

**STUDENT WORKBOOK IN
PALLIATIVE MEDICINE**

**Department of Medicine
Faculty of Medicine
Sabaragamuwa University of Sri Lanka**

First Edition 2021

*2021 Department of Medicine
Faculty of Medicine
Sabaragamuwa University of Sri Lanka*

ALL rights are reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior permission in writing from the author.

ISBN 978-624-97939-3-4

CLINICAL APPOINTMENT IN PALLIATIVE MEDICINE

1. Name of the student

.....

2. Year that passed GCE Advanced Level Examination

.....

3. Duration of the appointment

From:/...../..... to/...../.....

4. Name of the consultant

.....

CONTENTS

CHAPTER	<i>Page</i>
Preface	04
Authors	05
1. Introduction	06
2. Core Clinical Knowledge and Skills	09
3. Taking History from a Patient Who is in Need of palliative Care	11
4. Patient Assessment	15
5. Exercises	17
6. Common Case Scenarios	20
7. Case Scenarios	22

PREFACE

Students of the Faculty of Medicine, Sabaragamuwa University of Sri Lanka, study Palliative Medicine during the professorial appointment.

This workbook in Palliative Medicine is compiled to help students achieve essential knowledge and skills in the subject, identification of physical, social, psychological and spiritual suffering of patients due to illnesses and caregivers. It also helps to achieve knowledge and skills, on assessment of these patients in order to relieve / minimize the suffering, setting up goals of care to improve the quality of life of patients as well as caregivers, provide holistic care and to work as a member of the interdisciplinary team of Palliative Care.

We value your feedback to improve the workbook.

Dr Udayangani Ramadasa

Dr Champika Gamakaranage

Professor Saroj Jayasinghe

AUTHORS

Dr. G. Udayangani Ramadasa (UR). MBBS, MD, FCCP, DIP PALL MED (Clinical) RACP

Consultant Physician

Head and Senior Lecturer (Grade I), Department of Medicine, Sabaragamuwa University of Sri Lanka

Dr. Champika Gamakaranage (CG). MBBS, MD (Col), MRCP (Lond). FRCP (Lond)

Consultant Physician

Senior Lecturer (Grade I), Department of Medicine, Sabaragamuwa University of Sri Lanka

Prof. Saroj Jayasinghe (SJ). MBBS, MD, MD (Bristol), FRCP (Lond), FCCP, PhD (Col)

Consultant Physician

Consultant to the Department of Medicine, Sabaragamuwa University of Sri Lanka

Emeritus Professor, Department of Clinical Medicine, University of Colombo

Contribution

UR – Wrote the initial draft, compiled the history taking, examination, investigations and exercises sections and updated all the sections

CG – Updated and edited all the sections

SJ – Conceptualized the production of this book, compiled the mind map section and updated all the sections

OTHER CONTRIBUTORS

Dr K. S.N. Prasangani (KP) – contributed with language editing

BA (Hons) in Languages (SUSL), MA in Linguistics (Kelaniya), PhD in Applied Linguistics (UNIMAS, Malaysia)

Dr. U.U.K Udumulla. (UUK) – Contributed with designing mind maps and document editing

MBBS (SL), Demonstrator, Department of Medicine, Sabaragamuwa University of Sri Lanka

CHAPTER 1

INTRODUCTION

Dear Students,

We have prepared a series of workbooks to guide you during your medical appointments. These include 3rd year workbook, 4th year workbook and workbook for each short appointment and a workbook for the professorial appointment.

The appointments in finer specialties are organized based on the University Grants Commission guidelines and according to the needs of the Ministry of Health.

The short appointment in Palliative Medicine will give you the opportunity to study the discipline with exposure to specific case scenarios in more detail. This workbook is prepared to provide guidance to the students during the Palliative Medicine to cover the essential areas expected from an undergraduate. You are expected to learn the management plans in further detail. This includes the investigation, treatment of common medical conditions, management of common emergencies, which are essential clinical topics for an intern medical officer. This knowledge, skills and experience you gather during the short appointments will help you to understand patient problems in greater depth.

