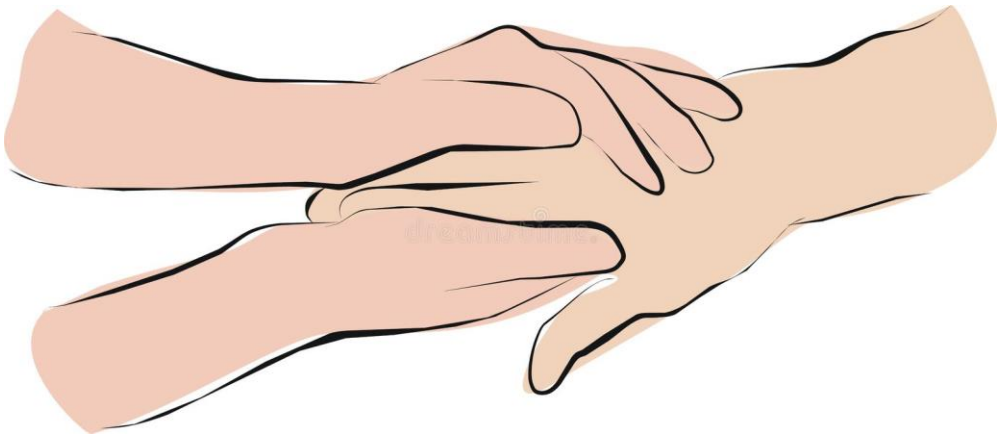
Development of Palliative care services in Northern, Sri Lanka:

A Guide for Implementation



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Title : Development of palliative care services in Northern, Sri Lanka: A Guide for Implementation

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Publisher : Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna, Sri Lanka

Pages : 60

Year : 2020

Printed by : Guru Printers
39/2, Adiyapatham Road, Thirunelvely,
Jaffna.

ISBN No : 978-624-5595-06-8

Forward

A common remark everyone hears frequently is ‘so much has changed’. Change of course is a permanent feature in everything and everywhere. Shorelines, mountain heights, vegetation, people, culture, beliefs, habits and you name it; everything has changed and continuing to change. In the medical scenario too the world is changing. Technological advances by leaps and bounds has helped to diagnose diseases and disorders more accurately, sub classify and provide better treatment; and more specifically surgical techniques, newer drugs, more specific to treat diseases and symptoms. All these have helped the humans to live longer. However nature is taking its toll in some other form. Over the last century, the technological advances have helped to significantly control parasitic infestations and bacterial infections all over the world. However, the viral infections had taken over from there and world is struggling with some viral diseases like HIV and COVID 19 without adequate treatment and proven immunological prevention methods. To add to this scenario of infectious diseases, longer life, wasting and deterioration of organ systems with the increasing life span; use of chemicals and micro plastics for agriculture, food preservation and comfortable living (?), are possibly increasing malignancies and chronic diseases. Most of these illnesses are not detected early and in addition, now have started occurring at a younger age. The advancing treatment systems are helpful in most instances to prolong life by controlling the disease rather than providing a complete cure.

These have resulted in more and more patient load every passing year, with hospitals struggling in the wards, clinics and outpatient departments. Alternative is to keep as many patients as possible in their homes and provide care at home level with active participation of the family, social

groups and helped and supervised by medical and allied staff. That is the idea behind Palliative Care. This idea as an organised patient care evolved from the work of Dame Cicely Saunders in 1967 and by 70s the idea was taken up in UK, Canada and USA. In India, Kerala state in South India too has initiated a very well organised Palliative Care for her patients and has a highly recognised operation.

Dr. Surenthirakumaran, of the Faculty of Medicine of the University of Jaffna had his training in Kerala in palliative care. Being a socially conscious qualified community physician and as the former head of the Department of Community and Family Medicine has written this book on Palliative care. Dr. Surenthirakumaran was a student leader (Medical Students Union President) during troubled 80s, in war-torn Jaffna, has now expressed his qualities as a leader in the society, actively participating in various research and social development programmes. He is the present Chairman of CANE, Jaffna (CAncer control North East, financed and helped by CANE UK, a charity). CANE is conducting a Palliative care programme for the cancer patients in the area. His experience from Kerala and other overseas exposures; discussions with the Medical fraternity in other parts of the country involved in palliative care; close contact with regional, provincial and national leaders in the health sector, has resulted in crystallising a development plan for Palliative care in the North. This book deals with detailed description of such a programme. It includes all activities of planning, execution, monitoring, and evaluating. This book expresses his ideas towards systematic development of Palliative Care in the North.

Palliative care has been started already in two districts in the North; it is still in rudimentary stages and this book describes how these services can be developed further to serve the entire North in an effective and efficient

manner, as part of health ministry function, assisted by the local society. I am sure those who will be studying this comprehensive text will come up with more ideas and of course with the changing times, local and national developments and policies; adjustments will have to be made. But here is something we already have in our hands, to start off in a big way.

After a little more than 50 years of experience as a medical officer, in the curative, preventive, administrative, educational, nongovernmental, volunteer sectors, I see an important need for palliative care right now, more than ever. I trust this book will encourage more staff to join the palliative care sector in government or non-government sector or to volunteer their services. I wish Dr. Surenthirakumaran and the readers success in their endeavours to provide palliative care or helping to provide palliative care.

Praying for the Blessings of the Almighty to all those who serve,

Dr.C.S.Nachinarkinian

Former Director, Teaching Hospital Jaffna

Board member CANE Sri Lanka

December 2020

Preface

The author is a specialist in Community Medicine and served as an academic for more than sixteen years at Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna. His main interest is non-communicable disease, epidemiology and health system development. Since 2014, he has been involved in the development of palliative care services in Sri Lanka, especially in the Northern Province. He was trained at the Institute of Palliative Medicine (IPM), Calicut, Kerala, India in 2015 and currently serves as chairman of CANE Sri Lanka. He also coordinated the initiative of Northern Province Strategic plan and leads the implementation of palliative care technical committee under the guidance of Provincial Director of Health Services northern province.

The experiences gained through involvement in the implementation of palliative care services motivated the author to choose the topic and write about it. The author also tries to document the historical efforts taken by various individuals and organisations to develop relatively modern and progressively increasing palliative care services in a resource limited setting.

Chapters are written in such a way as to explain how the services were developed and the challenges faced during the implementation. In addition, it covers future directions for implementing the comprehensive palliative care in Northern Province of Sri Lanka.

This book may be used as guide for the development of a provincial strategic plan and comprehensive services in palliative care.

Dr.R.Surenthirakumaran

December 2020

Preamble

Sri Lanka is in the advanced stages of demographic and epidemiological transition. There is a rising trend in the proportion of Sri Lankans suffering Non-Communicable Diseases (NCDs) such as, diabetes, heart diseases, strokes, asthma, cancers and mental health-related disorders. The deaths related to NCD could be sudden or have a prolonged course. The advancements in modern medicine and technology have resulted in increased life expectancy. Many patients with chronic diseases suffer many symptoms which affect their activities of daily living. This results in poor quality of life and agonizing deaths. The loved ones caring for these patients remain unsupported during this difficult process. The unpleasant experiences of a loved one leave deep rooted scars in the hearts of the family members affecting their health.

Considering the growing need for the care, many professionals and associations in Sri Lanka and later the government of Sri Lanka have taken a few initial steps to start the palliative care services. The palliative care services in Northern Province, was begun in 1993 by CANE. Now the Department of Health, Northern Province is committed to developing a comprehensive palliative care with the support of many partners. Two World Cancer Collaboration (TWCC) and International Medical Health Organization (IMHO), Canada are at the driving wheel to help implement the services. Although initial steps have been taken to provide the palliative specialist care in two hospitals and home care in two districts of Northern Province, while also running hospice with the primary facility, the province needs to exert more efforts in improving the quality of the care services for the people in the region.

Contents

List of Figures

List of Tables

Annexures

Acknowledgement

I would like to acknowledge to Dr. A Ketheswaran, Provincial Director of Health Services (PDHS) Northern Province Sri Lanka and the staff at the PDHS office for their contribution to develop the palliative care services.

I also acknowledge the board of directors of CANE UK and CANE Sri Lanka their support to develop the services and inspire me to involve in palliative care services.

My sincere acknowledgement for contribution made by the Two World Cancer Collaboration (TWCC) and International Medical Health Organization (IMHO).

I also acknowledge Dr P.A.D.Coonghe, Head, Department of Community and Family Medicine, University of Jaffna and the staff at the department for their support to compile the book.

My special acknowledgement goes to Dr. C.S.Nachinarkinian **f**or the guidance, editing and for the great forward message for the book. I also acknowledge Dr.Chrisanthi Rajasooriyar for her valuable input to improve the book.

My sincere acknowledgment to the Dean, Faculty of Medicine, University of Jaffna and the Vice Chancellor University of Jaffna for their support to publish the book.

Abbreviation

AIDS ..... *Acquired Immunodeficiency Syndrome*
CANE..... *Cancer Aid North and East*
CBOs..... *Community-based Organisations*
COVID19..... *Corona Virus Disease 2019*
HIV ..... *Human Immunodeficiency Virus*
ICRC ..... *International Committee of the Red Cross*
IMHO..... *International Medical Health Organization*
IMMR ..... *Indoor Morbidity and Mortality Record*
IPM ..... *Institute of Palliative Medicine*
MDT..... *Multi-disciplinary Team*
MOH ..... *Medical Officer of Health*
NCCP ..... *National Cancer Control Programme*
NCDs ..... *Non Communicable Disease*
NGO..... *Non-Governmental Organisations*
NNPC..... *Neighbourhood Network in Palliative Care*
NPCC..... *Northern Palliative Care Council*
NSFPCD ..... *National Strategic Framework for Palliative Care Development*
OMF..... *Oral and Maxillofacial*
PCCS..... *Palliative Care Consultation Service*
PDHS ..... *Provincial Director of Health Services*
PGIM ..... *Postgraduate Institute of Medicine*
PHC..... *Primary Health Care*
PMCI..... *Palliative care services at Primary Medical Care*
SLMA ..... *Sri Lanka Medical Association*
THJ..... *Teaching Hospital, Jaffna*
TWCC..... *Two World Cancer collaboration*
U.S..... *United states*
UK..... *United Kingdom*
WHO..... *World Health Organization*

Chapter 01

Introduction to palliative care

1.1 Background

Noncommunicable diseases (NCDs) tend to be of long duration in nature. The important characteristics of NCDs include insidious onset, chronic clinical manifestations and long-term disability in the face of poor control. Figure 1.1 shows the natural history of NCDs. Most of the patients are diagnosed in the later stages, particularly after developing serious symptoms or complications.

