## Sengamala Thayaar Educational Trust Women’s College

## (Affiliated to Bharathidasan University)

**(Accredited with ‘A’ Grade {3.45/4.00} By NAAC) (An ISO 9001: 2015 Certified Institution)**

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**DIETETICS**

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**PALLIATIVE CARE**

**Definition**

Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

## Improves Quality of Life

Palliative care teams focus on quality of life. They treat people suffering from the symptoms and stress of serious illnesses such as [cancer](https://getpalliativecare.org/whatis/disease-types/cancer-palliative-care/), [congestive heart failure (CHF)](https://getpalliativecare.org/whatis/disease-types/congestive-heart-failure-palliative-care/), [chronic obstructive pulmonary disease (COPD)](https://getpalliativecare.org/whatis/disease-types/chronic-obstructive-pulmonary-disease-copd-palliative-care/), [kidney disease](https://getpalliativecare.org/whatis/disease-types/kidney-disease-kidney-failure-palliative-care/), [Alzheimer’s](https://getpalliativecare.org/whatis/disease-types/alzheimers-disease-palliative-care/), [Parkinson’s](https://getpalliativecare.org/whatis/disease-types/parkinsons-disease-palliative-care/), [Amyotrophic Lateral Sclerosis (ALS)](https://getpalliativecare.org/whatis/disease-types/als-palliative-care/) and [many more](https://getpalliativecare.org/whatis/disease-types/).

# Chronic Obstructive Pulmonary Disease (COPD) and Palliative Care

Chronic obstructive pulmonary disease (COPD) is a condition in which the airways in the lungs become damaged. This makes it hard for air to flow in and out. Symptoms can include shortness of breath, low oxygen in the blood, coughing, pain, weight loss and the risk of lung infections. People may also suffer from emotional effects such as depression, anxiety, insomnia and social isolation.

A pulmonologist (lung doctor) will help you with the medical treatment of your COPD. But the symptoms of the disease also need careful management. Managing the symptoms and stress of COPD can be very difficult. This is why palliative care can be an important part of your treatment.

## COPD Symptoms and Treatment— How Palliative Care Can Help

Palliative care is specialized medical care focused on treating the symptoms and stress of serious illnesses like COPD.  Palliative care is available to you from the moment you are diagnosed and through the entire course of your illness. The goal of palliative care is to help you, and your family, achieve the best possible quality of life.

Palliative care is provided by a team of doctors, nurses and social workers who specialize in palliative care. The team gives you and your family an extra layer of support.

The palliative care team works in partnership with your pulmonologist and other specialists involved in your care. They will make sure that you and everyone else are “on the same page.” Navigating the health care system is often a challenge, but palliative care teams are experts at this.

Palliative care teams also help manage your shortness of breath by using medications that reduce the feeling of breathlessness. They can treat anxiety and depression with medications as well as talk therapy, massage and relaxation techniques. Having a chronic illness like COPD requires lifestyle changes. Palliative care specialists can help educate you on how to stay as healthy as possible during the course of the disease.

Palliative care teams are there to start and ease discussions between you and your family about your goals and what type of care is best for you.

# Congestive Heart Failure and Palliative Care

Congestive heart failure (CHF) is a chronic condition in which the heart is unable to pump your blood properly. It can cause breathing problems and other symptoms, such as weakness and swollen feet and ankles.

## Treating Congestive Heart Failure Symptoms—How Palliative Care Can Help

Palliative (pronounced “pal-lee-uh-tiv”) care is specialized medical care for people facing a serious illness like CHF. The goal is to improve quality of life for both you and your family. You can have palliative care at any age and at any stage of your illness. You can also have it together with curative treatment.

Palliative care is provided by a team of palliative care doctors, nurses and social workers. They work together with your cardiologist (heart specialist) to give you an extra layer of support.

The team has a wide variety of approaches to treating congestive heart failure symptoms. These may include medicines, but not always.

Palliative care teams are expertly trained to manage symptoms, side effects and stresses. For example, they may perform highly effective lymphatic drainage. This is a technique for reducing leg swelling and its associated pain.

They’ll educate you about how to stand, sit and lie down to improve your breathing. They’ll also train you in the use of fans, relaxation methods, meditation and breathing exercises to decrease any anxiety or panic that may accompany feelings of breathlessness.

## Additional Benefits of Palliative Care for CHF

Palliative care is also there to guide you and your loved ones through all the distress caused by CHF. The team will help you navigate the complex health care system. They will keep you, your family and all of your doctors informed, up to date and on the same page.

Palliative care specialists can help you plan in advance because CHF episodes can become worse, sudden and unpredictable. In fact, one of the most important things your palliative care team can do is help you fully discuss your health with your family caregivers.

