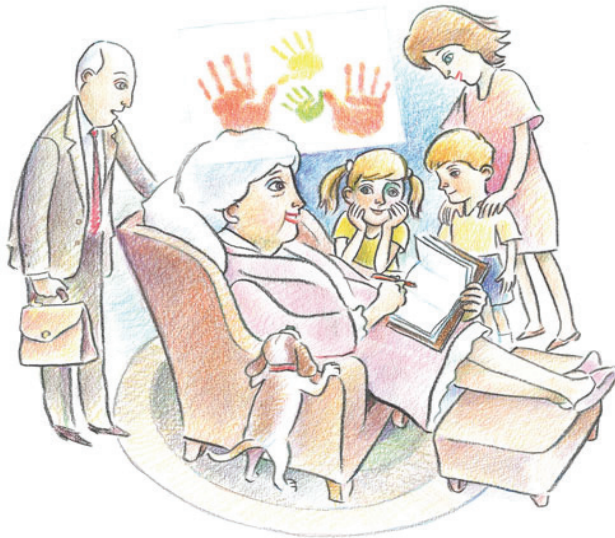


# Touch of Tender Loving Care: Basic Palliative Care Aspects at Community Setting



The College of Palliative Medicine of Sri Lanka

2024

**Touch of Tender Loving Care:  
Basic Palliative Care Aspects at Community Setting**

© 2024 The College of Palliative Medicine of Sri Lanka

978-624-93603-0-3

The material in this work is copyrighted with permission of the College of Palliative Medicine of Sri Lanka.

All other queries on rights and licenses, including subsidiary rights, should be addressed to the College of Palliative Medicine of Sri Lanka

**Author**

**Dr. Ishanka Talagala**

(MBBS, HNDIPPCA, MSc, MD)

**Editorial Panel**

Professor Samadhi Rajapaksa

Dr. Janaki Vidanapathirana

**Special appreciation to the Health System Enhancement Project  
of Asian Development Bank fund.**

**Printed by:**

Design Systems Pvt Ltd

93, Maligakanda Road,

Colombo 10.

Tel: 0112 694745

# Message from the Secretary, Ministry of Health

Palliative care aims at improving the quality of life of patients with a life-limiting illness, their family members and caretakers. With the increase of the greying population and the ever-increasing non-communicable diseases including heart diseases, diabetes and cancer, the number of individuals who require palliative care is increasing, and the demand is amassed.

The Sri Lankan health system has taken several initiatives to improve the palliative care service provision in the country. However, much improvement is needed in several aspects, including increasing awareness among the population including healthcare staff and implementing relevant changes in the healthcare service provision. Also, palliative care services must be provided at the primary care level and within the community.

Currently, there are eight hospices within the country providing palliative care services for the needy, free of charge. Considering the increasing demand for palliative care, it is important that the Ministry of Health work in collaboration with the private sector and non-governmental organizations, for the enhancement of palliative care service provision.

The College of Palliative Medicine of Sri Lanka (CPMSL), being the apex professional body that works towards enhancing the palliative care services within the country, has taken the initiative to bring the hospices together in establishing the “Hospice Sri Lanka Alliance” and will continue to improve the quality of service provision by providing technical support. I congratulate the CPMSL for this excellent achievement.

Since its inception in 2021, the CPMSL has conducted several activities across the country to enhance the quality of palliative care service provision and also has published several publications to improve awareness among the healthcare staff as well as the general public. This booklet also is one such important publication. I express my gratitude to the author and the CPMSL for this excellent publication.

I wish the CPMSL all the best in its future endeavours and wish that the College will work in collaboration with the Ministry of Health to improve the palliative care services in Sri Lanka, as an important stakeholder.

**Dr. P.G. Mahipala**

Secretary

Ministry of Health

# Forward

The College of Palliative Medicine of Sri Lanka (CPMSL) is the apex professional body in Sri Lanka which works towards establishing and enhancing palliative care services within the country. Since its inception in 2021, CPMSL conducted several activities across the country and accomplished several significant achievements as well as publishing an international journal (International Journal of Palliative Medicine, Sri Lanka).

The CPMSL is the only professional body in which the Council and the membership consists of representatives from different medical disciplines, showcasing the importance of multidisciplinary teamwork for the provision and enhancement of palliative care services. Further, the College collaborates with several health and non-health stakeholders as well as other professional colleges, in its activities.