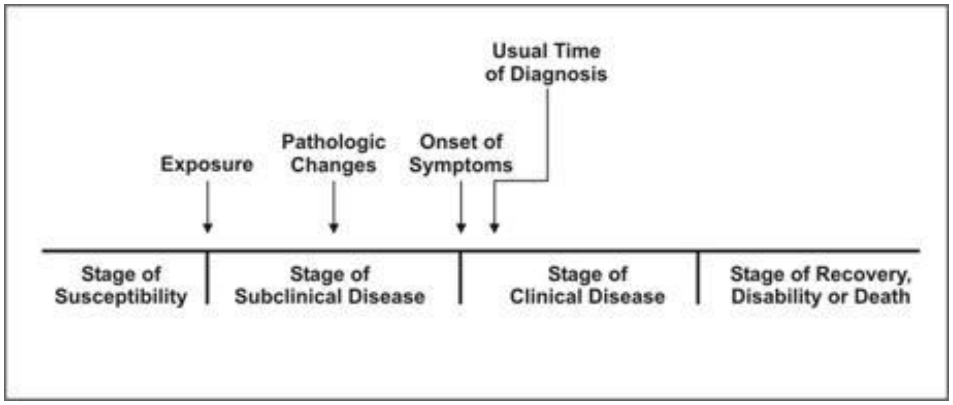

Figure 1.1: Natural History of Disease Timeline

Source: *Centers for Disease Control and Prevention. Principles of epidemiology, 2nd ed. Atlanta: U.S. Department of Health and Human Services; 1992.*

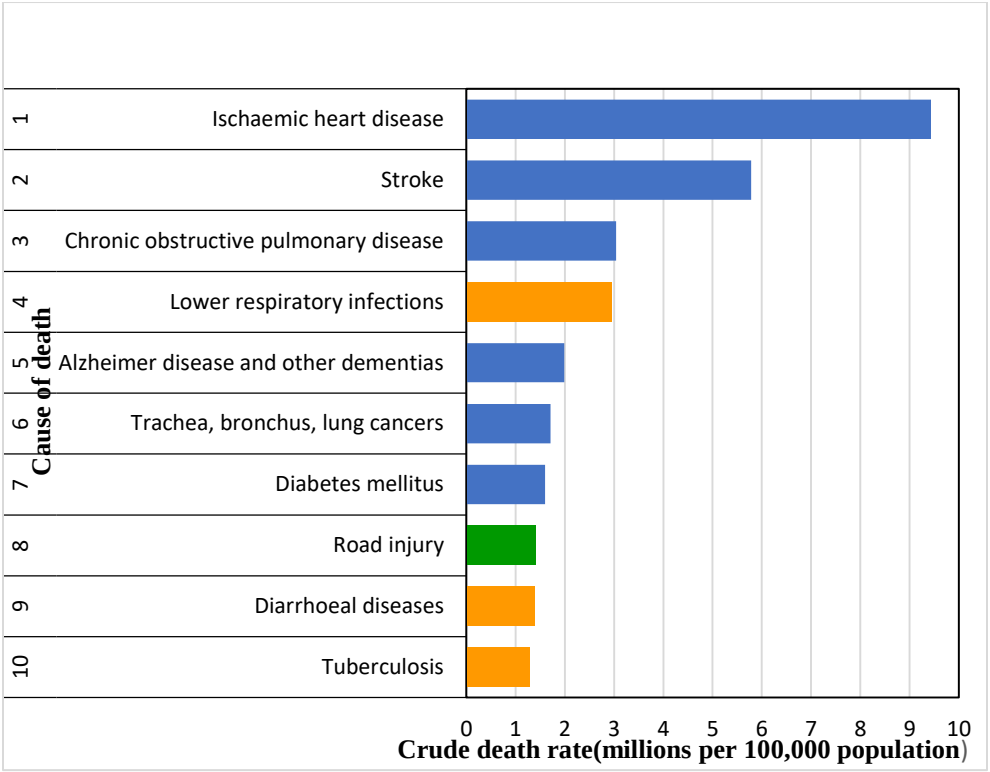

Figure 1.2: The top 10 causes of global deaths in 2016

Source: *World Health Organization. 2018*

According to the World Health Organization (WHO), NCDs, due to its chronic nature, constitute the top ten causes of global deaths. (Figure 1.2).

According to Global Action Plan for the Prevention and Control of Non-Communicable Diseases, comprehensive care for non-communicable diseases, encompasses primary prevention, early detection/screening, treatment, secondary prevention, rehabilitation, palliative care and attention and improvement of mental health as a priority for social development and investment in people(1).

The concept of palliative care was introduced with the development of hospice movement in the late sixties by Dame Cicely Mary Saunders.

Modern hospice has helped to establish the discipline and culture of palliative care in the management of pain and other symptoms (2).

1.2 Definition of palliative care

The term “palliative”, was obtained from the Latin word pallium, meaning a cloak. Palliative care aims to mask the symptoms and provide relief to the patients (3).

Palliative care needs to be integrated with curative care. The old concept was to integrate palliative care in the last stages of the disease, as shown in fig.1.3. Palliative care is mostly considered as an end-of-life care. Recently the concept of palliative care has changed, and there are many efforts to integrate palliative care with disease-modifying care or potential curative care. (Fig.1.3.). Hence, palliative care needs to be integrated with curative intent care of patients.

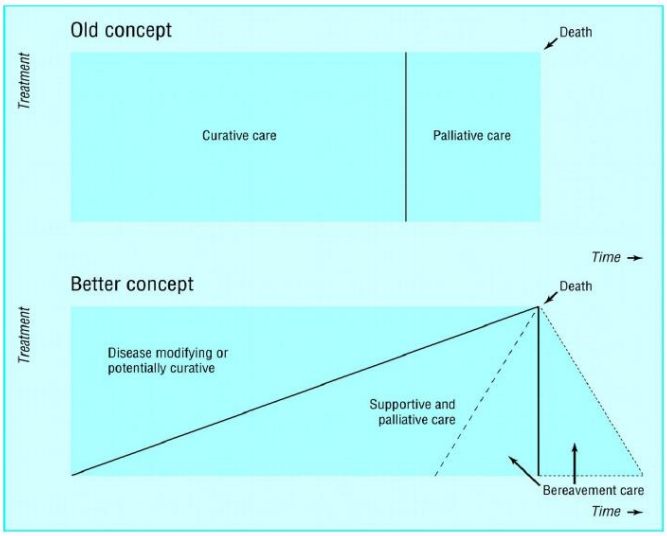

Figure 1.3: Changing paradigm of the concept of palliative care (4)

***Source**: Illness trajectories and palliative care [Internet]. Vol. 330, British Medical Journal.*

In 2002, the WHO has defined palliative care as follows;

"An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial and spiritual".

Palliative care includes:

- Relief from pain and other distressing symptoms.
- Affirming life and regarding dying as a normal process.
- Neither intends to hasten or postpone death.
- Integrating the psychological and spiritual aspects of patient care.
- Offering a support system to help patients live as actively as possible until death.
- Offering a support system to help the family cope during the patient's illness and in their own bereavement.
- Using a team approach to address the needs of patients and their families, including bereavement counseling, if needed.
- Enhancing quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO emphasises that the palliative care principles should apply to chronic paediatric disorders as well. As defined by WHO, 'palliative care should be active total care of the child's body, mind and spirit and also provide support

to the family. It begins with the diagnosis of illness and continues whether or not a child receives the directed treatment for the disease'. Effective palliative care requires a broad multidisciplinary approach which includes the family and the resources available in the community. The integration and mobilisation of community resources and utilisation of the support of family members, relatives and volunteers will be helpful in the successful implementation with limited resources. It can be provided in tertiary care facilities, in primary care centres, at home and even in institutions like children's homes.

Initially, people thought that palliative care is only for cancer. However, now, WHO emphasises the use of palliative care for a wide range of diseases. In adults, this covers most of the chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%), and diabetes (4.6%). Many other diseases such as chronic kidney disease, chronic liver disease, dementia, chronic neurological diseases, congenital anomalies and drug-resistant tuberculosis may also require such care. Among children palliative care may be needed for diseases like, congenital anomalies (25.0%), neonatal conditions (14.6%), protein energy malnutrition (14.1%), meningitis (12.6%) and HIV/AIDS (10.2%). (5)

Problems encountered by patients with incurable diseases include;

- *Physical afflictions:* Severe pain, incurable ulcers, frequent vomiting, breathlessness and other conditions;
- *Financial difficulties;*
- *Social issues:* loss of job, changes in interpersonal relationships, inability to fulfill societal and familial responsibilities.

- *Emotional problems:* isolation, fear, hopelessness, sense of guilt, fear of death, gloom;
- *Spiritual crisis.*

Patients suffering from life-threatening illnesses need supportive care in addition to the disease specific treatment. Supportive care helps the patient and their family to cope with the crisis. Hence, supportive care should be integrated with the treatment. It encompasses:

- Self-help and support;
- User involvement;
- Information sharing;
- Psychological support;
- Symptom control;
- Social support;
- Rehabilitation;
- Complementary therapies;
- Spiritual support;
- End of life and bereavement care

There are two main health and social care professionals who provide palliative care;

1. Those providing day-to-day care to patients and carers in their homes and hospitals;
2. Care provided by the specialist (consultant in palliative medicine, specially trained medical officers in palliative care, nurse specialist in palliative care etc.)