The team will use its communication expertise to help you achieve your personal goals while living with the disease.  They understand that every patient and every family is different. The team is there to help you and your family achieve the best possible quality of life as you live with CHF.

# Kidney Disease, Kidney Failure and Palliative Care

Kidney disease includes conditions that damage your kidneys and decrease their ability to keep you healthy. If kidney disease gets worse, wastes can build to high levels in your blood and make you feel sick. You may develop complications like high blood pressure, anemia (low blood count), weak bones, poor nutritional health and nerve damage.

Kidney disease also increases your risk of having heart and blood vessel disease. These problems may happen slowly over a long period of time. Diabetes, high blood pressure and other disorders can cause Kidney disease. Early detection and treatment can often keep chronic kidney disease from getting worse. Kidney disease may lead to kidney failure which requires dialysis or a kidney transplant.

## Palliative Care

Palliative (pronounced “pal-lee-uh-tiv”) care is specialized medical care for people facing serious illness like kidney disease. The goal is to improve quality of life for both you and your family. You can have palliative care at any age and at any stage of your illness. You can also have it together with curative treatment.

Palliative care is provided by a team of doctors, nurses and other specialists who work together with your other doctors to provide an extra layer of support.

## Kidney Disease, Kidney Failure Symptoms and Treatment— How Palliative Care Can Help

The challenges of kidney disease and kidney failure can be profound. In addition to the physical and emotional issues, you and your family also have to make difficult decisions about your care.

Palliative care specialists partner with you, your family, your kidney doctor (nephrologist) and other health professionals to provide pain and symptom management, communication, coordination of care, and family caregiver support.

Managing symptoms is a big part of palliative care. Blood pressure, heart disease, diabetes, depression, anxiety, other conditions, or treatments may cause symptoms. Working closely with your kidney doctor, the palliative care team will help control your symptoms through medicines and other therapies.

The team will also help you make critical decisions about your treatment options, including the one treatment offered to nearly every patient with advancing kidney disease: dialysis.

The team will help you match your goals to your treatment choices. They will help you understand and decide what dialysis might add to your quality of life. And they will help you balance that against any drawbacks.

Palliative care specialists can also help you decide when treatment might be more of a burden than a benefit. Whatever your treatment choice, the palliative care team will work side-by-side with your nephrologist and/or transplant team to support you.

Patients who need a kidney transplant turn to palliative care before, during and after surgery. Getting a transplant has its own risks and rewards so it has to be examined carefully before choosing it as a treatment option.

The palliative care team will always look at the whole person and the whole picture. They are there to enhance your quality of life as you live with kidney disease.

# Alzheimer’s Disease and Palliative Care

Alzheimer’s Disease is a type of dementia. Dementia means that a person has difficulty with memory, judgment and reasoning. This might mean not recognizing your surroundings or people familiar to you, or not being able to find the right words or do certain tasks. The biggest risk factor for Alzheimer’s Disease is age, but people under sixty can also develop the disease.

Facing Alzheimer’s Disease is very stressful for both the patient and family members. There is no cure for the disease, and patients will need more care and support as time goes on.

## Alzheimer’s Disease Symptoms and Treatment—How Palliative Care Can Help

Palliative (pronounced “pal-lee-uh-tiv”) care is specialized medical care for people facing serious illnesses like Alzheimer’s Disease. The goal is to improve quality of life for both you and your family. You can have palliative care at any age and at any stage of your illness. You can also have it together with curative treatment.

Palliative care is provided by a specially trained team of palliative care doctors, nurses, social workers and other specialists who work together with your other doctors to provide you with an extra layer of support.

Involving a palliative care team can be useful in several ways. Palliative care helps treat some of the symptoms of Alzheimer’s Disease, such as depression, anxiety and difficulty sleeping. The team can also teach you and your family about what might trigger some of the behavior symptoms and how to avoid them.

One of the main techniques used in planning your daily care is maintaining a routine. Others include physical exercise and memory therapy, which help you use your brain. A calm and quiet environment, proper lighting to decrease shadows and good sleep habits can help as well.

If you have other medical problems such as heart disease, lung disease or conditions that are painful, palliative care can ease the symptoms, including pain and stress, that these might cause.

Palliative care can be started any time after a diagnosis of Alzheimer’s Disease, but the earlier the better because a palliative care team can work as part of your support structure from the very beginning. The team helps manage your symptoms, but members of the team also focus on conversations about your goals, concerns and treatment options. They help you discuss what is important to you, how and where you want to be cared for and what level of care you would want in the future.

As the illness progresses, palliative care can help your family as they plan to care for you either at home, in an assisted living facility or a nursing home. Keeping you safe is critical. The team can give your family guidance and help them cope with these concerns and, later, with making decisions about feeding difficulties, infection, hospitalization and the best place for you to be cared for.