Your continuous assessments will be based on these workbooks.

Learning Outcomes in Palliative Medicine

At the end of the appointment students will be able to,

1. Identify patients and conditions which needs Palliative care
 - a. End stage cardiovascular diseases
 - b. Cancer
 - c. Chronic advanced respiratory diseases
 - d. Advanced chronic kidney disease
 - e. Chronic liver disease
 - f. Advanced Parkinson's disease, motor neuron disease and other progressive neurological disease
 - g. Advanced dementia
 - h. Congenital anomalies
 - i. Drug-resistant tuberculosis
2. Identify, assess, investigate and manage common physical problems such as pain, nausea, vomiting and breathlessness.
3. Assess physical, social psychological and spiritual distress of these patients as well as caregivers.
4. Understand different illness trajectories and natural history of different diseases and identify goals of care and the change of goals of care during the course of the illness.
5. Understand the concept palliative care, interdisciplinary team and the role of each member of the team.
6. Identify the "end of life" phase, diagnosis of dying, and terminal phase and describe different problems in each phase and their management.
7. Identify the needs of nutrition and hydration in end-of-life care.
8. Observe communication with patient and family members in breaking serious news, regarding treatment options and withdrawing and withholding treatment.
9. Identify problems of caregivers including bereavement.
10. Write case notes, daily status, referrals, discharge summaries, clinic notes and prescriptions.
11. Demonstrate empathy and maintain high ethical standards and be aware of legal implications of decisions.

12. Be an effective member of the healthcare team and know the health facilities and social support available to care for patients with life limiting illnesses in Sri Lanka.
13. Know the support provided by the health system, the social service sector and informal caregivers towards provision of care for patients in hospitals and in the community.
14. Know the cultural and religious aspects related to palliative care in Sri Lanka.

CHAPTER 2

CORE CLINICAL KNOWLEDGE AND SKILLS

At the end of the appointment, you should be competent in the technique of history taking, physical examination, patient assessment and clinical reasoning.

In addition to the cases, you are allocated during the appointment, you are advised to see the following presentations given in the next section on “Topics to cover during Palliative Medicine Appointment”

2.1 Clinical Presentations: Palliative Medicine Training

These are some of the key presentations that ought to be ‘covered’ during the Palliative Medicine training.

- Physical symptoms such as pain, nausea, vomiting, constipation, fatigue, breathlessness, restlessness and agitation
- Psychological problems
- Social problems
- Spiritual problems
- Family and caregiver assessment and needs
- Terminal care
- Making decisions of end-of-life care
- Ethical considerations of end-of-life care

2.2 EMERGENCIES

Following is a list of common palliative care emergencies.

- Severe pain (musculoskeletal/ neurogenic/ organ related)
- Acute dyspnea
- Major bleeding
- Acute function loss
- Acute anxiety
- Delirium
- Ongoing seizures
- Spinal cord compression
- SVC obstruction

2.3 Topics in Palliative Medicine

- Common clinical presentations and principles
- Pain and symptom control
- Management of terminally ill patients
- Illness trajectories and identification of palliative patients
- Ethical issues

CHAPTER 3

HISTORY TAKING

Patients in the advanced stage of a serious and/or life-threatening illness who are presented to the ward experience single or more often multiple physical symptoms or sudden change of the clinical condition.

When we communicate with patients who have life threatening diseases, we should focus on the symptoms and how do they affect the patient or in other words, the impact of the symptom to the patient, what kind of a distress the patient experiences, how this illness has affected the family and caregiver, information we need to identify the focus of the illness, details of the underlying illness and its severity, information about psychological, social and spiritual wellbeing of the patient and lastly the patients' needs, concerns and priorities.

When we are dealing with patients with life threatening diseases, patients might not present as we expect. Symptoms may not follow the usual pattern and present in different ways because each patient experiences them differently and they are multifactorial.