Day to day care includes the following;

1. Assess the physical, psychological, social, spiritual and information needs of the patient and the family;
2. Address the needs within their capacity;
3. Awareness as to when to seek advice from or refer to specialist palliative care services.

Specialist care services include;

1. Carrying out necessary assessments, provide advice and care for patients and families in all the care settings;
2. Provide specialist in-patient palliative care services;
3. Co-ordinate the care services at all levels including care at home;
4. Advice and support to all the people involved in a patient's care;
5. Bereavement support services which provide support for the people involved in a patient's care following the patient's death;
6. Education and training in palliative care.

Chapter 02

Models of palliative care

According to the WHO estimates, every year, 40 million people need palliative care. Amongst them, 78% live in low and middle-income countries. But worldwide, only 14% percent of those who need palliative care receive it (5). The need for palliative care keeps growing as modern medicine has led to increased life expectancy resulting in a rise in ageing population and the incidence of NCD. Most of the governments in resource limited settings are struggling to establish palliative care.

The WHO has identified many hurdles in offering palliative care which needs to be overcome. Palliative care is a neglected specialty in many national health policies and systems. Palliative care training for health professionals is at best, limited and at worst, non-existent. There is limited access for receiving the necessary pain relief medications. (5). Also, the cultural and social barriers, such as beliefs about death and dying and misconceptions that palliative care is only for patients with cancer or for those in their last stages of life, deters the successful implementation of palliative care. (6)

2.1 Developing palliative care services

In developing a comprehensive palliative care, the following basic requirements need to be considered;

1. Advance care planning
2. Access to services
3. Continuity of care
4. Preferred place of care.

2.1.1 Advance care planning

The services should provide an opportunity for the patient, family and the palliative care team to sit and discuss the plan and delivery of palliative care. It should address the preference of the patients.

2.1.2 Access to services

The care services must be available to all patients, wherever and whenever they require it, without delay. It should be affordable to all patients irrespective of their capacity. It is crucial to ensure the equity of the care. The necessary special care must be made available for children and the elderly as well.

2.1.3 Continuity of care

It is important to ensure the continuity of the care throughout the course of the disease and across the different settings in the healthcare system. This is the basic requirement of the delivery of palliative care. Palliative care should be made an integral part of all health care delivery systems such as hospitals, emergency departments, nursing homes, home care, assisted living facilities, outpatient services , schools and prisons. There is an essential need to build up a network of professionals and community together with the palliative care team to ensure better coordination and communication.

2.1.4 Preferred place of care

Most patients prefer to be cared for and breathe their last, in their own homes. In contrast to the preference of the patients, the place of death for most patients is the hospital. Palliative care should be available at all levels,

including at homes, and the patients must be given the opportunity to choose their preferred place of treatment. Palliative care and support needs to be available at home, nursing homes, residential homes for the elderly, hospitals and hospices or in other settings if required.

Globally many models were adopted to deliver comprehensive palliative care. The resource-rich countries adopted a model which is predominantly driven by the specialist palliative care services in hospitals and hospices.(7) The hospital-based palliative care model in developing countries faced a lot of financial challenges in delivery of good quality care.(8)

Another model which is successful in providing palliative care mainly in the community, with the available support of the community networks. This model was proposed in many developing countries. One of the well-established models is the South Indian Kerala model of Neighborhood Network in Palliative Care (NNPC).(9) Considering the chronic status of diseases which need palliative care services and the social costs involved, the model was initially established as an initiative of a non-governmental organization as part of a medical school in Northern Kerala. Gradually, it expanded further with the support of volunteer doctors, healthcare professionals and thousands of volunteers. The model was later incorporated with the Kerala state health services.(10)(9). Similar kind of models have been developed in many developing countries.

Based on the experiences and evidence of success stories, WHO proposed the following steps for consideration by countries in the development of palliative care services;

1. Setting up a palliative home-care service or integrating palliative home care into existing home-care services;
2. Establishing palliative care in a community setting;

3. Integrating palliative care services into a district or general hospital;
4. Establishing palliative care services for children including neonates;
5. Setting up a stand-alone palliative care centre or hospice;
6. Developing an integrated approach in a district.

These suggestions could be adopted for implementation based on the local situation.(6) The following table provides the details of a graded system of palliative care services.

Graded system of palliative care services*

	Palliative care			
	Palliative care approach	**Specialist support for general palliative care**		**Specialist palliative care**
Acute care	Hospital	Volunteer hospice service	Hospital palliative care support team	Palliative care unit
Long- term care	Nursing home, residential home		Home palliative care teams	Inpatient hospice
Home care	General practitioners, community nursing teams			Home palliative care teams, day- care centre

*Adapted from: Nemeth C, Rottenhofer I. *Abgestufte Hospiz- und Palliativversorgung in Österreich*. Wien: Österreichisches Bundesinstitut für Gesundheitswesen, 2004

Figure 2.1: Grade system of palliative care services

Well-functioning palliative care systems should ensure the interaction and integration between the different levels of care. During the course of the disease, patients may need support from different levels of palliative care services. Developing referral pathways will help the patients and families get regular uninterrupted care smooth care. The figure 2.2. below shows how the different levels of palliative care settings work in a well-established interactive network in providing end of life care in Australia.

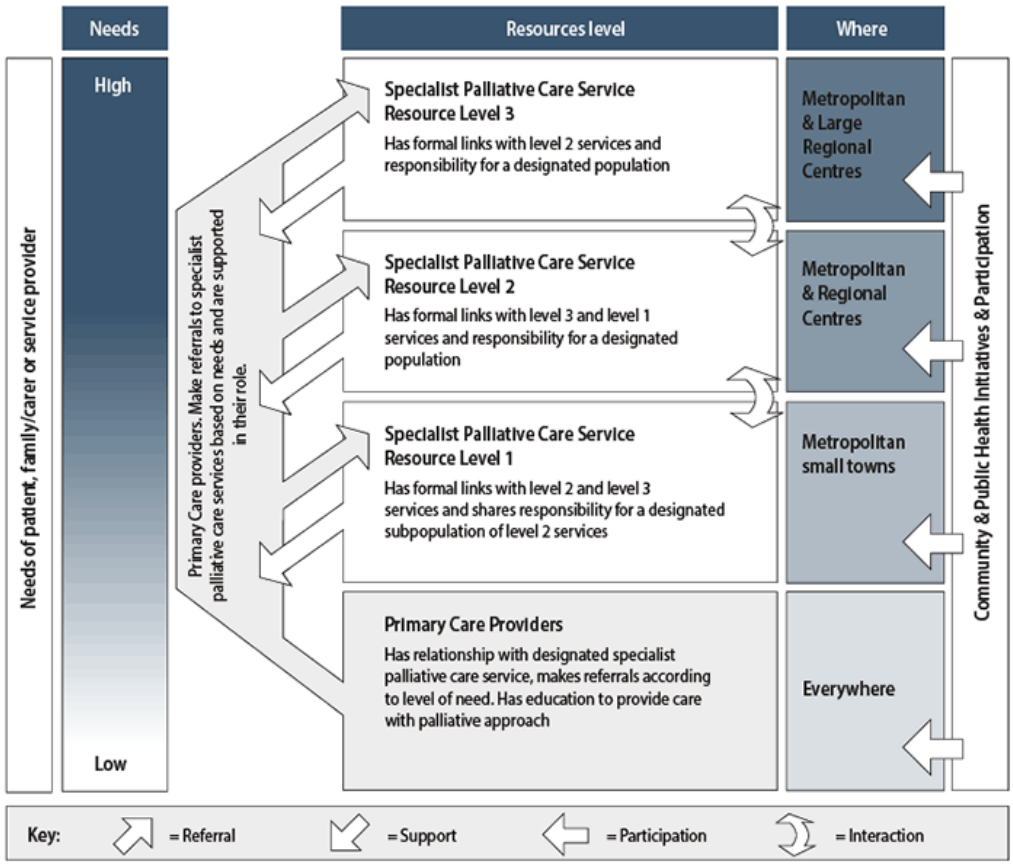

Figure 2.2: Showing the well-integrated palliative care services at different care level

Chapter 03

Palliative care needs in Sri Lanka

Population pyramid of Sri Lanka clearly shows that the population is ageing steadily and will reach its peak in 2041. (9) This transition will lead to an increase in the dependent population, with increased comorbidity. The environment they live in should be able to cater to their needs. It will also create many socioeconomic issues, leading to an increase in the already existing disparities within the community**.**

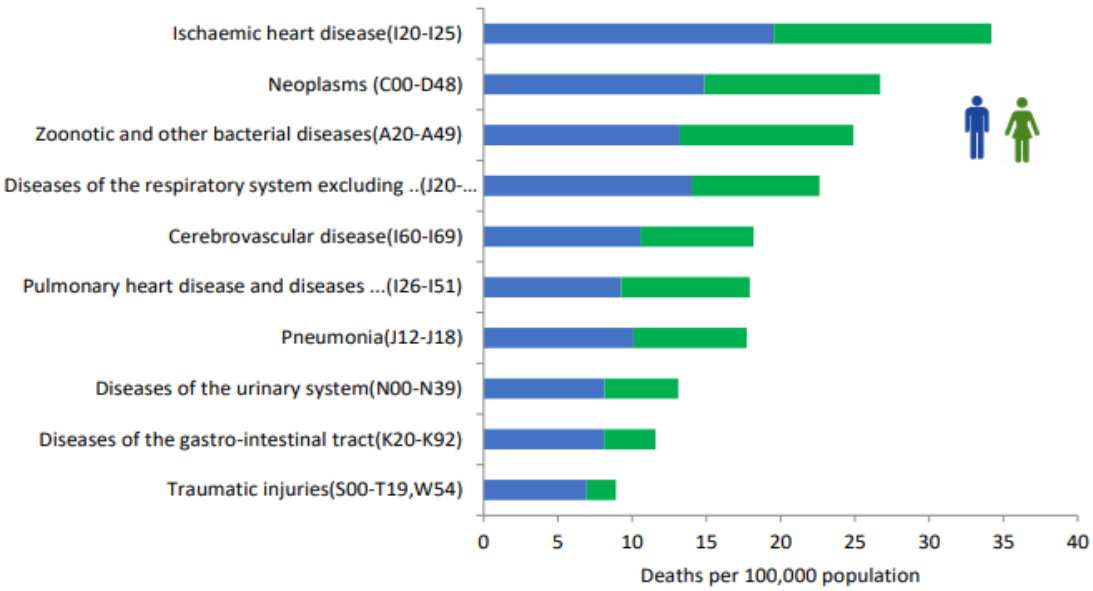

Figure 3.1: Leading causes of hospital deaths in Sri Lanka, 2018

Source: *Annual Health Statistics, Ministry of Health,2018*

According to the annual health statistics of Ministry of Health, Sri Lanka, leading cause of deaths in hospitals in 2018, were due to ischemic heart diseases, followed by neoplasm.

