National Policy on Palliative Care

2025-2030

Ministry of Health

Sri Lanka

Effective date:

1.Introduction

I. Background

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening or life limiting illness, through the prevention and relief of suffering by means of early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

The relief of pain and suffering of terminally ill patients diagnosed with diseases including end-stage cancer, chronic obstructive pulmonary diseases, chronic kidney diseases and AIDS is a common goal of medicine and human rights (Somerville, 1992).

Person centred attention to symptoms, psychological, social and existing distress in order to optimize the quality of life of patients, their families or close friends irrespective of a patient's age, sex, ethnicity, religion, income status, type of the illness or its stage is the cornerstone of palliative care. Delivery of palliative care should begin at the time of diagnosis of a life-threatening or life limiting illness and should continue throughout the illness period until death and into the bereavement period of the family (Murray, S.A et al. 2005).

Palliative care should be comprehensive in nature: should be available for patients with chronic as well as life-threatening or life limiting illness conditions and their families and / or caregivers; does not define a time frame on the delivery of palliative care; should be available across all levels of healthcare and should not be limited to one setting.

There is wide spread disparity globally as well as locally in the capacity, resources and infrastructure pertaining to the provision of palliative care for patients with life-threatening illness or life-limiting illnesses.

Universal health coverage cannot be achieved without palliative care. It is a key component of the right to health and the United Nations Sustainable Development Goal for good health and well-being. At the sixty-seventh World Health Assembly in 2014, the first ever global resolution on palliative care was released (WHA 67.19) requesting member states to

strengthen palliative care as a component of comprehensive care throughout the life course with special emphasis on primary health care and home-based care. Community based care reduces the expenses associated with accessing health facility for follow-up visits and unnecessary investigations and treatments thus making it cost-effective and apt for any low- and middle-income country settings. Equity is the central theme of UHC. Therefore, palliative care services should be an integral component of Universal Health Care models which would increase quality of life and mitigate sufferings of the poor and vulnerable and reduce their financial burden.

II. Burden of need for palliative care

It was estimated in 2017 that there were 56.8 million persons needing palliative care globally and 76% of the need was in low- and middle-income countries. The need was 17.0% in the South East Asia Region. The majority (67.0%) were adults over 50 years old and at least 7% were among the age group 0-19 years. It was further identified that only 12% of the need was being met (WHO 2020).

Information on burden of those needing palliative care in Sri Lanka is scarce. The decline in overall mortality and infant mortality has led to an increase in life expectancy in Sri Lanka Furthermore, demographic and epidemiological transition has led to an increase in the burden of people living with Non – Communicable Diseases. The Annual Health Bulletin (AHB) published in 2021, traumatic injuries were the leading cause of hospital admissions (3571.4 per 100,000), followed by Neoplasms (604.4 per 100,000) and Ischaemic Heart Diseases (493.1 per 100,000). Among 36,894 with mental disorders, 754 had dementia. The high number of traumatic injuries, neoplasms, and Ischaemic Heart Diseases leading to hospital admissions, along with the prevalence of mental disorders such as dementia, highlight a significant burden of chronic and life-limiting conditions in the population. These conditions often require comprehensive symptom management and end-of-life care, indicating the need for palliative care services to improve quality of life for affected individuals. Registrar General's Department reported 146,397 deaths in 2019, among which 15,448 deaths were due to malignant neoplasms and 7,043 were due to chronic lower respiratory diseases. This reiterates the need for an effective and efficient system which supports provision of quality palliative care.

Services for provision of palliative care

In Sri Lanka palliative care is delivered through a proposed integrated system which comprises of three components: Palliative Care Consult Services (PCCS) delivered at tertiary and secondary care level institutions, Community based palliative care delivered at primary care level curative institutions including home-based care and Hospice care.

Palliative Care Consult Services

Although PCCS were initially established at hospitals where the services of an Oncologist were available, establishment of PCCS was strengthened through the issue of a General Circular in 2020. The essential elements of the services delivered though PCCS are: appointment of an interdisciplinary team in each secondary and tertiary care hospital by the institutional head; establishment and provision of outpatient care through clinic sessions; establishment and provision of inpatient specialist consultative services; networking and linking with primary healthcare institutions to enable continuum of care through institutional and home based care by Pubic Health Nursing Officers (PHNO); collaboration with government, non-government and private hospices in care provision and coordination with all other relevant government and non-government agencies to ensure provision of extended holistic care.