PRESENTING COMPLAINT/S

Ask the patient or the family member the reason for admission, most common of which are pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, diarrhea, and anorexia. Some of the patients might come to the ward at the terminal stage to be cared for during the final days of his or her life. Some may be admitted due to sudden deterioration of their illness or wellbeing.

HISTORY OF PRESENTING COMPLAINT

Distress of the patient in history should be elicited by the patient's own words. In the comprehensive assessment, we need to ask for the characteristics of the symptom, contributing factors, aggravating and relieving factors, associated symptoms, the meaning of the symptom to the patient and the behavioral response. Ask more details about underlying illness and its complications, currently using medications, and past medications used, response of the medications, new onset or change of the illness.

Pain is a very common cause for admission and it is essential that doctors have the knowledge and skills to alleviate pain. If the patient is presented with pain, ask about the site of the pain, onset of pain, duration and the temporal nature. Ask about the characteristics of pain such as intensity, quality (e.g. somatic pain will be presented as aching or throbbing pain, visceral pain will be presented with aching cramping, gnawing and sharp pain, neuropathic pain will be presented as shooting, sharp, stabbing, tingling or burning type). Learn the corresponding Sinhala and Tamil terms. Find out whether there is radiation of the pain. Ask about disability and impact of the pain, any aggravating or relieving factors or any contributing factors. Find out the patient's idea or the explanation of the pain according to himself,

in other words what does the patient think as the cause for the pain, what is the impact of it on his physical, social, psychological and spiritual wellbeing and what actions that person is taking to manage or cope with the symptoms.

If the patient has already taken any treatment, find out what is/are the drugs with the doses, frequency, how long that these drugs are being used, whether the pain was controlled with those medications and side effects of medications. You need to find out any other non-pharmacological measures used to control the pain and whether the patient has undergone any intervention such as nerve blocks or radiotherapy.

Take details about patient's underlying illnesses such as if the patient has a cancer, the extent of the disease and whether the metastasis and treatments are given.

Apart from symptoms, ask patient's concerns, priorities and what is expected by the medical team. Explore the patient's wishes about the care of his illness and other aspects of life. Find out the fear of dying, feeling of loss, worthlessness, questions about the meaning of life, guilt and why only me? Explore the possibility of depression and anxiety. Find out the details about religion and the faith on how the religious rituals and beliefs impact to cope at this time.

Question the patient about his or her general conditions, i.e., ability to perform activities of daily living (i.e., basic activities such as mobility, washing up, dressing, bathing, using toilets etc.) and instrumental activities of daily living (which are the activities such as shopping, managing finances, cleaning the house and cooking which form essential activities to live independently). Ask about associated symptoms such as nausea, vomiting, fatigue, difficulty in swallowing, mental status, conscious level, whether the patient has capacity to manage his pain medication by himself or whether he needs assistance.

SYSTEMIC REVIEW

- **General**- Weight changes, appetite, fatigue, pain, or disability.
- **Cardiovascular system**- Palpitation, shortness of breath on exertion, chest pain, chest pain on exertion, dizziness
- **Respiratory system**, Shortness of breath, cough, wheezing
- **Gastro intestinal system**- Abdominal pain, constipation, loose stools, painful defecation, bleeding per rectum, melena
- **Genito urinary system**- Dysuria, frequency, smell of urine, painful or difficult micturition.
- **Neurological**- Gait, numbness of peripheries, weakness of limbs, conscious level, sleep pattern, memory status, tinnitus, cognitive impairment, visual or hearing impairment.
- **Musculoskeletal system**- Joint pain and swelling, myalgia, back pain or deformities, risk of falls.

PAST MEDICAL HISTORY

Most patients in palliative care know about their illness or diagnoses. In addition, ask about past medical illnesses, the control and the duration of these illnesses, complications and frequency of hospital admissions, and previous admissions to the emergency department or ICUs. Moreover, ask about any disabilities and suffering due to comorbidities and any surgical procedures undergone or any diagnosis of malignancies and recurrent infections.

History of immunization specially to influenza, hepatitis B, COVID-19.