You can receive palliative care in the hospital, outpatient clinic and sometimes at home.  Although Alzheimer’s Disease is difficult, when palliative care is involved some of the burden is eased and the best quality of life is achieved.

## Relieves Suffering From Symptoms and Stress

The goal of palliative care is to relieve suffering and provide the best possible quality of life for patients and their families.Symptoms may include pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, and anxiety. The team will help you gain the strength to carry on with daily life. In short, palliative care will help improve your quality of life.

And recent studies, including one published in the New England Journal of Medicine, have shown that patients with a serious illness who received palliative care lived longer than those who did not receive this care.

# Objectives and Goals

## [Register button](https://www.chifranciscan.org/content/chi-franciscan/en/health-care-services/palliative-care/palliative-care-academy/registration-for-palliative-care-academy)Program goals

* Improve the care of seriously ill patients and their families.
* Improve clinician satisfaction, by building generalist palliative care knowledge and clinical skills with an emphasis on communication across disciplines.
* Promote the understanding and integration of palliative care across the continuum of care for CHI Franciscan. Integration is accomplished by normalizing the utilization of palliative care in all patient care settings at any stage of illness and at all levels of skill from generalist palliative care to specialist palliative care.

## Program objectives

#### Professionalism

* + Reflect on personal and professional experiences and values related to care of the seriously ill or dying patient.
  + Reflect on how patients and families experience similar thoughts and emotions when faced with serious illness and subsequent loss.
  + Reflect on the losses related to the diagnosis of serious/life threatening illness.
  + Reflect on the importance of looking at symptoms as clues to the experience of suffering in illness.
  + Differentiate between curing and healing in person/family centered care.
  + Outline the clinician’s responsibilities during Code Status conversations.

#### Patient care/Medical knowledge

* + Examine the differences between the traditional model of curative/palliative trajectory versus palliative as a continuum of care.
  + Outline three tools to identify patients for whom transitions may be imminent.
  + Formulate two possible medical recommendations that match patient preferences.
  + Identify three reasons why it is important to prognosticate and why we do not do it.
  + Identify the questions and concerns of families surrounding the use of artificial hydration and nutrition in patients with advanced dementia.
  + Identify the concerns of clinicians surrounding the use of artificial hydration and nutrition in patients with advanced dementia.
  + Differentiate between chronic and acute pain.
  + Outline how to assess and treat breathlessness.
  + Develop a plan for pain/symptom management in the clinical scenario.
  + Understand decision-making hierarchy and substituted judgment.
  + Learn to assess decisional capacity.
  + Establish a functional goal when using opioids for pain management.
  + Using a clinical case, practice prescribing an opioid for acute pain management.
  + Review appropriate utilization of the POLST form in clinical settings and education of patients and families.

#### Interpersonal and Communication Skills

* + Practice the concept of “asking” before “telling”.
  + Recognize and respond to patient cues.
  + Participant will demonstrate the use of their self-selected “words that work” in eliciting the patient story and in establishing goals of care.
  + Identify three language tools which acknowledge uncertainty.
  + Define serious news and apply the House Model to communicating serious news.
  + Participants will identify patient verbal and non-verbal “cues” as well as their own communication “continuers” and “terminators” when discussing goals of care.
  + Participants will make medical recommendations based on what they identify as being important to the patient.
  + Practice using Code Status language.

#### Practice Based Learning and Improvement

* + Identify a five step model for establishing goals of care.
  + Practice using Teach Back to determine Health Literacy and eliciting substituted judgment from health care surrogates.

#### Systems Based Practice

* + Differentiate between specialist and generalist palliative care and the reason for incorporating generalist palliative care into practice.
  + Identify appropriateness of referral to palliative care and hospice.

## ypes of Palliative Care

**Approved by the**[**Cancer.Net Editorial Board**](https://www.cancer.net/about-us/cancernet-editorial-board)**, 02/2019**

Cancer and its treatment often cause problems called side effects. While treating the cancer is important, so is relieving side effects and symptoms. In fact, treatment of cancer and its side effects often happen at the same time. This is called palliative care or supportive care.

Palliative care works best when you start it as soon as you need it during the treatment process. People who receive palliative care along with treatment for the cancer often have less severe symptoms, better quality of life, and are more satisfied with treatment. You may have palliative care at any age and for any type and stage of cancer.

### Areas where palliative care can help

Palliative treatments vary widely and often include:

* Medication
* Nutritional changes
* Relaxation techniques
* Emotional and spiritual support
* Support for children or family caregivers

This article explains the several different types of palliative care and how they can help.

