Palliative Care for Cancer Patients in Primary Health Care

A Guide for Health Care Professionals

NATIONAL CANCER CONTROL PROGRAMME
MINISTRY OF HEALTH
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PALLIATIVE CARE FOR CANCER PATIENTS IN PRIMARY HEALTH CARE

GUIDE FOR HEALTH CARE PROFESSIONALS

National Cancer Control Programme

Ministry of Health - Sri Lanka

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Palliative Care: compassionate support on life's journey

Message of the Director General of Health Services

Sri Lanka is well recognised for having a high performing healthcare delivery system which provides free of charge, high impact but low cost interventions to reduce disease morbidity and mortality and improving the quality of life of all citizens. The Government of Sri Lanka launched the Policy on Healthcare Delivery for Universal Health Coverage in 2018. In this background Ministry of Health implemented the primary health care system strengthening concept to achieve universal availability and accessibility of health services in the country. Primary care is the first point of contact for healthcare and serves as the hub from which patients are guided through the system while building bridges between personal healthcare and patients families and communities.

The cancer burden in the country is increasing and preventive and curative services are being improved taking advantage of the evolving technical advances. Provision of palliative care is an integral component of continuum of care for cancer as identified in the National Strategic Plan for Prevention and Control of Cancer in Sri Lanka (2020-2024). Receiving appropriate palliative care is a right of each and every person who is suffering from life threatening illnesses including cancer. It is the responsibility of the Ministry of Health to strength the healthcare system to provide such care ensuring equity.

National Cancer Control Programme, as the focal point, has initiated and developed the “Palliative Care for Cancer Patients at Primary Care: Guide for Health Care Professionals” which would provide guidance to improve the quality of care in palliative care for patients seeking services at primary health care.

I thank National Cancer Control Programme for initiating, developing and publishing this guide, the multidisciplinary experts for providing updated technical expertise which are firmly rooted with evidence and World Health Organization for their partnership for completion of this important activity.

Dr. Asela Gunawardana
Director General of Health Services
Ministry of Health

Message of the Deputy Director General, Non-Communicable Diseases

With the demographic and epidemiological transition, the need for cancer care including palliative care services also continues to grow. The Sri Lanka National Health Policy 2016-2025, identifies the need to provide palliative care to all patients who are in need of such care for them to live and die with dignity. In addition, palliative care is identified as continuum of care in several other policy documents and strategic frameworks in the country.

Ministry of Health developed and published the National Strategic Framework for Palliative Care Development in Sri Lanka (2019-2023) targeting the integration of palliative care services at all levels of health care systems from the community level upwards. Developing and making available skilled multidisciplinary human resources for delivery of palliative care services at primary health care is also identified as an important strategic direction.

This guide is developed to provide orientation and guidance on palliative care for health care professionals at primary health care and I appreciate the leadership of National Cancer Control Programme taken to develop the guide. I would like to thank all the experts for their technical inputs despite their busy schedules and the extended partnership of World Health Organization for the development of palliative care services in Sri Lanka.

Dr. Champika Wickramasingha
Deputy Director General Non-Communicable Disease

Message of the Director, National Cancer Control Programme

It is estimated that palliative care is needed for 40% -60% of all deaths annually worldwide. The need of palliative care in Sri Lanka also continues to grow owing to the rising prevalence of non-communicable diseases and ageing population. National Strategic Framework for Palliative Care Development in Sri Lanka (2019-2023) developed by Ministry of Health identifies integration of palliative care services at all levels including primary healthcare as an important strategy for improving palliative care services in the country.

With the aim of strengthening palliative care services provided at primary care, National Cancer Control Programme developed this guide with the contribution of experts in the relevant fields. This book will guide healthcare professionals at primary care to practice palliative care with a holistic approach.

I thank Dr. Janaki Vidanapathirana, former Acting Director National Cancer Control Programme for the leadership provided for the successful completion of this activity. I wish to place on record my sincere appreciation and congratulate all the authors and all others who contributed for this activity for a job well done. I specially appreciate the partnership provided by the World Health Organization for this task and the National Steering Committee of Palliative Care and the Deputy Director General Non-Communicable Diseases of the Ministry of Health for the advice and guidance provided for the development of palliative care services in Sri Lanka.

Dr Eshani Fernando
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PREFACE

Integrating Palliative Care to Primary Health Services

Palliative care is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO 2014).

In Sri Lanka, the prevalence of cancer is increasing and the Government of Sri Lanka, affirms the importance of integrating palliative care into primary health care as the great majority of people need relief of pain and other distressing symptoms as an essential component of continuum of care. It is included in the National Strategic Framework for Palliative Care Development in Sri Lanka (2019-2023) and National Strategic Plan in Prevention and Control of Cancer in Sri Lanka (2020-2024).

Patients may prefer to access primary medical care institutions (PMCIs) as it is the closest health service to their homes or even wish to be treated at home, in a hospice or a community centre. Thus, it is medically and ethically necessary that palliative care is made available at all settings as it not only provide an opportunity to access palliative care but also reduce costs for health care systems and provide financial risk protection for patients' families. Primary healthcare providers should adopt a team approach in conjunction with the palliative care specialist to deliver a patient centered service, as a support system to the patient and the family to cope during the illness to improve the quality of life and in bereavement.

Primary health care providers with basic training in palliative care and symptom relief can respond effectively to most palliative care needs and arrange for transfer to a higher level of care, when necessary, preferably to the centre where the patient was seeking treatment for cancer. Emphasis should be given to continuity of care with the guidance of the Management Plan issued by the treatment centre, respect for patients' values, and equitable access to services, availability of local resources and attention not only to patients but also to their families and caregivers.

This document will serve as a guide for the Primary Medical Care Units (PMCU) and Divisional Hospitals (DH) in the country.

ABBREVIATIONS

ACE Inhibitor	Angiotensin-converting enzyme inhibitor
ACP	Advance Care Planning
BH	Base Hospital
BI	Barthel Index
CBO	Community Based Organization
CPR	Cardio Pulmonary Resuscitation
DH	Divisional Hospital
DGH	District General Hospital
DNA-CPR	Do Not Attempt Cardio Pulmonary Resuscitation
Level 2	Divisional Hospital and Above
Level 3	District General Hospital and Above
MOH	Medical Officer of Health
NCCP	National Cancer Control Programme
NGO	Non-Government Organization
NO	Nursing Officer
NSAID	Non Steroid Anti Inflammatory Drug
PCCS	Palliative Care Consult Service
PGH	Provincial General Hospital
PHC	Primary Health Care
PHI	Public Health Inspector
PHM	Public Health Midwife
PHNO	Public Health Nursing Officer
PHNS	Public Health Nursing Sister

PMCU	Primary Heath Care Unit
PPI	Proton Pump Inhibitor
QOL	Quality of Life
TH	Teaching Hospital
WHO	World Health Organization
mg	milligram
kg	kilogram
SC	Subcutaneous
IM	Intramuscular
IV	Intravenous
b.d.	twice a day
t.d.s.	three times a day

01

Palliative Care for Cancer Patients

Palliative care is an approach that addresses the person as a whole, not just their disease. The aim of this chapter is to introduce primary health care worker to the basic principles and goals of palliative care in order to provide palliative care at primary care settings.

Palliative Care as Part of Primary Health Care

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.

Primary health care has a great potential to deliver effective palliative care to patients, especially community based and home-based palliative care. integration of various primary care disciplines are important to deliver quality palliative care services. Good interprofessional collaboration between specialised palliative care teams and primary health care teams are also important to provide shared care for patients, which facilitate the continuum of care aimed at improving the quality of life of palliative care patients.

The Ministry of Health has identified provision of palliative care as an essential component within the continuum of care for people with chronic and life-threatening illnesses. Therefore, palliative care for cancer patients will be provided across all three levels of healthcare. Thus, the primary health care worker has an important role to play in providing palliative care.

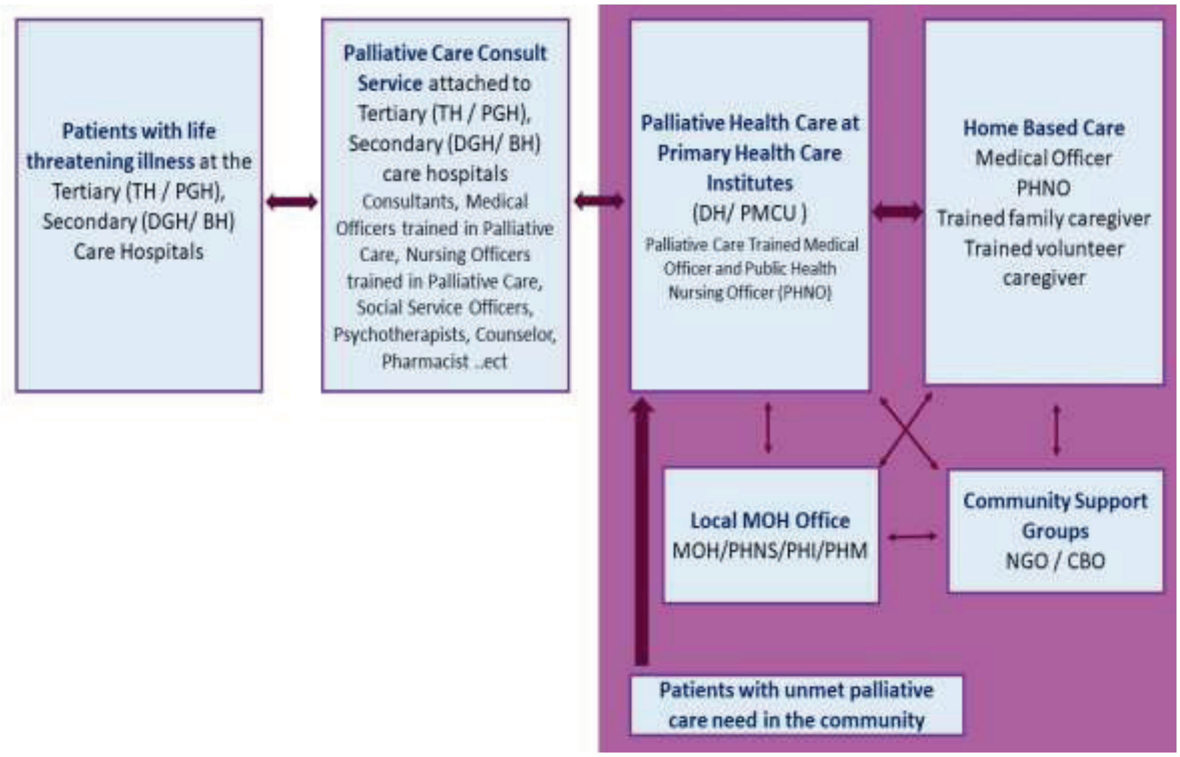


Figure 1.1: Proposed Model for Delivery of Palliative Care - Institutional Care to Home Based Care (*National Strategic Framework for palliative Care Development in Sri Lanka 2019-2023)*

Role of Primary Health Care Medical Officer in Providing Palliative Care for Cancer Patients

Primary care medical officer can be defined as:

- Medical officers working at Divisional Hospitals (former Rural Hospitals, Peripheral Units, District Hospitals) providing in-patient care
- Medical Officers working at Out Patient Departments of Divisional Hospitals
- Medical Officers working at Primary Medical Care Units (former Central Dispensaries)
- Fulltime or part time private General Practitioners

Primary care medical officer and his/her team is the closest first contact care provider for people who need palliative care. Currently home-based palliative care services are provided through Public Health Nursing Officers (PHNO) in a limited capacity. The primary health care (PHC) worker should be able to understand what is given in the Management Plan provided by the caring oncology unit and ensure continuity of care with the available resources and linking with the oncology treatment centre.

Role of Consultant Family Physician at Primary Health Care Palliative Team

Some of the DHs are now managed by Consultant Family Physicians and at these hospitals, they could provide leadership to palliative care teams at PHC level, will coordinate care with the specialist units and implement the care plans at the community level through the PHC team.

Definition of Palliative Care

> Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness. It prevents and relieves suffering by means of early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual.
>
> World Health Organization (2014)

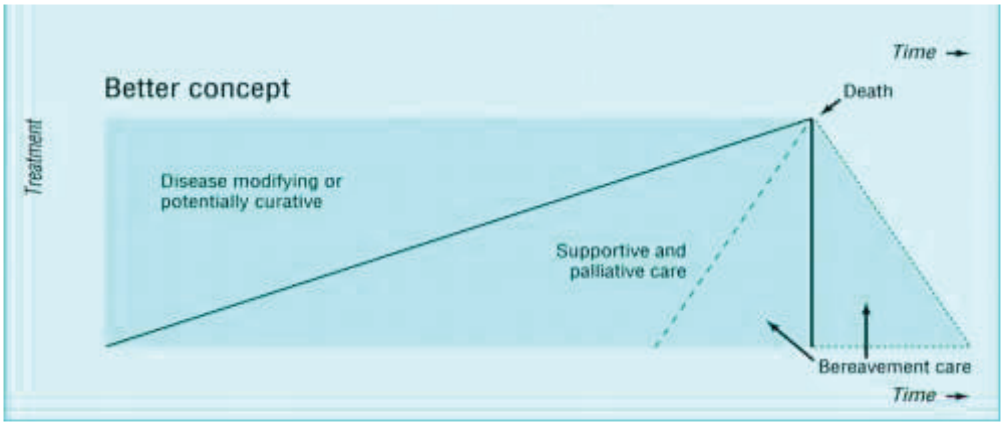


Figure 1.2 Spectrum of Palliative Care by Murray et al. (2005)

Palliative care is a holistic care for patients, as well as their family members provided by an interdisciplinary professional team based on the following principles.

- Patient centered
- Improves the quality of life (QOL) of patient as well as family/caregivers
- Holistic care based on the needs assessed by a team specialised in palliative care. The Spectrum of Palliative Care is shown in Figure 1.2
- Patients, families and caregivers have access to local government healthcare services to meet their needs
- Care is evidence-based, clinically and culturally safe and effective

Palliative care anticipates problems and aims to minimise the impact of the progressing illness. Palliative care gives a support system to help the patient to live as actively as possible during the course of the illness. It also offers a support system to the family to cope during this difficult period and during bereavement.

Health care providers should understand the meaning of the illness as well as the concerns of the individual, families and the care givers, acknowledging their concerns, sources of distress and need to respond to these effectively.

It is useful to note the following when providing palliative care:

- Palliative care is based on the needs of the patient, not on the patient's prognosis.
- It is appropriate at any age and at any stage in a life threatening illness and it can be provided along with curative treatment.
- It provides relief from pain and other distressing symptoms at any stage in the journey of patients living with cancer and at the time of death. Palliative care begins at the time of diagnosis of a life-threatening disease (e.g. cancer) and continues throughout the disease process until death and into the family's bereavement period as shown in Figure -1.2
- Care that is aimed at controlling symptoms whether from the cancer itself or the toxicity of treatment delivered concurrently with disease-directed therapies, is a key feature of patient-centered care.
- Palliative care is provided in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiotherapy .
- Palliative care affirms life and regards death as a normal process. Therefore, palliative care does not advance or postpone death.

Goals of Palliative Care for Cancer Patients

Goals of care are to improve quality of life of the individual and provision of care which may also positively influence the course of illness. Care will depend mainly on the stage of the disease and the natural course of the illness. There are four domains that need to be taken into account: **physical comfort, psychological, social needs and spiritual needs.** The needs and the concerns of the family and care givers should also be taken into consideration when setting goals.

However, goals will change with the course of illness. Therefore, the goals could be set with different objectives such as optimisation of function, optimisation of comfort, facing bereavement or it could be a combination of these and they could be changed depending on the needs of the patient and progression of the disease.

Team Work

Health care professionals and other groups such as clergy need to work with the patient as a team (interdisciplinary team) to develop goals of care that target patient's needs, values and preferences based on the Management Plan provided by the Consultant Oncologist. Primary health care providers take a lead role for arranging care at the community level and will be responsible for coordinating care with the oncology team as and when necessary.

Identification of correct goals in consultation with Palliative Care Consult Service for the individual is an important skill for the health care professional and the team considering the patient needs, preferences, underlying illness, severity of symptoms, impact on quality of life, services available and family concerns.

Importance of Initiation of Palliative Care from the Beginning

Studies have shown that **early focus** on care aimed at improving quality of life has improved patient satisfaction, reduced depression and anxiety, and lead to more consistent care with patient preferences. Thus identifying palliative care needs at the very early stages in the cancer journey will give better outcomes.

One of the goals of integrating palliative care earlier in the course of the disease is to improve early communication of the prognosis of the cancer with the patient and family in the setting of life-limiting illness. Having realistic discussions earlier in the course of disease has been shown to reduce aggressive end-of-life care and improve psychosocial wellbeing among patients and families. These discussions can inform and help patients to better understand their treatment choices and goals of care and thereby influence patient choices for care over the course of illness.

Patients presenting in advanced stages of cancer should also be provided with palliative care. Health care provider should also understand that patients with advanced cancer often have a significant burden of symptoms including dyspnoea, pain, nausea and fatigue that can cause distress and decrease quality of life (QOL). For patients with advanced cancer, providing palliative care irrespective of the stage will improve outcomes, including QOL and potential survival. The relevant specialist/s could advise the primary healthcare team on how to deal with such situations.

Palliative Care as Part of Continuum of Care

The PHC team can develop a "Treatment and Care Plan" taking into consideration the Management Plan issued by the oncology treatment centre and in consultation with specialists. Alternatives in the event of future change of the disease progression needs based on shifting priorities in goals of care should be clearly documented after discussing with patient and family members, in a manner that promotes informed decision making.

As disease progresses, continuity of care becomes increasingly important. PHC provider need to co-ordinate between services and information must be transferred promptly and efficiently between professionals to provide **shared care** while maintaining confidentiality.

Palliative Care for Paediatric Patients

Palliative care for children represents a special but closely related field to adult palliative care. World Health Organization's definition of palliative care for children and their families is as follows:

> "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family".
>
> **World Health Organization (2018)**

The principles of palliative care apply to other paediatric chronic disorders as well.

- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate the child's physical, psychological, spiritual and social distress.
- Effective palliative care requires a broad inter disciplinary approach that includes the family and implemented even if resources are limited.

02

Effective Communication for Palliative Care

Communication can be a therapeutic tool in palliative care. The aim of this chapter is to identify the importance of communication in palliative care, to learn basic communication skills and barriers to effective communication and strategies for breaking bad news and basic aspects of conducting a family meeting when providing palliative care.

Communication is a process that is essential for receiving and delivering information. In any setting and exclusively in a medical setting, 'communication' is the only method of providing and obtaining information about illnesses and its complications by sharing information between the patient and the medical team. Both verbal and non-verbal communication plays an important role. It has been said that communication leads to patient satisfaction.

Effective Communication

Effective communication can be mentioned as the cornerstone of therapeutic health care professional-patient relationships because effective communication creates an environment of trust for the patient and their relatives with the feeling of responding and involving. It also promotes the patients' and their relatives' disclosure of feelings. The seven Cs principles in effective communication:

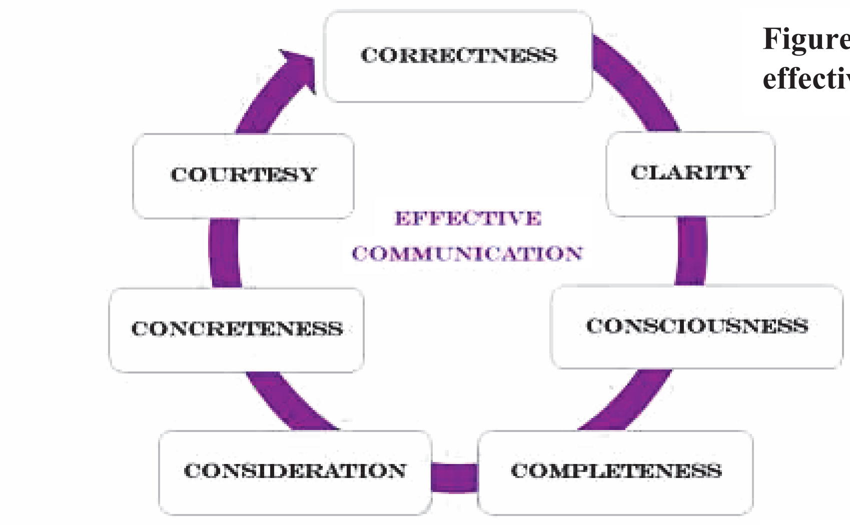


Figure 2.1 - 7Cs principles of effective communication

World Health Organization (2015)

Basic communication skills:

- active listening
- empathy
- paraphrasing
- respect and acceptance
- summarising
- reflecting

Active listening

- Usually listening is about hearing information from the patient but ‘active’ listening involves all our senses. This includes body language such as observing posture, gestures, movements, eye contact, talking style, and pauses in speech.
- Although it is about listening to the patient, it also needs careful 'attention' to all these factors that are displayed by the patient apart from listening to the words they tell you.

Empathy

- Experiencing someone else's feelings is known as sympathising and empathy is the ability to recognise emotions in others.
- When someone is suffering, we use consoling words to console him or her and it is sympathising. Showing empathy in counseling or palliative care is more than that and it displays through our behaviour. For instance, in a grief counseling session, the counselor does not cry together with the client when the client cries. Instead of that, we display empathy. The client can feel that the counselor feels his or her feelings. In sympathising, both may cry together. Therefore, empathic health care professional does not get emotionally unstable in patient’s emotional reaction.

Paraphrasing

- Paraphrasing helps the listener/counselor/medical team member to clarify what the patient has uttered as if she is hearing it from another person.
- Paraphrasing means retelling the patient what the patient has said and show understanding.
- Paraphrasing helps the patient to hear his worries from another person and relieve his or her mind.
- This avoids miscommunication/errors in understanding which has an impact on treatment plans or decisional choices.

Respect and acceptance

- One of the important aspects of communication is to respect what others have to say and acknowledge it.
- Every human being whether they are a patient or healthy person values self-respect, and it provides patients who are especially in a palliative care setting, confidence, and self-esteem

- Acceptance of their decisions, choices, and preferences might be problematic and medical teams might have ethical issues of accepting some patient's decisions. In these situations, it is important to provide as much information about the illness and treatment options with side effects and prognosis.

Summarising

- This step is usually taken at the end of a discussion of treatment options/introducing new treatment/discarding/optimising existing medication or at the end of disclosure of serious news about their medical condition.
- In summarising, the relevant professional, concisely reiterates several of the major highlights from their discussion. While summarising helps the professionals to review the overall program, it allows the professional and the patient to recognise a theme in what the patient is saying.
- Summarizing again serves the purpose of avoiding miscommunication, misunderstanding and allows patients to ask for clarifications.
- It is also good practice for a health professional to gather all important information about the patient and the condition and repeating it all as a summary, so they take away the most important things that need following or to make an informed decision.

Reflecting

- Reflections are the most important part of a communication process that allows the personal development of the medical team member.
- The patient or family members do not involve in this reflection part.
- Professionals can do self-reflection or reflection with their colleagues. This gives professionals to look back on their utterances, patients' and family members' responses, and overall communication process.
- Professionals can pick up on their feelings or mood and feed their perception back to patients and family members. Reflection further supports health professionals to get feedback from their superiors on their practices.
- It also serves another important purpose of 'unloading' the weight of the discussion as in a palliative care setting this could be even about 'death' that can become an emotional burden to the health practitioners.

Barriers for Effective Communication

There can be few factors that can reduce the effectiveness of communication between the patient and the medical team. As described below, there are multiple barriers for effective communication:

- Physical barriers - due to nature of environment, noise, poor listening
- Physiological barriers - personal discomfort, poor eyesight, etc.

- Sociopsychological barriers - attitudes such as great anger and sadness, feelings and emotions of the burden of responsibility, mental disorders, psychological stress, anxiety, and/or fear of negative evaluation by others, poor retention, closed mind, etc.
- Cultural barriers - misunderstanding
- Competence of the professionals- lack of knowledge and skills
- Language, age, gender, and illness status of the patient
- The use of medical jargon
- Lack of attention and unconcern by the doctor
- Distractions in the medical settings (e.g. constant telephone calls)
- Discomfort in disclosing serious/sensitive information
- Self-esteem issues and lowered confidence
- Lack of feedback on the doctors' communication skills
- Diversity in the multidisciplinary health team
- Characteristics of the patients and their family members

However, good communication skills support the medical health professionals to minimise the above mentioned barriers to effective communication.

Disclosing Bad News

Bad news is any information that adversely and seriously affects individual's view of his or her future.

Disclosure of bad news is not easy. This is a distressful task not only for the patient and their families but also for health professionals. Conveying bad news is a process of negotiation between patients and health professionals. They find it difficult to do it due to many reasons such as being afraid of unleashing a negative reaction, finding themselves powerless over emotional distress and insufficient training in breaking bad news.

Goals of an Interview in Breaking Bad News

Providing accurate information regarding the disease condition, persuade the patient and family to adopt recommendations provided by the consultant and to reduce the emotional impact and isolation experienced by the recipient of bad news.