Table 3.1: Number of deaths from major Non-Communicable Diseases (NCDs) in government hospitals of Sri Lanka, 2017

Major NCD	No. of deaths
Cardio-vascular diseases	15,031
Neoplasms	4,938
Diabetes Mellitus	803
Chronic respiratory diseases	4,577
Total	25,349

Source: Annual Health Bulletin, Ministry of Health ,2017

Major Non-Communicable Diseases (NCDs) were the cause of more than 25000 deaths in 2016 and constitutes 83% of the proportional mortality rate in Sri Lanka.

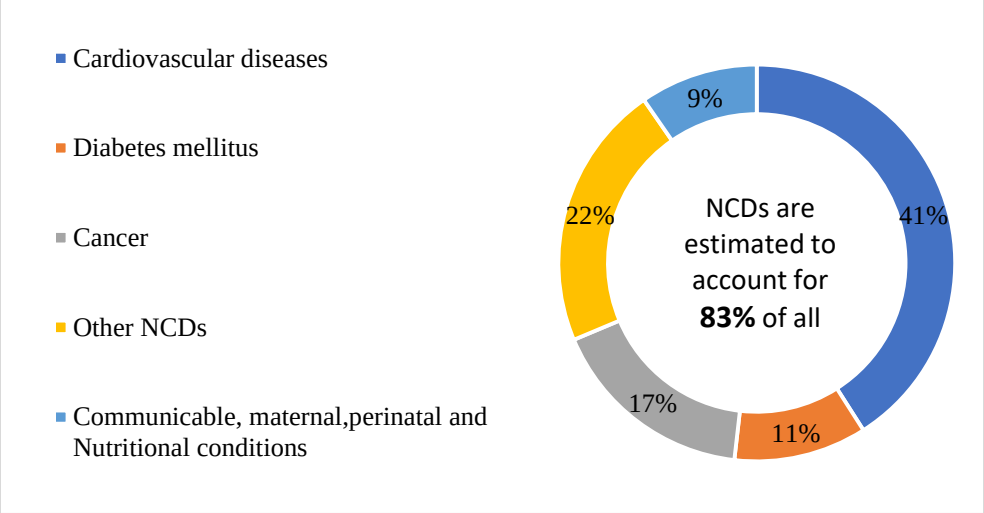

Figure 3.2: Proportional mortality rate by cause in Sri Lanka, 2016

Source: *World Health Statistics, 2018*

Chapter 04

Palliative care initiatives in Sri Lanka

Except for a few initiatives for home-based palliative care, palliative care in Sri Lanka was limited to hospice care, until the early part of 2010. In early 2010, taking into consideration the growing need for developing palliative care all over the world and in Sri Lanka, early initiatives were taken by the Sri Lanka College of General Practitioners. The aim was to sensitise health staffs, especially medical officers working in the state and private sectors with the support of a team of experts from Palliative Care Association, Kerala. There were about 300 doctors who received basic training in palliative care. National Cancer Control Programme (NCCP), Sri Lanka, also arranged a training programme for the doctors and nurses. A few doctors were also sent to India, to get certified in palliative care. NCCP also organised a 'train the trainer' programme with the support of Lien Foundation, Singapore.

Sri Lanka Medical Association (SLMA) formed a task force on palliative care and end of life care. (11) The SLMA taskforce developed a manual and guidelines relating to end of life care and a manual relating to palliative care for management of non-cancer patients. The SLMA task force also collaborated with the Ministry of Health, Sri Lanka, in relation to many aspects of the development of palliative care services in the country. The taskforce also advocated for the start of postgraduate courses in palliative care at the Postgraduate Institute of Medicine (PGIM), University of Colombo. Palliative Care Association of Sri Lanka was formed. The association also organised training programmes for health professionals and

advocacy programmes with various stakeholders on the need for palliative care. (12)

After the combined efforts of many, the PGIM has started the Post Graduate Diploma in palliative care for medical officers.(13) However, still, formal palliative care services are not available in the country, except for the few hospices which offer incomplete services to patients with advanced cancer. Most patients with debilitating diseases other than cancer are not getting the relevant care. Physical symptoms of cancer patients are usually addressed by the treating oncologist, as long as the patient is under his/ her direct care. Help from Anaesthetists is obtained to treat unbearable pain if the patient is admitted in a cancer hospital.

In addition to inadequate services, unavailability or short supply of essential medications to alleviate the critical symptoms of palliative care remains unresolved. Especially, availability of the oral forms of Morphine to help control pain for the patients outside the hospital is limited. Narcotic drug stocks were only available in major hospitals and supply of oral Morphine is very often irregular. The availability of fentanyl patches is limited due to high costs.

Through the course of the years, education and training programmes were increased for the service provider. Most of the initiatives are done by professional and non-governmental organisations. There are in-service training programmes organised by NCCP for the doctors and nurses. Except for the postgraduate diploma for medical doctors, there are no formal educations or training programmes available for the professionals to get skilled in palliative care. The need for incorporation of palliative care in the

undergraduate curriculum of medical students, nurses and other allied health professionals has been identified by the NCCP and initiatives had been taken to liaise with the relevant educational and training institutions. There is a huge need for basic training for family members and community volunteers but remains unmet.

Most importantly, there are no guidelines for practice/ delivery of palliative care in the country.

4.1 Policy/ National strategy:

Considering the rapid increase in elderly population and the morbidity and mortality due to major NCDs, many stakeholders have identified the urgent need to implement palliative care services in Sri Lanka. Sri Lanka National Health Policy 2016-2025, mentions that the mainstream health system should provide palliative care to all the patients who need such care, for them to live and die with dignity. Many policy documents in Sri Lanka has recognised the need of palliative care.

National Strategic Framework for Palliative Care Development (NSFPCD) in Sri Lanka, 2018-2022, was developed and launched in December 2019(14).

Overall call of the NSFPCD involves, improving quality of life of patients suffering from life-threatening illnesses and providing holistic support to them and their families by preventing and relieving suffering through evidence-based, multi-disciplinary and cost effective approaches (14).

Areas of support include;

- Pain and symptom management;
- Psychological, emotional, social and spiritual support;

- Support for families and caregivers in coping with the patient's illness and during bereavement.

The strategic document includes 11 strategies. Detailed descriptions are annexed. **(Annexure-1)**

Key features of the strategies are summarised below;

1. Making palliative care an essential component of comprehensive health care;
2. Integration of specialist palliative care and palliative care services across all levels of service settings.

Based on the present health care model, the strategic document has proposed a model of care from institutional to home-based care. Please see annexure. **(Annexure-2)**

The second strategy identified the need for integrating palliative care at all levels of the existing services. The following essential steps were identified for implementation;

4.1.1 Palliative care services in tertiary and secondary level hospitals:

4.1.1.a. Develop a qualified professional palliative care team: The vital step is to develop a skilled professional palliative care team to provide general specialist palliative care services. The role of the team would be to offer consultation services to support, advice, educate and mentor specialist and non-specialist teams and ensure the delivery of high-quality services. This team would represent the Palliative Care Consultation Service (PCCS).

- **Approach:** Phase out method, depends on institutional preparedness in developing the services and availability of human resources at tertiary and secondary care levels.

- **Coordination of care:** Director or the medical superintendent of the hospital.

- **Human resources:** Interdisciplinary team of PCCS including a consultant physician in palliative medicine as team leader (until a qualified specialist becomes available other PGIM board-certified specialist can be appointed).

- **Medical Officers:** availability of at least one medical officer on a full-time basis (preferably a doctor with a diploma in palliative care).
- **Nursing officers:** Experienced and committed nursing officers with training on the basics of palliative care. Availability of at least one nursing officer on a full-time basis.
- **Social service officer:** Arrange a social services officer with the support of the district social services officer. The officer needs to be trained in basic concepts of palliative care.
- **Counselor** – Get the support of a mental health team or trained doctors and nurses on counseling.
- **Pharmacist** – One of the hospital pharmacists with knowledge of drugs used in palliative care.
- **Health Care Assistants** – Male & Female

In addition to the officers mentioned above for formation of a palliative care team, availability of physiotherapists, speech therapists, occupational therapists, psychologists, nutritionist etc., will be ideally suited for optimal service delivery.