All patients needing palliative care should be referred to the PCCS team by the treating Medical Specialist who treats the primary medical problem needing palliative care. Thereafter, the patient will be registered for in-patient or out-patient care at the PCCS and provided holistic care. The interdisciplinary PCCS team should ideally be led by a Medical Specialist in palliative care. However, a Medical Specialist with special interest trained in palliative care could be the team leader in the absence of a Medical Specialist in palliative care. In addition, the Medical Specialist who refers the patient for PCCS, Medical Officer for Palliative Care (MOPC), Nursing Officer for Palliative Care, Social Service Officer, Counsellor, Pharmacist, Physiotherapist and Health Service Assistants should be included in the multidisciplinary PCCS team. A shared care plan should be developed by the PCCS team and thereafter the patient should be referred to the Primary Medical Institution (PMCI) which could be a Divisional Hospital or a Primary Medical Care Unit, nearest to the patient's residence.

Community based palliative care

Comprises of two components: institutional care at PMCI and home-based care. The patient who is referred by the PCCS team should be registered at the institution and care plan should be implemented by the Public Health Nursing Officer (PHNO) under the supervision of the Medical Officer in Charge (MOIC) of the institution. The PHNO is responsible for the provision of home-based care as well.

When complex care is needed for those are followed up at the PMCIs, they could be referred back to the PCCS whenever necessary. Patients with unmet need for palliative care could be identified by the PHNO or public health field staff during their field visits. Those patients should be registered at the relevant PMCI and may be referred to the PCCS for the development of a shared care plan. The services at PMCI level should be linked with the patient's General Practitioner (GP), area Medical Officer of Health (MOH), local religious leaders, community-based organizations & volunteers according to the need and wishes of the patient and family members.

The Sri Lanka Essential Service Package (SLESP) 2018 describes that palliative care, with priority given to pain relief and symptomatic management, needs to be delivered by dedicated teams at Divisional hospitals. This includes support for families, self-help groups, outpatient department (OPD) care, and home-based care,

There may be instances where patients and their family members prefer to receive palliative care services coordinated by their full time or part-time General Practitioner (GP). In such situations, goal of care and the shared care plan developed by the PCCS should be communicated with the GP. Furthermore, it is desirable that the treating GP communicates with the PCCS according to the needs of patients, with the closest primary care curative institution and office of the Medical Officer of Health (MOH) to arrange necessary care for the patient, family members and care giver and to ensure that the patient is registered at the primary care level.

Public health staff of MOH areas must register palliative care patients during field visits and refer them to the nearest PMCI. The PHNO should regularly update this information and

ensure patients receive the appropriate institutional or home-based care. The MOH office may support networking and collaboration among MOIC of primary care institutions, PHNO and Social Services, NGOs, religious groups, and community organizations for supportive care.

Home-based care and Hospice Care

Care should be in alignment with and be part of the shared care plan developed by the PCCS. It is important that home-based care is linked with care provision at PMCI, care by GPs, support by NGOO and community – based organizations. Patients and caregivers are trained on selected aspects of care by PHNOO during home visits. PHNOO under the guidance of the MOIC visit homes of patients needing palliative care residing in the empaneled area of the PMCI and provide the necessary services. They also provide emotional support for family members and guide family members on care provision.

Hospice is a model of high-quality, compassionate care for people suffering from a life-limiting illness. It provides expert medical care, pain and symptom management, and emotional and spiritual support tailored to the patient's needs and wishes. Hospice also provides emotional support to the patient's loved ones even into bereavement.

The goal of hospice care is to help people who are dying have peace, comfort and dignity, and to provide respite care as a temporary relief for caregivers. Provision of hospice care should be linked to PCCS and community -based care. Currently there are few institutions both public and private in Sri Lanka, which provide care of dying patients and respite care.

Human resources and medical supplies needed for PCCS and community-based care

Currently there are no Medical Specialists in palliative care in Sri Lanka. Available PCCS are being conducted and coordinated by Medical Specialists in Oncology and few Medical Specialists with special interest in palliative care or those who have been trained as master trainers in palliative care by the Asia Pacific Hospice and Palliative care Network (APHPN). Some Medical Officers and Nursing Officers who have received training also contribute to PCCS in selected hospitals, though many of those trained are not actively engaged in providing such care.

Medical Officers in charge of PMCI and PHNOO play a major role in the provision of community-based palliative care. PHNOO have been trained in palliative care and have been appointed to PMCI, where they are engaged in palliative care activities at institutional level and through home-based care.