Strategies for Breaking Bad News

Breaking bad news should be delivered in a structured manner. Usually, breaking bad news is done by the most senior medical professional in the team, which is the consultant treating the patient. While there are several protocols for the disclosure of bad news such as SPIKES protocol, PEWTER model, and BREAKS protocol, SPIKES protocol is described in this chapter.

SPIKES protocol

The SPIKES protocol is a very popular and good strategy to use for breaking bad news. This protocol emphasizes not only the most attributes of a bad news interview and methods of assessing the situation and how to respond constructively to what occurs.

THE SIX-STEP-SPIKES PROTOCOL

Step 1: **S**-Setting up the interview- Arranging privacy, building rapport, comfort
Step 2: **P**-Perception- Assessing the patient's perception
Step 3: **I**-Invitation- Obtaining patient's invitation
Step 4: **K**-Knowledge- Giving knowledge and information to the patient
Step 5: **E**-Emotions and Empathy- addressing the patient's emotions with empathetic responses
Step 6: **S**- Summarising- Summary, and strategy for future plan

Baile et al. (2000)

Step 1: Setting (physical context)

- Where to break bad news (e.g. a quiet room not preferably during ward round)
- Ask whether he/she prefers to have relatives
- The physical context of the interview (sitting down, body language, eye contact)
- Introduce yourself and get to know how others are related to the patient
- Listening skills (open questions to start, do not interrupt)

Step 2: Perception (finding out how much the patient knows or suspects)

- Ask what is known about the condition or what patient suspects
- Listen to the patient's level of understanding of the illness, accept denial, do not confront at this stage

Step 3: Invitation (finding out how much the patient wants to know)

- Ask the patient what details they need to know of the illness
- Accept patient's right to know, offer to answer later if they prefer

Step 4: Knowledge (sharing medical information)

- Use a language that the patient easily understands
- Provide information up to the patient's level of education, sociocultural background, and current emotional status

- Check whether the patient understood what you said
- Give any positive aspects first, give facts accurately about treatment options and prognosis

Step 5: Emotions and empathic response (responding to the patient's feelings)

- Identify emotion, identify cause/source of emotion,
- Respond in a way that you have identified the patient's emotion
- Not necessary to agree to the patient's viewpoint

Step 6: Strategy and summary

- Close the session, ask whether they want to clarify anything else
- Offer agenda for the next meeting (e.g. I will speak to you when we have the opinion of the Consultant Oncologist).

Conducting Family Meetings/Conferences

In the caring of patients with life-limiting illnesses, family members play a key role. Therefore, making family participation in the decision making is very important. The quality of care provided for patients and their family members is enhanced through family meetings in palliative care. Following purposes are expected from family meetings with patients and their family members:

- sharing information and concerns
- discussing diagnosis, treatment, and prognosis
- clarifying caring goals
- planning the caring strategies

Family Meeting Protocol

Health care professionals can use the following protocol to have a successful family meeting with patients and their family members.

A Recommended Protocol for a Successful Family Meeting

- **Introductions:**
  Start with a brief explanation of the purpose of the meeting and its goals, thank the family members in advance for taking time and being present.

- **Eliciting fears, concerns, and goals:**
  Give an opportunity to the family members to share their greatest fear, concern, or burden which they experience at this moment.

- **Getting the family to talk about the patient:**
  Often ask simply from the family members whether they are satisfied with the care given to the patient. Allow the family members to talk about the patient by focusing on the unique and special events of the patient. If family members lose the patient's focus, it will affect decision making. In decision making, patient's values, goals, and choices are very important.

- **Determining/clarifying the family's understanding of the medical facts:**
  To know their understanding of the loved one's disease, treatment, and prognosis, is important. It helps us to know about misconceptions and misperceptions of the family members.

- **Presenting recommendations and achieving a consensus on the direction of care:**
  Present the recommendations and achieve a consensus on the direction of care.

- **Preparation of the family:**
  Discuss from the most appropriate option to the least appropriate option. Be honest and open and not be shy to discuss a patient's diagnosis and prognosis. Prepare the family to cope with the process of the end-stage of the patient. Give a precise and understandable description of this process by avoiding medical jargon.

- **Experiencing the emotions of the moment:**
  Experience the family members' related to the end-of-life (If family members are more emotional and tearful, it is better to allow them to be few minutes without talking). To address the emotions of family members, use a protocol such as the NURSE protocol (Name, Understand, Respect, Support, and Explore).

- **Ending on a positive note:**
  End the family meeting with a positive note (e.g. health care professionals can ask some questions regarding their loved one, maybe an unforgettable event, personal or a humorous moment). Windup the meeting by acknowledging family members presence at the meeting.

It is obvious that communication skills are crucial to health care professionals in caring for patients and their family members in palliative care. Good communication between health care professionals and patients and their relatives/caregivers is very important to enhance the quality of life of these people.

03

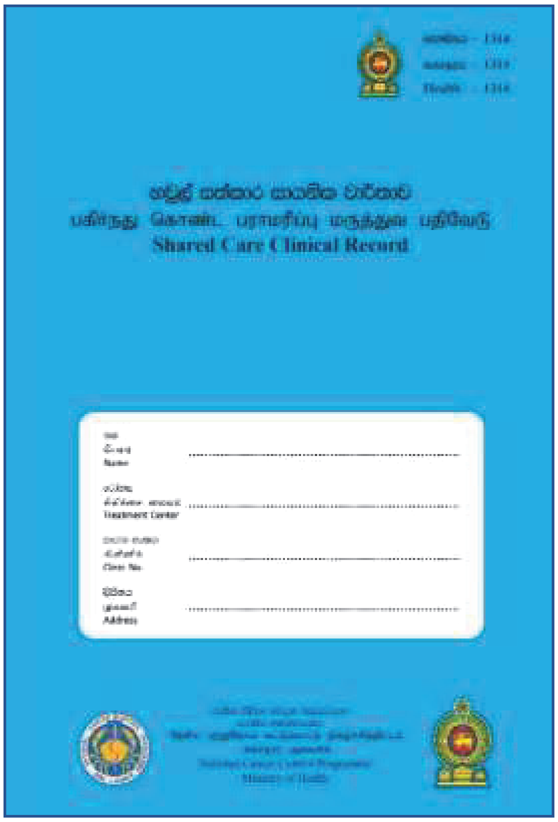
Patient Assessment in Palliative Care

The aim of this chapter is to describe the importance of assessment of a palliative care patient, demonstrate skills necessary to assess a patient with holistic approach, identify and prepare a problem list necessary to plan the management and to be able to draw genogram for patients undergoing palliative care.

Assessment of a Palliative Care Patient

Assessment of patient and family is the cornerstone for proper palliative care. Due to the wider scope involved in palliative care, the assessment is unique and extend beyond the usual patient assessment. As the approach is interdisciplinary, ideally the assessment should be done by several parties.

The immediate goal of patient assessment is to provide relief to suffering. Identification of sources of strengths in the family may be helpful in providing care recommended in the Management Plan and **Shared Care Clinical Record** which is issued by the treatment and care centre where the patient was treated for the cancer.



Shared Care Clinical Record

Name

Treatment Center

Clinic No.

Address

The main aims of palliative care are to:

- relieve symptoms
- improve quality of life
- address emotional and spiritual concerns of patient and family

To fulfill these, physical, psychological, social and spiritual aspects should be evaluated. Although assessment of a patient for palliative care should begin from the time of diagnosis of cancer, it is an ongoing process throughout the illness. The assessments should be ideally carried out at key transition points in the patient pathway as given below:

- at the diagnosis of a life limiting condition
- at episodes of significant progression/exacerbation of disease
- a significant change in the patient's family/social support
- at the patient or family request
- a significant change in functional status
- as patient enters the terminal phase (end-of-life)

Process of Patient Assessment

Setting the Scene

- Assessing a patient and family going through palliation can be emotionally challenging for the doctor as well. Be prepared for this
- Before starting the assessment, inform that some questions and discussions will be emotionally difficult and prepare the patient and family for that as well
- Select a comfortable place for the patient with privacy
- Let the patient decide who should be present from family and caregivers
- Building a good rapport with patient and family and being empathetic will facilitate the assessment (this will be discussed in chapter 2)

Aspects of Assessment

During the assessment focus on the following:

- background information
- symptoms
- functional status
- psychological assessment
- spiritual and emotional aspects
- social assessment

Background information

Before starting the assessment proper, it is necessary to gather information on the background situation including Management Plan and the Shared Care Clinical Record provided by the oncology unit.

This includes:

- basic details: name, address and contact number, age, sex, race, religion, marital status, occupation, educational background
- principal diagnosis with relevant brief clinical history and management provided
- complications and stage of the disease
- pre-existing other illnesses and allergies
- current medication of the referring oncology unit
- name of the consultant and the hospital where treatment was provided

Assessment of Physical Symptoms

Almost all the patients undergoing palliation invariably suffer from multiple symptoms. We need to take details of all the symptoms, including how these affect individuals, effect on activities of daily living and quality of life and the effect on family and caregivers.

Since one of the main aims is to relieve the pain, it would be necessary to focus on few aspects on pain such as location, quality, intensity, duration, frequency and associated aggravating and relieving factors (refer pain management in chapter 04).

Evaluation of other common symptoms encountered by these patients

Fatigue	feeling tired or exhausted, disproportionate to level of activity or not relieved by rest
Weakness	feeling physically weak
Problems of balance	recent falls, loss of balance
Respiratory symptoms	difficulty in breathing, cough, oropharyngeal secretions, sputum, heamoptysis, tracheostomy and related problems
Gastrointestinal symptoms	mouth - ulcers, dryness, candida infection, mucositis anorexia, nausea, vomiting, constipation fluids and food (intake, appetite, weight loss, diet supplements used, swallowing problems)
Urinary symptoms	dysuria, frequency, incontinence, blood in urine, anuria
Neurological symptoms	insomnia, confusion, delirium, numbness, sensation
Cognitive impairment	impairment in hearing, speech, vision, orientation
Problems related to skin and hair	dryness, itching, skin integrity, hair loss wounds - smell, discharge, fistula, pressure sores
Adverse effects of treatments	prompt the person to identify the main adverse effects of treatment

All these symptoms will be addressed in depth in different chapters,

For each symptom note:

- onset
- duration and progression
- aggravating and relieving factors
- any past and present medications

Attempt to find any underlying cause for the symptom as some causative factors can be addressed to alleviate the symptom. e.g. pain due to a bone metastatic lesion, vomiting as a side effect of a medicine, breathlessness due to an effusion or anaemia.

Ascertain the physical and psychological effects of the problem on the patient's normal activities/function and that of the family. Discuss the expected targets.

Assessment of Functional Status

Assessing the functional status will be helpful especially in training the caregivers and arranging the patient's environment. The following areas based on **Barthel Index** (BI) should be taken into account.

The BI measures the extent to which somebody can function independently and has mobility in their activities of daily living In the BI following functions will be assessed to identify the level of dependence:

1. feeding
2. bathing
3. grooming
4. dressing
5. bowel control
6. bladder control
7. toileting
8. transfer (bed to chair and back)
9. mobility on level surfaces
10. stair climbing

Instrumental activities of daily living could be assessed with the following:

- writing
- managing finances
- shopping
- cooking
- telephoning
- reading

After concluding the assessment health care team is in a position to encourage the patient to perform/ help in day to day activities and educate the caregiver to support the patient to minimise the sense of dependence.

If the patient cannot perform activities to maintain personal hygiene, washing, bathing, oral care and skin care ideally the nursing staff should train the patient/caregiver. If the mobilisation is minimal, special advice should be given on prevention and early identification of bed sores.

Psychological Assessment

Assess the patient's understanding about the disease and the present situation. What the different symptoms mean to the patient and level of emotions also should be assessed.

Their perception about the body image (cachexia, disfiguration) and if appropriate view on sexual relationships also should be explored.

Check the time since diagnosis, whether the patient understand about the disease and the prognosis, whether the patient has overcome the stage of denial and accepting the situation. This is of prime important before discussing with patient, if the patients' understanding has been poor, it might lead to unnecessary emotional reaction.

Assessor should discuss the expectations for the future and the goals. This will help the healthcare team and the family to plan the activities and to give priority in fulfilling expectations and reaching goals whenever possible.

Assessing the mood is also important. It is not uncommon to develop depression. Some patient may have anxiety, especially about their condition, future and the family.

In order to identify psychological concerns, an opening question may prompt the patient.

E.g. *is anything worrying you?*

do you have any emotional concern or distressing issues?

Mood and interests	*How is your mood?* *During the last month have you:* *– been feeling down and/or hopeless?* *– lost enjoyment in interests?* *Are you depressed?*
Anxiety	*Do you feel tense or anxious?* *Have you ever had a panic attack?* *Do you feel restless?*
Fears/worries	*Do you have any family problems?* *Do you have any unbearable problems?*
Adjustment to illness	*What is your understanding of your illness?* *Are you looking forward to anything? (check if individual can look and plan ahead)*

Pre-existing mental illness	*Patients with current or past mental health problems may be particularly at risk of psychological distress*
Resources and strengths	*What is a source of support for you?* *Look for a range of possible supports: people, hobbies, faith, beliefs*
Aggravating factors	*Are there psychological, social, emotional, spiritual issues that may be contributing to symptoms?*

Spiritual and Emotional Aspects

People have many different understandings to the word spiritual and how it impacts on their lives. When completing spiritual assessment, assessors need to be aware of alternative terms e.g. faith, belief, philosophy, religion, inner strength.

Spirituality may have a big impact on the physical and emotional wellbeing of a patient and on the coping mechanisms. Spirituality relates to the way in which people understand and live their lives in view of their core beliefs and values and their perception of ultimate meaning. Spirituality includes the need to find satisfactory answers to ultimate questions about the meaning of life, illness and death.

Attempt to explore emotions, be aware this may be very difficult to the assessor and patient both. Being empathetic will help patients to come out with their emotions. It is important to identify whether the patient is going through a period of existential suffering. It may be due to changing role in the family, fear of death, losing loved ones, physical pain and many other causes. Identifying the spiritual and emotional aspects will be very useful in planning the management.

Sources of hope	*What gives you hope (strength, comfort peace) in the time of illness?* Assess ideas about the meaning of life
Personal spirituality and practices	*What aspect of your spiritual beliefs do you find most helpful and meaningful personally?* (Assess patient's values and believes, assess patients' perception of dignity)
Effect on medical care and end-of-life issues	*How do your beliefs affect the kind of care you would like to be provided over the next few days/weeks/months?* Assess coping mechanisms

Social Assessment

In a palliative assessment it is very important to assess the social aspects to arrange support and caring for the patient, especially to arrange home care. It also will help in supporting the caregiver and family members.

Drawing a family tree is the best way to understand the family structure, relationships and resources. It should include members, their health status and this can include the details like occupation, income, relationship with other members and especially with patient to get a comprehensive idea about the entire family at a glance.

Also, it is important to know who make decisions, financial status, support available from other sources (e.g. friends, community organizations etc.). Assessor should explore their understanding of the disease and the emotional aspects. There can be members who will feel loss and grief more and whenever possible, counselling should be arranged for them to minimize the effect on their lives.

In our cultural setting, most of the time caregiver is a family member. If so, it is important to have a discussion with that person to identify his/her availability, social obligations, level of understanding about the patient's condition, aspects need to be trained as a caregiver etc. By doing this, health care team could arrange special training, respite care to give periods of breaks to the care giver on regular intervals to prevent the burnout effect.

Family and close relationships	Identify who support the patient /who care the patient Assess patients' relationships with friends and relations Who live with the patient? Any children/adult dependents? (Dependence-clarify patient is dependent or vice versa) Any concerns/worries regarding family or personal relationships
Work and finance	Assess patients' occupation / work (ability to continue to work) Evaluate previous, current and future financial situation
Community	Assess patients' and care givers' role in the community Assess the supportive groups in the community
Social and recreational	Member of any social organizations? Have grandchildren?

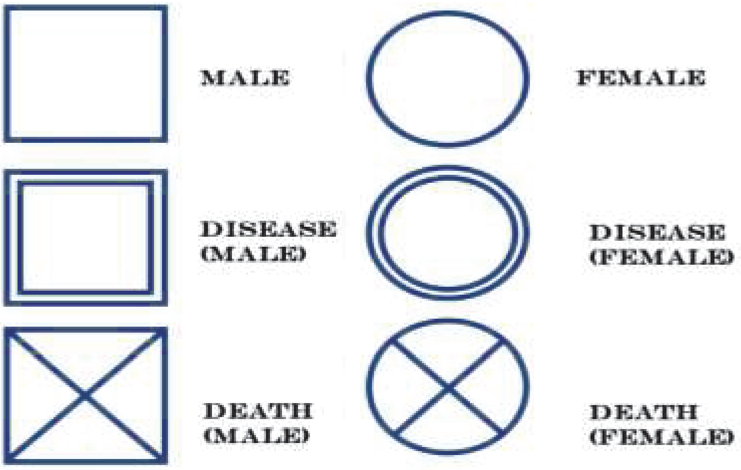
Ideal way to assess the social and family aspects is to have a family meeting. This will help family members also to express their views and share the caring among them to minimise the burden on one member (refer chapter 02)

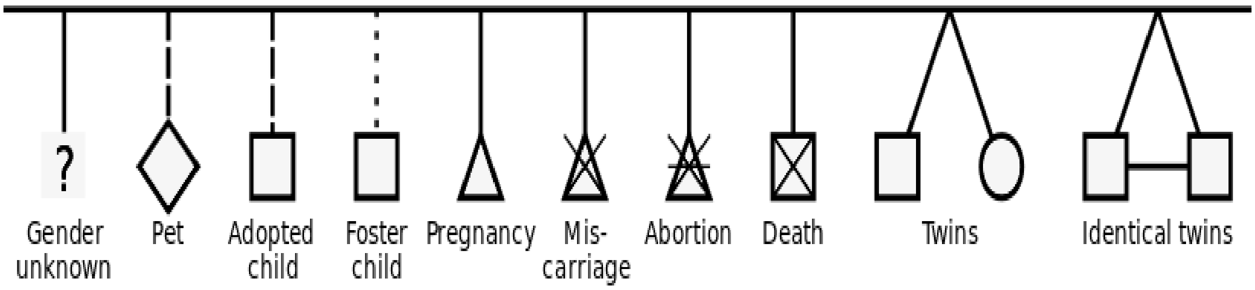
Family tree (Genogram)

Genogram is a family map or history that uses symbols to describe relationships, major events and dynamics of a family. Information such as age, date and cause of death of family members may be added.

E.g. Building a family tree for a 42 year old is shown below. The male parent is always at the left of the family and the female parent is always at the right of the family.

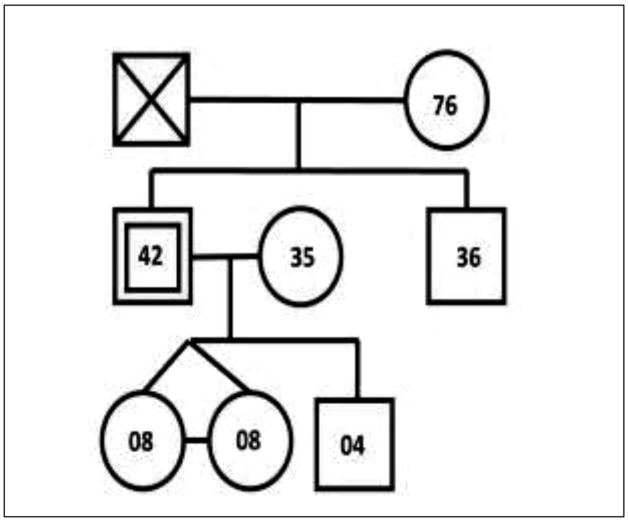
Genome symbols





Example :-

Mr. A is a 42 year old patient with lung cancer.
His mother is 76 years and lives with him.
His father is dead.
His wife is 35 years.
They have 3 children (8 years old identical twin daughters and 4 years son).
His brother is a 36 years old teacher, who lives separately.



Assessment of Devices

If the patient is on any device like nasogastric tube, percutaneous endoscopic gastrostomy tube, tracheostomy, colostomy, urethral catheter, doctor should assess whether they are in the appropriate position, maintenance and the need for change. Healthcare team and the cares should be advised accordingly.

Prepare a problem list as shown below after completing the assessment.

List out the identified problems according to perceived priority:

Domain	**Prioritised problems**
Physical	1. 2. 3.
Psychological	1. 2. 3.
Social/Occupational	1. 2. 3.
Spiritual	1. 2. 3.

04

Common Clinical Presentations of Cancer Patients

All cancer patients requiring palliative care should be assessed by a Consultant Oncologist to decide on cancer specific palliative treatment (e.g. radiotherapy or chemotherapy) for each symptom. The Management Plan will provide guidance on further management at primary care level.

Always refer to the Management Plan given by the oncology unit for each patient.

- All cancer patients requiring palliative care should be assessed by a Consultant Oncologist. The following clinical manifestations are commonly seen in cancer patients and may require management during palliative care.

- Primary healthcare worker should be aware that each cancer patient is given a Management Plan from the oncology unit or the treating specialised unit where the patient is registered and it will include follow up activities for patient's clinical presentations including palliative care.

Oral Thrush (Oral Candidiasis)

Candida is a fungal infection (also called yeast infection) that colonizes the surface epithelium of the alimentary canal and urogenital system of healthy human beings as normal flora. There are several distinct candida species which can cause diseases, and the most common pathogens are *C. albicans, C. glabrata and C. tropicalis*. Over growth of fungal infections take place when the local or systemic immune system is impaired involving oropharynx, esophagus, and vagina.

Oral fungal infections present as an indicator of an underlying disease such as diabetes mellitus, malignant tumours, chronic illnesses, chemotherapy and radiotherapy. Another cause of candidiasis is prolonged use of antibiotics. Prolonged antibiotic use could result in an alteration in the balance of the natural occurring flora in the mouth (and elsewhere) where the normal flora is damaged by antibiotic therapy to the advantage of the fungus, which then blooms. Damage to the mucus membranes and to the salivary glands also allow for colonisation of fungi.

Signs and symptoms

- burning sensation
- difficulty in swallowing
- presence of a white rash on the tongue, buccal mucosa

Dry mouth (xerostomia), upsets the balance of microorganisms in the oral cavity and promotes overgrowth of this fungus.

Causes	
Xerostomia	post radiotherapy or chemotherapy for head and neck cancers or drug induced xerostomia
Poor oral hygiene	including poorly cleaned teeth or dentures (acute atrophic candidiasis which presents with sore reddish palate), general debility
Smoking	significantly increases the carriage of candida
Corticosteroid	topical, systemic or inhaled
Diabetes	due to increased glucose content in the saliva and decreased immunity
Prolong antibiotics or Immuno-modulating drugs	due to disruption of normal flora

When a patient present with oral candidiasis the PHC medical officer should take a detailed history and carry out a comprehensive physical examination. The following are important during the assessment of oral cavity.

Examine the mouth on a daily basis. Features of a healthy mouth include:

- mouth is clean and moist with saliva
- gums, tongue and cheeks are healthy and pink
- teeth / dentures are clean and fit well
- no mouth ulcers or red or white patches

Management of oral candidiasis

Pharmacological Management

Topical application	for mild disease	Miconazole oral gel
Oral Antifungals	for moderate to severe disease or refractory to topical treatment	Fluconazole 100mg-200mg per oral daily for 14 days Itraconazole solution 200mg daily (80% with infection refractory to fluconazole will respond to itraconazole solution)

- ➢ If the patient is on any of the above oral antifungals and if the drugs are available with the patient continue as instructed in the Management Plan. For further instructions consult the specialist.

Non-pharmaceutical Management

Advice the family/care giver on the following:

Teeth and tongue should be cleaned at least twice daily for about 2 minutes with a small/medium bristle toothbrush and fluoride containing toothpaste
Dentures should be removed twice daily, cleaned with a brush and rinsed with water They should be soaked overnight in water or in 1% hypochlorite solution or use denture cleaning tablets. After soaking, the dentures should be cleaned with a brush
Adequate oral fluid intake should be encouraged
Lips should be moisturized with ice chips or lip balm

Oesophageal Candidiasis

Oesophageal candidiasis is common among immune-compromised patients. Medical officer should check the Management Plan whether the patient is on treatment for oesophageal candidiasis and follow the instructions given by the specialist.

The most common symptoms are pain on swallowing (odynophagia – which is not seen in oropharngeal candidiasis), difficulty in swallowing, and pain behind the sternum. Other symptoms include abdominal pain, heartburn, weight loss, diarrhoea, nausea, vomiting, and melaena.

The clinical diagnosis should be followed by an endoscopic examination. Therefore, discuss with the specialist and refer to the oncology /treatment centre. Endoscopy examination will show small white spots which are adherent to the esophageal mucosa which cannot be washed off with water irrigation.