The CPMSL members have written 6 booklets for community palliative care with objectives of improving the management of community palliative care. This booklet is targeting for Basic Palliative Care Aspects at Community Setting. The CPMSL thanks the author, Dr. Ishanka Talagala for writing this booklet. It has been written in very simple way with essential content. The CPMSL think this will benefit for the enhancement of community palliative care.

The CPMSL is grateful to Ministry of Health for the strong partnership and appreciate Health System Enhancement Project - ADB fund.

**The President and the Council  
College of Palliative Medicine of Sri Lanka 2023/2024**

# Table of Contents

About this Booklet	6
What is palliative care?	7
Palliative care services aim at improving the quality of life	8
Types of palliative care available to you	9
Palliative care	10
Frequently asked questions	11
Why palliative care is important to me?	11
Does palliative care mean I will die soon?	12
When should I start palliative care?	12
How do I get palliative care?	12
Can I still continue my other treatments?	13
Does palliative care shorten or lengthen my life?	13
Who will provide palliative care for me?	13
What if I am living alone?	15
Do I have to pay for palliative care?	16
Looking forward: Plan for the future	17
Respite care	18
Hospices available in Sri Lanka	18

## About this Booklet

This booklet has been written with the aim of increasing your knowledge on what is palliative care and what are its basic aspects at the community setting.

Palliative care is basically for anyone suffering from a life-limiting illness and also for their family members and care takers.

Palliative care aims at improving your quality of life and supports you to be active as long as possible and most importantly, it is not just end of life care. Therefore, palliative care is customized to each individual's needs.

This booklet will offer general information about palliative care and the services currently available in Sri Lanka. Information available in this booklet may answer or clarify some of your queries and help you think of what to ask from your healthcare team. It is important to note that palliative care services are provided in various ways in Sri Lanka currently, therefore, please ask for more details on the customized care based on your requirements from your healthcare team.

# What is palliative care?

Palliative care supports people those who are suffering from a progressive life-limiting illness to live their lives as fully and as comfortable as possible. The main aim of palliative care is to improve your quality of life, by addressing the issues/problems that you may have in relation to your physical, emotional, cultural, social and spiritual aspects.

Palliative care is provided on a person-centered approach. That means, you will be treated in the way that you would like to be treated, listen to what your needs are, what your preferences and what your values are. Further, this approach may prevent and relief of suffering due to your disease condition. Since, each and every individual is different from one another, the palliative care needs therefore, will also differ from person to person.

Thus, palliative care will involve you in planning your treatment and ongoing care.

Also, it is important to note that palliative care also aims at and supports in improving the quality of life of your family members and the caretakers as well.

Palliative care can be given at different settings; at home, in a hospital, in a hospice (an institution where only palliative care will be provided), at an elderly home, at an orphanage, or by community-based palliative care service providers.

In Sri Lanka, palliative care services are provided at home through the Public Health Nursing Officers or at the hospices. However, certain hospitals also conduct palliative care consultative services (e.g. Apeksha hospital, Maharagama).

Palliative care is generally provided by your palliative care team. This team may include Doctors (including your treating physicians and general practitioner/family Doctor), nurses, public health nurse, physiotherapist, occupational therapist, social worker, religious leader or a spiritual care practitioner and volunteers.

# Palliative care services aim at improving the quality of life of the;



**Patient** (who is suffering from a life-limiting illness; e.g. cancer, heart diseases, renal failure, lung diseases, diabetes mellitus, hypertension, stroke etc.)



**Family members**



**Caretakers**

# Types of palliative care available to you

Palliative care provides support and care, customized to meet your individual requirements and needs mainly across five areas.

## 1. Physical needs

- Palliative care providers will help you with alleviating/reducing the symptoms that you are suffering with, such as, pain, difficulty in breathing, nausea, vomiting, restlessness, constipation etc.
- They may even support you with moving around and may suggest changes that needs to be done in and around your house to make things easier and safer for you.
- They may even offer to take care of you for a certain period of time, so that your caretaker could get a short break.

## 2. Emotional needs

- Palliative care offers support for you, your family members and the caretakers to talk about any sensitive issue or anything that affects you. It may include the changes that the advanced disease has brought in to you or your family's or caretaker's life.
- You also seek help in deciding what is important to you, plan your future care and where you would like to receive the care.
- You even can share your feelings with a counsellor or a psychologist

## 3. Cultural needs

The care you would receive will be sensitive to your culture, ethnicity, background, values and beliefs

## 4. Social needs

Palliative care assesses your daily needs such as medical appointments, meals, obtaining medications, advice on financial issues, your social networking and help in establishing a supportive network

## 5. Spiritual needs

This support will be provided by the team when necessary.