Availability of adequate medicines and medical supplies is essential to ensure the capacity to deliver palliative care. Relief from common symptoms such as pain, nausea, vomiting, shortness of breath and bowel disturbances is crucial. Regulations and protocols pertaining to continuous supply of these items particularly for pain relief remain challenges to care provision.

Networking and linkage between levels of care

Excellent networking is essential to ensure efficient and effective palliative care provision There remains a major gap in the referral of patients needing palliative care for PCCS and ensuring continuum of care up to home-based care and back referral. Limited availability of trained healthcare personnel lack of motivation, conflict in the provision of care through public and private healthcare systems, migration of skilled work force and lack of coordination and partnership with stakeholders hinders networking and linkage in care provision. Further, lack of awareness on importance of monitoring, being inadequately trained and time restrictions for record keeping continue to pose challenges.

III. Context

This policy is in alignment with the 'Sri Lanka National Health Policy 2016 – 2025', the National Strategic Framework for Palliative Care Development in Sri Lanka 2019-2023 and the National Policy and Strategic Framework for Prevention and Control of Chronic Non-Communicable Diseases 2023-2033, Furthermore, this policy is guided by the National Policy & Strategic Framework of Prevention & Control of Cancers (2015), the National Elderly Health Policy (2017) and other sectoral policies relevant to palliative care.

The recommendations in the Report of the WHO South-East Asia Regional workshop on expanding availability and access to palliative care (December 2023) and proposed WHO round table model on palliative care were guiding elements in the development of this policy.

IV. Rationale

Palliative care needs to be integrated all levels of the healthcare system including primary health care level to ensure continuity of coordinated care. It is imperative that referral mechanisms and information sharing between different levels of the health system and types of health provider be strengthened so that patients experience integrated palliative care.

The legislative environment in the country places certain constraints to practitioners, patients and caregivers in developing robust advance care plans and shared care plans, challenging the delivery of optimum services which are consistent with values and preferences of the recipients of care. It is important to identify where patients and their families prefer to receive care during the provision of community-based care so that service provision could be adapted to meet patient preferences and need for compassionate care. The lack of a legal framework which defines whether or not to prolong life of those needing palliative care or reduce duration of life lived with suffering, place many constraints for healthcare workers.

Effective delivery of services at the point of care could be achieved if evidence-based approaches are used through adequate training of healthcare personnel / workforce, strict procurement procedures, supervised supply chains and research by multi-disciplinary teams.

Legislations enabling essential medicines, such as morphine and other opioid analgesics, to be procured, stored, prescribed and administered safely, while not creating barriers to access for those with genuine medical need, should be in place for the delivery of safe care. It is imperative that palliative care is incorporated into management plan of patients from the time of diagnosis, facilitated by an integrated healthcare delivery system which enables timely diagnosis and treatment with minimal delay.

In keeping with the Primary Health Care model described by WHO, palliative care services should be available at all primary healthcare level institutions both preventive and curative ensuring equitable access and availability of good quality services within reach of those needing care, particularly vulnerable, marginalized and hard to reach communities. Simple, cost-effective interventions which provide wide-coverage of those needing care should be identified and prioritized. Coordinated and collaborative care by government NGOO and

private sector is essential to maximize the utilization of available resources by recipients of care.

2. Policy principles

I. Right to efficient and effective palliative care
II. Individualized and ethical approach
III. Equitable access to appropriate services and Universal Health Coverage
IV. Engagement with families and communities
V. Multi-sectoral and multi-disciplinary approach

3. **Policy Statement**

I. Equitable, evidence based, comprehensive, patient centred quality palliative care
II. Integrated care continuum spanning tertiary, secondary and primary levels along with home and community
III. Adequate, equitably distributed and competent health care workforce fit-for-purpose
IV. Legal provisions addressing palliative care to safeguard patients, families and healthcare workers

4. **Policy Goal**

To ensure that all patients suffering from life-threatening and life limiting conditions endure minimal or no suffering from symptoms, receive optimum spiritual and psycho-social support and die in a dignified manner.

5. Applicability and scope

This policy applies to all people regardless of age, gender, sexual orientation, race, religion, socio-economic status or geographical location.