The gold standard for the diagnosis of oeophageal candidiasis is by histological examination. Biopsy or brushing of the esophageal mucosa is taken during endoscopy, and staining by using hematoxylin and eosin will confirm the presence of pseudo hyphae, which is an important basis for the diagnosis of esophageal candidiasis.

The following treatment is used in the management of oesophageal candidiasis:

Oral antifungals	Fluconazole 200-400mg daily for 14-21days OR
	Itraconazole 200mg daily for 14-21 days OR
	Voriconazole 200 mg twice daily for 14 to 21 days

If the patient is on any of the above oral antifungals and if the drugs are available with the patient continue as instructed in the Management Plan. For further instructions consult the specialist. The following systemic therapy is recommended for severe infections.

Systemic therapy	Fluconazole 200mg-400mg IV (3-6 mg/kg) daily for 14-21 days OR
	Fluconazole 400mg/day IV (6mg/kg) for 14-21 days OR
	Amphotericin B IV (0.3-0.7mg/kg) daily for 14-21 days

For fluconazole refractory disease, itraconazole, posaconazole or voriconazole oral or intravenous solutions can be used at similar doses as above but for a longer duration of 14-21 days.

Liver function test should be carried out when patients are on oral or systemic antifungal therapy.

Respiratory Symptoms

Respiratory symptoms are among the most common symptom in patients who receive palliative care. Dyspnoea (breathlessness), for example, can occur in more than half of patients who are dying, and the incidence increases as death approaches.

Dyspnoea (Breathlessness)

Breathlessness has a reported incidence of 30 to 74% of people near the end-of-life. A careful evaluation of the nature of the breathlessness is important and it should not be under estimated. Listening to descriptors (the language that the patient uses to describe the sensation) of the quality and quantity of dyspnoea is important in choosing management.

Breathlessness will only rarely be expressed purely in physical terms, in addition cough, haemoptysis, hiccup and pleural pain are present in a considerable number of patients. The assessment of breathlessness should use a multidimensional approach, as with the assessment of pain. Identifying the cause(s) is an essential step in effective management.

Causes

- It is often multifactorial
- It is not always possible to understand treatable cause

Symptom	Cause
Air flow obstruction	This can be related to large air ways (tumour producing either extrinsic or intrinsic obstruction laryngeal palsy, radiation stricture) Smaller air ways (asthma, emphysema, chronic bronchitis, lymphangitis, carcinomatosis)
Decrease effective lung volume	effusion, ascites, pneumothorax, tumour, lung collapse, infection
Increase lung stiffness	pulmonary oedema, lymphangitis, carcinomatosis, pulmonary fibrosis, mesothelioma
Decrease gas exchange	as above plus pulmonary emboli, thrombotic tumour, tumour effect on pulmonary circulation

Pain	pleurisy, chest wall infiltration, rib/vertebral fractures
Neuromuscular failure	paraplegia, motor neuron disease, phrenic nerve palsy, cachexia, paraneoplastic syndrome
Left ventricular failure	congestive heart failure
Ascites, pleural effusion	organ failure
Increase ventilator demand	due to anxiety, anaemia, metabolic acidosis

Assessment

- Careful assessment of each situation to identify probable causes is an essential starting point.

- Pay particular attention to the descriptions the patient gives of the sensation and experience of breathlessness and ask specifically *"How would you describe your breathlessness today?"*.

- Severity and perception for each individual is important as dyspnoea may have a variable effect on quality of life at the end-of-life, varying with the cause(s).

- Therefore, it is important to ask the patient about their feelings of dyspnoea rather than rely on clinical findings.

Dyspnoea has at least five main components, each of which must be attended to:

- Sensation (what it feels like?)
- Perception (how it is viewed in the context of the illness?)
- Distress (does it cause suffering or grief?)
- Response (how individuals react?)
- Reporting (the language used to relay these elements)

Non-pharmacological management

Increase draughts of fresh air	use fans and open windows
Psychological support	address anxiety and fear by active listening and exploration of the meaning of breathlessness
	explanation and reassurance (educating the patient about dyspnoea can reduce the anxiety that patient feel when short of breath)
	relaxation techniques
	relearning breathing patterns and control
	discuss coping strategies
Avoid heavy meals	small frequent meals are preferred
Music therapy and art therapy	to distract the feeling of breathlessness
Physiotherapy	get advice from a Physiotherapist

Pharmacological management

Opioids **The palliative care team can prescribe what is suitable to the patient** **Check the Management Plan and seek specialist advice**	**for opioid naive patient**-immediate release (IR) Morphine 2.5mg oral 4-6 hourly
	if unable to take orally give 1-2mg 4-6 hourly SC (*Injections available at level 2 not in PHC level*)
	for patients on opioids for pain, increase the regular dose by 25% - 50%
	breakthrough or rescue doses to be given as required same way as in pain. The dose is usually increased by 25-30% depending on tolerance and response
Oxygen	a draught of fresh air may be as effective as oxygen for many patients Efficacy of oxygen varies between patients but if saturations is less than 90% oxygen may have some benefits For some patients, it may make their feeling of dyspnoea worse to have their face covered up by an oxygen mask or nasal prongs.
Nebulized normal saline	0.9% Sodium Chloride 5 ml as required to loosen secretions

Bronchodilators (nebulized /inhaled) e.g. salbutamol	for patients with reverse airway obstruction
Corticosteroids e.g. dexamethasone	for patients with lymphangitis carcinomatosis, bronchial obstruction or radiation pneumonitis: dose 6-12 mg mane oral (with PPI cover) stop if no effect after about 7 days reduce gradually to lowest effective dose
Benzodiazepines (short acting) **e.g. midazolam, lorazepam, alprazolam**	in anxious patients where other methods have failed, lorazepam 0.5mg-1mg sublingually, Dose can be titrated up to 2.5mg sublingually SOS (*Lorazepam 1mg tab only available in level 2*) regular lorazepam 0.5mg-1mg oral 8 hourly can be prescribed for patients with anxiety
Antibiotics	if infection is suspected, antibiotics may decrease secretions in patients in the final terminal phase e.g. hours to days, antibiotics will make a little difference to the course of events even if infection is suspected
Diuretics	if congestive heart failure or pulmonary oedema present
Anticholinergic **e.g. Hyoscine butyl bromide or glycopyrrolate**	if secretions are worrying Hyoscine butyl bromide - 0.4mg as single dose SC, if effective, use 0.3-0.6mg SC 4 hourly (*Hyoscine inj. available at level 3, 10mg tab available in level 2)*

Treat/remove causes where possible with treatment	complications of cancer e.g. pleural effusions/ ascites- seek advice from specialist. May need drainage if anaemia is present - packed cell transfusion may be useful. Seek advice from specialist

Cough

Cough is often associated with other symptoms such as dyspnoea, wheezing or chest tightness. It is a defensive mechanism, like pain, it can have a detrimental effect on the quality of life as it interferes with communication, food and drink intake and sleep.

- ➢ Review the Management Plan, take a history from the patient/family member/care giver and do an assessment
- ➢ A comprehensive clinical assessment is necessary to identify the underlying cause and management
- ➢ Consider X-ray chest if appropriate

Common causes and some considerations in the management are listed below:

Acute respiratory infection	• nebulizing with 0.9% sodium chloride • antibiotics • maintaining hydration
Asthma	• bronchodilators • steroids
Cardiac failure and pulmonary oedema	• diuretics • ACE inhibitors
Chronic Obstructive Pulmonary Disease (COPD)	• bronchodilators • steroids • cough with tenacious sputum e.g. a productive cough may respond to steam/moist inhalation • physiotherapy
Malignant obstruction (tumour)	• consult the oncology unit and refer to Consultant Oncologist for radiotherapy/ chemotherapy/laser therapy. • consider corticosteroids if given in the Management Plan
Oesophageal reflux	• PPI: e.g. omeprazole
Pleural effusion	• discuss with specialist and if facilities are available do a pleural tap if not refer to specialist centre for drainage
Treatment related	• review the medications given in the Management Plan (e.g. ACE inhibitor induced cough)

Commonly used drugs in the management of cough

Cough suppressants may be useful in dry non-productive cough e.g. codeine, pholcodine, morphine.

Codeine : 15-30mg orally 4 hourly (*not available at PHC level*)

Morphine :

- Should be used if the cough is not suppressed by codeine or other means.
- May not be appropriate in productive cough as retaining the mucus may encourage infection.
- **Seek specialist advise before commencing /increasing dose of morphine**
- Starting dose depends on patients' previous exposure to opioids. (*not available at PHC level, 10mg, 15mg, 30mg, 60mg tab available at level 2*)

Patients who have a past history of been on codeine	commence on morphine 5-10mg oral 4 hourly or (2.5-5mg SC/IV 4 hourly) breakthrough dose every hour as required	Seek specialist advise
Patients who are already on morphine for pain	increase morphine dose by 20%	

Opioid naive patients	morphine 2.5mg oral 4 hourly (or 1-2mg SC/IV) and a breakthrough or rescue dose every hour as required	Seek specialist advise

Corticosteroids: e.g. dexamethasone, prednisolone

Often used to treat cough associated with endobronchial tumours, lymphangitis or radiotherapy pneumonitis e.g. dexamethasone 8mg oral mane (*dexamethasone 0.5mg tab available at PHC level, 4mg and 8mg available at level 3*)

- **If tenacious secretions are difficult to clear with coughing, consider using nebulized hypertonic saline**

Salivary Secretions

Excess respiratory secretions are common in patients near the end-of-life. They are caused by fluid pooling in the upper airways, arising from one or more sources:

- Saliva (most common)
- Bronchial mucosa (e.g. inflammation/infection)
- Pulmonary oedema
- Gastric reflux

Management

Semiconscious or unconscious patient	• patient is not usually troubled by the secretions • explain to family members as they may find the secretions distressing, particularly if the patient has noisy rattling breathing
	• position the patient semiprone, to encourage postural drainage, unless the secretions are caused by pulmonary oedema or gastric reflux, when the patient should be more upright
	• suction of the upper airway is usually reserved for unconscious patients, as it can otherwise be distressing

Hiccups

Hiccups are defined as respiratory reflex characterised by spasm of the diaphragm resulting in a sudden inspiration and closure of the vocal cords. The phrenic nerve and the brain stem are involved. Hiccups are distressing and exhausting. It can affect a patient’s daily living and social functioning. The symptom should be attended to with urgency.

Primary health care team should have an understanding of the underlying cause of hiccups and the table below gives some of the causes:

Head	neurological disease affecting the medulla such as brain tumours and metastasis, strokes and infarctions and encephalitis
Neck	any irritation of the phrenic and vagus nerve e.g. goiter, neck tumours
Thoracic	oesophageal disorders such as cancer, reflux oesaphagitis, hiatus hernia, mediastinal tumours, myocardial infarction, thoracic aneurysm
Abdominal	gastric stasis and distention (the most common cause) e.g. bleeding. upper abdominal causes, e.g. liver disease (hepatomegaly), ascites, diaphragmatic irritation
Metabolic	renal failure, hyponatremia, uraemia, hypercalcaemia, magnesium deficiency
Drugs	steroids, diazepam, cisplatin, etoposide, paclitaxol
Psychological	personality disorders, hysteria, grief reaction

Assessment

- The PHC medical officer should carry out a careful assessment to identify the causes
- Consider the severity of the condition, duration and impact on patient’s quality of life

Management of Hiccups

- Hiccups often stop spontaneously. Treatment is only required if hiccups are persistent and causing the patient discomfort and distress
- First try simple non-pharmacological methods

Non pharmacological management

- Sipping ice water or swallowing small pieces of crushed ice to cause pharyngeal stimulation
- Swallow sugar 1-2 tea spoons
- Interrupting normal breathing for example holding breath or breathing into a paper bag to elevate the p CO_2 level
- Lightly rubbing mid line of the soft palate for 1 minute with a swab to stimulate the naso-pharynx
- Passage of nasogastric tube
- Massage of external auditory canal

Pharmaceutical management

Gastric distension +/- gastro-oesophageal reflux	manage gastric reflux and distention • omeprazole 20 mg -40 mg oral b.d. • domperidone 5-10 mg oral t.d.s.	
	• metoclopramide 5-20 mg oral t.d.s.	do not use in intestinal obstruction it is a dopamine antagonist which is used also in the treatment of nausea and vomiting
	• antiflatulent e.g. simeticone (*Not available at PHC level*)	
Diaphragmatic or phrenic nerve irritation	• baclofen – is a gamma amino-butyric acid agonist used as a skeletal muscle relaxant and an antispasmodic agent. 5-20mg t.d.s. for 3 days (*Available at level 3 not in PHC level*)	**seek specialist advice to commence therapy**
	• antiepileptic – gabapentin 300mg oral nocte (*Not available at PHC level, its available in level 3*)	
	• nifedipine – 10-20mg oral t.d.s. (*Available at PHC level*)	
	• midazolam – (*Not available at PHC level, inj. and 7.5mg available at level 3*)	
Central nervous system tumour/meningeal irritation	anticonvulsants may be useful such as:	**seek specialist advice to commence therapy**
	• phenytoin 200-300mg oral nocte (*100mg tab Available at PHC*)	
	• carbamazepine 100-200mg oral b.d.	
	• clonazepam 0.5-1mg oral b.d. (*Available only at level 3*)	Several of the above may have to be tried. None are consistently reliable
	• nifedipine 10-20 mg oral t.d.s.	
Systemic causes (metabolic, infections)	antipsychotics e.g. • haloperidol 1-5mg oral 4-12 hourly 0.5-1 mg t.d.s.	**Seek specialist advice to commence therapy**

	per oral /SC/ IV (*inj 5mg/1ml and 1.5mg Tab available at PHC level*) • chlorpromazine 12.5-50mg per oral 6-8 hourly (*Not available at PHC, available at level 2*)	
	• midazolam (*not available at PHC level*)	
	• baclofen oral 5-10mg t.d.s. (*not available at PHC level*)	
Cerebral compression/ irritation by disease/ tumour	dexamethasone 4-8mg oral mane may reduce compression/ irritation. (*0.5mg tab available at PHC level*) • stop if no benefit after a week • if beneficial need to gradually reduce dose	**seek specialist advice to commence therapy**
Phrenic nerve block may be considered in intractable cases		

Seizures

Seizures are paroxysmal episodes of abnormal electrical conductions in the brain resulting in sudden onset of transient neurological symptoms. Status epilepticus is defined as continuous seizure activity lasting more than 30 minutes or intermittent seizures without recovery of consciousness.

Causes

- Brain metastasis or primary brain tumour
- Hepatic encephalopathy
- Hypoxic encephalopathy/Hypercarbia
- Stroke
- Infections of the central nervous system
- Drug toxicity (e.g. pethidine/meperidine)
- Uremic seizures
- Metabolic or electrolyte abnormality
  - Hypoglycaemia
  - Hyponatraemia
  - Hypercalcaemia

Non-Pharmacological Management

- Turn patient left lateral position and prepare suctioning
- Give supplemental oxygen

Pharmacological Management

- Check the Management Plan

If the Management Plan has prescribed medications in the event of a seizure follow instructions but inform the consultant.
If no medications are prescribed as an urgent need commence on midazolam and immediately seek advice from the specialist.

Recommended	
Midazolam 1.0-2.5mg SC/IV stat (*not available at PHC level, inj available at level 2*)	if persists repeat dose once after 15 minutes
Alternative	
Use rectal diazepam in consultation with a specialist. (5mg, can be repeated 15min later)	

The specialist may prescribe the following or advise to refer to a specialist unit :

- Midazolam 10mg buccal or 5mg SC or IV if route accessible lorazepam 4mg
- if seizures persist phenytoin (15-20mg/kg/day) IV as an infusion at a rate less than 50mg/min, (*Not available at PHC level, available at level 2*)

If seizures persist despite phenytoin infusion

- Phenobarbitone IV bolus (10-20 mg/kg) to run at a rate <25mg/min followed by maintenance: 0.5-3.0mg/kg/hour (*Not available at PHC level, available at Level 3*)

For refractory seizures:

- Clonazepam 0.25-0.5mg oral b.d. – t.d.s. oral/NG (*available at level 2*) and/or
- Phenytoin 300mg daily (*100mg available at PHC level*)
  or
- Levetiracetam 500mg oral b.d. (*available at level 3*)

Other drugs	
Corticosteroids	Dexamethasone is helpful in the prevention and management of seizures which are secondary to brain metastasis, by decreasing the oedema surrounding a tumour mass
Radiation	can be helpful in preventing seizures in patients with metastatic brain disease

Lymphoedema

Lymphoedema is swelling that occurs when protein rich lymph fluid accumulates in the interstitial tissue. It is a physical manifestation of inadequate lymph flow leading to tissue swelling. Fluid transport is impaired primarily by removal of lymphatic channels and nodes during resection of tumour and nodal sampling, resulting in accumulation of protein rich fluid in the interstitium. The stagnant fluid can lead to progressive changes in the tissue and places the limb at risk for infection.

This lymph fluid may contain plasma proteins, extravascular blood cells, excess water, and parenchymal products. Lymphoedema is one of the most poorly understood, relatively underestimated, and least researched complications of cancer or its treatment.

Symptoms of Lymphoedema

- Fullness, tightness or heaviness in an extremity
- Inability to wear rings, bracelets or other jewelry, clothing feeling tight
- Altered sensation

Assessment of Lymphoedema

- Pre-operative, bilateral upper extremity function should be assessed to provide a baseline. Following which post-operative measurements are compared with the pre-operative findings.

Simple circumferential tape measurements (Pre and post-operative).

Circumferential measurements should be taken at 4 points:

Circumferential measurements
1. metacarpophalangeal joints
2. wrists
3. 10 cm distal to the lateral epicondyle
4. 12 cm proximal to the lateral epicondyle

- A difference of more than 2.0 cm at any of the 4 measurement points may warrant treatment of lymphoedema, provided that tumour involvement of the axilla or brachial plexus, infection, and axillary vein thrombosis have been ruled out.
- Patients with less of a measurement difference between their extremities (preclinical lymphoedema) may also benefit from skilled therapy interventions as well, especially if they present with reduced range of movement, strength, and/or functional limitations.

The following can be considered depending on the stage of lymphoedema:

Lymphatic Exercise

Specific exercise is beneficial for all patients. Although heavy activity may temporarily increase fluid load, appropriate exercise enables the person with lymphoedema to resume activity while minimising the risk of exacerbation of swelling.
Compression garments or compression bandages must be worn during exercise to counterbalance the build-up of interstitial fluid.

Considerations for Designing an Exercise Program:
1) Allowing adequate rest intervals between sets
2) Avoiding weights that wrap tightly around an extremity or clothing that causes constriction
3) Wearing compression sleeves or bandages during exercise
4) Maintaining hydration
5) Avoiding extreme heat or overheating

Skin and Nail Care

- thorough hygiene is recommended to decrease the infection on the skin. Low pH moisturizers will help to keep skin from drying and cracking
- damage to skin can result in infections and wounds which might lead to cellulites. generally, injections, vaccinations, venepuncture, and intravenous access in the axillary-dissected upper extremity have been contraindicated

Bandaging

- the patient should receive two garments at a time for each affected body part: one to wear and one to wash and dry
- having two garments ensures that the patient does not wear a dirty or wet garment which promotes bacterial or fungal infection
- properly fitted garments are essential for long term control of lymphoedema. Garments should be washed daily so the garment lasts long

Important to remember

Since lymphoedema is a lifelong condition, patient education in self-management is very important:

- to reduce the risk of developing lymphoedema or worsening, all patients with or at risk of lymphoedema should be instructed in essential selfcare
- important to seek advice from physiotherapy department

Treatment for Lymphoedema in Specialized Units

Complete Decongestive Therapy (CDT) is the main treatment for lymphoedema. Experts who treat lymphoedema consider CDT the “gold standard” of treatment.

Components of CDT
1. Manual lymph drainage
2. Multilayer, short stretch compression bandaging
3. Lymphatic exercise
4. Skin care
5. Education in lymphoedema self-management and elastic compression garments

Manual Lymph Drainage

It is a light, skin technique performed by certified lymphoedema therapists designed to improve fluid removal from congested areas where the lymphatics are not working properly and rechannelling into lymph vessels and lymph nodes that are functioning.

Nausea and Vomiting

Introduction

Nausea is an unpleasant feeling of the need to vomit, often accompanied by autonomic symptoms whilst vomiting is the forceful expulsion of gastric contents through the mouth.

Nausea and vomiting may be behavioural adaptive mechanism to avoid the ingestion of toxins. There are other physical and psychological triggers that can lead to the experience of nausea and vomiting.

Antiemetic drug therapy is primarily for the control of nausea and vomiting. All antiemetics have the potential to produce significant side effects, e.g. hyoscine hydrobromide crosses the blood brain barrier and may cause sedation, agitation or confusion.

Individuals with protracted nausea and vomiting are likely to have poor control of other symptoms, if unable to have their usual medication.

It is important to differentiate regurgitation from vomiting. Obstruction of the oesophagus and consequent regurgitation can be reported as vomiting. Regurgitation will never be relieved by antiemetics but associated persistent nausea may respond to the appropriate medication.

Common Causes of Nausea and Vomiting	
Gastrointestinal	Pharyngeal irritation Gastric outlet obstruction Gastric compression Gastric irritation Gastric stasis
Drugs	Chemotherapeutic agents Opioids Antibiotics NSAIDs
Metabolic	Renal failure Hypercalcaemia

	Liver metastases with impaired liver functions
Neurological	Primary brain tumours Brain metastasis
Psychological	Anxiety/fear
Others	Radiotherapy Infection Pain Anticipatory nausea Myocardial infarction

Management of nausea and vomiting at the primary healthcare level

Assessment

Take a history

- a separate history for both nausea and vomiting
- volume, pattern etc.
- exacerbating and relieving factors
- bowel habits
- medication

Carry out a physical examination

- signs of dehydration, sepsis and drug toxicity
- central nervous system
- abdomen (e.g. organomegaly, bowel sounds, succession splash)
- cardiovascular system (pulse rate, blood pressure)

Blood investigations

- blood urea and serum electrolytes
- liver function tests
- serum calcium levels
- blood glucose

The above baseline investigations are necessary in the management but discuss with the specialist. Since most of the tests may not be available in the PHC institution, collect samples and send to a higher facility.

Management

Non pharmacological management

- Control of malodour
- Avoidance of large meals
- Avoidance of exposure to food odour
- Calm environment
- Psychological approaches

Pharmacological management

Check the Management Plan	
Discontinue any drugs thought to be responsible for nausea and vomiting in consultation with the treating specialist	• discuss with the specialist and commence antiemetic /s or what has been recommended in the Management Plan • the parenteral route may reduce tablet burden which may be a contributing factor to nausea. Buccal or sublingual medication administration may be helpful but may trigger symptoms of nausea or vomiting in susceptible individuals
Use each antiemetic to maximum dose before changing or adding in another agent	identify and treat underlying causes if possible
If nausea and vomiting is multi-factorial, the specialist may consider a broad spectrum antiemetic	use the non-oral route if vomiting prevents drug absorption on consultation's advice. e.g. in bowel obstruction

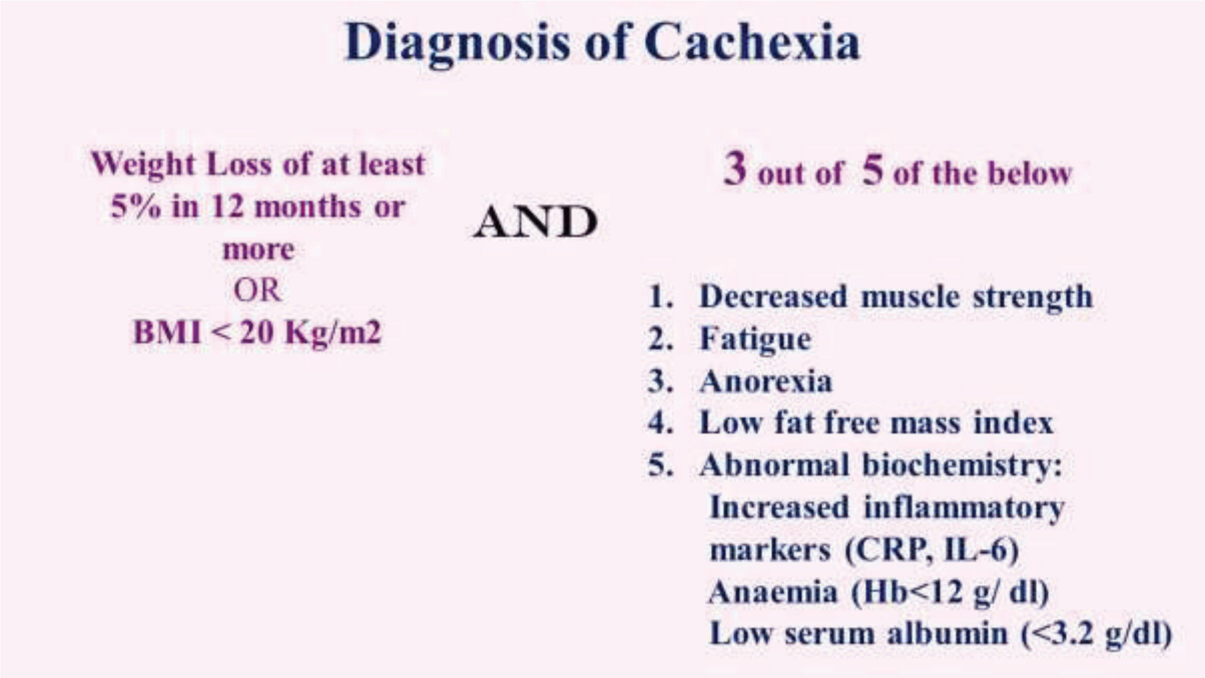
The following gives the antiemetic class and the receptor where the drug acts to educate the PHC workers. Some of these drugs may not be available at your institution, nevertheless patients may be on some of these therapies recommended by palliative care specialists and included in the management plan.