- **Space: S**pace should be available for consultations by consultant, medical officers and nursing officers. A family consultation room should also be available.
- **Equipment:** One desktop computer, printer, portable hard disk, filing cabinets, telephone, fax and internet services, necessary

medicines & equipment for patient management, essential medicines for symptom management, equipment for patient care - wheelchair, home oxygen, folding beds, air mattresses, nebulisers, syringe pumps, subcutaneous cannula etc. are other necessaries.

- **Services**:

  Outpatient clinic sessions: Initially, one clinic session per week and subsequently increase the number of sessions per week based on the number of patients and other needs. Availability of formal referral from other units of the hospital.

- **Palliative care in-patient consultation service:** receive and accept referrals from any unit of the hospital. The patient remains under the care and in the ward of the referring consultant. A suitable member of the palliative care team should visit each patient and provide advice and inputs daily or as needed. The team should meet daily or frequently as necessary to discuss the actions and progress of each patient and maintain relevant records.
- **Linking with palliative care services at primary care level:** The goals and the role of the primary care units for each palliative care patient will be identified in the shared care plan developed by the PCCS. This plan should be communicated to the respective primary care settings - divisional hospitals/primary medical care units/general practitioners who use a common standard format, developed for the purpose.
- **Linking up with hospices:** PCCS should develop close collaboration with government, non-government & private

hospices for the provision of co-ordinated palliative care services. The closest PCCS should arrange necessary technical guidance and clinical supervision, including training of hospice staff.

- **Coordination with other government and non-government institutions:** PCCS should co-ordinate with social service officers attached to the district /divisional secretariat offices, non-governmental organisations etc., to co-ordinate extended holistic care. All caregivers should be educated and empowered by regular multi-disciplinary team (MDT) meetings and family discussions. If the patient or family members feel that they need any other special care or other alternative care, they should have the freedom to choose, in accordance with the patient-centred care.

4.1.1.b. Palliative care services at hospices:

- ✓ Residential care facilities for palliative care patients
- ✓ Daycare facilities for palliative care patients
- ✓ Training of caregivers
- ✓ Training of health care staff on palliative care

- **Human resources:** Carefully selected and ideally permanent staff comprising; medical, nursing and other supportive care staff, in addition to any volunteers.
- **Training:** Regular in-service training should be arranged for the staff.
- **Quality of care:** It is essential to conduct regular clinical audits to improve the services of hospice care.

- **Communication links:** Hospices should develop direct communication links with the palliative care consultation service from which patients are referred to the hospice.

4.1.1.c. Palliative care services at Primary Medical Care Institutions (PMCI):

These services play an important role; Patients are usually referred to the PMCI by the Palliative Care Consultancy Service, along with a shared care plan;

Patients are registered at the primary medical care institutions (divisional hospitals and primary medical care units) as part of the shared care plan. Whenever necessary, these patients can be referred back for advanced care;

Patients who need palliative care services, but remain unattended, can be presented to the PMCI. Patients identified by the Public Health Nursing Officer attached to the PMCI during their field visits should also be registered at the PMCI and may be referred to the Palliative Care Consultation Services for the development of a new shared care plan;

The services at primary care should be linked with the patient's general practitioner, local MOH office, local religious leaders, community based organisations and volunteers etc., according to the needs and wishes of the patient;

All the staff, especially medical officers and nursing officers at the PMCI should receive formal training on palliative care. The head of the PMCI should ensure that medical officers and nursing officers at primary care level have access to guidelines on palliative care.

4.1.1.d. Palliative care services by the general practitioners:

Some palliative care patients and their caregivers may prefer to receive palliative care services co-ordinated by their full or part-time general practitioner. In which case, the goal of care and shared care plan developed by the PCCS should be communicated with the general practitioner.

In such circumstances, the general practitioner must communicate with the PCCS according to the needs of the palliative care patient. The general practitioner should also share plans with the closest PMCI, MOH Offices etc., to arrange necessary care for the patient and caregiver.

Standard formal training should be given to all the general practitioners on caring for palliative care patients.

4.1.1.e. Palliative care services by the Medical Officer of Health (MOH) office:

MOH should be informed regarding any needs of palliative care patients in the community, identified by the MOH office staff.

MOH office needs to co-ordinate with the closest primary medical care institution to arrange palliative care services.

MOH office can co-ordinates with social service officer and counselling officer, attached to the divisional secretariat, non-governmental organisations (NGO), religious-based organisations and other community-based organisations, to arrange supportive care.

4.1.1.f. Palliative care services at home-based level

Home-based palliative care must be guided by the Primary Medical Care Institution where the patient is registered or by the patient's general

practitioner as part of the shared care plan of the palliative care consultancy service.

This service should be linked up with the primary care medical institutions and the secondary care hospital, for specified advanced care if needed.

With the appointment of Public Health Nursing Officer, delivery of home-based palliative care can be initiated and linked with the closest primary medical care institution.

Still then, existing initiatives which are mainly coordinated by the hospitals and non-governmental organisations (NGO) should support in the care of the patients. Regular audits as well as feedback of the patients and public are recommended to assess and improve the service delivery.

Chapter 05

Palliative care initiatives in Northern Sri Lanka

5.1. Introduction

Northern Province is one of the nine provinces in Sri Lanka, severely affected by the protracted civil war, which ended in 2009. For administrative purposes, the province is divided into five districts. According to the Provincial Council, Northern Province, the total population in Northern Province was 1,249,740. Almost half the population live in Jaffna district.

Table 5.1: Distribution of district population by sex

S/No	District	No. of Individuals		Total Population in NP
		Male	Female	
1	Jaffna	298,858	317,146	616,004
2	Kilinochchi	70,578	74,635	145,213
3	Mannar	78,978	84,352	163,330
4	Mullaitivu	67,382	70,240	137,622
5	Vavuniya	91,509	96,062	187,571
Total		**607,305**	**642,435**	**1,249,740**

Source: *Vital Statistics, Office of the Chief Secretary-Planning Northern Province(Details as at 31.12.2019)(15)*

Ageing population of Sri Lanka increased from 7.3% to 10.8% between 2009 and 2019.

Table 5.2: Distribution of elders over the age of 60 districts in Northern Province and National

District and National	Old Age (>60) population	
	Total number	percentage
Jaffna	84434	13.4
Kilinochchi	9969	7.9
Mullaitivu	7860	6.3
Vavuniya	14985	11.9
Mannar	8252	6.6
Sri Lanka (National)	21,413,249	10.8

Sources: *Census of Population and Housing of Sri Lanka, 2012*

Due to the civil conflict over 30 years, many young people died or migrated. The districts of Jaffna and Vavuniya have a higher proportion of elderly people than the national average. There are no recent surveys on NCDs in Northern Province; hence, actual burden of diseases is not available. According to the annual statistical information of Indoor Morbidity and Mortality Record (IMMR), the NCDs such as ischemic heart diseases, neoplasm and respiratory diseases, contribute to a major proportion of deaths in the province.

Based on the needs, the Department of Health, Northern Province, has been working with the network created with the support of local and international well-wishers for provision of palliative care.

Palliative care services in the Northern Province, particularly in the district of Jaffna, started in the early nineties. Palliative care initiatives were started by non-governmental organizations working with cancer patients.

The treatment centre for cancer patients was established in Tellipalai base hospital in early seventies but was never functional due to the civil war. Patients from northern province had to travel more than 400 km to the National Cancer Institute in Maharagama, until year 2005. First consultant oncologist Dr.N.Jeykumaran started his services in 2005. During the war, the district of Jaffna, was disconnected from the rest of the country. The only available mode of travel was the cargo ships. Cancer patients underwent great difficulty in accessing proper cancer treatments at National Cancer Institute of Maharagama. Travel for the cancer patients was facilitated by the International Committee of the Red Cross (ICRC). Patients were taken by ship for treatment.

Unavailability of the services within the district, combined with travel difficulties, complicated matters in obtaining proper treatment for the cancer patients. Meanwhile, there were a lot of terminally ill patients in the district. A few professionals and well-wishers from the district and abroad, especially from UK, organised palliative care services in Jaffna.

The organization, Cancer Aid North and East (CANE), was established in 1993 by a group of professionals from UK. A Medical Oncology unit was established at the Teaching Hospital, Jaffna by late 2004 and a radiation Oncology Unit at the Tellipalai Base Hospital in 2005 in the midst of many challenges and the ongoing war. This initiative gave a deep sense of relief to the public.

Figure 5. 1: Cane Sri Lanka Hospice in Uduvil Jaffna

5.2 Early history of CANE in Jaffna in providing palliative care services in Jaffna.

Mr. Indrasenan, the coordinator for CANE in Jaffna, was instrumental in establishing a cancer care unit in Jaffna. He first visited cancer patients with Mrs. Ann Watson and some nursing aides, to help the patients. The team visited the places by three wheeler and later on in Mr.Indrasenan's car. In the meantime, Mr. Indrasenan was looking for a temporary place to set up a cancer clinic. They looked for many places and later, Mr. Indrasenan arranged his sister's home at Palam Road, Jaffna, to establish the cancer care home. Thereafter, all cancer related activities were computerised by Mr.Sabanayagam, who came from the UK. He also conducted interviews for the post of office assistant and selected Ms. Sukirtha. Periodical cancer wellness clinics were conducted at the Palam Road home. Cancer mobile clinic was also initiated, with the help of Mr. Indrasenan, whose car was utilized in visiting patients. His daughter, Dr. Natheera Indrasenan, came from UK to operate and guide the cancer wellness clinic. While services were run from the temporary premises the need for a permanent building arose.

5.3 Establishment of CANE Cancer Hospice in Inuvil, Jaffna

When CANE was looking for land to construct a permanent structure, Dr.Aru Thirumurugan found a land and donated it to CANE. Present day CANE hospice was built in 2006, by CANE Jaffna, with the support of well-wishers from UK. The location was selected because of its proximity to the cancer treatment centre in Thellipalai. Majority of the fundraising to meet the hospice's objectives were carried out in the UK, by CANE UK. The hospice started its services in 2007, ever since; the hospice has been providing care for the cancer patients. The hospice's operational funding support is provided by CANE UK, since inception.