6. Policy implementation

(I) Strategies

Strategy 1: Strengthen leadership, direction and governance in palliative care provision**.**

Strategy 2: Adopt an integrated approach to deliver coordinated, quality palliative care across the health system for provision of effective and efficient services for patients and their families and / or caregivers.

Strategy 3: Ensure adequate and appropriate distribution of resources to provide quality palliative care to patients and their families and / or caregivers at all levels of care.

Strategy 4: Engage patients, their families, communities, interdisciplinary teams and other relevant partners in decision making and delivery of palliative care

Strategy 5: Ensure uninterrupted supply of essential medicines and appropriate technologies across all levels of care.

Strategy 6: Establish a robust monitoring and evaluation mechanism and a strong research agenda for expansion and scaling up of service delivery.

Strategy 1: Strengthen leadership, direction and governance in palliative care provision.

1.1 Foster and strengthen stewardship functions and advocate to prioritize palliative care services.

1.2 Ensure quality palliative care services through legislative provisions including End of Life Care decisions and terminal care.

1.3 Establish sustainable and feasible networking mechanisms among all stakeholders to enable optimum service delivery.

1.4 Ensure financial risk protection of patients and their families.

Strategy 2:

Adopt an integrated approach to deliver coordinated, quality palliative care across the health system for provision of effective and efficient services for patients and their families.

2.1 Expand community-based care linking available services at primary care level.

2.2 Improve standards of palliative care at secondary and tertiary care levels.

2.3 Establish integrated patient centered care approach for service delivery including private sector organizations.

2.4 Ensure the registration and licensing of government and private palliative care providers to enable quality assurance.

2.5 Provide comprehensive support for families with patients receiving palliative care

Strategy 3: Ensure adequate and appropriate distribution of resources to provide quality palliative care to patients, families and / or caregivers at all levels of care.

3.1. Ensure a competent healthcare workforce, supported by efficient recruitment, equitable distribution, and effective retention mechanisms across all levels of care.

3.2. Ensure reliable mechanisms to ensure the efficient and effective use of skills within the trained healthcare workforce.

3.3. Provision of adequate and appropriate infrastructure to support high-quality healthcare delivery.

Strategy 4: Engage patients, their families, communities, interdisciplinary teams and other relevant partners in decision making and delivery of palliative care

4.1 Empower caregivers in their roles and responsibilities in the delivery of care

4.2 Strengthen existing mechanisms and introduce innovative methods to encourage community participation in the provision of palliative care

4.3 Establish a coordinating mechanism among interdisciplinary teams for continuum of care

Strategy 5: Ensure uninterrupted supply of essential medicines and appropriate technologies across all levels of care.

5.1 Facilitate timely availability of essential medicines and appropriate technologies for the management of patients at all healthcare levels.

5.2 Ensure uninterrupted supply of medicines, supportive devices and other logistics for home based care in agreement with the referral hospital.

Strategy 6: Establish a robust monitoring and evaluation mechanism and a strong research agenda for expansion and scaling up of service delivery.

6.1 Develop a comprehensive Management Information System (MIS) to enhance service delivery and improve patient outcomes.

6.2 Implement a monitoring and evaluation framework to facilitate evidence-based decision-making.

6.3 Strengthen research capacity, ensure resource availability, promote collaborative research, and facilitate knowledge sharing.

