

Touch of Tender Loving Care: Caring for Caregivers



The College of Palliative Medicine of Sri Lanka

2024

**Touch of tender loving care:
Loving Care: Caring for Caregivers**

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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 Loving Care: Caring for Caregivers. The CPMSL thank two authors: Dr. Manudi Vidanapathirana and Dr Deshan Gomez 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**

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1. Who is this handbook meant for?

A caregiver is someone involved in the physical, mental, social and spiritual care of someone who is terminal ill or is dependent on others for constant care (E.g. bedbound, physically or mentally incapacitated).



1.1 Types of caregivers

There are different types of caregivers:

Primary caregiver:	A primary caregiver is an individual who has the main responsibility of providing physical, mental, social and spiritual care for a patient. The primary caregiver may be a family member or a paid professional caregiver.
Secondary caregiver:	An individual who supports or complements the care given by the primary caregiver. This may involve helping the primary caregiver with certain tasks or filling in for the primary caregiver at times. They are not responsible for the full-time care of the individual. This may be done by a family member, or a paid caregiver.

Family caregiver:	The provision of unpaid care to a relative, partner, friend, or neighbour who needs care is referred to as family caregiving. Family members may play the role of primary, secondary caregivers or care supporters.
Care supporter:	An individual who assists with physical and personal care, mobility, meal times, and social care such as booking appointments. Care supporters are generally needed for patients with cognitive disabilities such as in dementia.

If you fall in to any one of the following categories, then this handbook is for you!

- Anyone involved in the physical, mental, social and spiritual care of someone who is terminally ill or dependent
- Anyone living with someone who is terminally ill or dependent
- Anyone with a loved one that is terminally ill or dependent
- Anyone with an interest in care-giving as a life-skill

1.2 Tools for assessing whether someone needs long-term care

The following factors are used to assess whether an individual requires a caregiver to help with their day-to-day life.

1. Mobility during the last 3 months

This refers to whether the individual is able to move about from one place to another, both within the home environment or outside the home. An individual who requires help with mobility off the bed, or within the home environment, is likely to require the help of a caregiver to attend to their activities of daily living.

2. Activity level during the past 3 months

This refers to the extent to which the individual is able to carry out their routine tasks, and engage in their commitments/ errands/ hobbies.

3. Ability to care for self

This is an individual's ability to attend to toileting and grooming by themselves.

4. Eating and drinking by self

This refers to an individual's ability to handle cutlery or use their hands to handle food/ food-containing dishware in order to feed themselves.

5. Conscious level

This refers to the individual's level of responsiveness to their surroundings.

6. Experience of pain during the past 3 months

An individual who experiences debilitating pain, due to advanced joint disease, cancer etc. are unlikely to be able to care for themselves, since pain would act as a limiting factor.

7. Experience of other disabling physical symptoms during the past 3 months

Symptoms such as muscle weakness, joint stiffness, dizziness, vertigo, persistent nausea etc. if persistent will interfere with an individual's activities of daily living.

8. Experience of anxiety/ depression during the past 3 months

Sri Lanka does not have a validated tool at present to assess the need for long-term care of an individual. The above factors are derived from various international tools, and can be used as a rough guide to assess whether someone is in need of caregiver support.

1.3 Caregiving as a life-skill

As a result of the rising numbers of patients/ individuals in need of long-term care, caregiving is now starting to be recognized as a life-skill that all individuals must have. One can never predict when one may have to assume the role of a caregiver. It is a life-skill that within itself has a gamut of multiple other skills. Caregiving requires the skills of communication, resourcefulness, time-management and empathy. It also requires certain virtues such as patience, and ability to remain positive.

2. Caregivers, you are not alone!

‘Never believe that a few caring people can’t change the world.
For indeed, that’s all who ever have.

Margaret Mead

American cultural anthropologist

2.1 Encounters faced by caregivers

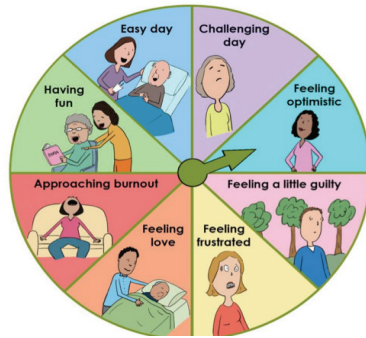
Caring for a terminally ill or dependent patient is a unique life experience. Oftentimes, one’s own plans and goals are derailed, and the care of the patient will take priority. As a result, caregiving can be a life-altering event for many people for a period of time.