DRUG HISTORY

Find out the drugs used and current doses, frequency and the prescriber, and when was the last visit to the doctor, and the compliance. Explore for polypharmacy, any adverse effects or allergies for drugs. Find out any dietary supplements' used by the patient and herbal remedies, over the counter medications and local applications.

The faith about medications, physical and psychological dependence.

Smoking, use of illicit drug and alcohol history

Find out whether the patient is a smoker or an ex-smoker and if yes, look for withdrawal symptoms.

If the patient used to take alcohol, find out the type of alcohol, the amount for a week and any complications or whether the patient is alcohol dependent and any withdrawal symptoms and any features of withdrawal of illicit drugs.

NUTRITIONAL HISTORY

Question the patient about the number of main meals, frequency, type and quantity of food intake. Find out about any special diets which the patient prefers. Ask about the content of proteins, fiber and vitamins, and details of food supplements and vitamins of the patients who are at the beginning off the illness.

Find out the patient's interest in food, appetite, chewing or swallowing difficulties, feeling of taste, smell. How does it affect his nutrition and what are the measures taken to overcome the above mentioned problems?

SOCIAL AND PERSONAL HISTORY

Find out the insight of the family about the condition and the possible complications and prognosis. How the patient is coping with the illness and the impact on family and the coping mechanisms. The physical, social, psychological and spiritual wellbeing of the patient. Find out the grief and grief reaction of the patient and family members. Knowledge and skills of the caregiver in looking after the patient. The living arrangements at home are questioned in detail.

The health status of the caregiver and the financial status of the family needs to be explored. Find out the closest hospital available and the way of transport in an emergency, depending on the stage of the illness, and the predicted course and outcome of the illness, care plan and the place of terminal care. Explore the distress of the family, losses of the family members, impact of this illness of the patient for the wellbeing and future of the other members of the family.

Find out the level of social support by relatives, friends, neighborhood and government and non-governmental organizations. Discuss about the General Practitioner close by. Ask about the occupation, the particular job and where the person was employed. Inquire if the patient is aware of facilities to obtain financial help from Employers Provident Fund (EPF) or Employers Trust Fund (ETF), Presidents Fund or 'Samurdhi'.

CHAPTER 4

PHYSICAL EXAMINATION

General examination

Observe the patient, whether dyspnoeic, cachectic, happy or in pain, alert or drowsy, tired, and hygiene, smell especially in patients who are having malignant wounds, fistulae or stoma.

If dyspneic, posture, and use of accessory muscles.

See whether the patient is comfortable, nutritional states, hydration states, pallor, jaundice, cyanosis. Look for edema, ascites, bruises, echometric patches, ulcers, bed sores, swelling and tenderness of joints, deformities, wasting of muscles, any wounds, stoma, tubes, surgical scars and radiotherapy scars.

Record the weight and the BMI.

If they are examined at the bedside, look for protective padding or a protective mattress. Examine the oral cavity, look for nutritional deficiencies, fungal infections, teeth and problems due to dentures.

Examine all the systems and look for evidence of cardiac failure, pericardial effusion, pericardial rub, pleural effusions, bronchospasm, evidence of pneumonia, crepitations or bronchial breathing in lungs.

Abdominal examinations of pain or tenderness, lumps, palpable liver, spleen or ascites. Per rectal examination in patients who have constipation.

Check for orientation, mini-mental examination.

Use the following performance scales to assess the clinical deterioration of the patient.

ECOG Performance status

0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

Those who are keen could read other scales such as the Karnowski Performance Scale.

CHAPTER 5

EXERCISES

1. Palliative care

- a. What is Palliative care?
- b. Write the WHO definition of Palliative care 2002
- c. Write the core concepts in Palliative care
- d. What are the diseases which need palliative care?
- e. Where do you give palliative care?

2. Natural history of life-threatening illnesses

- a. When do you start palliative care?
- b. How long will the care continue?
- c. Explain the trajectories of different disease types.
- d. Why is it important to know the natural history of illnesses?