Drug	Site of actions	Anti-Emetic class	Drug availability at primary care setting
	Vomiting Centre		
Hyoscine butyl bromide		anticholinergic	*not available in the PHC but 10 mg tab available in level 2 and above*
Olanzapine		5HT2 antagonist	*5mg tab and 10mg tab are available at PHC*
	Chemo Receptor Trigger Zone		
Haloperidol		anti dopaminergic	*1.5mg tab are available in the PHC*
Metoclopramide		anti dopaminergic	*10mg tab and 10 mg injection is available in PHC*
Prochlorperazine		anti dopaminergic	*10mg tab are available in PHC*
Domperidone		anti dopaminergic	*10mg tab are available in PHC*
The following two drugs are used in the management of nausea and vomiting			
Ondansetron		5HT3 antagonist	*Not available at PHC but 4mg tab are available in tertiary care*
Aprepitant		NK1 antagonist	*Not available in Sri Lanka*
	Gastrointestinal Tract		
		anti dopaminergic	*10mg tab, and 10mg injections are available in PHC*

○	**Vestibular Apparatus**		
Prochlorperazine		Antidopaminergic	*10mg tabs are available at PHC*
Hyoscine butyl bromide		Anticholinergic	*Not available at PHC but 10mg tabs are available at level secondary and tertiary levels*

Anorexia and Cachexia

- Primary anorexia is the absence or loss of appetite for food
- Cachexia is a complex metabolic syndrome associated with underlying illness and characterized by loss of muscle with or without loss of fat mass
- The prominent clinical feature of cachexia is weight loss in adults (corrected for fluid retention) or growth failure in children (excluding endocrine disorders). Anorexia, inflammation, insulin resistance and increased muscle protein breakdown are frequently associated with cachexia



Diagnosis of Cachexia

Weight Loss of at least 5% in 12 months or more
OR
BMI < 20 Kg/m2

AND

3 out of 5 of the below

1. **Decreased muscle strength**
2. **Fatigue**
3. **Anorexia**
4. **Low fat free mass index**
5. **Abnormal biochemistry:**
   Increased inflammatory markers (CRP, IL-6)
   Anaemia (Hb<12 g/ dl)
   Low serum albumin (<3.2 g/dl)

Common causes of cachexia

- inactivity
- endocrine
- inflammation
- anorexia
- nausea and vomiting
- side effects of anticancer therapies
- medications for symptom management - e.g. given for pain, dyspnoea, depression
- oral problems - dry mouth, mucositis secondary to chemotherapy, oral candidiasis, oral herpes simplex virus infection
- gastrointestinal motility problems - reflux oesophagitis, gastric stasis, constipation

The PHC medical officer should refer to the management plan, take a detail history keeping in mind the causes of cachexia and carry out a physical examination.

Take the following into consideration when taking the history

- try to identify any reversible cause/s that affect appetite and feeding
- assess appetite and identify symptoms such as pain, constipation, nausea, vomiting depression that may be causing decrease appetite
- assess ability / difficulty in swallowing and chewing

Management

Drug Induced Complications	
Some drugs may • induce nausea, e.g. antibiotics, opioids • irritate the gastric mucosa, e.g. NSAIDs, antibiotics • delay gastric emptying, e.g. opioids, cyclizine, tricyclic antidepressants.	**Consider** ✓ reassessing the need for the drug and whether it can be given in a different form or by an alternative route can be beneficial. ✓ co prescribing PPI to protect gastric mucosa ✓ encourage smaller meals

If reduced appetite is due to gastric stasis/early satiety, consider the following:

- Metoclopramide 10mg orally three times daily half an hour before meals

The following drugs are prescribed by specialists when managing cachexia:

Dexamethasone 4mg mane will normally be effective within 1 week	Medroxyprogesterone 400mg mane is slower to act than steroids (>2 weeks) but has fewer side effects. However, effectiveness is not sustained and it should not be continued long term due to side effects. (short term use only)	Megestrol acetate 160mg oral mane. If poor effect after 2 weeks is increased up to twice a day. Takes several weeks to achieve full effect, but results can last for several months
The specialist may also consider the following :	✓ if anorexia persists, adding an appetite stimulant ✓ co-prescribing a PPI to protect the stomach ✓ prescribing antidepressants, if anorexia is associated with depressive symptoms ✓ vitamin supplementation - instances of anorexia can be attributed to taste alteration and studies have shown that zinc or vitamin B deficiency may be the cause	

The PHC team can advise the family/caregiver on the following:

- serving small portions of food preparations as aaggressive feeding can make symptoms such as nausea, vomiting and pain worse
- attractively presented and served at a correct temperature can often tempt the unwilling patient
- eating is a social activity and for some people company is valuable
- at the other extreme, it is important to provide privacy for people who feel embarrassed about their eating habits

Important to remember:

- anorexia cachexia is usually not simply reversed with improved nutrition
- educating the family and caregiver that wasting is a part of the disease process and not due to poor feeding
- there is no evidence that providing nutritional support either enterally or parenteral improve morbidity or mortality in terminally ill patients

Pain management

Primary health care physician should be able to appreciate that the pain management is one of the most essential components in the continuity of care of terminally ill patients seeking medical advice at primary healthcare services. An understanding of the concept of total pain in palliative care is vital to provide relief to the patient and thereby make the patient and family comfortable.

Total pain

Total pain includes physical, psychological, social, and spiritual dimensions/causes for patient pain experience, that is crucial for successful patient assessment and management. A clear conceptualization of pain for the palliative care patient population is necessary, and the concept of ''total pain'' may serve as the basis for pain assessment to intervene successfully. It is important to assess patients' pain, hurting, or suffering through a multidimensional scale (multidimensional evaluation) that allows for the appreciation of all possible causes and influences.

Definition by the International Association for the Study of Pain (IASP)

> Pain as the unpleasant, subjective, sensory and emotional experience associated with or resembling that associated with actual or potential tissue damage or described in terms of such damage.
>
> ***IASP (2018)***

- for routine practice, pain is considered as "what patient complains as pain or hurt"
- in the management of a patient presenting for pain management in a primary healthcare institution
- as the first step - greeting the patient and introduce yourself and the palliative care team and make the patient and family comfortable would be advisable. Briefly explain what steps you and the team will be taking in pain management

Review the Management Plan issued by the specialist centre and use it as the guidance document. If further advice is required it is advised to contact the treating consultant.

Management of pain is based on 3 approaches: R-A-T

1) Recognise
2) Assess
3) Treatment of pain

Recognise

Pain may not be obvious at times and the degree of pain may not be what is being observed. Therefore, a detailed history will be useful and a discussion with the patient and family is important.

- Listen to the patient, caregiver and family to understand their experience, patient's perception of pain, and the gauge the preference of type of pain management.
- Show empathy and explain what will be done in your centre to help alleviate the pain.
- Get details on the presence of other co-morbidities (e.g. diabetes, hypertension) and on-going and past medications.

Pain Assessment

It is important to recall that 'pain" is one of the 5 vital signs during clinical assessment of a patient. (pulse, blood pressure, respiration and temperature). For cancer patients, pain is multifactorial, therefore thorough history and careful examination may be needed. Consider appropriate investigations if management decision is altered.

Some causes of cancer pain

- disease related – due to the direct invasion of tissues or organs by cancer, distention of organs or pressure on surrounding structures of the cancer

  It could be bone pain, nerve, raised intra cranial pressure, organ related (pain arising from liver may present as shoulder tip pain and in the right upper hypochondrium, colic pain from bowel obstruction or bladder spasm). Pain due to spinal cord compression is also common.

- treatment related – chemotherapy, radiotherapy, surgery
- debility – from pressure sores, severe cachexia
- other related illnesses – e.g. arthritis, osteoporosis, vascular disease etc.

The Goal of the PHC physician is to provide immediate relief of pain to the patient as given in the Management Plan. This needs careful history and thorough clinical examination and if needed investigations.

Pain assessment

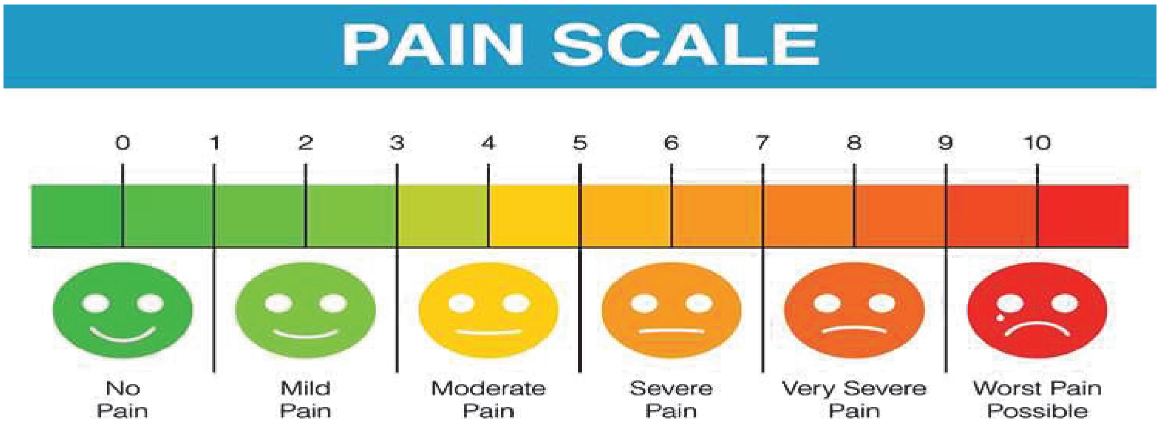
1. A comprehensive pain history should be taken:

S- site
O- onset
D- duration
C- character
R- radiation
A- associated symptoms
T-timing
E- exacerbating and relieving factors
S-severity
P-provoking factors

2. **Type of pain**

- duration related-acute/ chronic/ acute on chronic
- cause related -cancer/ non cancer
- mechanism related -neuropathic/ nociceptive/ mixed
- other contributing factors
- social/ psychological/ spiritual/ physical

3. **Assess the severity using the pain scale**



Physical examination

It is essential to conduct a comprehensive clinical examination including a neurological assessment and musculoskeletal examination. Clinical examination includes sensory assessment to detect areas of hyperesthesia, allodynia and analgesia. Preferably indicate these areas on a sketch of a man for future assessment. Record all clinical findings.

Clinicians should assess for:

- functional impairment due to pain
- non-verbal clues and pain behaviour
- signs of pain sensitisation
- adverse effects of pain medications

Examination findings provide crucial information on pain assessment, especially when dealing with patients who have impaired verbal communication skills due to cognitive disability, impaired consciousness or terminal stage.

Set up treatment plan in consultation with the specialist

Check the Management Plan and set treatment target/s with the logistical support available at the PHC centre.

Depending on the situation targets could be:

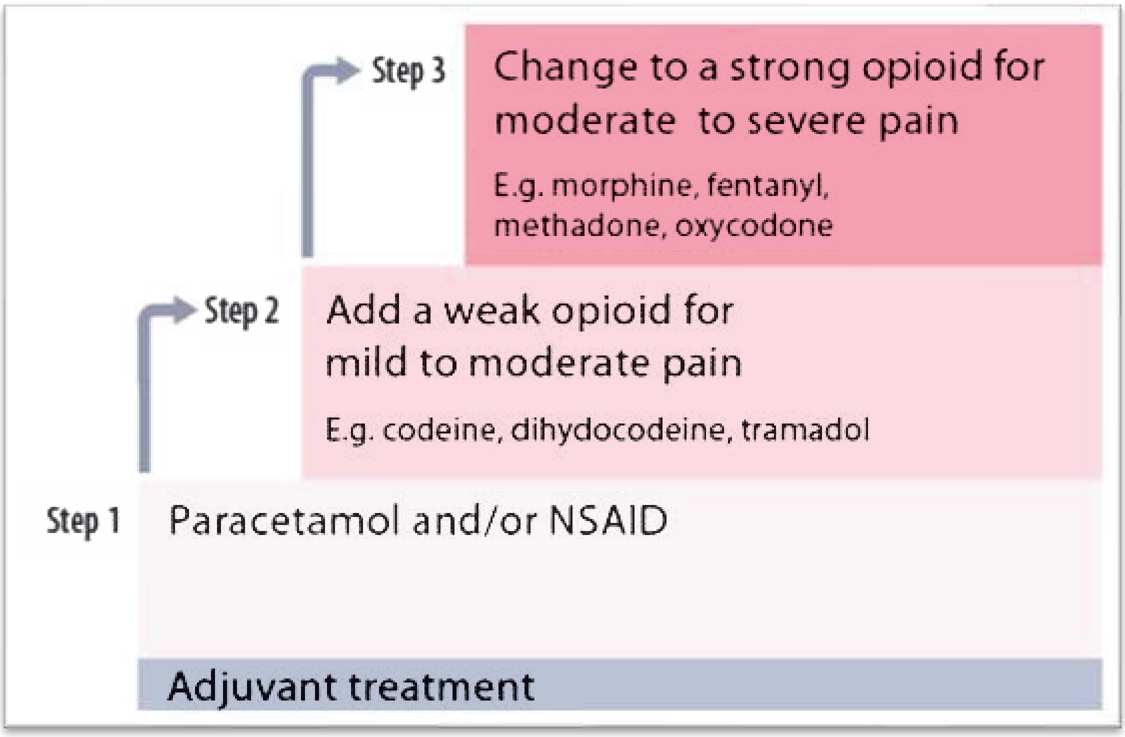
- reduction of intensity of pain up to a patient satisfied level
- enhancement of physical functions – walking, improvement of sleep, improving the mood, interacting with others
- end-of-life care support

Take into consideration the following when settings targets:

- assess the level of knowledge of patient and family on pain management
- discussing with the patient regarding the available treatment options, their complication and benefits in order to cooperate with the treatment plan
- helping the patient and family/ caregiver to share responsibility of pain management
- analgesics prescribed in the Management Plan (preferably in consultation with the consultant)

Pharmacological management of pain

Use the knowledge you have on the **WHO – three step analgesic ladder :**



WHO (2018)

WHO step wise analgesic ladder

Step 1 – Non-opioid ± adjuvant

Non-opioid oral analgesics include: paracetamol and NSAID

Paracetamol.

- start on paracetamol 500mg-1g oral 4-6 hourly
- maximum 4g /day
- 15mg/kg in a patient with body weight < 50 kg

NSAIDS

- ibuprofen 5mg/kg 6 hourly
- diclofenac sodium 1mg /kg oral 8 or 12 hourly (maximum of 150 mg daily)

Commonly used **adjuvants**

- amitriptyline/ nortryptaline – 10-25mg oral nocte increased up to 75mg a day
- carbamazepine – initially 100mg oral 1-2 times a day increased gradually according to response
- gabapentin – 300mg oral once daily (on day-1), then 300mg twice daily (on day 2), 300mg oral 3 times a day (on day 3) up to 3.6g oral daily

If step 1 medications are not adequate to relieve pain go to step 2

Step 2 (Moderate pain) Use weak opioids ± Step 1 medications ± adjuvant

- tramadol 50 mg oral 6 hourly
  or
- paracetamol 500mg + codeine 8mg (2 tablets) every 6 hours

If step 2 treatment does not help to relieve pain stop step 2 drugs and proceed to step 3

Step 3 (severe pain) Use strong opioid ± Step 1 medications ± adjuvant

Consider starting **oral morphine** IR in consultation with a specialist.

Patients who present with severe pain may have to be commenced on step 3 drugs and can consider de-escalation with adequate control of the pain. If patient is responding, review regularly to titrate the exact dose requirement and to assess for side effects and pain level. If patient is not responding, consider transfer to a higher centre.

Side effects of opioids

- constipation
- nausea and vomiting
- sedation
- delirium
- respiratory depression - rare with appropriate dosing
- physical dependence

Always consider anticipated side effects and take necessary precautions when prescribing opioids.

Non pharmacological management (depending on the facilities available)

Physical	bed rest bracing (immobilization) manipulation and mobilization traction bracing	cryotherapy exercise physiotherapy ultrasound transcutaneous electrical nerve stimulation
Psychological	patient education recreational activities meditation	relaxation therapy music therapy counselling
Surgical	palliative surgeries fixations/ decompressions	
Oncological	chemotherapy radiotherapy hormonal therapy	
Interventional	destructive vs. non-destructive techniques	
Complementary	acupuncture, massages, aromatherapy, herbal therapy etc…	

Seek specialist specialist's opinion in the following instances:

- resistant pain
- presence of significant co-morbidities
- persistent requests for hastened death
- families that have had several losses and unresolved grief

When patient is discharged from the hospital ensure:

- patient or caregiver or a family member is knowledgeable how the medicine should be continued at home
- have enough drugs to be used during the prescribed period
- is knowledgeable of adverse effects
- information given on whom to contact when needed

Wound care

Fungating Wound

Fungating wound is a descriptive term, literally meaning fungus like or mushroom shaped lesion. It is generally caused by solid tumours when they rupture through the skin due to its growth and relative ischemia of the superficial skin. There is associated infection mainly anaerobic causing the typical odour unique to these wounds.

Assessment of wound care:

- complete history
- physical status
- psychosocial life
- quality of life of the patient and family
- nutritional assessment
- wound assessment - size, colour, location, exudates, bleeding, pain, odour, maggots

Treatment

Every malignant wound is unique in its appearance and presenting symptoms. Treatments for fungating wounds generally involve multimodality treatment.

Surgery

- If feasible, can remove the wound completely. It may need tumour excision combined with reconstruction of the area. Usually this is a major under taking and involves extensive tissue dissection. Hence very ill patients may not tolerate this kind of surgical trauma.
- Wound debridement has no meaningful role in managing these wounds. Irrigation with water and judicial use of antibiotics may help to reduce the wound odour and make the patient socially accepted.

Chemotherapy

- may relieve tumour symptoms and decrease mass
- effectiveness depends on tumour responsiveness to chemotherapy

Radiotherapy

- destroy malignant tumour cells thereby reducing the size of the wound
- alleviating symptoms such as exudates, bleeding and pain
- with radiotherapy treatment wound may initially deteriorate as malignant cells die and skin reactions occur

Hormonal blocking agents

- used for hormone sensitive tumours
- response is slow, and may take 4-6 weeks before decrease in progression and size of wound is noted

Nursing Interventions

Wound care

- patient and family education regarding, dressing procedure, frequency of dressing changes, extra equipment and cleansing solution required

Infection

- assess for clinical signs of infection (fever, redness, heat, oedema, elevated white blood cell count, purulent discharge, odour)
- refer to wound debridement as medical advice
- use topical and oral metronidazole for treatment of odour and infection
- apply metronidazole soaked gauze directly to wounds with deep cavities or with vaginal tumours
- use of silver sulfadiazine to control pseudomonas infection, if wound is dry
- use slow-release iodine products
- specialised antimicrobial dressing to control infection at site

Bleeding Control

- prevention is the best therapy for controlling bleeding
- use normal saline irrigation to moisten adherent dressing
- use vaseline gauze on the wound bed to prevent trauma at it condition when removing the dressing
- avoid frequent, unnecessary dressing changes

use haemostatic dressing agents for slow capillary bleeding e.g. silver nitrate

Exudate Management

dressings e.g. non adherent contact layers, hydrogel, are used in specialist centres in management of exudates

Odour Control

- bath as requires
- clean the wound gently with normal saline
- use advance dressing
  - ✓ charcoal dressings
  - ✓ topical metronidazole
  - ✓ slow release iodine products
- minimise the bacterial concentration in the wound by timely wound dressing
- modify the environment: provide adequate room ventilation, use of air freshener spray or pleasing perfumes

Skin care

- promote skin hydration by drinking adequate water
- cleanse gently
- moisturize skin with hydrophilic lotions and creams
- avoid damage the skin by scratching from nails or fine things
- avoid use of topical irritants such as soap, alcohol or perfumes
- use of topical corticosteroids application as medical advice.
- protect skin with using suitable skin barrier (silver dressing, zinc oxide cream etc.)
- to prevent pruritus use hydrocolloid dressings
- educate the patient to maintain cleanliness around the wound to prevent infection

Seek expert opinion for the following:

- increase in amount/malodorous exudate
- pruritus/cellulitis
- severe emotional distress
- increase or change in pain
- bleeding
- fever
- any major change in the wound

Nutrient management

- encourage the patients to get required regular meals and snacks throughout the day
- educate importance of protein for healing wounds
- educate the family and patient regarding good sources of protein (meat, fish, poultry, eggs, milk, cheese, yogurt, nuts/seeds and legumes etc.)
- maintain good hydration
- consider oral supplementation (micronutrients)
- refer to the dietitian as needed

05

Psychosocial and Spiritual Aspects in Cancer Palliative Care Patients

Psychosocial wellbeing of patients undergoing palliative care, contribute to the minimization of symptoms, support in daily life activities, improvement of quality of life and preparation for death. The aim of this chapter is to create awareness on identifying psychosocial and spiritual issues of cancer palliative care patients and the means of addressing them.

Diagnosis of cancer is almost always devastating news to the patient, the family and loved ones. It is important to introduce the concepts of palliative care as an essential component in continuum of care to the patient, family and loved ones.

Palliative care is expected to reduce the symptom burden, psychological distress, social and spiritual problems and help the patient and family to cope with the dying process when they enter into end- of- life.

The diagnosis of cancer is invariably associated with many negative emotions such as fear, anxiety and grief. As the patient approaches end- of- life and also when caring for the dying patient, many psychosocial problems of the patient and the family need to be addressed such as:

- issues of self-esteem
- adaptation to the illness and its consequences
- loss of hope
- lack of purpose and direction
- dependency and passiveness induced by being cared for
- fear of the future
- communication problems with the family and health professionals
- the need for increased coping strategies

Identifying and attending to psychosocial needs of palliative cancer patients should be a prioritized component of care by the primary health care professionals. The ongoing long term relationship of the patient and the family with the primary health care staff ensures the better understanding of the psychosocial problems within a social and family background. The primary health care professionals must be able to:

- provide emotional support to the patient and the family
- coordinate the care effectively within the service
- raise awareness among health care professionals about patient's coping skills and identify areas of functional deficit
- to refer on to more specialised services where appropriate

Most of the time, patients who are in their end of life have to make complex decisions where their families are part of the decision making process. The primary health care professionals can help them in decision making for their spiritual, legal, existential or medical problems. They also can prepare the family and loved ones for grief and bereavement.

It is important to identify that significant proportion of patients suffer from co-morbid mental health conditions requiring professional support by a mental health team.

The following psychological conditions can be seen most commonly by patients receiving palliative care:

Depression	feeling sad, loss of interest in activities once enjoyed, trouble sleeping or sleeping too much, loss of energy or increased fatigue etc.
Anxiety and panic disorders	excessive, ongoing worry and tension, restlessness, trouble concentrating, muscle tension, palpitations, sweating etc.
Delirium	disturbance of consciousness, attention, thinking, perception, memory, psychomotor behaviour, emotion and the sleep-wake cycle
Dementia	cognitive changes such as loss of memory, difficulty in communicating, difficulty with visual and spatial abilities, difficulty with problem solving etc. and psychological changes such as depression, anxiety
Insomnia	difficulty in falling asleep at night, waking up during the night, daytime tiredness or sleepiness, irritability, depression or anxiety etc.
Suicide ideations	severe sadness or moodiness, hopelessness, sudden calmness, withdrawal, changes in personality or appearance, dangerous or self-harmful behaviour, making preparations, threatening or talking about suicide

Patients who are having symptoms of psychiatric illnesses need to be assessed carefully and referred to a Consultant Psychiatrist for further management. Those patients can be offered following procedures:

- Individual counselling / family counselling
- Introducing them to peer support groups where they can share their experiences
- Identifying and referring patients and caregivers who have symptoms of depression or any other psychological conditions to a Consultant Psychiatrist for specialised care

The failure to address the psychological issues of palliative cancer patients and their families will result in the suffering of the patient and the family. Therefore, as health care professionals it is important to address unmet psychosocial needs of patients and their families to minimise suffering, to improve the quality of life and wellbeing and to prepare for the death with dignity.