While caregiving can be a fulfilling experience, it also has its own set of challenges.

- It is labor-intensive.
Physically caring for another individual, helping them with feeding, dressing, toileting and moving, has a huge physical toll on the caregiver.
- It can be mentally-exhausting.
Having a list of tasks, where the priority is always someone else’s needs can affect a person’s mental peace. As a result, no matter how much love you have towards the patient or how much positivity you start the process of caring with, as the length of time spent caring gets prolonged, negative emotions can set in. This is worse in instances when the caregiver is forced in to that role, due to lack of a choice or if the relationship between the caregiver and patient, was strained prior to the illness set in.
- It can interfere with the caregiver’s career
- It can interfere with the caregiver’s responsibilities towards him/herself and their own family
- It can interfere with the caregiver’s financial stability
- It can interfere with the caregiver’s social-life
- It can interfere with the caregiver’s spirituality

2.2 Common feelings experienced by caregivers

Caregiving can be a fulfilling experience, and a lot of caregivers report retrospectively that the experience changed them for the better. The experience can involve intimate and vulnerable moments with one's loved one, that only the caregiver is privy to. This can give a sense of fulfillment to the caregiver to be able to be present with their loved one through this profound, life-altering journey. It can also help to provide closure as the progression to the end-of-life is witnessed right throughout by the caregiver.



Some positive feelings experienced by caregivers are:

- A sense of privilege at being able to give back to one's loved one
- Self-fulfillment
- Gratitude for the time that they get to spend with their loved one at the end-of-their life
- Moments of pure joy and mental satisfaction
- A sense of accomplishment or personal growth
- Spiritual fulfillment

However, since caregiving is an intense process, it is also natural for caregivers to experience negative feelings, and they should not feel disturbed by experiencing these emotions. It is a natural part of the process of caregiving.

Some negative feelings experienced by caregivers are:

- Feeling emotionally overwhelmed or stressed
- Feeling isolated
- Sadness
- Hopelessness
- Guilt that they are not doing enough
- Anger

- Anxiety about the workload
- Anticipatory anxiety of their own future
- Fear of loss
- Compassion fatigue- Numbing of the care and consideration you feel for loved ones' and their experiences, due to being repeatedly exposed to negative events, requiring the caregiver to generate sympathy
- Loss of self-confidence/ identity
- Envy

2.3 Physical symptoms experienced by caregivers

There can also be certain physical symptoms that caregivers commonly experience. These are:

- Change in appetite- either an increase or decrease
- Nausea
- Insomnia
- Headaches
- Backache/ muscle pain (depending on the labor required to care for the individual)
- Exhaustion and fatigue

These are all very natural, and all caregivers are prone to experiencing some of these feelings/ symptoms at some point.

2.4 Signs that you need a little help

While experiencing negative feelings from time to time is common, certain negative feelings can be unusual. Some of them in fact, can mean that caregivers may need to seek medical help.

- Burnout- A state of being physically and emotionally exhausted/ overwhelmed, that the caregiver feels they can no longer manage day-to-day tasks, or continue caregiving.

Signs of burnout are:

- A strong urge to run and hide from responsibility
- Feeling scattered and frantic.

- Forgetting important details or an inability to concentrate.
 - Inability to read more than a few sentences without losing concentration.
 - Increased use of alcohol, drugs, or tobacco
 - Major changes in your eating patterns.
 - Significant weight loss
 - Inability to sleep
- **Depression**
 - Persistent sadness
 - Constantly feeling the need to cry
 - No longer enjoying activities that were previously enjoyable
 - Easily becoming tired
 - Changes to appetite or sleep
 - Hopelessness
 - Feeling worthless or guilty
 - Ideas of suicide

If you find that you are experiencing any of the above, please seek the help of a medical professional.

3. Importance of caring for the caregiver /self-care

'If your compassion does not include yourself, it is incomplete'

Jack Kornfield
American writer

The caregiver simply cannot pour from an empty cup. It is important that the health and wellbeing of the caregiver is prioritized, so that the process of caregiving is fulfilling and optimal for both the caregiver and the patient. The best possible caregiving can only be given when the caregiver is also of sound physical and mental health.