3. Holistic care

- a. What is holistic care
- b. What are the 4 domains of holistic care?
- c. Explain the things need to be explored in each domain you mentioned in 3.b

4. Good death

- a. When do you call it “end of life”
- b. What is meant by the terminal phase?
- c. How do you recognize the “end of life” phase of different diseases?
- d. What is the importance of diagnosing the phase of “dying”?
- e. What are the main components of “good death”?
- f. Describe how you would give mouth care and skin care?
- g. Explain how you manage following distressing symptoms at the terminal stage.
 - I. Breathlessness
 - II. Restlessness and agitation
 - III. Respiratory secretions/ death rattles
 - IV. Terminal secretions

5. Pain

- a. What is pain?
- b. What is “total pain”?
- c. What are the causes for pain in a patient with malignancies?
- d. List the causes of pain in a patient with non-malignant diseases.
- e. Explain how you would use the 11-point pain scale.

- f. Draw the WHO pain ladder.
- g. What are the different opioid preparations available in Sri Lanka and the mode of delivery?
- h. How do you commence morphine and titrate it?
- i. What is break through medication?
- j. What are adjuvant analgesics and give indications.
- k. What are the non-pharmacological measures that can be used in the management of pain?

6. Gastrointestinal diseases

- a. What are the common causes of nausea and vomiting in a palliative patient?
- b. Write pharmacological management of each different condition you mentioned in 6 a.
- c. What are the non-pharmacological interventions in the management of nausea and vomiting?
- d. Briefly describe the common causes for constipation in palliative patients.
- e. What are the different types of laxatives available in Sri Lanka?
- f. How are you going to assess and manage a patient with constipation?

7. Breathlessness and cough

- a. Write four causes of breathlessness commonly seen in palliative patients?
- b. Describe the breathing, thinking and functioning model of assessment of breathlessness.
- c. Outline the management of breathlessness.
- d. What are the drugs you can use in management of refractory breathlessness?
- e. Give the indications and the dose of each drug you mentioned in 7 d?
- f. Mention non-pharmacological interventions you can use in management of breathlessness describing the mechanism of action
- g. How do you manage “panic attacks”?
- h. State the drugs you can use in intractable cough.

8. Assessments of needs and setting up realistic goals

- a. What are the needs of following categories?
 - I. Patients
 - II. Care givers
 - III. Health care professionals
- b. What are the goals in management of a palliative patients?
- c. What are the factors you need to take into account in setting up goals?
- d. Explain how goals would change with the progressions of the illness.

9. Interdisciplinary team

- a. List the members of the interdisciplinary team of palliative care.
- b. Describe briefly the role of each member of the team you mentioned in 9a.

10. Write short notes on

- a. Quality of life of patients
- b. Losses of palliative patients
- c. Losses of family caregivers
- d. Grief and bereavement
- e. Spirituality
- f. Dignity
- g. Palliative care services available in Sri Lanka

11. Ethical considerations in Palliative care

Write notes on

- a. Advanced care planning
- b. Futile interventions
- c. Consent and capacity
- d. Withdrawal and withholding treatment
- e. DN- CPR (Do not – Cardiopulmonary resuscitation)

12. Nutrition and hydration (answer very briefly)

- a. How would you assess the nutrition needs of a palliative patient?
- b. What are the indications for parenteral nutrition in “end of life” care?
- c. State the indications for tube feeding and its complications.
- d. When would you consider IV or S/C fluids in a palliative patient?

CHAPTER 6

COMMON CASE SCENARIOS

1. A 78 years old patient with carcinoma of lung has undergone radiotherapy. 2 days after completion of radiotherapy, he was febrile and became agitated. He was suspicious about his daughter and refused food. He was very ill, mild dyspneic and had bilateral ankle edema.
 - a. What is your diagnosis?
 - b. Write three possible causes for his condition.
 - c. What immediate investigations would you perform in this patient?
 - d. Outline your plan of management.

2. A 71 years old male who was diagnosed to have carcinoma of prostate presented with severe pain in his hips.
 - a. What are the causes for his pain?
 - b. State the immediate investigations you would request in this patient?
 - c. How do you manage his pain?

