**

• Clear communication with the patient and family/primary caregiver is of prime importance.

• symptom management is the main focus, physical and psychological.

• Timely discussion over the treatment plan with realistic approach is of utmost importance.

• Treatment involves correcting what can be corrected (e.g., treating oral candida - fungal infection contributing to odynophagia – difficulty in swallowing), counselling to help patients accept limitations imposed by the disease (e.g., a patient with COPD, chronic lung disease may not be able to walk in the garden, but supplying a wheelchair may allow them to go out), and drugs to control symptoms.

• Treatment is planned for each individual with attention to detail, its impact is monitored closely, and it is discontinued if ineffective.

**Who provides Palliative care?**

Palliative Care is multi-disciplinary approach, provided by Palliative Care Specialists, Nurses, Social Workers, Counsellors, occupational therapists, physiotherapists, home care and personal support workers, and volunteers are just some of the people who may be involved.

This team approach focuses on enhancing Quality of Life of the patients and their caregivers, promoting well-being and enables patient to live as well as they can with their life-limiting illness.

**When is palliative care provided?**

Palliative care can be provided to patients of any age & at any stage in a life-limiting illness. Palliative Care should be provided early in the course of illness trajectory to facilitate good symptom control and improve Quality of Life and makes the journey of illness experience positive.

**Where is palliative care provided?**

Palliative care can be provided anywhere, wherever patients are living – at Home, in a Residential Hospice, in Hospital or in a Personal Care Home. The best place to receive care is usually the place that best matches your needs.

Most of the people/patients choose to stay at home for as long as they can. Family members, with support from the Palliative Home Care team, may decide that they want to be the main caregivers in the home. Cities like Mumbai-Thane have supports in place and services to help patients and families provide care at home.

**Who can Benefit from Palliative Care?**

Palliative care is beneficial for patients diagnosed with any life limiting/serious illness, regardless of the stage of illness. It is ideally provided early and throughout the illness, together with life prolonging or curative treatments.

**What is the difference between palliative care and hospice care?**

Palliative care can begin right from the diagnosis along with the curative treatment whereas hospice care begins after the active treatment for the disease is stopped and when it is clear that the person is not going to survive the illness. Hospice care is primarily for the end-of-life care management.

**What is the main goal of palliative care?**

The main goal of palliative care is to relieve the suffering of the patients and their families. The suffering could be physical, psychological, emotional and spiritual.

**Two important points to note during advanced stage of illness:**

Dehydration

• Dying patients drink less (due to weakness, nausea, decreased level of consciousness). When this is chronic, the body slowly adapts and thirst is not felt.

• Good mouth (oral) care is all that is required when decreased intake is part of the dying process.

• Reassure relatives that it is the disease that is killing the patient, not the dehydration.

 “Death rattle”

• The patient is usually unaware. Reassure the family of this.

• If excess secretion is causing distress or discomfort to the patient or the family, use hyoscyamine, glycopyrrolate or a scopolamine patch.

**Important FAQ’s:**

1. *If I agree to palliative care does that mean ‘I am giving up?*

No, absolutely not.

The goal of palliative care is to make you comfortable and help you achieve the best possible quality of life. You can have palliative care while you are undergoing treatments that may cure or reverse the effects of your illness also. In fact, Palliative Care can help you cope with aggressive treatments by getting your pain and symptoms under control to help you fight the disease.
Palliative care also helps patients to complete their disease related treatment

1. *How do I know if palliative care is right for me?*

Palliative care may be right for you if you are experiencing pain, distress and other symptoms due to any life-limiting illness. Life-limiting illnesses include but are not limited to: Cancer, Cardiac Disease, Respiratory Disease, Kidney Failure, Neurologic Conditions, etc. The focus is on symptoms, pain, distress, etc. Palliative care is appropriate at any stage of a life-limiting illness and you can get it along with treatment meant to cure you.

1. *Should I wait for my physician to discuss palliative care or hospice care?*

Absolutely NOT!

As a consumer, you're encouraged to explore all of your healthcare choices. Palliative care professionals’ services with your physician, when necessary, as he/she directs your care. There are many levels of care to consider when diagnosed, and medical care is provided under the direction of your personal physician or by the palliative care team member, as appropriate.

1. *Could I be addicted to the medication used for my pain and symptoms?*

No!
Addiction to medication prescribed for pain relief is a common fear, but is highly unlikely. Palliative Care Doctors are experts in preventing problems and side effects of strong pain medications.

1. *Could taking pain medicine hasten my death?*

No!
Appropriately prescribed medicine will not hasten death. Your Palliative Care Doctor has the expertise to devise a medication plan that makes you comfortable, and is safe.

1. *If I receive palliative or hospice care, will I still be able to see my personal doctor?*

Absolutely!
Your Palliative Care Doctor coordinates care with your other doctors and helps you navigate the often-complex health care system

1. *Is hospice just for last few days or weeks of life?*

Patients are eligible for hospice care if they have very short time to live (as prognosticated by the treating doctor). Unfortunately, most people don't receive hospice care until the final days of life, possibly missing out on weeks of helpful care and quality time.

1. *Does hospice and palliative care centre only serve patients who have cancer?*

No!
Hospice & Palliative Care Center also provides care for patients with chronic and life limiting conditions such as Chronic Lung Disease, Neurological Conditions, Heart Disease, and others. The focus is on symptoms, pain, distress, etc., and on those who have any illness.

1. *Does palliative and hospice care serve only adults?*

No!
The programs and services of Hospice & Palliative Care Center are designed to meet the needs of anyone dealing with a life-limiting illness.
Children and their families are offered a specialized paediatric program, created to meet their unique needs and challenges.

​**G​​uidelines for End-of-Life Care**

A “Good death” is the right of every dying patient. In the UK, a world-wide survey was done for Quality of Death in 2015 and India was ranked 67th amongst 80 countries. With this background, the document for implementation of “Guidelines for End of Life Care, AIIMS, New Delhi” was developed by task forces from various disciplines of health care followed by internal peer review.

The aim of developing the document was to develop practical procedural guidelines to identify the terminal stage of illness, ensure care at all levels – physical, emotional, social and spiritual, to minimize the symptoms and enable dignified dying process for chronically and terminally ill patients.

The document includes the following seven steps-.

❖ Step 1: Recognition of “Futility of Further Management” by primary clinician.

❖ Step 2: Clinicians Consensus on futility of further management.

❖ Step 3: Early and detailed explanation of prognosis with proper communication and documentation of disclosure by patients and/or family members for withholding life support.

❖ Step 4: Assessments before initiation of end-of-life care

❖ Step 5: Continuous assessment of daily supportive care plan

❖ Step 6: Documentation of daily progress note

❖ Step 7: Feedback

**Ber​​eavement**

The period after a loss during which grief is experienced and mourning occurs.

With bereavement, physicians deal primarily with patients grieving over the loss of a loved one, but they also deal with patients grieving over the anticipated and real loss of health, the future, physical abilities, roles, and relationships. Physicians grieve the loss of patients they have cared for. There is a normal grieving process that people experience. Most will adapt, but a quarter will develop major depression or complicated grief reaction. The grieving process is amenable to positive and negative influences, so awareness of those who are at risk can help to target care.

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