Two of the dignitaries, late Dr. Ms. Canagaratnam, a former Director Hospital, Jaffna and late Dr. N. Sivarajah, former head of Department of Community Medicine, University of Jaffna were looking after the hospice's functions and ensured the delivery of good quality care. The cancer hospice was refurbished in 2020.

5.3.1 Environment of the hospice

The convivial settings of the hospice provide tranquility and hope to the patients. There are two separate open wards for both females and males with a bed capacity of 24. There is a prayer hall for spiritual support, catering to all religions. The hospice offers its services free of charge.

5.3.2 Human resource at the hospice:

Initially, available health care assistants were recruited and CANE trained them with the support of health care trainers from the Department of Health, Sri Lanka and Faculty of Medicine, University of Jaffna. Currently, most of the health care assistants receive basic training in nursing and palliative care.

Also, most of the nursing assistants receive training from a local non-government nursing training institute and qualify for either certificate in health care assistance or diploma in nursing. These qualifications are approved by the private health authority of Ministry of Health, Sri Lanka.

The hospice has only one full time nursing staff with a bachelors and masters degree in nursing. Only one visiting medical officer is available to look after the medical care of the patients.

Office management is done by an administrative officer and a clerk. There are two cooks available to prepare meals for the staff and patients.

5.3.3 Services rendered by the hospice:

Hospice provides care for the patients who come from far off places for radiotherapy and chemotherapy at Tellipalai Trail Cancer Hospital (TTCH). During the course of the treatment, they stay at the hospice and the hospice provides medical and nursing care. Free transport services are provided by the hospice to the treatment centre. The vehicle was donated by Australian Medical Aid Foundation, a charity in Australia.

The hospice also provides care for the patients who do not have support at their homes until death. Post death services are also provided.

During the stay in the hospice, all the patients receive the necessary palliative care. Nurses, nursing assistants and community volunteers work with patients and address their needs by providing support even after they go back home.

5.3.4 Main Challenges:

1. Getting trained full time medical and nursing officers; hospice is not able to provide the actual palliative care needed due to the difficulty in recruiting medical officers and nursing officers.
2. Getting adequate funding to meet the monthly expenses of the hospice. Currently, CANE UK provides the funding support. Over the years, CANE UK has been facing difficulties in raising the necessary funds. The expenditure has increased with the development of the hospice.
3. Present hospice has an open ward which is not ideal to offer palliative care. Patients need rooms with attached toilet for privacy and comfort. This need has been noted by both CANE trustees and the local health authorities.
4. CANE, initially started to provide services for cancer patients. Over the years, the concept of palliation broadened to provide care for non-cancerous patients. Recently WHO identified around 70% of the palliative needs in non-cancerous patients. Hence, CANE is keen on changing the mandate and the name the facility as “Anpalayam”. Currently, the hospice services are limited, only cancer patients. There is an urgent need to develop a plan for providing hospice care for non-cancerous patients.

5.3.5 Way forward:

Build a model hospice and expand hospice services to other districts. Currently, the trustees and health authorities in Northern Province are working together to find solutions for at least one functional hospice in northern province.

Initiatives were taken to obtain land in a convivial place. A large plot of land in a scenic location has again been identified by Dr. Aru Thirumurugan. Currently, health authorities, CANE trustees and well-wishers are working together for a suitable model by scouring successful models in the country. CANE trustees and the provincial health officials are planning to visit a few recently developed successful models in Sri Lanka and thereafter develop a suited model hospice for Northern Province.

The need for getting a few supportive in-service palliative care services in other districts of Northern Province was identified. With the ongoing programme of strengthening the primary care services by Ministry of Health, Sri Lanka, it was decided to allocate a few beds to provide palliative care services at primary care institutions. After identifying the institutions, the challenge would be in recruiting the necessary human resource.

- **Identifying necessary resources**

Two approaches are adopted, first is to train the medical officers and nurses in palliative care with the support of Two World Cancer collaboration (TWCC) and International Medical Health Organization (IMHO), Canada. Second approach, is following the successful Indian Kerala model of training health care assistants, nursing assistants, community volunteers and family members with the support of the nonprofit training institutions. It is yet to be discussed regarding support by CANE and other community support organisations. This will increase the human resource potential that is needed urgently to expand the services.

- **Getting additional funding support.**

CANE, in collaboration with the Northern Palliative Care initiative and under the guidance of the health services provincial director and his team,

are set to raise funds through the local streams. This has been planned based on the Indian experience of getting the neighborhood support team. CANE started to get the local support group to work with the team. The group will also work to create awareness about palliative care. It is also planned to approach big businesses and philanthropists to support the endeavor. For this purpose, there is an advocacy programme initiated through the website and social media.

5.3.6. Other supportive services provided by CANE

- Assistance for some investigations that are not available in the public hospital, on the recommendation of the Oncologists is provided to those under the poverty level;
- Awareness programs on early detection of cancer to the public;
- Referrals to get monthly medical allowances from government and non-governmental organisations;

5.3.7. Future plans

Initiating center-based screening programs for breast and cervical cancer, by;

- Conducting mobile screening programs in remote areas
- Expanding awareness programs
- Increasing financial assistance for specialized investigations

Figure 5. 2: Environment of CANE Hospice

Chapter 06

Developing palliative care services in the Northern Province

6.1 Early stage of care development

Although home based care was pioneered by CANE, there were many challenges in sustaining the project. The main challenge was in getting trained personnel to deliver services. It is stipulated in the Ministry of Health strategic document regarding home care and use of existing service networks like MOHs, public health staff, PHNOs and primary medical care institutions. There are many constraints in the existing system, especially the priorities and capacity, hinder the provision of new types of services.

In early 2015, a group of doctors and nurses, under the leadership of Dr.Ranjan Mallawaarachchi - Oral and Maxillofacial (OMF) surgeon working at district general hospital, Vavuniya - trained the nurses in providing home based palliative services. Dr. Ranjan Mallawaarachchi took the initiative to form the Northern Province Palliative Care Association and also tried to set up in-ward palliative care services at Cheddikulam hospital Vavuniya. In addition, Dr.J. Pratheepan, a General Physician who was trained in palliative care in Australia, started an outpatient clinic at Teaching Hospital, Jaffna. His clinic was supported by the home based palliative care team under the guidance of Dr. Surenthirakumaran, who was trained at Palliative Care Association Calicut, Kerala, India. Later on, Dr. Ranjan was transferred to another part of the country and Dr.J. Pratheepan migrated to Australia. Thereafter, Dr.A. Ragupathy, another General Physician trained in

palliative care, conducted the clinics at Teaching Hospital, Jaffna. Unfortunately, with his untimely demise, the services were discontinued.

Several efforts to restart the palliative care services in Northern Province were not sustained for long.

In consideration of the challenges and sustainability, professionals in this field wanted to set up a well-integrated approach for the palliative care services in Northern Province.

A Strategic Management Plan for the Ministry of Health and Indigenous Medicine Northern Province, Sri Lanka for the years 2016 to2018.(16) The document identified ten key priorities. of the ten priorities identified, comprehensive palliative care was one immediate priority to be attained.

The document emphasises the development of the community based palliative care and a strong integration of different levels of care provided by the health system of Sri Lanka. (16)

6.2 Northern Palliative Care Council (NPCC) and care development

For the implementation of palliative care, Northern Palliative Care Council (NPCC) was formed. The need for palliative care was also highlighted in a health development conference in Toronto, Canada. One of the key note speakers, Dr. Lawrence Loh, who was the Officer of Public Health, Peel Region, Canada, introduced the charity called Two World Cancer Collaboration (TWCC). (17)This Canadian based charity, helped many developing countries in cancer control and palliative care development. Dr.Stuart Brown, a primary care, palliative care expert, with a varied work

experience in many developed and developing countries, came forward to support the initiative of Northern Provincial Council.

Figure 6. 1: Fact-finding visit of TWCC and other palliative care experts to Northern Province

A team consisting of palliative care experts from Canada, the UK and India , visited to Northern Province and assessed the needs and feasibility in 2017. The visit was coordinated by International Medical Health Organization (IMHO), Canada, Dr. Meera Selavakone, a general practitioner from Toronto and Dr.Jonathan Pearce a primary care palliative care expert from Vancouver Canada, who played a crucial role in planning and executing the visit. Details of the visit and the recommendations made by the team is annexed. (annexure3) An Indian team also visited under the leadership of Dr. Gayatri Palat, from Cancer Association, Hyderabad, India, with team which was helpful for the future planning of training and goals based on their experiences.

As a result of the visit and initial steps, it was decided to arrange a training programme for the doctors and nurses in the main hospitals. Indo American Cancer Association offered a scholarship for two doctors and nurses to get trained in Hyderabad. Northern Palliative Council decided to select one medical officer and a nursing officer from Tellipalai Trail Cancer Hospital and one from District General Hospital, Vavuniya. The training was to help running the out-patient palliative care services in these two institutions and also in planning the start of a care home for the patients following treatment in the OPD. The need to meet the operational costs of the home care services was crucial. IMHO and TWCC came forward to organise a fundraising effort in Toronto, Canada. CANE agreed to coordinate the home care services, while continuous fund raising efforts were carried out in the annual event of 'Canadian Walkathon', during September 2018. Dr Varagunan, President IMHO Canada played a vital role.

Figure 6.2: Fundraising activity in Toronto Canada to support the home care palliative care services in 2018

6.3 Home based Palliative care services

The successful fundraising event and training of doctors created the ideal environment for starting the home care services in Jaffna and Vavuniya districts. Two young medical officers, Dr. S.Mathurahan and Dr.C. Gowsihan provided leadership to their dedicated nursing team in starting the home-based palliative care services in February 2019. The nurses trained by NCCP, Sri Lanka and Dr. Ranjan also joined the team.