3. A 65 years old patient with advanced cardiac failure presented with severe shortness of breath and the patient was given oxygen, IV frusemide and optimized his cardiac medications. He was dependent on oxygen and had shortness of breath even at rest. He was bed bound due to breathlessness and he needed assistance even for self-care. He was depressed and socially withdrawn. This is the 3rd hospital admission during the last four months.
 - a. List the problems you identify in this patient.
 - b. Explain the disease trajectory .
 - c. Outline your management.

4. A 62-year-old patient who was diagnosed to have advanced chronic obstructive pulmonary disease has recurrent hospital admissions with episodes of shortness of breath. He was very anxious and developed panic attacks at home. He was physically as well as psychologically dependent on oxygen.
 - a. List the problems you identify in this patient.
 - b. Outline pharmacological and non-pharmacological measures in the management of his panic attacks.

4 weeks later he was presented with exacerbation of breathlessness and fever. He was restless and confused. Blood pressure was 80/50Hgmm. His urine output was only 10ml over the last 6 hours. On direct questioning, he had been refusing feeds and was very weak over the last 1 week.

 - c. Explain his clinical condition giving reasons. His daughter asks you about her fathers' prognosis.
 - d. Describe how you would communicate with her.

5. A diagnosed patient with breast cancer who had undergone surgery and radiotherapy 2 years back has defaulted follow up presented with exacerbation of back pain. She complained of numbness of both lower limbs and had passed urine about 2 hours before this happened.
 - a. Describe the possible examination findings in this patient.
 - b. What is the most likely diagnosis?
 - c. State the investigations you would do to confirm your diagnosis.
 - d. Outline your management.

6. A 59-year-old patient who was diagnosed to have advanced lung cancer presented with profuse bleeding with hemoptysis. Patient and the family members knew the prognosis of the condition.
 - a. How do you explain the current condition of the patient to the family members?
 - b. How would you manage this patient?

7. A 78 years old patient with dementia presented with fever and shortness of breath. His oxygen saturation was 92 % without oxygen and had bilateral crepitations, mainly in the right-side lower zone.
 - a. Outline the management of this patient

After a week she clinically improved from her acute condition, but had difficulty in swallowing. She was conscious and rational and continued to have short term memory impairment which was worse than before this febrile illness. She was able to get her activities of daily living with minimal help.

 - b. Describe her disease trajectory.
 - c. How would you manage her swallowing problem?
 - d. What is the place of PEG in this patient?

8. A 71 years old patient who was diagnosed with motor neuron disease had difficulty in swallowing and speech. He was wheelchair bound due to weakness of lower limbs. But his upper limbs were normal. He was looked after by his 72 years old wife who had osteoarthritis of both knees. The only child had passed away after a road traffic accident at the age of 21 years. The patient was very worried about his wife.
 - a. Identify problems in this case scenario.
 - b. List the members of the interdisciplinary team in the management of this patient.
 - c. Explain the role of each member of the interdisciplinary team.
 - d. Explain the importance of advanced care plan in this patient.

CHAPTER 7

CASE SCENARIOS

In this section we expect you to write histories (minimum of 3 cases as complete documentations) of patients that you encountered during your training in Palliative Medicine.

This book is peer reviewed and recommended as a teaching and learning material for the Department of Medicine, Faculty of Medicine Sabaragamuwa University of Sri Lanka, by the following experts,

1. Dr. Niroshan Lokunarangoda

MBBS (Col). MD Medicine (Col), MRCP(UK), PGCME(Col),

MRCP (Acute Medicine), MSc (Med Toxicology). MRCP (London), FRCP(Edin)

Head and Senior Lecturer and consultant Cardiologist

Department of Medicine

Rajarata University of Sri Lanka

2. Dr. Dumitha Govindapala

MBBS. MD (Col). MRCP (UK). FRCP (Lon). FACP (USA)

Head and Senior Lecturer and consultant Physician

Department of Medicine

Faculty of Medicine

General Sir John Kotelawala Defence University, Sri Lanka