(II) Responsibility and authority

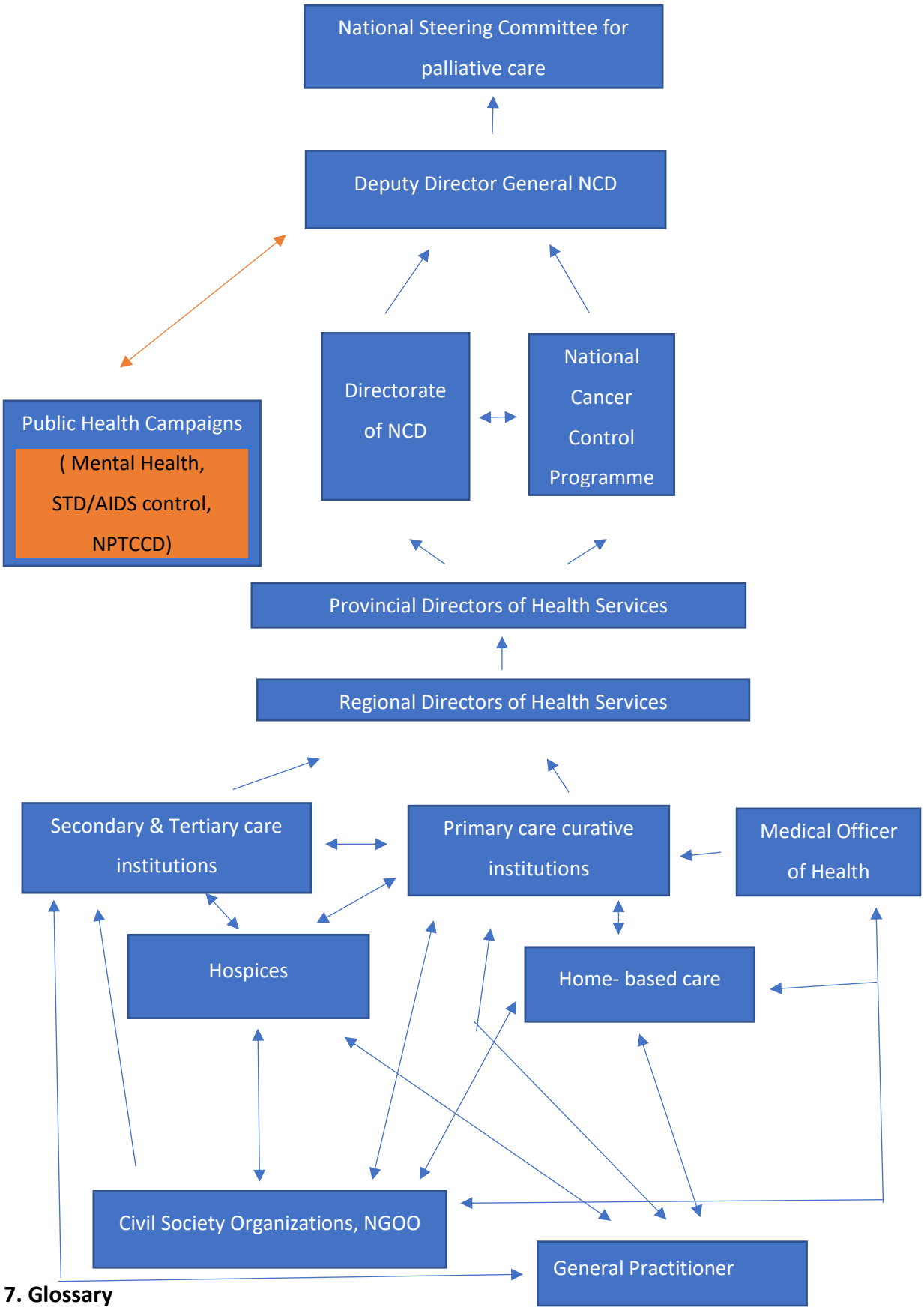
The National Steering Committee for Palliative Care which is chaired by the Director General of Health Services will provide the necessary guidance for policy implementation. The Deputy Director General NCD will be responsible for the implementation of the policy. The National Cancer Control Programme will coordinate activities related to cancers while the Directorate of Non- Communicable Diseases will be responsible for chronic and acute NCDs. Other public health campaigns such as the Directorate of Mental Health, Directorate of Youth, Elderly and Disabled, National STD, AIDS Control Campaign, National Programme for Control of Tuberculosis and Chest Diseases and Family Health Bureau will be responsible for the coordination and implementation of the palliative care component under their purview and shall be responsible for the achievement of the policy goal. Medical Officers for NCDs (MONCD) will act as district level focal points in the coordination of provision of palliative care

(III) Monitoring and Evaluation

The National Strategic framework for Palliative Care in Sri Lanka 2025-2030, which is in alignment with the national policy will enable effective implementation of the policy in partnership with all stakeholders. The Deputy Director General (NCD) will be responsible for monitoring the implementation of the policy. The monitoring of implementation of the policy at regional level would be the responsibility of Regional Directors of Health Services.

An evaluation will be conducted at the end of three or five years and the recommendations will be used in the next amendment of the policy document.

Proposed organizational structure for policy implementation



7. Glossary

Annexes

Sri Lanka National Health Policy (2016 - 2025)

National Policy and Strategic Framework for Prevention and Control of Chronic Non-Communicable Diseases (2023-2033)

National Strategic Framework for Palliative Care Development in Sri Lanka (2019-2023)

National Policy & Strategic Framework of Prevention & Control of Cancers (2015)

The National Elderly Health Policy (2017)

UHC policy 2018