Provision of Information on Palliative Care

Early integration of palliative care is essential in managing patients with advanced cancer. Lack of knowledge on palliative care and the available services, are evident as a significant barrier in providing palliative care to cancer patients. Therefore, the primary health care professionals should arrange a family meeting to discuss informational needs. Educational leaflets and booklets on palliative care can be used as an incentive during those discussions. These educational materials can be obtained free of charge from NCCP and in the web site www.ncccp.gov.lk

Financial and Social Support

When a person is diagnosed with a life-threatening illness requiring palliative care, the patient and the family may undergo many financial and social challenges. Even though the government pays for most of the treatment procedures and the drugs, they will have to bear the cost of some urgent investigations and treatment procedures, transportation, lodging and many other direct and indirect expenses.

Employment related problems such as termination and reduced wages due to long term absence to work may add to the financial difficulties of the family. Therefore, it is important to understand the social and financial problems the patient and the family encounter and provide them the necessary guidance to overcome those difficulties. They can be referred to the social service officers working at the hospital as well as at the divisional secretariate office of the area. There are many government and non-government organizations in the area which can support the patients and the families in need.

The primary health care staff can develop a network among the supportive groups in the area and link them with the needy patients and their families.

Spiritual Concerns

It is observed that lack of spiritual support by healthcare providers is associated with poor quality of life of the patient and dissatisfaction of the patient care. Hence, the health care staff must identify the spiritual needs of the patient and the family and provide necessary guidance to improve the spiritual wellbeing.

Spiritual values differ from person to person. Religion also plays a vital role and the support of the religious leaders will improve the spiritual wellbeing. Good spiritual practices help the patient to reduce anxiety towards the end-of-life, cope with pain and suffering and ultimately, to experience have a peaceful death in the end.

06

Palliative Care Emergencies

A palliative care emergency describes a symptom situation that is serious and demands immediate and skilled specialist attention. The aim of the chapter is to describe major emergencies in palliative care such as acute pain crisis, hypercalcaemia, superior vena cava obstruction, spinal cord compression and bone fractures.

Some acute events in malignancy must be treated as an emergency if a favorable outcome is to be achieved. As in any emergency, the assessment must be as prompt and complete as possible.

In patients with advanced malignancy, factors to be considered:

- nature of the emergency
- general physical condition of the patient
- disease status and likely prognosis
- associated pathologies
- symptomatology
- likely effectiveness and toxicity of available treatments
- wishes of the patient and caregivers

While unnecessary hospital admission may cause distress for the patient and caregivers, missed emergency treatment of reversible symptomatology can be disastrous.

Assessment

- What is the problem?
- Can it be reversed?
- What effect will reversal of the symptom have on patient's overall condition?
- What is your medical judgment?
- What does the patient want?
- What does the caregiver want?
- Could active treatment maintain or improve this patient's quality of life?

Major Emergencies in Palliative Care

- Acute pain crisis
- Airway obstruction
- Bleeding
- Hypercalcaemia
- Seizures
- Superior vena cava obstruction
- Spinal cord compression
- Venous thromboembolism
- Bone fractures
- Acute anxiety and depression

Acute Pain Crisis

Pain crisis as an event in which the patient reports pain that is severe, uncontrolled, and causing distress for the patient, family members, or both.

The assessment and management of an acute pain crisis in the setting of advanced illness is challenging.

Management

- make a pain diagnosis
- differentiate reversible from intractable causes of pain
- decide on further workup
- selecting the opioid and monitoring and treating opioid adverse effects
- titrating and rotating opioid and co analgesics
- consulting experts to treat a pain crisis as quickly as possible to prevent
- unnecessary suffering
- co-opting the available institutional resources

The timely intervention of a palliative care team can provide the staff, patients, and their families the benefit of an interdisciplinary approach help the patients address goals of care understand the benefits and risks of treatment decisions meet the psychological, social, and existential needs of the patient and the family.

Hypercalcaemia

- Hypercalcaemia is the commonest life-threatening metabolic disorder encountered in patients with cancer.
- The incidence varies with the underlying malignancy, being most common in multiple myeloma and breast cancer (40-50%), less so in non-small cell lung cancer, and rare in small cell lung cancer and colorectal cancer.
- The pathology of hypercalcaemia is mediated by factors such as parathyroid related protein, prostaglandins, and local interaction by cytokines such as interleukin 1 and tumour necrosis factor.
- Bone metastases are commonly but not invariably present.
- Non malignant causes of hypercalcaemia particularly primary hyperparathyroidism, which is prevalent in the general population.

Clinical features

Mild Symptoms

- nausea
- anorexia and vomiting
- constipation
- thirst and polyuria
- abnormal neurology
- cardiac arrhythmias

Severe symptoms and signs

- gross dehydration
- drowsiness
- confusion and coma

Management

- Mild hypercalcaemia (corrected serum calcium concentration <3.00 moll/l) is usually asymptomatic, and treatment is required only if a patient has symptoms.
- Severe hypercalcaemia, however, treatment can markedly improve symptoms even when a patient has advanced disease and limited life expectancy to make the end stages less traumatic for patient and caregivers.
- Treatment with bisphosphonate normalises the serum calcium concentration in 80% of patients within a week.
- Treatment with calcitonin or mithramycin is now largely obsolete.
- Corticosteroids are probably useful only when the underlying tumour is responsive to this cytostatic agent such as myeloma, lymphoma, and some carcinomas of the breast.

- Some symptoms, particularly confusion, may be slow to improve after treatment despite normalisation of the serum calcium.
- Always consider treating the underlying malignancy to prevent recurrence of symptoms, since the median duration of normocalcaemia after bisphosphonate infusion is only three weeks.
- If effective systemic therapy has been exhausted, or is deemed inappropriate, oral bisphosphonates (such as clodronate 800 mg twice daily) or parenteral infusions (every three to four weeks) should be considered.
- Maintenance intravenous bisphosphonates may be administered at a day centre or outpatient department.
- Oral preparations have the disadvantages of being poorly absorbed and have to be taken at least one hour before or after food.
- The evidence for intravenous or oral bisphosphonates is equal, and choice depends on the individual.

Superior Vena Cava Obstruction

- This may arise from occlusion by extrinsic pressure, intraluminal thrombosis, or direct invasion of the vessel wall.
- Most cases are due to tumour within the mediastinum, of which up to 75% will be primary bronchial carcinomas.
- About 3% of patients with carcinoma of the bronchus and 8% of those with lymphoma will develop superior vena cava obstruction.

Aetiology

- Carcinoma of the bronchus 65-80%
- Lymphoma 2-10%
- Other cancers 3-13%
- Benign causes (rare): benign goiter, aortic aneurysm (syphilis), thrombotic syndromes, idiopathic sclerosing mediastinitis
- Unknown or undiagnosed

Clinical features

Symptoms

- tracheal oedema and shortness of breath
- cerebral oedema with headache worse on stooping
- visual changes
- dizziness and syncope
- swelling of face, particularly peri orbital oedema
- neck swelling

Signs

- rapid breathing
- peri orbital oedema
- suffused injected conjunctivae
- cyanosis
- non pulsatile distension of neck veins
- dilated collateral superficial veins of upper chest
- oedema of hands and arms

Management

- It is an oncological emergency requiring immediate treatment.
- If it is the first suspected presentation of malignancy the patient should be transferred for further management to a specialist unit, after immediate care has been. advanced disease patients need relief of acute symptoms. Dyspnoea and a sensation of drowning can be most frightening. High dose corticosteroids and radiotherapy should be considered.
- In non small cell lung cancer palliative radiotherapy gives symptomatic improvement in 70% of patients, with a median duration of palliation of three months. Up to 17% of patients may survive for a year.
- If radiotherapy is contraindicated or being awaited corticosteroids alone (dexamethasone 16 mg/day) may give relief.
- In those for whom further radiotherapy is not indicated, stenting (with or without thrombolysis) of the superior vena cava should be considered.
- Urgent initiation of pharmacological, practical, and psychological management of dyspnoea is paramount and usually includes opioids, with or without benzodiazepines. Opioid doses are usually small such as 5 mg oral morphine every 4 hours.
- Review all corticosteroid prescriptions in view of their potential adverse effects.
- Recommend stopping corticosteroids after five days if no benefit is obtained, and a gradual reduction in dose for those who have responded.
- It is recommend stopping corticosteroids after five days if no benefit is obtained, and a gradual reduction in dose for those who have responded.

Spinal Cord Compression

Presentation of spinal cord compression can be very subtle in the early stages. Any patient with back pain and neurological symptoms or signs should have radiological investigations, with magnetic resonance imaging when possible.

- This occurs in up to 5% of cancer patients.
- Spinal cord compression can arise from intradural metastasis but is more commonly extradural in origin.
- In 85% of cases cord damage arises from extension of a vertebral body metastasis into the epidural space, but other mechanisms of damage include vertebral collapse, direct spread of tumour through the intervertebral foramen (usually in lymphoma or testicular tumour), and interruption of the vascular supply.
- The frequency with which a spinal level is affected reflects the number and volume of vertebral bodies in each segment about 10% of compressions are cervical, 70% thoracic, and 20% lumbosacral.

Clinical features

- The main problem in clinical practice is failure of recognition. It is not uncommon for patients' weak legs to be attributed to general debility, and urinary and bowel symptoms to be attributed to medication.
- Neurological symptoms and signs can vary from subtle to gross, from upper motor neuron to lower motor neuron, and from minor sensory changes to clearly demarcated sensory loss.
- The earliest symptom of spinal cord compression is back pain, sometimes with symptoms of root irritation, causing a girdle like pain, often described as a “band,” that tends to be worse on coughing or straining.
- Most patients have pain for weeks or months before they start to detect weakness.
- Initially, stiffness rather than weakness may be a feature, and tingling and numbness usually starts in both feet and ascends the legs.
- In contrast to pain, the start of myelopathy is usually rapid.
- Urinary symptoms such as hesitancy or incontinence and perianal numbness are late features.
- Increasing compression of the spinal cord is often marked by improvement or resolution of the back pain but can be associated with worsening of pain.
- Examination may reveal a demarcated area of sensory loss and brisk or absent reflexes, which may help to localise the lesion.

Management

- Prompt treatment is essential if function is to be maintained: neurological status at the start of treatment is the most important factor influencing outcome.
- If treatment is started within 24-48 hours of onset of symptoms neurological damage may be reversible.
- It is important to remember that more than one site of compression may occur, and this is increasingly recognised with improved imaging techniques.
- In patients unfit to undergo more detailed investigations, plain radiology can reveal erosion of the pedicles, vertebral collapse, and, occasionally, a large paravertebral mass. These may help in the application of palliative radiotherapy.
- In contrast to myelography with localised computed tomographic x rays for soft tissue detail, magnetic resonance imaging is now considered the investigation of choice: it is non-invasive and shows the whole spine, enabling detection of multiple areas of compression.

Management of spinal cord compression

Key points

- Except for unusual circumstances give oral dexamethasone 16 mg/day
- Urgent treatment, within 24 hours of start of symptoms
- Interdisciplinary approach involving Consultant Oncologist, Consultant Neurosurgeon, Consultant Radiologist, Medical Officer, Nursing Officer, Physiotherapist, Occupational Therapist

Treatment options

- Continue with dexamethasone 16 mg/day *plus*
- **Radiotherapy only**
  - For most situations
  - Radiosensitive tumour without spinal instability

- **Surgery and radiotherapy**
  - Spinal instability, such as fracture or compression by bone
  - No tissue diagnosis (when needle biopsy guided by computed tomography not possible)

- **Surgery only**
  - Relapse at previously irradiated area
  - Progression during radiotherapy

- **Chemotherapy**
    - Paediatric tumours responsive to chemotherapy
    - Adjuvant treatment for adult tumours responsive to chemotherapy
    - Relapse of previously irradiated tumour responsive to chemotherapy

- **Corticosteroids alone**
    - Final stages of terminal illness and patient either too unwell to have radiotherapy or unlikely to live long enough to have any benefits

Bone Fracture

- Bone metastases are a common feature of advanced cancer.
- Bone fracture may also be due to osteoporosis or trauma.
- Fractures can present in a variety of forms, including as an acute confusional state.

Management

- If fracture of a long bone seems likely, as judged by the presence of cortical thinning, prophylactic internal fixation should be considered.
- Once a fracture has occurred the available options include external or internal fixation their relative merits are determined by the site of the fracture and the general condition of the patient.

Radiotherapy is usually given in an attempt to enhance healing and to prevent further progression of the bony metastasis and subsequent loosening of any fixation.

07

Role of a Nursing Officer in Palliative Care

The aims of this chapter are to identify the professional responsibility in providing care. Describe the nursing officer's role in palliative care and the general and specific competencies required for nursing officers to provide palliative care in primary healthcare settings.

Palliative care, guided by the principles of primary health care, would extend the nursing officers role to include that of an advocate. Palliative care is central to expressing and reflecting the essence of nursing and nursing care because it encompasses spiritual, emotional, family and other non-clinical dimensions. Primary health care in this context extends beyond the health care system itself to include accessibility, community care, and the social determinants of health.

In providing care, the nursing officer

- should be able to promote an environment in which human rights, values, customs and spiritual beliefs of the individual, family and community are respected
- ensures that the patient has received sufficient information on which to base consent for care and related treatment
- holds in confidence personal information and uses judgement in sharing this information
- engage with community in initiating and supporting actions to meet the health and social needs of the public, in particular those of vulnerable populations
- shares responsibility to sustain and protect the natural environment from depletion, pollution, degradation and destruction

Professional nursing practice is based on a philosophy that nursing is interpersonal and holistic in nature. This implies that the nursing officer uses the nurse patient relationship as the foundation or care in order to address the patient's and family physiological, emotional, psychosocial, spiritual needs. The outcome of an effective nurse patient relationship involves certain crucial attitudes and behaviours on the part of the nursing officer. These attitudes and behaviours allow the nursing officer to empathise with the patient and to be sensitive to the patient's needs without becoming overly involved in the patient's situation.

Role in Palliative Care

Encompasses many interconnected dimensions. Dimensions of the nurse's role:

- Valuing
- Finding meaning
- Empowering
- Connecting
- Doing for
- Preserving integrity of self and others

While some of these dimensions are more task oriented, others are largely attitudinal and reflect the interpersonal and holistic nature of nursing. They imply that the nursing officer as a professional and cannot be separated as a person, if a therapeutic nurse patient relationship is to be achieved.

Valuing

The nursing officer should have a basic belief in the inherent worth of all human beings, regardless of any particular characteristics of any one individual. Valuing allows the NO to be able to continue to respect and provide care to the patient, even under adverse conditions.

Finding meaning

The nursing officer should be able to assist patients to find meaning in their situations. This includes:

- helping patients to focus on living until they die
- assisting them to make the best of their situation
- offering hope
- encourage to reflect on their life
- helping them to fulfill spiritual needs
- helping the patient to acknowledge death by talking openly about death when patients and families want them to do so

Empowering

Involves facilitating, encouraging, defusing, mending, and giving information.

Facilitating

Builds individual and family strengths. The nurse facilitates by involving the patient and family in planning strategies, offering suggestions, explaining options, and providing information. Through these actions the nurse shows respect for the rights of the patient and family and their ability to make decisions. The nurse should also recognise limitations and help them to work toward a more positive outcome.

Encouraging

Is when the nurse acknowledges patient and family abilities, supports choices, and encourages patients and families to do what they choose.

Defusing

Is helping patients and families to deal with their negative feelings and giving them the opportunity to express them. By listening openly and not acting defensively, the nurse allows the person to express anger.

Mending

Helps to facilitate healing among family members by interpreting behaviours and enabling individuals to see each other's point of view.

Giving information

Relates to the nurse providing information about medications, symptoms and management of pain and other symptoms. This strengthens the patient's and family's capacity to understand and manage by themselves.

Connecting

Establishing a therapeutic relationship. This involves introductions, establishing credentials, explaining roles, collecting baseline information, and explaining how to contact the nurse.

Doing for

- it is focused on the physical care of the patient
- it involves controlling pain and symptoms, making arrangements such as discharge planning and helping families to access equipment, and helping with hands-on care

Team collaboration involves consulting and negotiating with other team members, sharing information while maintaining confidentiality, serving as a liaison between various institutions and programs, mediating on behalf of the family and often explaining, encouraging and pleading for the benefit of the patient and family.

Preserving own integrity

- the nurse's ability to maintain feelings of their self-worth, self-esteem, and energy levels in the face of routine exposure to suffering, pain and loss.
- involves reflecting on what the nurse regards as important and gives meaning to life and the work that the nurse is doing.
- it is also influenced by the nurse's evaluation of the care he/she has given to a patient and feeling that it has helped the patient.
- self-awareness, being able to acknowledge his/her own feelings and reactions is also integral to preserving one's own integrity.
- this enables the nurse to assess whether he/she is doing the right thing for the right reason and helps him/her to maintain perspective, as well as an awareness of one's own limitations.

The nursing officer needs to accept that he/she cannot do all and be all to everyone and should know when to draw the line. The system needs to ensure that resources are in place to prevent nursing officer burnout and compassion fatigue.

Providing effective pain care is a moral imperative for palliative care nurses:

- effective pain management is integral to patient safety and ethical nursing practice.
- ineffective pain management affects the overall health experience of many patients and their families, and places patients at increased risk for morbidity and mortality.
- inadequate pain relief hastens death by increasing physiological stress, potentially diminishing immune-competence, decreasing mobility, worsening tendencies toward pneumonia and thromboembolism, and increasing work of breathing and myocardial oxygen requirements.
- ineffective pain management disrupts the relationships between nurses and their patients between nurses and physicians, and between nurses and other professionals; it is a factor that affects the quality of nurses' work life.

General Competencies

Should engage in relational practice, which is characterized by:

- skill with listening
- ability to engage in difficult conversations
- ability to be present with patients
- responsiveness
- respect for patient's life
- appreciating patient and family choices and strengths
- collaborative care and fostering dignity

Being present does not take more time, it is simply a more focused way of interacting in which the nurse lets go of his or her own concerns and calls for the sharing of oneself through full attention to the other. Being present, like the art of nursing and caring, also results in improved mental wellbeing for the patient and nurse and an improved physical wellbeing for the patient.

2. Cultural Competence

Nursing officer should be able to demonstrate knowledge of and skill in utilizing the principles and standards of palliative and end-of-life care in a culturally relevant context as given below:

- It is an ability to interact effectively with people of different cultures.
- Comprises four components:
    - awareness of one's own cultural worldview
    - attitude towards cultural differences
    - knowledge of different cultural practices and worldviews
    - cross-cultural skills

- It results in an ability to understand, communicate with, and effectively interact with people across cultures.

3. Reflexivity

The nursing officer should be able to critically reflect on the values, beliefs, and assumptions underpinning culturally relevant practice and be aware of the influences and discourses that impact on the caring process.

4. Ethical conduct

Should engage in palliative care according to the International Council of Nurses Code of Ethics and Standards for Nursing Practice.

5. Congruence

Should demonstrate intentionality in practice; the congruence between adopted knowledge, values, and beliefs and those used in practice.

6. Patient/family centered care

Should engage in patient/family-centered care defined as a relational practice that focuses on family as defined by the patient.

7. Evidence-based practice

Should utilise evidence-based practice, defined as an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient and family to decide upon which course of action is most appropriate.

8. Interprofessional Collaboration

Should show the ability to collaborate interprofessionally to address patient/family needs:

- Interprofessional collaboration is practice that integrates concepts and knowledge from all involved health disciplines/professions, and includes anyone who works under a formally accredited organization.
- It includes volunteers who are under the supervision of the organization (thus differentiating them from family members who provide care).

9. Advocacy

Should act on behalf of the patient or the nursing profession to assure the delivery of quality nursing care and to promote professional standards of practice. The skills of advocacy include mediating, coordinating, clarifying, resolving conflict, and assisting the patient to acquire, interpret, and utilise health care information.

Specific Competencies

The specific competencies in a nurse are intended to address particular issues and needs that contribute to suffering and impact on quality of life in patients who are dying or living with advanced or life-limiting illness.

Self-awareness

Should possess self-awareness of personal attitudes, beliefs, and values about death and dying. It includes care of self, understanding one's own needs, developing one's own support and knowledge networks, being open to learning, and knowing how to be dealing with suffering.

Holistic Assessment

Should be skillful in conducting holistic individual and family assessments, including pain, dyspnoea, nausea, vomiting, and other symptoms. This also includes assessment of psychosocial, emotional, and spiritual issues relevant to palliative and end-of-life situations. It should demonstrate knowledge and skills in managing pain and symptoms.

Communication skills

Should possess necessary communication skills and an ability to engage in end-of-life decision making and planning, and negotiate modes of care on an ongoing basis while being respectful of the client and remaining open to potential change.

Knowledge of cultural and spiritual issues

Should possess knowledge of cultural and spiritual issues that impact on end-of-life care and the ability to recognise and be present to assist the patient and family in their experiences of suffering.

Attending to Psychosocial and Practical Issues

Should demonstrate ability to assess and attend to individual/family psychosocial and practical issues such as discharge from hospital, planning for death at home, funeral arrangements, and planning for life without their loved one.

Ethical Knowledge and Skill

Should possess and apply appropriate ethical knowledge and skill in acting in the best interest of the patient and family while recognising and attending to one's own moral distress and dilemmas with regard to end-of life decision making.

Responding to the Unique End-of-life Needs

Should recognise and respond to the unique end-of-life needs of special populations while assisting them to realise optimal quality of life, e.g. elders, children, those with cognitive impairment, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and other unique and marginalised populations.

Ability to Support

Should be able to demonstrate knowledge of grief and bereavement and the ability to support others.

Self Care

Should care for self while supporting others in their grief and bereavement. Real compassion is uplifting and contributes to personal growth; unresolved grief causes pain, which can contribute to fatigue. The nurse recognises his or her limitations, and issues that could contribute to emotional exhaustion.

Knowledge in Available Care

Should understand the full range and continuum of palliative and end-of-life care services and the settings in which they are available (e.g. home care). Comprehensive knowledge, facilitates provision of timely, high quality palliative and end-of-life care in any setting of the patient's choice.

The nursing officer should have the ability to:

- educate and mentor patients and family members on end-of-life care needs
- identify the need for respite care for family members
- appropriately and safely delegate care to other caregivers (e.g. personal care workers)

08

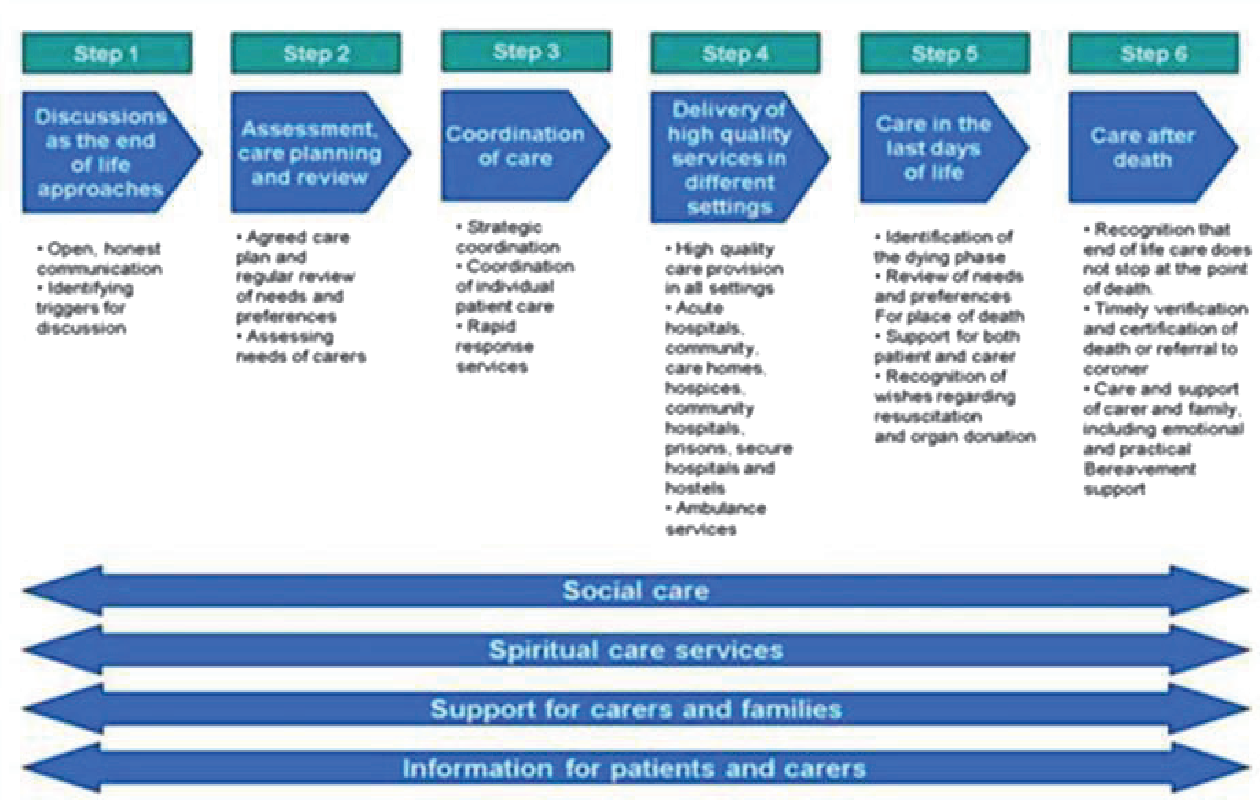
End-of-Life Care: Last Few Days and Hours

The aim of this chapter is to understand physiological changes, signs and symptoms occurring during the dying process and how best the primary healthcare team supports the patient and family with the guidance of the Consultant Oncologist.