# Palliative care



## What?

Patient centred care: Palliative care team will work with you to assess what you need



## Where?

At a place of your choice: Palliative care team will discuss with you and your family members to find the best place for your care. It could be at home, hospice, hospital or at a community set up.



## When?

Palliative care should be started at the time of diagnosis of the life-limiting illness and can be given and continued along with the treatment for the disease condition.



## Who?

Palliative care team consists of people with different skills to support you. The team may include a medical practitioner, nurse, public health nurse, physiotherapist, social worker, volunteer etc.



### Services?

Palliative care team will help you to improve your quality of life, and help you to live in the most fulfilling way you can. This may include, alleviating your symptoms, support you to spend time with your family, friends and social networks, improve your activeness, discuss and record your goals and preferences for future care. Also, the team will provide emotional support, grief support, respite and may support with financial assistance to your family and carers.

## Frequently asked questions



### Why palliative care is important to me?

- It reduces your physical and psychological suffering
- It supports in improving your quality of life
- It improves your independence
- It gives you a dignified way of living
- It reduces unnecessary hospital admissions
- It improves the quality of life of the family members and caretakers.

## Does palliative care mean I will die soon?

- Initiating palliative care does not mean that your treating physician and the team have given up hope or that you may die soon.
- Palliative care is about supporting you to live fully as you can, within the limitations of your illness, and improve your quality of life.
- You don't have to stop your treatment to initiate and/or to continue palliative care
- Whatever the stage of the disease that you are in, your palliative care team will adjust your care to meet your preferences and changing needs

## When should I start palliative care?

It is best to initiate palliative care at the time of diagnosis of your life-limiting disease and needs to be continued.

It is **NOT** the last aid, or **NOT ONLY** the care at the end-of-life, as it is commonly believed in the society

Initiating palliative care sooner rather than later will reduce stress on you, your family and the caretaker.

## How do I get palliative care?

You can ask from your treating physician, family Doctor or other healthcare professional about the services you may need and referral.

You or your family members may also contact a palliative care service



## Can I still continue my other treatments?

- If you are under palliative care, you still can continue active treatment for your disease.
- Your treating physician will give the relevant instructions or your palliative care team will discuss with the physician in managing relevant side effects from the treatment and maintain your quality of life.
- If you have cancer, treatment methods such as surgery, drug therapy, and radiation may also be used as a part of palliative treatment
- It is important to note that the aim of palliative care is not to cure the disease, but to control it and relieve your symptoms

## Does palliative care shorten or lengthen my life?

- Palliative care treats death and dying as a normal part of life
- The treatment and the care provided in palliative care does not aim at making you live longer, rather, supports you to make the best out of the time you have within the limitations due to the disease.

## Who will provide palliative care for me?

- Family Doctor
- Public health nursing officer
- Treating physician/Specialist
- Nursing officer
- Health assistants
- Psychologists
- Physiotherapist
- Social worker
- Religious leader

- Volunteers

- Your palliative care team members have received a specific training for palliative care service provision
- The team be multidisciplinary and will consist of medical, nursing, allied health professionals, Grama Niladhari, social workers and volunteers etc.
- The team will offer you a range of services to assist you, your family and caretakers throughout your illness.
- The team will monitor your progress regularly and adjust your care accordingly.
- The team will be in communication with your treating physician/ specialist and/or may refer to the specialist as and when necessary
- If you are at the end of life and have cultural/religious beliefs or family customs related to dying, death and bereavement, inform the palliative care team about those, so that they can provide you relevant care respecting those (Advance care planning).

- You may get palliative care from;

- Home
- Hospice (an institution which focuses on the provision of palliation)
- Hospital
- Community set up

- ❖ You might mostly prefer to stay at home and receive palliative care services. This may include a range of services that will be provided to you regularly or occasionally, based on the requirement.

- ❖ Please note that hospital palliative care units and hospices are currently designed for short-term stay, to



address your worsening symptoms or for respite care. The team will manage your acute condition and discharge you with a plan for care at home.