The benefits of caring for caregivers are:

- Improving the caregiver's physical, mental, social and spiritual well-being
- Enabling the caregiver to live a meaningful life
- Enabling the caregiver to maintain their identity or sense of self
- Helping the caregiver establish boundaries between their caregiving and personal needs
- Preventing caregiver burnout
- Enabling the caregiver to achieve personal growth
- Enabling the best possible care to be delivered to the patient

4. Strategies for caregivers to care for themselves

Some strategies that caregivers can use to care for themselves through this unique period are:

- **Prioritize your own health**

Eat balanced meals with nutritious food at regular intervals.

Make time for physical activity for yourself.

Pay attention to your personal hygiene

Don't forget your own medicines and medical check-ups.

These can seem frivolous in the midst of all the important things that you need to do, but making the time for these, can be a long-term investment for your ability to continue caregiving, and for having the energy for other commitments out of caregiving.

- **Setting new goals for yourself- Meaningful living**

Oftentimes, your priorities in life will change once you take on the role of caregiving. Your personal goals and career, can take a back step, once you step in to your new role. As a result, caregivers can feel a sense of loss of personal control, or that their life is slipping away from them. To avoid this feeling of helplessness, it is important to identify what your new goals are, in this changed setting. While your goals may now be different, it is still important to identify what your personal values and priorities are, so that your life has a purpose.

Your new priorities may now temporarily be centered around the person you're caring for, and your personal goals may need to be temporarily put on hold. But to maintain a sense of control it is important to identify, why your patient's priorities, may temporarily take precedence over your own.

E.g.- Your new goals can be:

- Ensuring my loved one/patient has a comfortable and pain-free end-of-life
- Ensuring my loved one/ patient has good company and love in the last stages of their life
- Learning about my patient/ loved one's illness and the best ways to manage symptoms

- **Focus on the benefits of personal growth**

Caregiving equips you with a set of skills, attitudes and knowledge, that you should take pride in. Reflect regularly on how you have grown emotionally.

E.g. I am now more selfless, I am able to handle more tasks than earlier, I have matured, I have a better understanding of the meaning of life, I have a better understanding of my priorities in life

- **Making time for respite and relaxation**

If possible, try and make time for 3 different kinds of breaks.

- i. A break that gives you a sense of accomplishment E.g. Gardening, sewing a quilt, painting a picture
- ii. A break related to social interaction E.g. Making time to meet old friends
- iii. A break giving complete relaxation E.g.- Listening to music, watching a movie, meditation

It is understandable that it may not be possible to make time for all three kinds of breaks, in which case, focus on at least one, depending on which type you most enjoy.

- **Find humor**

Laughter is one of the best tools for dealing with difficult moments. If your loved one/ patient is able to speak, reminisce with them about stories from the past, read to them from humorous books/stories, or watch comedies together. Even if your loved one is unable to speak or respond, you may do this in your own time, for your own mental health.

- **Gratitude list**

Make a daily list of things you are grateful for. You can add various fulfilling moments you had during the day to your gratitude list.

E.g. I'm grateful that I got to eat my favorite meal today, I'm grateful that the neighbor stopped by and brought a cake, I'm grateful that I got to watch a sunset in peace

- **Sharing your feelings with someone you can trust**

When you're starting to feel overwhelmed, it is important to share your feelings with someone you can speak freely with. Troubles that are shared are often halved.

- **Delegate day-to-day tasks.**

As a caregiver, you can make a list of ways that others can help you and when they ask, give them a specific assignment.

E.g.: Grocery shopping, picking up medications or doing other errands, cooking a meal, sitting with your loved one/ patient while you take a break (for a walk, or other self-care), spending time with the patient (reading, writing letters, playing cards, etc.), helping with housework (laundry, or yard work), caring for pets

- **Engaging in relaxation therapies**

E.g. Guided imagery, music, yoga, massage therapy, going for counselling, art therapy

- **Engaging in spiritual activities**

E.g. Meditation, chanting, praying, engaging in religious activities

- **Pet therapy/ animal-assisted therapy**

Pet therapy is the use of guided interactions with an animal for a specific purpose. There are multiple uses for pets, when it comes to terminally ill patients, but in the case of a caregiver, a pet can be used to cope

with mental stress. The benefits of pet therapy for caregivers are reduced stress and anxiety, improved job satisfaction, reduced feelings of loneliness and isolation, and improved ability to deliver care to the patient.