End-of-life care refers to health care, not only of patients in the final days or hours of their lives, but more broadly care of all those with a terminal illness or terminal condition that has become advanced, progressive and incurable.

During this period medical testing and specific treatment is often stopped. But the person's care continues with an emphasis on improving the quality of life and that of their loved ones, and making them comfortable to have good death. Some people remain at home while receiving treatment, whereas others enter hospital or other places where there are facilities.

Without waiting for final days, it is very important to have Advance Care Planning (ACP) from the beginning of care.



Physiological Changes, Symptoms and Signs During Dying Process

With an advanced malignancy, death usually occurs after a person becoming weaker over a period of time. It is not always possible to predict how long someone will live. However, some common symptoms and signs show that a person is reaching the final days of life. Understanding these signs and symptoms relieves their anxiety and allows better planning to face the end. There are various physiological changes which occur during the dying process and signs and symptoms that people experience may be which vary from patient to patient. Correct understanding of these changes will minimise unnecessary interventions and professional anxiety as well.

Followings are commonly encountered physiological changes, symptoms and signs during the dying process and their management.

Weakness and Fatigue

Weakness and fatigue usually increase as the patient gets closer to death. During the last days or hours of life, it is likely that the patient will not be able to move around in the bed or raise his or her head. Joints may become uncomfortable or may be painful. Continuous pressure on the same area of skin might cause skin ischemia and lead to pressure ulcers. These may become painful or odoriferous if they become infected and these may more easily be prevented than treated.

Management:

- patients who are too fatigued and having difficulties in moving, require passive movements of their joints every 1 to 2 hours
- minimise the risk of pressure ulcer formation:

    - advise to turn the patient from side to side every 1 to 2 hours
    - protect areas of bony prominence with hydrocolloid dressings and special supports. A draw sheet can assist caregivers to turn the patient and minimise pain and shearing forces to the skin
    - if turning is painful, consider a pressure-reducing surface (air mattress or airbed)
    - intermittent massage before and after turning, particularly to areas of contact can be comfortable and reduce the risk of skin breakdown by improving circulation and shifting oedema

Decreasing Appetite, Food Intake and Wasting

Most patients lose their appetite and reduce food intake long before they reach the last hours of their lives. The reasons are multifactorial. Most of the reasons become irreversible closer to death. Patients may not feel hungry due to the least energy requirement during the last days. Same thing is given in bullets:

Management

- Explain to the family or caregiver that loss of appetite is normal at this stage and patient is not feeling hungry with the low energy requirement.
- Educate the families to avoid parenteral or enteral feeding of patients at the end of their lives as it neither improves symptom control nor lengthens life.
- Help them to understand that anorexia may be protective, as the resulting ketosis can lead to a greater sense of wellbeing and diminish pain.
- Whatever the degree of acceptance of these facts, it is important for physicians to help families and caregivers realise that the food pushed upon the unwilling patient may cause problems (e.g., aspiration) and increase tension.

Dehydration

Most patients also reduce their fluid intake or stop drinking entirely long before they die. This is a concerning agony for the family members as well as for the care givers as they worry that the dehydrated patient will suffer, particularly if the patient becomes thirsty. Therefor it is necessary to understand that this is an expected event at the end-of-life and dehydration in the last hours of living does not cause distress, in fact may induce sense of wellbeing with the stimulation of endorphin release.

Management

- Maintain patient's comfort and minimiae the sense of thirst, even in the face of dehydration.
- Maintain moisture in mucosal membranes with meticulous oral, nasal and conjunctival hygiene.
- Moisten and clean oral mucosa every 15 to 30 minutes with either baking soda mouthwash or an artificial saliva preparation to minimise the sense of thirst and avoid bad odors or tastes and painful cracking.
- Treat oral candidiasis with a topical or a systemic antifungal (if the patient is able to swallow)*
- Coat lips and anterior nasal mucosa hourly with a thin layer of petroleum jelly to reduce evaporation.
- Avoid perfumed lip balms and swabs containing lemon and glycerin, as these can be both desiccating and irritating, particularly on open sores.

* ***Not available at PHC level***

- Apply physiological saline solution every 15 to 30 minutes or artificial tears every 3 to 4 hours to avoid painful dry eyes.
- If they are still taking some fluid but are is eating, offer sips of liquid through a straw or from a spoon. Salt containing fluids such as soups, soda water, sport drinks, vegetable juices may help to maintain electrolyte balance and minimise the risk of nausea from hyponatraemia.
- parenteral fluids:
    - Occasionally use particularly where the goal is to reverse delirium
      But, **usually not considered** due to:
        - intravenous lines can be cumbersome and difficult to maintain
        - excess parenteral fluids can lead to fluid overload resulting in peripheral or pulmonary oedema, worsening breathlessness, cough and orotracheobronchial secretions, particularly if there is significant hypoalbuminaemia
        - potential to prolong the dying process, which may be undesirable
        - patients with peripheral oedema or ascites have excess body water and salt and they are not dehydrated

Decreasing Blood Perfusion and Renal Failure

As cardiac output and intravascular volume decrease towards the end of life, there will be evidence of diminished peripheral blood perfusion

Typical symptoms and signs include:

- Peripheral cooling
- Mottling of the skin (livedoreticularis)
- Venous blood may pool along dependent skin surfaces
- Urine output falls as perfusion of the kidney diminishes leading to oliguria or anuria (or oliguria or anuria as perfusion of the kidney diminishes due to dropping urine output)
- Tachycardia
- Hypotension - parenteral fluids will not reverse this circulatory shut down.

Neurological Disfunction

Neurological dysfunction occurs due to multiple nonreversible factors such as hypoxaemia, metabolic imbalance, acidosis, toxin accumulation due to liver and renal failure, adverse effects of medication, sepsis, disease related factors and reduced cerebral perfusion.
With all these:

- most of the patient’s experience, decreasing level of consciousness
- some become agitated delirious due to central nervous system excitation, with or without myoclonic jerk that leads to coma and death

Additionally:

- changes in respiration
- loss of ability to swallow
  loss of sphincter control

Decreasing Level of Consciousness

Management

- Helps to reduce family distress
- Assume the unconscious patient can hear everything

> While we do not know what unconscious patients can actually hear, but it is believed that at times their awareness may be greater than their ability to respond. Therefore, advice families and professional caregivers to talk to the patient as if he or she was conscious.
>
> Encourage families to create an environment that is familiar and pleasant.

Terminal Delirium

Frequently presents with:

- confusion about time, place, and/or identity of loved ones
- restlessness
- visions of people and places that are not present
- pulling bed linens or clothing (caused in part by changes in the patient's metabolism, restlessness, and/or agitation, with or without day-night reversal)

Management

This may be very distressing to the family. Prior education and warning of the family, the possibility of experiencing such a situation at the end of life may help for correct approach of management without much anxiety.

If death is not imminent, treat underlying cause. If death is imminent, it will not be possible to reverse the underlying causes.

When moaning, groaning, and grimacing accompany agitation and restlessness, they are frequently misinterpreted as pain. Some believe that patient get sudden severe pain at last hours which was under good control but it is a myth. Trial of morphine may help but at the same time opioids might make worse the delirium.

Medications for delirium

Benzodiazepine

- Lorazepam 1–2 mg oral or predissolved in 0.5–1.0 ml of water and administered against the buccal mucosa (2–10 mg/24 hours with 3–4hrs repetition)
- Midazolam infusion of 1–5 mg SC or IV hourly, preceded by repeated loading boluses of 0.5 mg over 15min *(not available at PHC level)*

Neuroleptics medications

- Haloperidol (0.5–2.0 mg SC\IV\rectal 6 hourly to start and titrated
- Chlorpromazine 10–25 mg oral 6 hourly to start and titrated. Given intravenously or rectally, is a more sedating alternative

The primary health care physician/ medical officer should discuss with the treating Consultant Oncologist and decide on the medications necessary and ensure such drugs are available to the patient when needed.

Changes in Respiration

Breathing pattern may be indicative of significant neurological compromise during dying process:

- Breaths may become very shallow and frequent with a diminishing tidal volume
- Periods of apnea and/or Cheyne-Stokes pattern respirations may develop
- Accessory respiratory muscle use may become prominent
- A few (or many) last reflex breaths may signal death

Management

- Educate and support the family and caregivers to understand that unresponsive patient may not be experiencing breathlessness.
- Opioids and `benzodiazepine’ might help.

Loss of Ability to Swallow

During last hours with impaired neurological function, accumulation of secretions leads to gurgling, crackling or rattling sounds with each breath (death rattle).

Management

- Avoid oral intake due to risk of aspiration.
- Reduce the production of saliva and other secretions. Ideally this should be done using medications (e.g.: Scopolamine and Glycopyrrolate). In Sri Lanka, use of medications is very limited as these drugs are not commonly available. At very limited occasions, Atropine is used as an alternative (0.2-0.4mg SC) but it has undesirable cardiac and central nervous system excitation.
- Use repositioning to clear accumulated fluids
- If excessive fluid accumulates at the back of the throat and upper airways, it may need to be cleared by repositioning or postural drainage.

  - Turning the patient onto one side or a semi prone position may reduce gurgling.

  - Lowering the head of the bed and raising the foot end of the bed while the patient is in a semiprone position may cause fluids to move to the oropharynx from which they can be easily removed.

Avoid suctioning because it is frequently ineffective as fluids are beyond the reach of the catheter

Loss of Sphincter Control

Loss of sphincter control in the last hours of life may lead to incontinence of urine and/or stool which may distress to the patient as well as family members.

Management

- Cleaning and skin care.
- Urinary catheterization may minimise the need for frequent changing and cleaning. However, not always necessary if urine flow is minimal and can be managed with absorbent pads or surfaces.

Pain

Many people fear that pain will suddenly increase as the patient dies, but there is no evidence to suggest this. However, pain assessment may be very difficult in semiconscious or unconscious patient.

Spiritual Care

This is also an important part in end-of-life. The patient's spiritual pain may be relieved by allowing him or her to express their feelings and sufferings. The patient may have deep feelings for their family members. Sometimes they may have unresolved conflicts or guilty feelings he or she may want to resolve before dying.

In palliative care, responsibility for spiritual care is shared by the whole team. According to the Sri Lankan culture it is important to provide facilities to accomplish spiritual desires depending on the patient's religion and their request to religious observances.

Psychological Care

Psychological care is also an important part in a patient in end-of-life. Regular communication with the patient in a gentle and sensitive manner is essential when you approach a patient in end-of-life.

The way the patient interprets the disease and the symptoms may be a cause for his or her sufferings itself. Therefore, it is important to assess how the patient feels about their situation to relieve their suffering. Deep probing of the situation may not be appropriate. The most important thing at this moment is comfort and peace of mind.

Bereavement Care

Advanced care planning help to family, for loss which in turn minimise the risk of psychological disturbances after patient's death. At the request of the family, health team could support through bereavement.

09

Managing Loss, Grief and Bereavement During Palliative Care

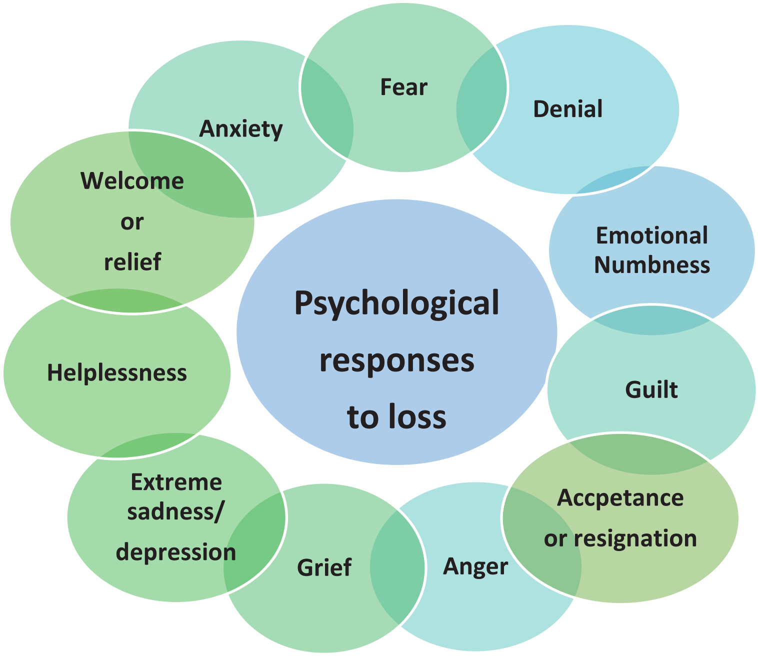
When a person loses someone close to them, it is natural to grieve. The aim of this chapter is to identify and differentiate concepts of loss, grief and bereavement during palliative care and to recognise physical, emotional, cognitive and psychosocial aspects related to loss, grief and bereavement at different stages in palliative care.

Loss

Loss is a universal aspect of life limiting illness. In palliative care settings, loss is related to ‘death’ of a significant person in a persons’ life. There may be secondary losses which can occur because of the progressive disabling illness.

Secondary losses

- loss of mobility
- loss of capacity to carry out activities of daily living
- loss of independence
- loss of autonomy
- fear of suffering, isolation, loneliness
- capacity to work, loss of employment and loss of income
- loss of hope for living without the person who died
- sense of unfairness
- loss of meaning for life feeling
- worthlessness and losing sense of dignity
- concerns about appearance of body image
- loss of the social network
- feeling of being a burden to others
- loss of future dreams
- loss of life



These common psychological responses may occur not only at diagnosis, but at any stage of the illness. If all of these become unmanageable or significant, it can have a major impact on mental health and wellbeing of the close relative or the caregiver.

Grief

This is the personal emotions, feelings and reactions that are expressed in various ways that can be directly related to the diagnosis of a life-threatening illness and death of the patient.

Grieving after loss is a normal process. However, some grief reactions become complicated and seriously compromise health of an individual.

The family, caregivers and friends in general may show different types of grief reactions due to the sadness and loss of the person they cared.

Grieving is a Process with Overlapping Stages:

- First there is ***disbelief and shock*** about the diagnosis of life-threatening illness, death, timing of the death even death was imminent.
- The period may be shorter if death was expected within the time frame predicted due to terminal illness. Then this ***'numbness***' can be replaced ***with bouts of high and low intense distress***. Cognitive, auditory and sensory awareness about the person who died with memories, dreams and thoughts are common.
- Physical problems related to anxiety and sleeplessness, loss of appetite and sometimes even showing symptoms of the deceased person has been identified with some caregivers.
- The ***questioning*** about events related to death, finding an answer to the reasons for the death or even discussing matters of faith, religion and how it occurred is another phase where '***meaning***' of the situation is constructed.

- It is common to find symptoms of depression, social withdrawal, sadness, poor concentration at any time after the death of a significant person to them.
- ***Rebuilding-*** the self-identity with the loss and even move forward in different directions by taking new roles and adjusting is also part of the bereavement process.
- Eventually, most people will be able to remember the deceased with certain sadness but without overwhelming feelings and emotions.
- Coping methods are used to ‘getting back’ to normal routines as much as possible but for some people it may affect negatively and may use self-harming or maladaptive practices which need attention from health practitioners or relatives.

Expressing Grief

There are unique and different ways caregivers grieve about the death of the patient depending on religious, social and ethnic differences:

- crying (sobbing or loudly)
- being quiet
- blaming others
- avoiding others (social isolation)
- using harmful substances (alcohol or other such habits)
- talking with others
- complaining about psychosomatic issues after the death (some symptoms similar to what the deceased had)

‘Grief’ is a normal emotional behaviour

Having understood, the PHC team should now be in a good position to empathize with the family and respect the way they choose to go through the grieving process and provide possible support.

The loss and grieving process can lead to self-harm of the care giver at different stages in palliative care. Therefore, it is necessary to monitor the grieving process of the caregiver.

Grieving can happen at different stages of the illness.

There is no time frame for grieving process after death of the patient.

It is important to monitor whether there are abnormal behaviours within the grieving process characterised by prolonged disruptions hindering their daily routine (whether in palliative care setting or at home) such as:

- avoidance
- distancing and addiction to harmful behaviours

If the above characteristics are observed, discuss with the family and provide an opportunity to meet, a psychiatrist or a psychologist as there is no bereavement counsellors in Sri Lanka.

Bereavement

- This is the process that the family, caregiver or friends go through after the death of the patient.
- It includes identifying the loss, grief reactions, accepting death and trying to continue their lives after death of the patient as normal as possible.
- This would normally start with 'intense grief' that they may feel due to the death of a loved one.
- There is no specified period or a specific way that bereavement can occur.
- It can depend on the religious beliefs, values and attitudes each person hold about death of a loved one and the rituals and processes that may help the grieving person to overcome this.

How to Help With Loss, Grief and Bereavement

It is important that medical and support teams in palliative care settings can **provide a 'preparatory help' anticipating the loss.** It may reduce the intensity of the loss and help the grieving person to adjust back into their life.

Reasons for lack of readjustment:

- **Situational:** unexpectedness of the death, financial burden, multiple loss situations, ethnic and cultural issues about practices after death
- **Individual:** pre-existing health problems (mental and physical), being very close to the deceased, being widowed, being a young person, loss of a child and its believed that ambivalent relationship with deceased person will lead to high sense distress due to unresolved issues caused by guilt
- **Environmental:** perceived lack of social support from others increases this risk. Among elderly and younger groups, this can be due to loss of mobility and family problems that make it difficult to overcome grief and build new bonds

Positive Outcome and Personal Growth

Adaptation following loss and bereavement may also be associated with personal growth (habits, behaviours, actions and reactions) for a reasonable proportion.

Renewed sense of meaning, selfawareness, increased empathy, reprioritised goals, and values, deepened spirituality, and increased altruism can all result in positive appraisal and growth of social and spiritual dimensions of the bereaved family and caregiver.

Importance of observation and monitoring grieving process

- Observing and monitoring the relatives or the grieving persons' behaviour at least within last few days or hours in the palliative care setting is important
- It may help you to identify at risk or self-harming display of actions or utterances (verbal and non-verbal) that requires basic (informal discussions) to secondary (counseling) or tertiary level (psychiatric assessment/assistance) interventions
- Specifically, paying attention to vulnerable individuals of the deceased such as children, elderly and disabled and those with complicated health issues is also important

Using your intuition and experience within the health care system may be valuable and can be utilized in such palliative care settings with further training and assistance from professionals to manage grief, loss and bereavement aspects of a patients' and their caregivers lives.

In the processes of grieving and bereavement some **factors that the primary health care team could consider** are listed below:

- identifying individuals that can experience a complicated grief state due to vulnerabilities
- providing support for the death arrangements if required
- providing information on practical issues (registering a death, aspects of sadness and grief, contact details on available social or psychological services)
- opportunity to speak or meet with support groups or community services/religious groups who might help afterwards in adjustment processes

10

Palliative Care for Pediatric Cancer Patients

All pediatric cancer patients requiring palliative care should be assessed by a Consultant Oncologist to decide on cancer specific palliative care. The aim of this chapter is to understand symptom management of pediatric palliative care and how best the primary healthcare team supports the patient and family with the guidance of the Consultant Oncologist

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when the life limiting or life-threatening illness is diagnosed, continues regardless of whether or not a child receives disease directed treatment and extends all through the disease trajectory into bereavement support. Effective paediatric palliative care requires a multidisciplinary approach.

Cardinal rules in managing paediatric palliative patient

The first rule :

- Do not panic.
    - Listen to the parents. In terminal care, the parents assume a pivotal role in the care for their child. Parents have a much deeper understanding of the child's medical, nursing and social needs.
    - Take a good history from all sources, start to examine methodically.
    - Develop a plan of action, go through it with the parents in the language they understand.

The second rule : Document, discuss and disseminate information to all your care team.
The third rule : Remember to retain a sensitive professional distance.

Symptom Management

A good understanding of the pathology of the cancer and physiology of the symptoms makes management a simple and logical process.

Anorexia

Causes

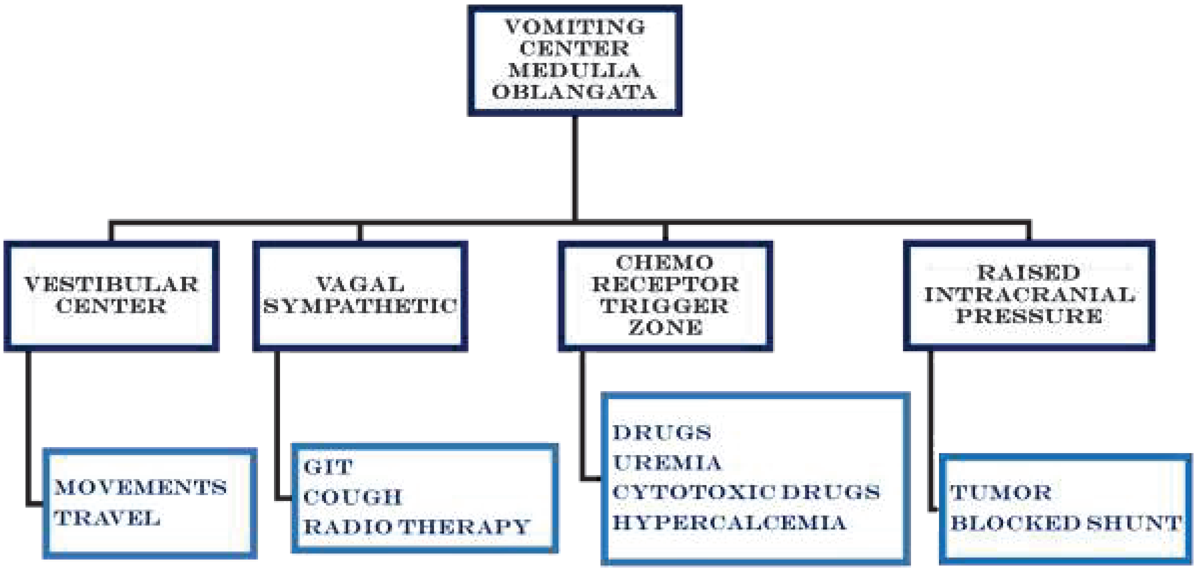
- pain
- nausea and vomiting
- altered taste/smells
- dyspepsia
- constipation
- oral/oesophegeal thrush
- drugs
- radiotherapy/chemotherapy
- anxiety
- depression

Treatment

- treat the cause
- reassure the parents that the inactive child may need less food
- encourage smaller, more frequent meals of child’s favourite food
- offer meals on a small plate and drinks using straws

Nausea and Vomiting

It is important to understand the cause of nausea and vomiting.



Management

- identify and treat the correctable cause e.g. pain, infection, drugs, biochemical etc.
- certain smells may antagonize nausea
- remove leftover food immediately
- advise staff and parents against the use of strong perfumes
- avoid strong odours
- encourage small, frequent meals
- use antiemetics according to their mode of action

Constipation

Causes

- inactivity
- metabolic
  - hypercalcaemia
  - hypokalaemia
- dehydration
- neurological
- fear of opening bowel due to pain
  - rectal tears/ fissures
- drugs
  - e.g.opioids, anticholinergics anticonvulsants
- social – shy/nervous about using toilets outside the home

Management

- We should predict the possibility of constipation and treat it prophylactically. e.g. Start bisacodyl for children aged 6-12 years: (5-10 mg oral once daily) as with adults, encourage increased fluid intake and exercise when appropriate.

I. Take a proper history and examine the child (including per rectal examination to assess for the presence of hard stool in the vault and rule out impaction) to identify the underlying cause(s) of the constipation

II. Start with lactulose, build up the dose over a week

III. If no improvement, add bisacodyl suppository or orally (dose given below)

- If the child is on an opioid start syrup cremaffin (combination of liquid paraffin (1.25 ml), magnesium hydroxide (3.75 ml) and sodium picosulfate (3.33 mg) (if syrup cremaffin is not available, use magnesium sulphate crystals) dose – 5-10ml per day.