## What if I am living alone?

- If you are living alone or your family and friends are living far away, depending on the requirement and circumstances, you can stay at home, at a hospice or hospital.
- You can ask support from:
  - Area public health nursing officer
  - Area public health midwife
  - Volunteer palliative care organizations
  - Grama Niladhari
  - Religious leaders
  - General Practitioner or your family Doctor



- Don't avoid palliative care just because you hope that there will be a cure for your disease
- Having palliative care does not mean that you have to stop your treatment or giving up your hope
- When you undergo palliative care, you may find that you focus on the things that are most important to you, such as, having meaningful relationships or obtaining effective pain relief.
- As your disease progresses, your goals may change. Palliative care will support you to be more mobile, independent, control your pain, so that you can achieve more, by living comfortably as you can for as long as possible.

## Do I have to pay for palliative care?

- There are palliative care services that are free in the public health system, such as;
  - The care you receive from the public health nursing officer at your home
  - The care you receive at the state sector hospital
  - The care you receive at the hospices
- Certain palliative care services are available for which you may have to bare the cost:
  - For certain equipment necessary for care
  - For certain medicines or wound dressings
  - If you hire your own nurse for 24x7 assistance
  - If you go to a private sector hospital or private hospice
  - Respite services (short-term care that charge a fee)
  - If you hire a physiotherapist/psychologist privately
  - When you consult your general practitioner, family Doctor or specialist (in private sector)



## Looking forward: Plan for the future

- If you wish to know your expected outcome (prognosis) of the disease, you may ask your treating physician. Having an idea about your prognosis will allow you to focus on what you would like to do.
- Feeling low or depressed is common after the diagnosis of a life-limiting disease or knowing that you have a poor prognosis. Discuss with your family and friends, your family doctor or specialist, psychologist, social worker or religious leader/adviser.
- When diagnosed with a life-limiting disease (e.g. cancer), discuss with the palliative care team about your goals and preferences for care, amount of treatment you want etc.
- Advance care planning will help your family to respect your wishes and decisions.
- Advance care planning can be started at any time and may include:
  - Making decisions on what is important to you for quality of life. Think of what matters to you the most.
  - Deciding on treatments that you may or may not want, including where you want to receive your care (e.g. home)
  - Give directions to your advance care. E.g. Write down the instructions for your future medical care in a legal document
  - Appoint a substitute decision-maker.
  - (A substitute decision maker is someone you legally appoint to make medical decisions for you when necessary in the future)



## Respite care

- Caring can be very demanding and may affect the caretakers' physical and emotional wellbeing.
- Respite care lets someone else to take over caring for a while, so that your care taker can have a break
- In our culture, sometimes your family members may feel guilty about leaving you with another person. But, taking a break will allow them to take care of you more effectively.
- You may require respite care for a couple of hours, overnight or few days.
- Respite care can be given at home, hospice or at hospital.
- You may have to pay for the respite care.
- It is better to find out the respite care services available before you actually need them.

## Hospices available in Sri Lanka

No.	Name of the Hospice	Address	Contact Number
1	Shantha Sewana Hospice, Maharagama Sri Lanka Cancer Society	No: 65, Hospital Road, Maharagama	0112-585879 0112-840312
2	Cancer Care Hospice Kurundankulama Anuradhapura Cancer Care Association Sri Lanka	Cancer Care Mawatha, Mihintale Road, Kurundankulama, Anuradhapura	025-3243077 077-3409787

3	CANE Hospice Jaffna	5, Sabapathipillai Lane, Uduvil, Jaffna	021-2240258
4	Sri Sathya Sai Suwa Sewana Hanwella	Sathya Sai Suwa Sewvana. Cancer Hospice. Hanwella	036- 2254902
5	Institute of Palliative Medicine, Matara Palliative Care Trust of Sri Lanka	27, Akuressa Road, Nupe, Matara	041-2226766 077-3409787
6	Sahana Sewana Hospice Maharagama Palliative Care Association of Sri Lanka	No. 10A, 2 <sup>nd</sup> Lane, Ambagahapura, Maharagama	077-3355187 077-0531645
7	Eastern Cancer Care Hospice Eravur	450, Savukkady road, Savukkady, Eravur	076-5343434 076-0582248
8	Suwa Arana - Pediatric Palliative Care Center Maharagama. Indira Cancer Trust	No 63, Hospital Road, Maharagama	0112-850414 0112-363211



*For further technical assistance please contact:*

College of Palliative Medicine of Sri Lanka

No. 06, Wijerama house,

Wijerama road, Colombo 07.

Telephone number- 076 5469982

Email - [officecpmsl@gmail.com](mailto:officecpmsl@gmail.com)

Web: [www.cpmsl.lk](http://www.cpmsl.lk)