Figure 6. 3: Homecare team visiting and seeing the patients

The combined efforts made it possible to start the integrated palliative care services in two districts. Dr.A.Ketheswaran, Provincial Director of Health Services (PDHS) played a vital role to start the services. His continuous support was crucial to run the sustainable services. The team is able to provide in-ward and out-patient palliative care services at the Tellipalai Trail Cancer Hospital and the District General Hospital, Vavuniya. Consultant Oncologists at both the hospitals provide specialist support to the team in providing the services. Out-patient clinics are conducted once a week. The

team also receives referrals from different units in the hospital for palliative care services. The team also conducts home visits at least two times a week. The team is able to see 4 to 5 cases in a session. The Jaffna team is able to cover mainly the cancer patients in need of palliative care and only a few non-cancerous patients. The Vavuniya team, however, is able to cover at least 20% of non-cancerous palliative care patients. The Jaffna team is able to cover mainly the cancer patients in need of palliative care and only a few non-cancerous patients. The Vavuniya team, however, is able to cover at least 20% of non-cancerous palliative care patients.

At the beginning, when the services were started, the local palliative care teams felt the need of expert support in handling the complicated palliative care cases. Initially, monthly case discussions were organised with the team of experts from Canada, UK, Australia and India. Later a 'WhatsApp' group was formed to provide immediate onsite support to the team. This made the effort more efficient and improved the local capacity in handling the cases better. The initiative has been operating successfully and were able to provide services for more than 350 patients in both institutions.

After the successful initiation of sustainable services in these two districts, NPCC and the other expert teams planned to expand the services to other districts. It was decided that the same methodology would be followed and to approach the Regional Directors Health Services (RDHS) of the districts of Kilinochchi, Mullaitivu and Mannar to identify a suitable and dedicated medical and nursing officers for training at Hyderbad cancer centre. IMHO, USA and AMAF, Australia came forward to sponsor the cost of the training and plans were made to send the team in May 2020 for the training.

6.4 Effect of COVID 19 on the development of palliative care

COVID 19 pandemic affected Sri Lanka by the beginning of 2020 creating many interferences and barriers for many developments. Similar to other activities, it also impeded the plans for the training programme of the medical officers and nurses. Considering the ongoing, long term pandemic, the team was forced to look for other alternatives.

The group planned to start an online training programme and to also send the medical officers to the field with the existing home care team for hands-on experience in handling the palliative care cases. They could also be offered opportunities for involvement in a few case discussions to gain experience. The group also invited the palliative experts to conduct the training programme. Since the training programme was online, with local resources, openings were available for more trainees to participate. Hence, it was decided to invite at least two medical officers from each institution including Vavuniya and Thellipalai.

The group planned to develop a curriculum with the support of MNJ Institute of Oncology and Regional Cancer Center, Hyderabad, India and TWCC. It was also decided to start more short-term training courses on palliation for the medical officers and nurses working in primary care.

COVID 19 pandemic affected the home care services as well. There were many interruptions due to lockdown and the ongoing community transmissions. The team also adopted many alternative ways to maintain care. Most of the time, the team used online consultations and used the support of family members for the care.

Chapter 07

Future Directions to take the services to next level

7.1 Strengthening of ongoing services:

a. Expanding institution based palliative care services in all the institutions from base hospital level and above.

Currently, only two institutions in the province have institutional based palliative care services. At least one institution from each district should be able to provide the palliative care services. It is ideal to identify the institution and work with the heads of institutions in achieving this target.

There is an urgent need to commence palliative care services at the Teaching Hospital, Jaffna (THJ), which being the largest tertiary care institute in the province, The NPPCC, with the Director of THJ have initiated this process, which needs to be expedited by identifying a focal point.

To supervise and support the palliative care services in the institutions, a senior consultant, preferably a consultant general physician and a consultant Oncologist, for the cancer patients, should be available. The teams should be meeting regularly to optimize quality of care and possibly carry out an audit on a regular basis.

The existing palliative care providing institutions, should increase the frequency of the number of out-patient clinics to at least two clinics per week to improve accessibility of the care.

All the institutions need to identify and designate a place for the out-patient palliative care clinic, together with all the necessary facilities. The visibility of the clinic should be ensured to help people be more aware of the availability of the new services.

Develop an institutional referral system for both in-patient and out-patients. Networking to be established with primary care institutions and home care team. This should be maintained as a written document and all the heads of institutions should agree to implement with regular supervision.

All the treatment units should allocate at least one or two beds in their respective units, offer the in-ward palliative care services. Care of the patients must be provided by the treatment team, with the support of the institutional palliative care team. Palliative care team should visit the units daily and observe the progress of the patient.

All the units should ensure the availability of the minimum level of medications and other medical supplies, based on the WHO guide. All the pharmacists, nurses and relevant staff related to the supply chain should be trained to enable them to have a basic knowledge of palliative care. Heads of institutions need to give importance to the maintenance of uninterrupted supplies.

b. Strengthen the palliative care services at primary care level;

Ongoing Primary Health Care (PHC) strengthening project of the Ministry of Health, Sri Lanka, with the support of World Bank, incorporated the component of palliative care in the service package, to be delivered in a shared cluster manner. NPPCC should make use of the opportunity and implement palliative care services in all the primary care institutions of northern province.

All the primary health care doctors and nurses must be encouraged to participate in the training programme conducted by the NCCP, Sri Lanka and

other agencies. NPPCC could also introduce a training programme for the staff.

Institutional palliative care team should be included in the shared cluster package and work with the team.

Primary health care institutions with in-ward facilities should allocate a few beds to provide palliative care. Information must be shared with the public about the availability of these services.

It is of paramount importance, to maintain the uninterrupted supply of essential palliative care medications and other medical supplies, especially for terminally ill patients. This will reduce the anxiety of the carers.

All the PHC centres, should work with the area public health team, the social services officers at the divisional secretariat and the community-based organisations (CBOs), to develop a community palliative care network. The network should advocate on the mobilisation of resources with the local leadership and care of the patients.

NPPCC should carry out regular audits on the quality of care and provide feedback to the heads and those in charge of the institutions.

c. Hospice based palliative care;

There is only one hospice with limited facility available in Jaffna. Facilities and services in the hospice need to be strengthened. There is an urgent need to expedite the process of building the model hospice. The model hospice should include staff training facilities.

Identify a suitable place and the resources to have a minimum of one hospice per district.

Train more healthcare assistants and other categories of staff to support the care in the hospices.

Hospices should engage with the community by involving them in voluntary programmes. Youths must be encouraged to volunteer in the programmes. Networking could be facilitated by palliative care services in the province.

d. Developing community network to strengthen the home-based palliative care;

NPPCC should work with social service organisations, non-governmental organisations, religious organisations and community-based organisations to create a palliative care movement to support the initiatives and the services provided. CANE could support the NPPCC to develop and run the network. There must be a clear plan for the creation and functions of the network. As an initial step, NPPCC should form a sub-committee to draft a document for the purpose. This could be further facilitated by developing a website and social media accounts and have a designated team to upload the materials for the dissemination of information. Creating active social media groups will attract more volunteers to join and work for the development of palliative care.

7.2 Education and training

Education and training are mandatory to improve the standard of care in the province. Currently, there are a few initiatives taken in the province: few doctors and nurses have been trained by experts outside of Sri Lanka, to provide palliative care; Two institutions have functional palliative care services at institutional and community levels; One consultant oncologist completed the 'training the trainer' programme in palliative care; An international network, with a group of palliative care experts has been

initiated; COVID19 pandemic created a new way of training through online programmes.

Considering all this, the NPPCC needs to plan 'training of trainer' programmes for identified group of specialist, primary health care staff and educationalists in the province. This will help to develop a group of locally available resources to provide sustainable education and training programmes in the province.

NPPCC should work closely with NCCP and the ministry of health, to develop and run the palliative care training programme. It also needs to find ways to encourage the staff to participate in these local training programmes.

PGIM of the University of Colombo offers postgraduate degree courses for the medical officers. There is a need for postgraduate short courses for medical officers. All the other categories of health staff also need either short courses or diploma/degree programmes in palliative care. Considering this, the local university can form a team to identify the courses and develop the suitable curricula for the different courses.

NPPCC can also ensure the inclusion of palliative care in all the relevant undergraduate curricula, with the support of NCCP, Sri Lanka.

Plan, develop and implement regular in-service programmes for all the categories of staff.

CANE can initiate regular training programmes to train the community volunteers and family members. This will help manage patients in their home environment.

7.3 Strengthening the provincial level strategies and monitoring mechanisms

NPPCC should meet regularly. It is very important to develop a strategic document based on the strategic document published by the Ministry of Health, Sri Lanka, for the implementation of palliative care in northern province. This could be a guide for the comprehensive implementation of the palliative care in the province.

NPPCC also needs to strengthen palliative care services at district level to strengthen the delivery palliative care. Ideally, introduce an online data collection mechanism for monitoring purposes. The strategic document should identify the key indicators for the implementation. The monitoring could be done by the staffs at all levels. It would also be useful to arrange regular evaluation programmes.

7.4 Mobilise more resources by expanding network;

Present network has been developed comprising a few local and international well-wishers but the numbers are insufficient. The success of the implementation of comprehensive palliative care depends on developing a good strategic partnership to mobilise resources. (16) Partnerships should be developed at different levels. High-level partnerships should be formed with the various ministries at the national and provincial levels to mobilise the resources. High-level collaboration would be useful in working with international organisations (WHO, World Bank etc.), and also to work with international palliative care organisations. Middle level partnerships could be developed with philanthropists, private banks, companies and big businesses to establish the buildings for the hospices, clinics and wards. The grass roots level of partnership is needed to build up community volunteers.

NPPCC should identify the immediate, intermediate and long term needs and then package it attractively enough for the partners to support the requirements.