IV. Can use micro / fleet enemas

V. If manual removal is necessary, then use a topical anaesthetic gel before the procedure

- **If the child is distressed with constipation**:

Hard Stool	Soft Stool or Empty Rectum
use glycerine suppository (*Glycerin available at PHC level*, *Glycerin suppository 2mg available at level 2*)	Use bisacodyl suppository **Bisacodyl should not be used in children aged 4 years or younger** **Children 4 – 10 years:** one suppository (5 mg) daily or 1 tablet of 5mg in the evening **Children over 10 years:** one suppository (10 mg) daily or 10mg tablet in the evening

Diarrhoea

Causes

- gastroenteritis
- malabsorption / diet
- concurrent illness e.g. colics
- post radiation/ chemotherapy
- drug induced e.g. antibiotics
- faecal impaction with overflow

Management

- oral rehydration solution (Jeewani)
- treat for the cause of diarrhea
- use of live yoghurt or soya milk can sometimes help with malabsorption
- if simple methods fail, can use loperamide (*Not available at PHC level, tablet available at level 4*)

Recommended First Day Dosage Schedule of Loperamide (oral) :

2-5 years: 1 mg t.d.s. (3mg daily dose) (13 to 20 kg)

6-8 years: 2 mg b.d. (4mg daily dose) (20 to 30 kg)

9-12 years: 2mg t.d.s. (6mg daily dose) (greater than 30 kg)

Subsequently, 1 mg/10 kg body weight to be administered only after a loose stool

Total daily dosage should not exceed recommended dosages for the first day.

- Nappy rashes are common and barrier cream should be used at the time of onset of diarrhea.
- Expose the skin to air and apply cream contains benzalkonium chloride solution, cetrimide and white soft paraffin. Cream contains cetrimide and paraffin preparations with or without miconazole cream will help in the treatment of nappy rashes.

Cough

Causes

- infections
- gastroesophegeal reflux
- lung metastases
- neurodegenerative disorders
- heart failure
- seizure activity

Management

- treat the underlying cause
- hold the child propped up
- give humidified oxygen via a face mask
- **nebulize with normal saline/ salbutamol / ipratropium bromide**

Children 0 – 5 years of age (for treatment of acute asthma only):

  - **Ipratropium bromide** 125 - 250 micrograms (e.g. half to one vial of 250 micrograms in 1ml) up to a total daily dose of 1 mg (4 vials).

Ipratropium bromide should be administered no more frequently than 6 hourly in children less than 5 years of age

Children 6 - 12 years of age:

  - **Ipratropium bromide** 250 micrograms (e.g. one vial of 250 micrograms in 1ml) up to a total daily dose of 1mg (4 vials).

- physiotherapy with or without suction
- can use cough suppressants
- for refractory coughing – nebulize local anesthetic such as lignocaine/Lidocaine 2%, 0.8 mg/kg/dose to 2.5 mg/kg/dose in Normal Saline nebulized 3-4 times daily (*Lignocaine 2% injection only available in PHC*)

Mouth Care

Causes of mouth problems

- oral candidiasis
- mouth ulcers – traumatic or aphthous
- poor oral hygiene
- bleeding gums from
  - haematological malignancy
  - liver disease
  - clotting disorders
- dry mouth from
  - mouth breathing
  - oxygen that has not been humidified
  - drugs – morphine, hyoscine or amitriptyline
  - local radiotherapy haematological malignancy

Management

- careful and gentle cleaning of teeth and gums
- apply a lip balm to prevent dryness and cracking
- oral thrush – apply miconazole oral gel gently around the mouth (*Not available at PHC level*)
  - oral fluconazole 3mg/kg once daily (more effective than topical agents) (*Not available at PHC level*)
- bleeding gums – tranexamic acid mouth wash (*Not available at PHC level*)

- (tranexamic acid 500 mg tablet dissolve into 10-15 ml of water)
  gel foam local application (*Not available in PHC level*)
  If not settles, child needs to be transferred to a tertiary care for palliative platelet transfusion

Dyspnoea

Breathing has become unpleasant, fast or difficult. Correct early treatment can be very rewarding and helps parents to develop confidence in the care team.

Causes

- pain
- anaemia
- infection
- pleural effusion/ pneumothorax
- left ventricular failure
- hepatic/renal impairment
- metabolic causes
- ascites
- anxiety, fear or claustrophobia
- cerebral tumours
- respiratory muscle dysfunction:
  e.g. neurodegenerative disorders
- mediastinal tumours:
  e.g. lymphoma, Germ cell tumours
  lymphadenopathy

Management

- calm the situation down and reassure both the child and parents
- allow normal breeze/air to come inside (open the closed windows/doors)
- small dose of diazepam, midazolam, (*Available at level 2 and 3*) or chloral hydrate (*available at level 3*) can be helpful for relieve the anxiety

Children>12 years old

- Diazepam 0.12-0.8 mg/kg/day oral in divided dose 6-8 hourly , OR
- Diazepam 0.04-0.2 mg/kg IV/IM 2-4 hourly ; no more than 0.6 mg/kg within 8 hours

e.g. Midazolam buccal/oral/intranasal <20kg: 0.3-0.5mg/kg/dose, >20kg: 5-10mg/dose
Dose can be repeated (*Not available at PHC level*)
IV/SC - 0.1-0.2mg/kg/dose 4-6 hourly (dose can be titrated)

- Oxygen via nasal prongs – 1l/min (24% delivered)
  2l/min (28% delivered)
  Venturi mask 2l/min (24% delivered)
- For thick secretions – nebulize normal saline can be helpful
- Beware that some children can have reflex bronchospasm

- nebulized salbutamol/ipratropium bromide can produce symptomatic benefit even without the presence of wheeze
- oral morphine in half analgesic doses can help settle dyspnoea

Doses – 0.05-0.1mg/kg/dose oral 4 hourly or as needed
0.025-0.05mg/kg/dose SC/IV 4-6 hourly

- treat the underlying cause

e.g. left ventricular failure – commence diuretics
chest infection – commence on an appropriate antibiotic
palliative chemotherapy or radiotherapy- discuss with the treating specialist
pneumothorax – if facilities are available treat accordingly

Indications for transferring a terminally ill child to a specialized care hospital:

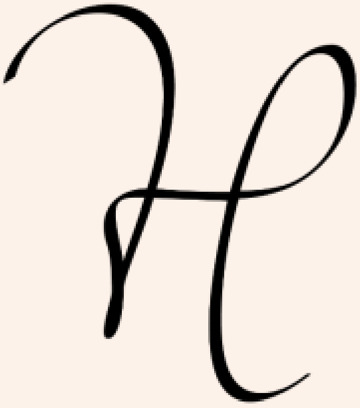
If any medical emergency situation is noted, transfer the patient immediately to the closest cancer treatment hospital:
e.g. severe sepsis, superior vena cava obstruction, acute bleeding, stridor,
spinal cord compression, uncontrollable convulsions

There is much more to support the terminally ill child and family than just the symptom control. Primary health care team should be concerned about the emotional, social and spiritual needs of the child, siblings, parents, grandparents, family and society around the child. The child and their parents need to be supported with compassion and understanding combined with expert symptom assessment and management.

Children often understand more about their illness than we realize or acknowledge, and it is best to answer their questions as honestly as possible. Children may also use art, drawings, or play as a way to express what they are feeling inside, and this can be a helpful way to explore a child’s fears, sadness, and hopes.

11

Palliative Care Services in the Community



Palliative care services are available in three settings. 3 ‘H’ –

(1) Hospital

(2) Hospice

(3) Home

Availability of Palliative Care Services

1. **P**alliative **C**are **C**onsult **S**ervice (PCCS) – This is multidisciplinary dedicated palliative care service provided in tertiary and secondary level hospitals.
2. Specialist Care - provided by the relevant treating specialist unit
3. Palliative Care in Primary Care - in **P**rimary **M**edical **C**are **I**nstitutions [**D**ivisional **H**ospitals and **P**rimary **M**edical **C**are **U**nits and General Practitioners
4. Home based care - by trained government community healthcare team or volunteers
5. Hospice care
6. Private sector

- The contribution of community palliative care services in coordination with primary and specialist care is essential as the majority of palliative care patients live balance period of their life at their home as shown in figure 11.1
- Only few palliative care patients may need specialist care during the disease trajectory and majority of patients’ total palliative care can be offered at the community.

Figure 11.1: Distribution of levels of care

Palliative Care Services at Home-Based Level

- Home-based palliative care is coordinated by the primary medical care institution where the patient is registered or by the patient's General Practitioner. Patients need to be registered in the palliative care register maintained at the PMCU.

- Public Health Nursing Officer is responsible in home visits and assesses palliative care needs at the home based setting. PHNOs have undergone a six months training on community-based care which includes a component in palliative care. Based on the identified needs, in consultation with the medical officer in charge, palliative care services need to be arranged at the primary medical care institution or at home. It is preferable to obtain guidance from the PCCS specialist or cancer treatment unit. Family members and care givers should be educated and empowered to provide supportive care for the palliative care patients.

- Area MOH office field staff (MOH, PHNS, PHI, PHM) can communicate with PMCU to identify patients with unmet palliative care needs in the community. Also, MOH staff can facilitate in mobilising community resources for provision of palliative care in community setting.

- The officials attached to Divisional Secretariat, community-based organizations should be encouraged to be involved in delivery of palliative care services and they should be provided with basic training in palliative care as per their roles and responsibilities.

- The shared care model proposed at the 'National Strategic Framework of Palliative Care Development in Sri Lanka 2019-2023'is applicable when organizing home based palliative care services.

Organizations / persons involved in delivery of palliative care in community setting:

Name of the Institute / Persons	Type of service
Clergy	Arrangement of religious rituals for the palliative care patients in advance according to the religion of the patient. Empower the patient and family members to face the terminal phase of the life.
Religious based organizations	Coordinate voluntary care for needy palliative care patients. Arrange financial support to the needy patients.

Social Service Officer attached to the Divisional Secretariat Office	Arrange financial support to the needy patients. Coordinating government welfare funds and provision of assistive devices for the palliative care patients. Coordinating other registered charity organizations for financial support for needy patients.
Counseling officer attached to the Divisional Secretariat Office	Identify psycho social needs of palliative care patients and family members and arrange necessary interventions.
'Grama Niladhari'	Coordinate with other officers attached to Divisional Secretariat Office to arrange social support.
Other community based organizations including elderly societies	Voluntary caregiver role for needy palliative care patients. Arrange financial and other livelihood interventions for the families with palliative care patients.

Palliative Care Services at the Hospice

- Hospice is a dedicated institute where supportive care is provided for the patients' emotional, social, and spiritual needs in addition to the care for the remaining physical symptoms following active disease specific treatment.

- Hospice care provides comfort and quality of life by continuing the care prescribed in the management plan to reduce the suffering of pain and other symptoms rather than cure. Therefore, the concept of holistic care is practiced at the hospice level with special emphasis on symptom management and end-of-life care by interdisciplinary teams.

- Interdisciplinary care: Care given by active involvement of medical, nursing staff, physiotherapists, pharmacists, social service officers, clergy and volunteers in delivering palliative care. The hospice authorities should as much as possible engages the active involvement of above personnel.

Services provided at the hospice

1.Hospice home care service – hospice team visits patients at home to provide necessary palliative care

2. Inpatient hospice service- provide residential care facilities for palliative care patients

3.Hospice day-care service- provide day care facilities for palliative patients

4.Respite care - arrangement of respite care for the families of the palliative care patients managed at home. (respite care- hospice staff takeover the palliative care patient for a brief period allowing family members / primary care givers rest for few hours to days)

5.Education centre - training for health care staff / volunteers on palliative care

6. Research centre

There are few hospices functioning in Sri Lanka. The services offered at these institutes are free of charge. Hospices available in Sri Lanka :

Name of the Hospice	Contact Details	Address	Home based Palliative care
“Shantha Sevana” Hospice Managed by the Sri Lanka Cancer Society	http://www.cancersocietysrilanka.org/facilities/shantha_sevana.htm 0112585879 0112 840 312	Maharagama	No
"Pilika Rakawarana Piyasa" managed by the Cancer Care Association	025 3890357 025 3243077 025 2056003	Kurundankulama, Anuradhapura	No
Institute of Palliative Medicine managed by the Cancer Care Association	0 41 222 6766 076 878 7484	Matara	No
“Sahana Sewana” managed by the Palliative Care Association	0112 840 312	Maharagama	No
Cancer Aid for North and East (CANE) Hospice	0212240258	Chunnakam, Jaffna	Yes
***EASCCA* Hospice managed by the Eastern Cancer Care Association**	https://easccahospice.com/ 076 0582248 070 3079242	Batticaloa	No

Voluntary organizations offer home based palliative care, daycare and supportive services free of charge are as follows:

Name of the organization	Address	Contact Number / Website	Services
Cancer Care Association - Head Office	Maharagama	*0113155229* *076 4912787* *077 340 9787*	Supportive care services for cancer patients and their families
Heal the Life "Divisetha"	Gampaha	*0774143222* http://healthelife.lk/en	Supportive care services for cancer patients and their families
Cancer Care Association- Galle Branch	Karapitiya	*0714454738* 0 71 852 7927 077 569 6000 https://cancercaresl.com/hbpc/	Home-based palliative care services, cancer community centre for rehabilitation of cancer patients, cancer day care centre and other supportive care services
Cancer Survivours Support Network	Maharagama	*0771657376* https://www.facebook.com/Cancer-Survivors-Support-Network-1270906686362074/	Supportive care services for cancer patients and their families
Indira Cancer Trust	Maharagama	*0112363211* *http://www.indiracancertrust.org/*	Supportive care services for cancer patients and their families
Sahana Suwa Community Palliative Care	Colombo	*0117600444* *https://www.sahansuwa.org/*	Home based palliative care services and supportive care services

12

Ethical Issues in Palliative Care

Health care professionals need to adhere to ethical principles in patient management. Palliative care should be provided by primary health care physicians and the team with a good understanding of these ethical principles which will facilitate health professional in decision making and practice of medicine for terminally ill patients.

This chapter addresses some ethical considerations to mitigate ethical dilemmas during the course of provision of palliative care.

Making decisions

When making decisions in palliative care, knowledge about the evidence available and the natural history, usual outcome of the disease, and the outcome of each proposed interventions is paramount. It is important to understand that, series of values held by all stakeholders including, patient, family and health care team, influence in making decisions, considering the social, cultural and spiritual aspects of life. If the views are different, doctor should find a way to support or disagree with the patient based on his/her knowledge based on evidence. There can be disagreement with patient and doctor, doctor and others in the interdisciplinary team or in between different specialists.

When there are disagreements with the patient, doctor should make sure that the patent was given enough information. Doctor should skilled enough to develop trust with the patient and the family.

When dealing with patients with life limiting illnesses it is important to have evidence based knowledge regarding physical illness trajectories and the trajectory of social, psychological and spiritual aspects, possible interventions at each different stages of the illness and outcome of those interventions. The palliative care team should be able to setup realistic goals to each individual patient, understanding the goals would change with the progression of the illness.

Main reason for disagreement is that the death is normally considered harm to the patient and urges to prevent death as life is always good to be promoted. However, there are medical situations in which this description is a question. e.g. Persistent vegetative stage. Family members may believe that artificially maintained life of their loved one is good, and they may request even intensive care in life threatening situations.

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Basic principles of ethics

Autonomy
Beneficence
Non maleficence
Justice

Autonomy

It is the right of the individual patient to make decisions regarding personal matters. Patient has the autonomy of thought, intention, and action when making decisions. The patient must understand all the risks and benefits of the procedure and likelihood of the success. Patients may choose among treatment options or refuse care, even if the recommended treatment is lifesaving. Medical team should respect the patients wish.

Patients with less than 18years of age the guardian can give the consent on behalf of the patient. If the physician thinks that it is not the best interest of the patient, he can make decisions in an emergency or can go for second opinion from a suitable person. If there's enough time left, can get a magistrate's order to appoint a proxy to make decisions on behalf of the individual.

Decision Making Capacity

Patient should have appropriate insight to make an informed decision. Decision making capacity should be assessed for the particular situation. For example a person might not be competent to make a decision for a complex situation but he or she would be able to make simple decisions.

A guide to ascertain whether or not patient has decision making capacity:

- Acknowledgement of relevant information - the patient should understand the diagnosis of the disease and the proposed treatment
- Appreciating one's circumstances - patients must be able to acknowledge what disorder or disease process they have and understand the impact on life
- Logical use of information - the patient should be able to give evidence that they have recognizable reasons for their views or conclusions
- Communication of choice - the patient must be able to communicate the preferences of one choice over another

When dealing with patients with reduced decision making capacity, the physician should act in the best interest of the patient.

In Sri Lanka, appointing a proxy, living will or advanced directives or durable power of attorney for health care decision making are not legally binding.

Beneficence

Care and the treatment provided is with the intent of doing good for the patient involved and promote their overall wellbeing. It is important to recognise changing needs and preferences during the course of the illness. Goals of care should be regularly reviewed.

- Everything is done or said should be for the patient's good
- Being honest with patients, which is nearly all situations will be of benefit to the patients
- patients should not be exposed to unnecessary investigations and unnecessary or useless therapies which are not evidence based
- Uses not only to physical good but also to psychological, social and existential wellbeing
- should be differentiated from paternalism ('doctor knows best')

Non-maleficence to Minimize or Do No Harm

It is important to understand `the potential risks of any treatment offered to a patient. Harm increases in frail elderly and those who have co-morbidities.

If the intent of therapy constitutes beneficence, even if the procedure results in harm, it is ethically justifiable on double effect. The principle of double effect is a rule of conduct often used to determine when a patient may legally and ethically perform an action from which two effects will follow, one bad, and the other good.

Justice

Limited resources should use responsibly while protecting vulnerable populations. Premorbid quality of life and potential outcome after treatment need to be considered.

In relation to health, justice refers to the equitable allocation of health care resources according to need not according to wealth, class, creed etc.

Informed Consent

Informed consent is the process in which a health care provider educates a patient about the risks, benefits, and alternatives of a given procedure or intervention. Consent is not required in emergency situations where patient is unable to give consent. Once patient improves the doctor can get consent for further interventions from the patient.

Basic elements of informed consent

Assess patient's (in the event of a child parent or guardian) competence to make decisions and the willingness to participate in the decision-making process.

- **Information**
  - The physician is obligated to describe the intended treatment procedure, its benefits and associated risks and available alternatives.
  - The patient should be counseled as to the likely course of the disease, if no treatment or procedure is undertaken.
  - The information provided should be comprehensive but should easily understand.

- **Principles of respect dignity**
  - Respect for people's dignity includes respect for their emotions, relationships, reasonable goals, privacy and bodily integrity. Respecting these personal characteristics should be acknowledged and should considerate in all aspect of care, even though the patient is incapacitated when health decisions are made.

What is death in medical practice?

The definition of death in Sri Lanka is given in the transplantation Act No 48 of 1987, it states that irreversible cessation of all functions of the entire brain, including the brain stem, is death.

However, in the circular for National organ donor programme for diseased donor organ transplantation of Ministry of Health (No.1-37/2010) defines death as brain stem death, and has given authority to remove organs for transplantation.

Withdrawing or Withholding Treatments

The goal of palliative care is to maintain the quality of life while neither hastening nor delaying death as death is the natural end-of-life. Whether it is applicable to offer or to withhold or withdraw a certain therapy depends on the balance between the possible benefits and the potential risks of the treatment, depending on the patient's best interests.

Switching off the ventilator could be considered only in patients with whole-brain death or brain stem death confirmed by two physicians who are not involved in the management of the patient in the circular issued for organ donation.

Cardio Pulmonary Resuscitation (CPR)

CPR includes the management of airway, intubation, and pharmacological interventions to stimulate the heart, chest compressions, and defibrillation.

Do Not Attempt Cardio Pulmonary Resuscitation (DNA-CPR)

- The procedure, CPR was never intended for use in patients dying an expected death from chronic fatal medical illness.
- Physicians are under no obligation to perform the medical procedure of CPR when the procedure is contraindicated.

Medical Futility

- A clinical action serving no useful purpose in attaining a specified goal for a given patient.
- Medical futility occurs when there is certainty that a particular action will fail in achieving the goal such as time or improving quality of life. These treatments should be discussed along with a frank explanation of why the specific treatment is not beneficial. These discussions will help to clarify goals of care.
- In Sri Lanka the DNA-CPR and withdrawing from ventilator, are not legally binding, except for organ transplantation when patient is confirmed of brain stem death or whole brain death. Duty of the physician is to act for the best interest of the patient.
- The reassurance of the patient and the family that the medical team will not abandon care even when specific treatments are deemed futile are of utmost importance.

Confidentiality

- Protection of privacy of information about another person is confidentiality. It is challenged when keeping electronic medical records. It is ethically challenged in situations like child abuse, elder abuse, expressed homicidal intensions, positive test for serious contagious disease. In those situations, physicians can breach confidentiality for the betterment of the patient or when there is a threat to health care staff.
- Palliative care team has responsibility divulging personal information in multidisciplinary team meeting where nonprofessional staff members involved.
- Every situation needs to be evaluated in its own context, so that patients, families and caregivers can achieve comfort and trust in the final decisions.
- Palliative care is not euthanasia and it accepts death as a natural event. Palliative care does not either hasten or postpone death. Patient would unlikely to request euthanasia, if patient and the family is prepared, addressing their physical, social, psychological and spiritual needs well in advanced from the beginning of the life-threatening illness.

13

Care of the Caregiver

Caregivers are tasked with the important duty of providing support and encouragement for the patient as well as themselves. This chapter explains the care that should be provided by the family to the care giver to ensure everyone cooperates and work in harmony as a team to provide the best care for the patient. In addition, the PHC team needs to educate the patient and the family to appreciate the caregiver and making the environment pleasant and comfortable for the caregiver.

Caregiver is referred to any family member /relative/ friend/ neighbour who provide a broad range of assistance to an adult or child with a chronic illness/ disability condition. Caregiver plays a pivotal role in providing care for the patients.

Roles of the Caregiver

- organization of appointments
- medication acquisition/dispensing
- symptom management
- meals and nutritional assistance
- assisting with personal care
- managing finances
- supervision of treatment
- transportation
- emotional support
- coordinating care
- communication with others

Usually, caregiver receives a little support and assistance to achieve these tasks and therefore he/she is very susceptible to stress / health risks and can become “burned out” easily. Therefore, understanding the care givers status and being in constant touch, appreciating of the support they are providing and making them comfortable in their role will produce positive results.

Assessment of the Caregiver

Primary health care team should assess the caregiver periodically and identify strength and weaknesses and address those needs.

Assessment of the caregiver's knowledge and skills on managing the illness of the patient:

- information related to illness
- care giving techniques
- community resources
- care givers roles and responsibilities

Caregiver knowledge and skills on maintaining selfcare

Caregivers should take care of themselves as a top priority from the beginning of the course of caregiving. They should be educated about ways of self caring and how to cope up with their emotions.

Ways of Selfcare

1. Seek help early
2. Eat well
3. Exercise regularly
4. Express the feelings
5. Regular health check-ups
6. Plan free time
7. Ask for assistance
8. Join or form a support group
9. Pay attention to emotions
10. Personal hygiene

It is a fact that caregivers are providing a challenging job. Patient and the family and also the PHC team should make the person understand that everyone appreciate the important role he plays and their gratitude to him/her. The cares giver should be given facilities to maintain good health and comfortable stay (e.g. sleeping facilities, balance diet, recreation facilities)

Kind words of appreciation, getting the person involved in other activities at home (gardening/washing a car) or even giving a gift would help the caregiver to feel happy. In such a background it will be easier for the caregiver to share his/her concerns if there are any. The primary health care team could also help the family in relation to caregiver's issues. Such caregivers will interact with others to share their concerns early to resolve the issue.

There is evidence that, caregivers who seek help early in the caregiving process are, on average, able to provide better care for a longer period of time.

Family and Caregiver Interactions

- Express the feelings - There will always be many demands on time and attention - job, family, caring for loved one, etc. The family and even the patient should understand that care givers at times may feel helplessness, show anger/ fear or even guilt. Everyone at home should work with a clear understanding of the caregiver's role. Care giver and or the family should have some strategies to overcome these problems. When these feelings arise, or when conflicts occur, the parties concerned (care giver and family) should discuss them with the individuals involved or with a support group or a counsellor.
- Any health problems of caregivers should be noted (pre-existing as well as recent onset) and discussed with the PHC team or the General Practitioner. If any medical attention is required the family should arrange it. If the caregiver has to take any medicines for any ailments it should be taken as instructed by the treating physician. If there are signs of depression in the caregiver it should be identified immediately and a mental health professional should be consulted.

  Educate the family that the caregiver should not feel solely responsible, they can ask for assistance.

Ask for Assistance

Ask other family members for help when need, or contact organizations that help. Consider joining a support group (see below) for care providers. Mental health centres can also help to deal with any difficult feelings caregivers may have.

Join or Form a Support Group

Support groups allow caregivers to:

- Discuss their concerns and frustrations
- Receive and offer emotional encouragement
- Share practical solutions to caregiving situations

The Apeksha Hospital and some other cancer treatment hospitals have support groups for caregivers.

Pay Attention to Emotions

Emotions are signposts to let you know when you need assistance or support. Often, when caregivers feel angry, frustrated, sad or inadequate, they try to make the feelings go away instead of figuring out what their emotions are telling them that they need. Having these feelings are completely normal, and almost every caregiver experiences them at some point in the caregiving process. Obtaining the support one needs early in the process will benefit both caregiver and the patient.