### Social

You might find it hard to talk with your loved ones or caregivers about how you feel or what you are going through. Or you might need a support group or a ride to and from treatment. A social worker can help with these situations. For example, they can:

* Help you plan a family meeting
* Suggest ways to organize people who want to help
* Help you find medical information, rides, or services

A social worker can also provide palliative care for family members and caregivers. For example, if they feel overwhelmed, the social worker can help them figure out what kind of help they need and find it.

### Emotional

Having cancer can make you feel many different emotions, such as sadness, anxiety, or anger. It can also make you very stressed. A support group, counselor, psychologist or other specialist can help you understand and cope with these emotions.

To find help, talk with your health care team about how you feel. You can also find [**ways to cope with emotions**](https://www.cancer.net/node/25109).

### Spiritual

Having cancer can bring up many spiritual questions. You might struggle to understand why you got cancer. Or you might want a greater purpose after surviving cancer.

If you belong to a faith community such as a church, synagogue, or other group, your spiritual leader or community members might be able to help support you spiritually. A hospital chaplain can also provide spiritual support, whether you are religious or not. Chaplains work with people of all faiths and those who do not have a specific faith. Learn more about [**spiritual support**](https://www.cancer.net/node/39321).

### Mental

Cancer symptoms, treatments, and medications can all affect how your mind works. For example, if you are not sleeping enough, you might feel stressed and have a hard time thinking clearly. Or you might be very anxious about whether your treatment is working.

Palliative care for mental health includes exercise, counseling, meditation, and possibly medication to help with anxiety, depression, or sleep problems. A counselor, support group leader, or psychologist might suggest that you do activities that help you reduce stress and anxiety, such as yoga, creating art, joining a group of other cancer survivors, or volunteering for a cause you find meaningful.

### Financial

Cancer treatment can be expensive. This might be a cause of stress and anxiety for you and your family. In addition to treatment costs, you might find that you have other extra expenses, such as the cost of traveling to a cancer center for care.

Talk with your health care team about any financial concerns. A social worker or financial counselor can provide palliative care for these concerns. For example, they might:

* Help you talk with your health care team about the cost of care
* Explain billing and insurance, or find someone who can do this
* Help you apply for medical leave or disability payments
* Find programs that provide free or low-cost medicines

Learn more about [**managing financial considerations**](https://www.cancer.net/node/24865).

### Physical

Physical side effects of cancer and its treatment depend on several factors. These include your type of cancer, its stage, the treatment, and your general health. Physical side effects can include:

* Pain
* Fatigue (being very tired)
* Nausea, vomiting, and loss of appetite
* Breathing problems, such as being short of breath
* Sleep problems

Palliative care for physical side effects might include anti-nausea medicines, physical therapy, or help with nutrition. You might see a palliative care specialist, sleep specialist, pain specialist, or another professional for help with [**physical side effects**](https://www.cancer.net/node/25238).

### Palliative care after cancer treatment

Sometimes, physical side effects can last after treatment ends. Doctors call these “late effects” if they happen or last for months or years after treatment.

Palliative care specialists can help treat late effects. This is an important part of survivorship care. Learn more about [**long-term side effects of cancer treatment**](https://www.cancer.net/node/25396). Ask your doctor if your treatment is likely to cause any late effects.

### For children

As your child prepares to start cancer treatment, you might worry about treatment-related side effects. But palliative care is also available for children. It is an important part of your child’s treatment plan, regardless of his or her age or the stage of disease.

Talk with the health care team before your child starts cancer treatment. Ask about the possible side effects of treatment and palliative care options. Tell the health care team if your child has new side effects or changes in side effects so the team can treat them quickly.

### For caregivers and children

Palliative care is not only for the person with cancer. It can also include support for caregivers and children of people with cancer.

Loved ones often provide important physical, practical, and emotional support to the person with cancer. Caregivers can also experience stress, anxiety, depression, and frustration. Palliative care can help caregivers balance providing care while also improving their quality of life.

If you are a parent with cancer, you may need extra support from others for your children. This might include after-school care or help with making their meals. Taking care of your own health helps you be a good caregiver.

Your health care team or a social worker can help you find palliative care for caregivers and other family members.

### For older adults

Palliative care can be especially important if you are 65 or older. Older adults can have more physical side effects, especially from chemotherapy. And your body might not recover as quickly from surgery as in the past. You may also be concerned about the following:

* Will treatment affect my ability to live on my own?
* Will treatment affect my memory?
* How will cancer treatment affect my overall quality of life?

Learn more about [**concerns for adults older than 65**](https://www.cancer.net/node/25131), including tips and possible side effects of treatments.

**The Principles of Palliative Care**

* Affirms life and regards dying as a normal process.
* Neither hastens nor postpones death.
* Provides relief from pain and other distressing symptoms.
* Integrates the psychological and spiritual aspects of **care**.
* Offers a support system to help patients live as actively as possible until death.