One of the best strategies to gather support, both in terms of manpower and resources, is through web and social media based forums and discussions.

7.5 Research and development

The goal of palliative care is to relieve the symptoms and pain and provide comprehensive care for good quality of life of patients. (17). The recently developed concept is gathering pace due to the present needs. It covers the care of many diseases and symptoms. People may respond to the treatment and health-related interventions differently. The resources available for the care are limited.

It is very important to understand the effectiveness and efficiencies of the services that are developed at all levels. Carrying out research in palliative care is a challenge due to its diversity and limited funds. (18)

Chapter 08

Conclusion

The growing need for palliative care is recognized at the national and provincial levels. Several steps have been undertaken to introduce palliative care services at different levels of care. The initiatives were undertaken by professionals, associations and foundations.

Ministry of Health, Sri Lanka, has identified palliative care as an important form of care to be provided for the patients and their families. The policy document includes the provision of palliative care, based on which, NCCP, Sri Lanka was identified as a focal point. National Strategic Framework for Palliative Care Development (NSFPCD) in Sri Lanka 2018-2022, was developed and launched in December 2019.

There are a few hospices functioning in the country which are mainly supported by the non-governmental organisations. There are a few initiatives for providing home care. Short term training programmes for doctors and nurses were conducted, in addition, postgraduate diploma in palliative care is offered for medical officers at PGIM.

Many initiatives have been undertaken in the Northern Province. The first home care service was developed in 1993, and the first hospice was developed in 2006. These services were pioneered by CANE UK and CANE Sri Lanka, however, there are still challenges to implementing the actual hospice care.

Department of Health, northern province has undertaken many initiatives to form a palliative care council to systematise the palliative care development. TWCC and IMHO, Canada, together with other partner organizations played

a critical role in the development of hospital based and home based specialist palliative care in two districts.

NPPCC plays a pivotal role with the support of well-wishers in creating the services in the province, however, many challenges still exist. The next few years will be crucial in the development of a comprehensive palliative care in the province.

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Annexures

Annexure 1: National Strategic Framework for Palliative Care Development (NSFPCD) in Sri Lanka 2018-2022

Overall Goal

To improve quality of life of patients with life-threatening illnesses and their families by offering them a holistic support system for prevention and relief of suffering through evidence-based, multi-disciplinary and cost effective approaches

The areas of support would include

- Pain and symptom management
- Psychological & emotional, social and spiritual support
- Support for families and caregivers to cope during the patient's illness and bereavement period

Guiding Principles

1. The delivery of palliative care should be respectful and responsive to the needs, preferences and values of the persons receiving care and their families and carers
2. Care should be of high quality and evidence based
3. Should provide adequate integration across sectors and through various care settings
4. Services should ensure that care is accessible and equitable

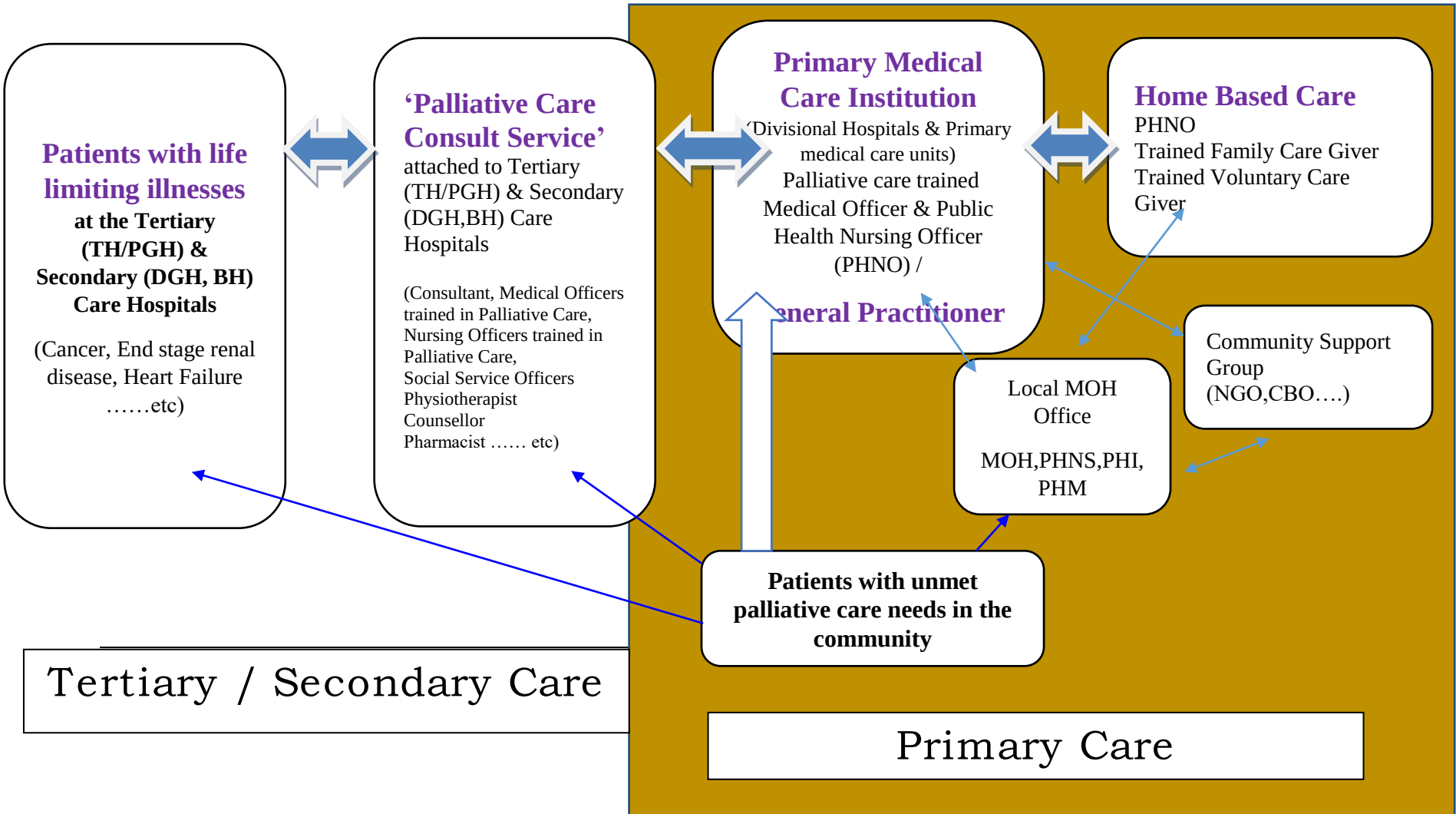
Strategies

1. Ensure that palliative care is recognised and resourced as an integral component of the health system by making palliative care as an essential component of comprehensive health care
2. Facilitate the effective integration of specialist palliative care and palliative care services across all levels of service settings, namely at

tertiary, secondary, primary and at community level.

3. Develop and make available skilled multi-disciplinary human resources and infrastructure for delivery of palliative care services at institutional and at community levels.
4. Ensure that patients and their families receive palliative care services they need when and where required & adherence to protocols & guidelines in palliative care
5. Ensure availability of essential drugs & technologies for provision of palliative care at all levels: tertiary, secondary, primary and community level
6. Build partnerships with government and non-governmental organizations for delivery of palliative care
7. Empower family members, care givers and general public for the provision of palliative care
8. Encourage research related to palliative care in assessing needs for palliative care and suitable models for implementation of palliative care services.
9. Ensure adequate financing & resource allocation for cost effective delivery of palliative care
10. Strengthen legislative framework for delivery of palliative care
11. Ensure monitoring & evaluation framework for palliative care services

Annexure 2: Institutional to home-based care model (Annexure 2)



Annexure 3: Recommendation of TWCC visit and developing palliative care

Domain	Activity	Action		Comment
EDUCATION	Workshops	Review Grant opportunities Discuss dates Discuss content	Stuart Jonathon Suren Meera (S)	? UICC
	Hyderabad residential courses	Review funding? Dates? Personnel	Gayatri; Mr. Jagannath	
	ZOOM lectures	D/w Dr Suren	Jonathon and Stuart	Could be done soon
	ECHO	D/w pediatricians?	Gayatri /Megan	
	Educational Material	Review appropriate on line material Books (? PANG)	Meera (R) Swarup	
	Self Care	Review appropriate resources etc.	Erin	
	Nursing educational Material and guidelines	Review resources	Swarup	
	Educational resources etc. For care of 'differently-abled'	Review resources	Erin	

Domain	Activity	Action		Comment
POLICY/Drug Availability	Workshops	Include administrators in workshops	Meera (S) Stuart	
	Narcotics Availability	Review Situation in SL. Review possibility of meeting in Colombo with SL regulators	Stuart & Meera (S)	Facilitated by Canadian High Commission (Mr. McKinnon)
	Difficult to access meds.	Review possibility of funding for fentanyl patches	Meera (R) and Meera (S)	
	Re-activation of NPPCA		Suren	? Resources needed
	Evaluation tools	Review of most appropriate tools	Gayatri, Meera (R)	
	Essential Medications List		Stuart Fatima (clinical pharmacist; with TWCC)	
Domain	Activity	Action		Comment
Implementation	Core Team formation Including oncologist, pediatrician and long term neurological disability	F/u with Suren and director of Teaching Hospital	Stuart /Meera (S) Suren	? Stuart to be in contact with Dr. T. Sathiyamoorthy ? Dr. Gita Sathiadas
	"Re commissioning of CANE Hospice"	Review of CANE UK commitment	Meera (R)	See recent comments in Letter form Meera

		Draft programme for a ‘new CANE Hospice’, with Budget		
	Increase in Home Care Capability	Review of funding opportunities	Meera (S) /Meera (R) and Stuart	
	Palliative Care for survivors of CME War /Tsunami	Review of options, materials, collaborators	Erin	