The PHC team should understand that the following are commonly seen emotions among caregivers and they should provide the family with the correct advice on how to mitigate these issues. The PHC team could also discuss with the caregiver and provide support as a counsellor.

Commonly seen emotions among caregivers:

- grief
- anger
- loneliness
- inadequacy

Grief

- Grief is the mixture of feelings we experience when we have lost something or someone dear to us.
- Most people associate grief with the feelings you have when a loved one dies.
- As a caregiver, one may experience many losses over the caregiving journey - including the loss of the relationship with the person you are caring for, social relationships that one had put on hold with the own family or friends, and the progressive loss of independence that the loved one is going through with the advancing disease process.
- To cope, ask them to talk about their feelings.

Anger

- There will probably be times a caregiver is angry at everything and everyone.
- There may be occasions when one may be using anger to mask other emotions, like sadness or fear.
- It is good to identify a few specific things that the caregiver is angry at and it may be that such things need to be readjusted quickly to expect a positive outcome.
- Maybe caregivers need to get help from other family members or talk to a friend to “vent." their feelings. Talking will help them feel that they are not alone, and help them realise that their efforts are both supported and appreciated.
- The family can seek help of an outsider (friend, clergy) or the PHC team to intervene and support the caregiver to overcome the anger.
- To cope with anger, the caregiver needs to look at it objectively. The PHC team should be able to help the caregiver to make him/her understand that it is incorrect to direct the anger at the person for whom you are caring. Let the caregiver use the energy that anger can give in positive ways to make changes, to exercise, to get things done that might otherwise have been neglected.

Loneliness

- They may feel isolated from their friends and community.
- After bereavement of the patient, the caregiver who has been sharing years of love and memories with the dead person or with the family may feel lonely and alone.
- Loneliness signposts that the caregiver is starting to grieve over the loss of a relationship.
- To cope, they need to try talking, praying or writing about loss, joining a support group, arranging to spend time with friends or attend services at the spiritual community. One may find nurturing relationships where least expects from them.

Inadequacy

- Caregiver will probably feel inadequate at some point of the caregiving journey.
- Feeling inadequate is often the result of being unable to meet the expectations placed upon caregiver by both himself and others.
- Feeling inadequate may be telling that he need help from other sources, or that he needs to learn new skills, or need to change the expectations.
- One may be feeling inadequate because the loved one's health continues to decline.
- This is part of the caregiving process and not something over which one has control. Care giver should be supported to cope by trying to accept these challenges using their strengths.
- PHC team could intervene and get the caregiver linked to someone who is able to help, as it will give them additional support and will help them feel more in control.

Respite Care

It is a short term break for caregiver, someone else takes the caregiver's position and care of the person, so that the caregiver can have a break. A break can give him/her time to do everyday activities or just to relax, deal with stress and look after themselves.

Respite care can be given by family or friends or by a respite service. It can take place at home, in the community, at a centre or in a residential care facility. Respite care can be from a few hours to a few weeks. The caregiver can organise for regular respite care or he/she might want to have respite care just now and again.

Respite care in an emergency: The family caregiver might be able to get emergency respite care at short notice if he or she suddenly find that he/she cannot provide care, for an example if he or she are ill or injured. It's a good idea to make an emergency care plan, in case someone else needs to take over from the present caregiver for in an emergency.

Other Considerations

Some community organizations offer care for particular groups (for example, activities for children or cultural groups). They may also offer activities for the person he/she care for, such as social events or therapy sessions.

Some caregiver groups also offer activities for caregivers (for example, chatting or yoga or exercises classes) to help them get a break.

As health care providers it is our duty to assess the needs of the caregivers and provide services which will help them to mitigate the challenges faced during the journey of caring for a patient. If the PHC team is of the view that the caregiver needs additional support they should educate the caregiver as well as the family on the need to refer to such institutions for support.

14

Caring for Health Care Workers

Protection and promotion of health is important in every workplace, but healthcare settings can be particularly challenging environments. The aim of this chapter is to identify the importance of selfcare in a health worker treating palliative care patients and to describe the basic aspects of burnout.

Working as a health care worker treating palliative care patients has many rewards. It can also be challenging and stressful. Stressors from work with palliative patients such as taking certain ethical decisions and breaking bad news contribute to emotional suffering of them. They are often confronted with death and suffering of patients. It is evident that working in a palliative care setting may lead health care workers to physical, psychological and emotional exhaustion leading to stress and burnout. Therefore, health care professional must remember to care for themselves and cope with stress and the emotional impact of their work related activities. The challenges for healthcare working in government settings may be different to those working in private sector.

Selfcare

Selfcare is described as balancing your care for the patient while caring for yourself which is very important in maintaining your good health.

Selfcare strategies

In the work place setting:

- Reflective practice
- Accessing other staff support
- Identifying your boundaries
- Regulation of workload
- Team work
- Harmony at work
- Use of humour and laughter

Outside the work place setting:

- Separating work from your home
- Meditation
- Spiritual practice
- Positive social relationships
- Rest and relaxation
- Preventative health behaviours
- Accessing support from other health care professionals
- Shared responsibility

Burnout

Burnout is characterised by fatigue and frustration which is usually related to work stress.

Signs and symptoms of burnout:

1. Boredom
2. Decreased quality of care
3. Depression
4. Fatigue
5. Frustration
6. Gastrointestinal disturbances
7. Headaches
8. Insomnia
9. Staff turnover
10. Low morale
11. Physical/emotional exhaustion
12. Weight loss
13. Impaired job performance (decreased empathy, increased absenteeism)
14. Deterioration of physician patient relationships

Management

It is useful for the PHC team to be aware of the following techniques and advice the family accordingly which would help to minimise the challenges faced by caregivers.

Prevention and early detection are the best approaches to minimise the risk of serious consequences from burnout. A variety of lifestyle management techniques will help health workers to maintain balance in their lives and decrease the risk of burnout.

Lifestyle management techniques:

1. Monitoring for and recognising symptoms early
2. Maintaining good nutrition
3. Maintaining spiritual life; meditating; spending time in nature
4. Grieving losses effectively
5. Decreasing overtime work

6. Exercising: aerobics, yoga, tai chi
7. Maintaining a sense of humour
8. Seeking consultation if symptoms are severe
9. Discussing work related stresses with others who share the same conditions; visiting counterparts in other institutions; looking for new solutions to problems

A health care worker should identify and work with emotions that may affect patient care. This involves looking at him, situational, and patient risk factors that can lead to his emotions and thus influence patient care.

The steps include:

1. Identify the factors that predispose to emotions that might affect patient care.
2. Monitor for signs (behavioural) and symptoms (feelings) of emotions.
3. Name and accept the emotion.
4. Identify possible sources of the emotion.
5. Respond constructively to the emotion.
6. Step back from the situation to gain perspective.
7. Identify behaviours resulting from the feeling.
8. Consider implications and consequences of behaviours.
9. Think through alternative outcomes for patients according to different behaviours
10. Consult a trusted professional colleague.

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Annexures

Catheterization of the urinary bladder

Urinary catheterization is an **aseptic** method of introducing the catheter into urinary bladder through the external urethra for withdrawal of urine.

Principles involved

- Pathogenic Organisms are transmitted from the source to a new host directly on by contaminated articles.
- Cleaning an area minimise spread of organisms.
- Lubricant reduces friction.

General instruction

- Observe strict aseptic techniques to prevent the urinary tract infection.
- Catheterization should be done slowly and never use force.
- Always catheterize in a good light.
- Lubricate the catheter well before introducing into the urinary tract.

Preliminary assessment

- Doctors orders for any specific precautions
- Identify the purpose of catheterization
- Level of consciousness
- Any contraindications
- General condition of the patient
- Mental status to follow instructions

Preparation of patient and environment

- Explain the sequence of the procedure
- Provide privacy
- Position the patient in dorsal recumbent
- Place the macintosh and towel under the buttocks
- Provide adequate light by placing extra spot light

Equipment

A sterile tray containing:

- Catheter of correct size
- An antiseptic
- Cotton swabs
- Pair of sterile gloves
- An artery forcep
- Sterile kidney tray-1 prefilled syringe with sterile water
- Sterile towel, sterile drainage tubing and collection bag
- Lubricant

A clean tray containing

- Macintosh and towel
- Flashlight or spot light
- Kidney tray
- Plaster and scissors
- Bed pan to empty the urine from the kidney tray
- Urobag or collection bag

Procedure

- Scrub hands as for a surgical procedure
- Lift the draping sheet back towards the abdomen
- Open the sterile tray with aseptic technique
- Place the sterile towel
- Place the sterile kidney tray on the sterile towel in front of the patient
- Lubricate the catheter and place it in the sterile tray ready for insertion
- Clean the perineum with the cotton balls dipped in the antiseptic lotion using the forcep
- Discard the swab in the paper bag and discard the forceps in and unutterable kidney tray
- Pick up the catheter with the gloved hand, holding about 7.5 cm from the tip and place the distal end in the sterile kidney tray
- Gently insert the catheter about 5 to 7.5 cm (female) the urine will flow into the kidney tray
- Attach the drainage tubing if and indwelling catheter is put in

Cleaning the perineum in female patients

- Clean only in one direction
- Use one swab for one swabbing
- Clean labia majora on both sides
- Clean the labia minora on both sides
- Clean the vulva

Cleaning the perinium for male patients

- Retract the foreskin during the cleaning process
- Draw the penis upward and forward at 90 degree angle to the patients' leg in order to straighten the urethra before the catheter is introduced
- Foreskin is replaced as quickly as possible after the insertion of the catheter

After care

- Wash and dry the perineum
- Remove the drapes, replace the cloth
- Place the patient comfortably
- Wash hands
- Record the procedure in the nurse's record sheet

Colostomy Care

Purpose of colostomy care

- Skin protection
- Receptacle for drainage
- Patient acceptance and selfcare

Equipment

A clean tray containing:

- Mackintosh with draw sheet
- Kidney tray/ paper bag
- Pair of clean gloves
- Colostomy bag
- Gause swabs
- Gause pad/ tissue paper
- Stoma measuring guide
- Pen or pencils and scissor
- Skin barrier

Procedure	Rationale
Gather equipment	Ensure that everything is there to render the care
Encourage patient to look at the stoma	It encourages participation in the stoma care
Explain the procedure to the patient	To gain confidence of the patient
Provide privacy	For smooth performance of procedure
Wash hands and wear gloves	To prevent infection
Spread mackintosh and draw sheet	To protect linen/ mattress
Remove used pouch and skin barrier gently by pushing the skin away from the barrier	Reduces trauma, jerking, irritates skin and can cause tear
Remove clamps and empty the content into bed pan. Rinse the pouch with tepid water/ Normal Saline	To minimise the odour and growth of microbes
Discard the disposable pouch in paper bag	To minimise the odour
Observe stoma for color swelling, trauma and healing. Stoma should be moist and pink	To find out complication
Cover the stoma with a gause swab	To prevent the fecal matter from contacting with skin
Clean peristomal region gently with lukewarm water using gauge pad, don’t scrub the skin, dry by patting the skin	Stoma surface is highly vascular. Skin barrier does not adhere to wet skin
Remove gause and clean stoma with gauze	
Use the pouch if it is drainable using a clamp or clip	
Remove gloves and wash hands	
Make the patient comfortable	

Documentation

Record the procedure with following details: date/ time, amount, colour, consistency of fecal matter, sign of any infection

Nasogastric Feeding

Preparation of the patient and environment

- Explain procedure to patient
- Ask patient for any history of allergies
- Auscultate for bowel sounds before feeding
- Check placement of gastric tube by mean of aspiration

- Position patient to high Fowler's position or elevate head if bed 30 degrees
- Place a towel under the chin
- Examine the appearance of aspirated contents

Equipment

A clean tray containing:

- Large volume syringe (50ml)
- Required feed a fluid
- Kidney tray
- Stethoscope
- A glass with water for flushing the tubing
- Continuous infusion set in continuous drip method is ordered
- Towel
- Disposal gloves
- Measured glass to measure the fluid intake

Procedure

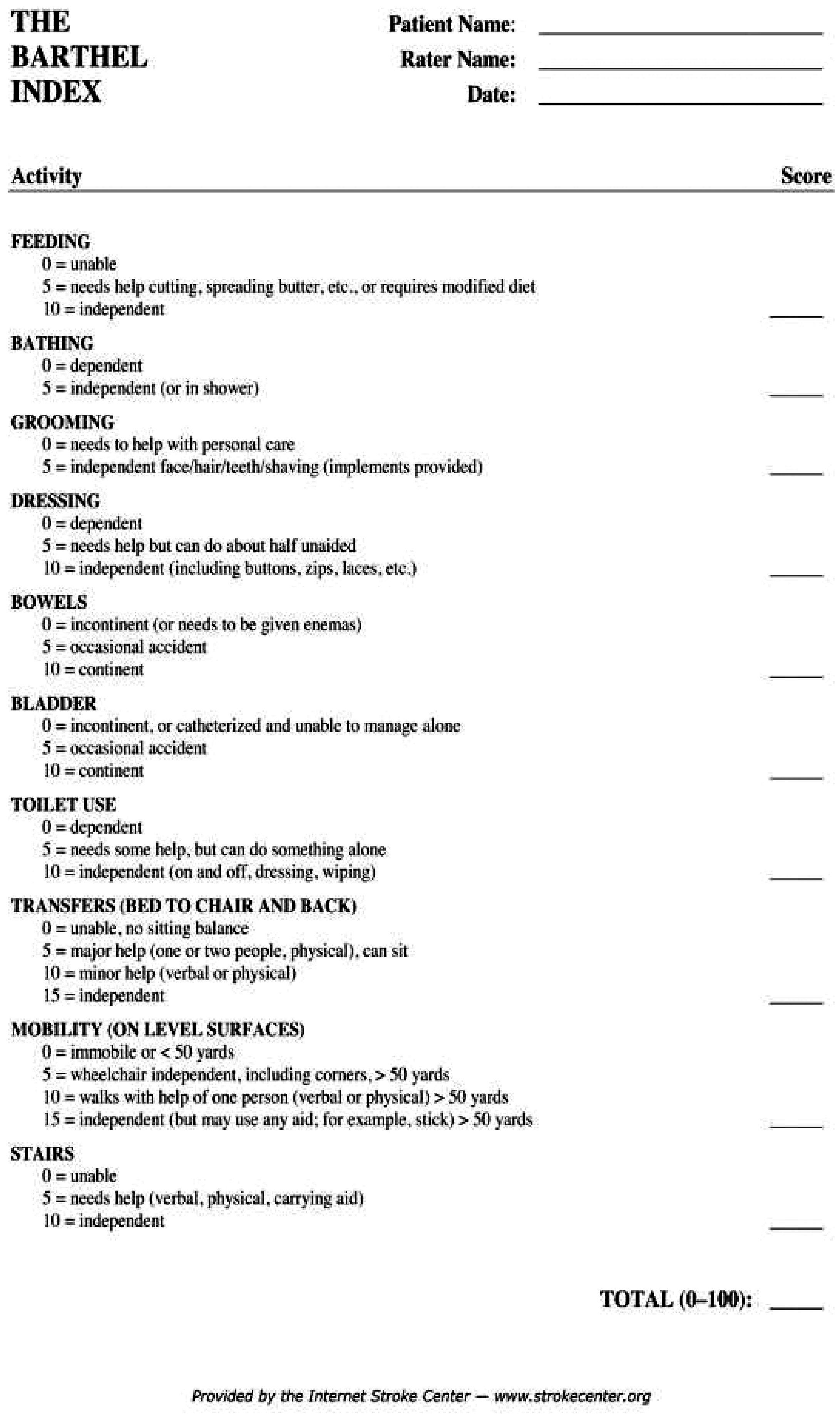
- Wash hands and put clean gloves.
- Pinch proximal end of the feeding tube and elevate to 18 inches above the patient's head. Fill the syringe to empty gradually, refill until prescribed amount has been given to the patient.
- If continues drip method is used hang the feeding bag to the pole above 18 inches above patient's head connect end of the bag to the proximal end of the feeding tube and set rate.
- Regulate the drip rate to permit the formula to infuse over 20 to 30 minutes by adjusting the height of the feeding bag or adjusting the rate of flow.
- When the tube feedings are not being administered, clamp the proximal end of the tube.
- Rinse the tube with plain water at the end of feeding.
- Re clamp the gastric tube.
- Remove gloves and wash hands.

Post procedure care

- Cover the of the feeding tube with its plug or cap to prevent leakage and contamination of the tube.
- Leave the patient in semi-Fowler's or high fowler's position for at least 30 minutes.
- Rinse all reusable equipment with warm water. Dry it and store it in a convenient place for the next feeding. Change the equipment every 24 hours or according to your facility's policy.
- The patient and family members are gradually included in the activities.
- Weight is checked daily and watch for sudden gain in weight.
- Observe for signs of dehydration (dry mucous membranes, thirst and decreased urine output)
- Watch for possible complications.
- Record amount of feeding, patient's response to tube feeding and untoward effects in nurses notes and record intake in fluid balance chart.

Complications of tube feeding

- Mechanical – nasopharyngeal, luminal obstruction, mucosal erosions, tube displacement, aspiration
- Gastrointestinal – cramping, distention, vomiting, diarrhea
- Metabolic-hypertonic dehydration, glucose intolerance, hyperosmolar nonketotic coma, hepatic encephalopathy, renal failure, cardiac failure



THE BARTHEL INDEX

Patient Name: ____________________

Rater Name: ____________________

Date: ____________________

Activity **Score**

FEEDING
0 = unable
5 = needs help cutting, spreading butter, etc., or requires modified diet
10 = independent _____

BATHING
0 = dependent
5 = independent (or in shower) _____

GROOMING
0 = needs to help with personal care
5 = independent face/hair/teeth/shaving (implements provided) _____

DRESSING
0 = dependent
5 = needs help but can do about half unaided
10 = independent (including buttons, zips, laces, etc.) _____

BOWELS
0 = incontinent (or needs to be given enemas)
5 = occasional accident
10 = continent _____

BLADDER
0 = incontinent, or catheterized and unable to manage alone
5 = occasional accident
10 = continent _____

TOILET USE
0 = dependent
5 = needs some help, but can do something alone
10 = independent (on and off, dressing, wiping) _____

TRANSFERS (BED TO CHAIR AND BACK)
0 = unable, no sitting balance
5 = major help (one or two people, physical), can sit
10 = minor help (verbal or physical)
15 = independent _____

MOBILITY (ON LEVEL SURFACES)
0 = immobile or < 50 yards
5 = wheelchair independent, including corners, > 50 yards
10 = walks with help of one person (verbal or physical) > 50 yards
15 = independent (but may use any aid; for example, stick) > 50 yards _____

STAIRS
0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent _____

TOTAL (0–100): _____

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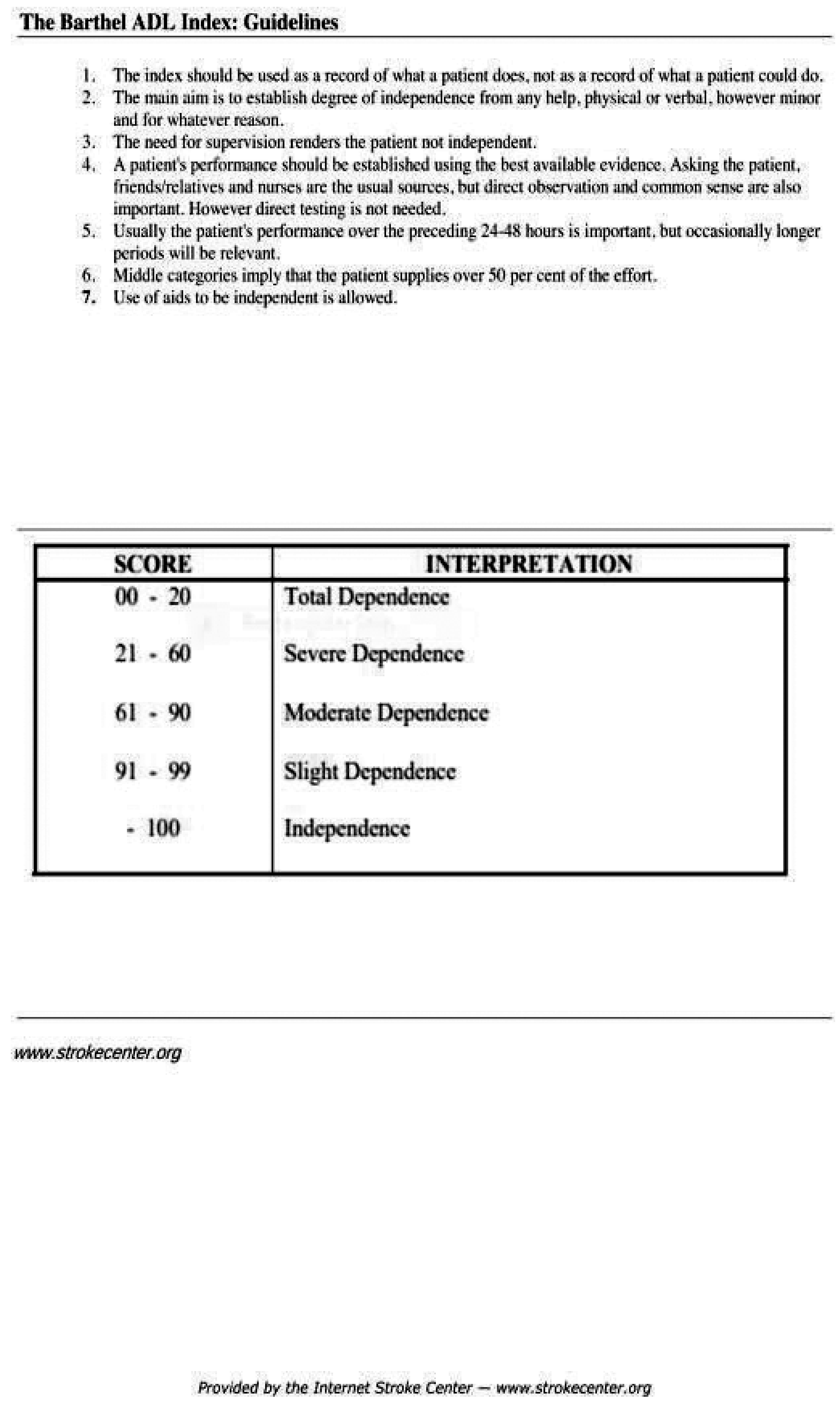

The Barthel ADL Index: Guidelines

1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

SCORE	INTERPRETATION
00 - 20	Total Dependence
21 - 60	Severe Dependence
61 - 90	Moderate Dependence
91 - 99	Slight Dependence
- 100	Independence

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Guide for care givers to protect palliative care patients from COVID - 19 in the community

Palliative care patients are a vulnerable group for COVID -19. Therefore it is important to protect them from COVID - 19 in the community/home.

1. Prevent / reduce the transfer of the patient across homes. If the patient is ambulatory, explain him/her the importance of staying at home in preventing COVID -19
2. Avoid overcrowded places such as religious places
3. Restrict visitors, friends and relatives
4. Avoid unnecessary gatherings / parties in the household
5. Avoid contact of the patient with people who are sick in the household
6. Keep the patient in a separate clean room or in a physically separable space
7. Arrange a hand washing facility (if soap and water are not readily available, keep a bottle of sanitizer) at the entrance to the house
8. Arrange a hand washing facility (if soap and water are not readily available, keep a bottle of sanitizer) at the entrance to the patients' room
9. The patient must wear a protective face mask in the presence of others
10. The caregiver and all others must wear a mask when attending the patient
11. Both care giver and the patient have to maintain good hygienic practices
    - Frequent hand washing with soap and water for 20 seconds
    - Wash your hands before and after caring the patient
    - Avoid touching your eyes, nose and mouth with unwashed hands.
12. Always maintain 1 meter distance unless it is necessary for caretaking
13. Protective measures must be taken while coughing and sneezing: Always cover your mouth and nose with a tissue when you cough or sneeze or use the inside of your elbow and do not spit. Throw used tissues in the trash.
14. Equipment such as wheel chairs / walking aids must be cleaned with disinfectants with special attention to its wheel rims and other touchable surfaces
15. Nutrition and hydration must be looked in to. A balanced diet must be offered to the patient with the available ingredients. Repeating the same menus is justified in a lock down situation. Adequate tolerable water intake must be maintained according to medical advice.
16. Look after the mental wellbeing of the patient: Facilitate engaging in religious activities, hobbies and recreational activities at home
17. When getting respite care (temporary care taker) a COVID19 risk assessment should be done according to the local medical guidelines
18. If the patient is having respiratory symptoms like cough, sore throat, fever, difficulty in breathing; seek medical advice. Act according to their advice. Do not panic in such situations

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National Cancer Control Programme
Ministry of Health

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