- **Improving communication skills**

While learning a new skill may seem like more work, improving one's communication skills can actually make the process of caregiving easier in the long-run, and prevent any stressful situations from arising. It will help the caregiver to deliver better care, communicate better with other parties involved and avoid misunderstandings. Good communication is a tool for avoiding potential stress-provoking events in future.

5. Support Services

The following is a list of various kinds of palliative care services, that you may seek help from.

5.1 State Hospitals providing palliative care

- National Cancer Institute of Maharagama
- Ratnapura Teaching Hospital
- Karapitiya Teaching Hospital
- District Hospital, Nuwara Eliya
- District Hospital, Monaragala
- Some Primary Healthcare units

5.2 Pain management clinics

- National Cancer Institute of Maharagama
- National Hospital of Sri Lanka, Colombo
- Karapitiya Teaching Hospital
- Colombo South Teaching Hospital, Kalubowila
- North Colombo Teaching Hospital, Ragama
- Army Hospital, Narahenpita
- Certain private hospitals

Institute	Service provided	Telephone number
Sri Lanka Cancer Society- Shantha Sevana Hospice, Maharagama	In-patient hospice care	011 2585879 011 2840312 0812225423 (Kandy) 0776329705 (Anuradhapura) 0914986197/ 0914380501 (Galle)
Cancer Care Association, Head Office, Homagama	Support services for cancer patients and their families	076 4912787 0773409787
Cancer Care Association Hospice, 'Piliika Sarana Rekawarana Piyasa', Anuradhapura	In-patient hospice care	025 3890357 025 3243077 025 2056003
Cancer Care Association, Galle branch	Home-based palliative care Cancer community Centre for rehabilitation of cancer patients Cancer day-care center Other supportive services	077 5019787
Palliative Care Trust Institute of Palliative Medicine, Matara	In-patient hospice Care	041 2226766 076 8787484
Sri Sathya Sai Suwasewana Hospice, Hanwella	In-patient hospice Care	036 2254902
Cancer Aid for North and East Sri Lanka (CANE) Hospice, Jaffna	In-patient hospice Care	021 2240258

Institute	Service provided	Telephone number
Sahana Suwa Community Palliative Care, Colombo	Home-based palliative care and other supportive services	011 7600444
Eastern Cancer Care Hospice, Batticaloa	In-patient hospice Care	075 0796849
Sahana Sevana Hospice, Maharagama Palliative Care Association of Sri Lanka	In-patient hospice Care	077 7143287
Indira Cancer Trust Maharagama	Support services for cancer patients and their families	011 2363211
Heal the Life (Divisetha), Gampaha	Support services for cancer patients and their families	077 4143222 071 8677959
Cancer Survivors Support Network, Maharagama	Support services for cancer patients and their families	077 1657376
Enterostomy Society	Support services for patients with stomas	0718676290

5.3 Mental health services

There are specialized mental health clinics at all state teaching hospitals, provincial/ district and base hospitals in Sri Lanka, headed by Consultant Psychiatrists. Most of the clinics provide outreach services for the community.

5.4 Coordination of community palliative care for shared care- Public Health Nursing Officers

Community-based palliative care is delivered by a cadre of public health

nursing officers, who are trained in providing community-based palliative care. They extend home visits when necessary, and play a role in adjoining hospital/ institution based care to community care.

5.5 Social and Financial Services

- Presidents Fund can be obtained after submitting the necessary documents as requested in the website (www.presidentsfund.gov.lk)
- Information on various Disability Allowances can be obtained from the area Divisional Secretariat or Grama Niladhari's Office.

5.6 College of Palliative Medicine of Sri Lanka

College of Palliative Medicine in Sri Lanka is a group of multi-disciplinary health care professionals that aim to enhance the quality of palliative care in Sri Lanka by promoting evidence-based palliative medicine. They conduct various educational programs on palliative care island-wide, are involved in policy-making decisions related to palliative care and facilitate research related to palliative care in Sri Lanka.



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