

Palliative Care

A Workbook for Carers



**INSTITUTE OF
PALLIATIVE MEDICINE**



WHO Collaborating Centre for
Community Participation in
Palliative Care and Long Term Care



Sri Aurobindo Society
SANJEEVAN

AN INTEGRAL APPROACH TO END-OF-LIFE CARE

SANJEEVAN Palliative Care Project

(A joint venture between Sri Aurobindo Society and
Institute of Palliative Medicine)

Supported by a project grant from Tata Social Welfare Trust

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Palliative Care - A Workbook for Carers

Second Edition

March 2022

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Printed by Harvest Printing Services Pvt.Ltd., Kerala, India.

Design and layout by Jithesh James

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Palliative care - A workbook for carers is published by Institute of Palliative Medicine which is a WHO Collaborating Center. The views expressed in this publication do not necessarily represent the decisions or Policies of World Health Organization.

Contents

Foreword

Acknowledgements

1.	Why This Workbook?	11
2.	How To Use This Workbook?	14
3.	What is Palliative Care?	15
4.	Community Participation in Palliative Care	21
5.	Ethical Issues	25
6.	Communication Skills	31
7.	Physical Problems	43
8.	Spiritual Issues	48
9.	Socioeconomic & Emotional Issues	55
10.	Mobilising Local Resources	64
11.	Nursing Care	67
12.	Carers Issues	76
13.	Death and Dying	78
14.	Grief and Bereavement	81
	Appendix 1 - Reporting Format For Community Volunteers	84
	Appendix 2 - Proposed Modules For Sensitization and Training Programmes	87
	Notes	91

Foreword

Looking after the ill and disabled has been an age-old tradition in all civilized societies. Increasing expectancy of life results in a large percentage of older men and women in society and a global transition of diseases towards chronic incurable illness has made knowledge and skills in caring more relevant today than ever before.

The philosophy and practice of palliative care, which emerged as a response to the feeling of helplessness before incurable and terminal illness, has evolved much over the last few decades. Community working closely with healthcare professionals is being recognized as the best way to offer holistic, compassionate care to people living with progressive incurable illness.

It is estimated that 40 million incurably ill and dying people need palliative care every year; 86% of this huge population do not have access to the care that they desperately need. This situation can be improved only if palliative care becomes part of a package of basic care. In 2014, the World Health Assembly resolved to make ‘mainstreaming’ of palliative care into primary healthcare a priority for healthcare systems. Guidelines and tools for various stakeholders in this area are being generated by World Health Organization (WHO). As part of this, WHO has suggested a structured 16-hour training programme as basic training for community volunteers (Planning and Implementing Palliative Care Services—A Guide for Programme Managers World Health Organization 2016 http://www.who.int/ncds/management/palliative-care/palliative_care_services/en/).

Community-based care is essential as patients with advanced diseases require continuous care and attention for the rest of their lives. They are also in need of regular social, psychological and spiritual support in addition to medical and nursing care. Care should be readily accessible and available as close to home as possible.

WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care has been given the mandate by World Health Organization to support its efforts

with development of structured education and training programmes in palliative care and long-term care. This workbook is an attempt to address training needs of carers in the area of palliative care and long-term care.

Palliative Care - A Workbook for Carers has been developed through a series of workshops, drawing on the experience of Institute of Palliative Medicine (IPM) in community-based palliative care activities that offer structured 20-hour training for carers in the community in line with the WHO guidelines in the area of community-based palliative care. This will hopefully serve as a useful resource to training programmes for family carers and community volunteers.

The first edition of this publication was used to train more than 4000 carers over the last four years. The publication has now been revised following feedback from trainers and trainees and review by experts. We hope that the second edition will continue to serve the purpose in a more effective way.



Dr Suresh Kumar

*Director, WHO Collaborating Centre for Community Participation in
Palliative Care and Long Term Care*

Acknowledgements

This workbook was prepared under the leadership and guidance of WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care.

The following people contributed technical content for the first edition.

Dr Suresh Kumar (Institute of Palliative Medicine), Dr Sheeja Rajan (Government Medical College, Kozhikode), Mohan Venkat (SANJEEVAN Palliative Care Project), Saif Muhammed (Institute of Palliative Medicine), Amjith Kumar (Neighbourhood Network in Palliative Care), Shan Ramesh Gopan (Neighbourhood Network in Palliative Care), Vetri Selvan (SANJEEVAN Palliative Care Project), Dr Jairam Ramakrishnan (Medicine Sans Frontiers) and Dr Ajmal Rahman (Kerala Government Health Services).

Heleina Thompson (University of Iowa, Department of Health and Human Physiology) and Puja Narula (Sri Aurobindo Society) helped with language editing and Dr Anwar Husain (Institute of Palliative Medicine) recreated the illustrations.

Further contribution for the second edition from following people:

Sreekumar P C (Institute of Palliative Medicine), Dr Ajitha P (Caring for Childhood Cancer and Chronic illness), Sathiapalan K K (Institute of Palliative Medicine), Safareena F M (Institute of Palliative Medicine), Abdulla P (Kozikode Initiative in Palliative Care, Meenakumari (Institute of Palliative Medicine)

The workshops for the generation of the workbook were supported by SANJEEVAN Palliative Care Project, Puducherry, which is a joint venture between Sri Aurobindo Society and Institute of Palliative Medicine.

Printing of this workbook was made possible by a grant to SANJEEVAN Palliative Care Project by Tata Social Welfare Trust.

1

Why This Workbook?

The philosophy and practice of palliative care has evolved much over the last few decades. Increasing expectancy of life and global transition of diseases have made palliative care more relevant today than ever.

World Health Assembly in 2014 had resolved to make ‘mainstreaming’ of palliative care a priority for healthcare systems. WHO has come out with various documents, manuals and tools to facilitate this process. The book is aimed to support the World Health Organization recommended 16-hour training for community volunteers in palliative care (<http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf>). The training programme, as indicated in this workbook, can be run either as a single 20-hour course or as a 1+3+16 hour series.

Candidates undergoing this participatory training programme are advised to get exposed to a supervised homecare training in the field. It is advisable to make at least four home visits as part of training (Guidelines for supervised home visits is given in the chapter of socio economic and emotional issues)

This document has been named Workbook for Carers instead of a workbook for community volunteers, because community volunteers are a subgroup of the larger pool of carers who generally require the same knowledge, attitude and skills.

CAREGIVER (CARER)

“There are four kinds of people in this world:

those who have been caregivers,

those who are currently caregivers,

those who will be caregivers,

and those who will need caregivers.”

~Rosalynn Carter

A caregiver (carer) in palliative care is a person caring for an individual (patient) who has some physical, emotional, psychosocial or spiritual problems due to advanced disease or old age. The carer's intervention helps to improve the patient's wellbeing. The intervention can be through contributing time, energy and or money. Caring for a person with advanced illness is demanding work, which often means going through extreme stress and a wide range of emotions. Caregiving without adequate knowledge, skills, support and self-care can cause harm to the patient and also increase the risk of adverse health effects on the carer.

Carers are conventionally divided into paid carers, family carers and volunteer carers. This division is very often arbitrary and refers only to the perceived motivation behind the carer's assistance to the patient. The skills and knowledge for the 'caregiver' (carer) in palliative care are the same irrespective of whether that person is a paid, family or volunteer carer. Ideally, the carer should be a compassionate presence to the patient and also have certain practical skills and knowledge to support the patient.

This workbook aims to improve the skills and knowledge of the carer in palliative care.

A carer assisting a person at the end of life should have the following prerequisites:

- Know about the patient's biomedical, psychosocial and spiritual status
- Know how to communicate to the person in a supportive way, which basically involves a lot of listening skills
- Know the basics of nursing care
- Know how to administer medicines prescribed
- Know when and where to seek help, for the patient and also oneself

Core Competency of Volunteers in Palliative Care (Kozhikode Initiative in Palliative Care)

1. Should know how to identify patients requiring palliative care
2. Should know how to assess and document the social, psychological and emotional needs of the patient and family
3. Should know how to mobilize social support for the patient and family
4. Should know how to support the patient and family emotionally
 - Addressing sadness
 - Addressing anger
 - Addressing anxiety

5. Should know when to refer an emotionally disturbed patient to a professional psychologist
6. Should know how to explore spiritual issues with the patient
7. Should know how to address basic psychosocial and spiritual issues of a dying patient
8. Should know how to offer bereavement support after the patient dies

This workbook aims to serve the twin purposes of being a self-learning tool for the carers and potential carers and also a manual for a 20-hour structured course for carers including community volunteers

2 How to Use This Workbook?

This document has been generated as a workbook to support a structured training programme for family carers and community volunteers interested in looking after incurably ill, terminal or elderly patients at home.

The strategy is that of facilitated learning in groups. The 20-hour training programme can be completed in three consecutive days or as separate modules over a period of time. Each of the modules also indicates the time required to run it.

It is advisable to divide the participants into subgroups, with 5–6 members in each subgroup, to ensure participation of all. All the activities mentioned are done in subgroups and one person from each group reports back to the full team of participants for feedback and comments. Individual modules have been prepared in such a way that they can also be run as ‘standalone’ sessions covering particular topics.

Each session has activities aimed to generate information and knowledge from the participant groups, followed by sessions by facilitator to summarize/ complement/ challenge the observations. Sessions intended to impart/improve practical skills have participatory demonstrations by the faculty. The idea is to add on/complement the locally available information/knowledge/skills. Approximate duration required is mentioned with each session to help to provide the training programmes. These are only for guidance as there may be variations in requirements between groups.

Broad outlines of suggested schedules of the 20-hour training programme, 1-hour sensitization programme and 3-hour ‘entry point’ training is given at the end of the workbook.

3

What is Palliative Care?

(60 MINUTES)

INTRODUCTORY STATEMENT

We all have to die one day. Only a small percentage of people die suddenly and unexpectedly. Many of us will have a period of multiple problems before we die. This can be due to an incurable progressive disease or old age with multiple diseases. Most people suffer a lot during this period. Palliative care is the exploration of what can be done to help people during this phase in their life.

ACTIVITY

There is a 32-year-old lady with advanced breast cancer in your neighbourhood. She has two children aged 8 and 6. Her husband is a manual labourer. The treating doctor has told the husband that her disease is not responding to treatment and the patient is likely to die in 6–9 months. You visited her yesterday. She complained of pain all over the body. She looked very worried. As a neighbour, what can you do to help this patient and her family? Who all can you seek help from?

- Discuss in small groups (10 minutes).
- List your suggestions (5 minutes).
- Exchange with other groups (10 minutes).



INTERACTIVE SESSION

Use the WHO definitions and the info graph for a 15 minute interactive teaching session to discuss what is palliative care, the need and why it is not available to all the needy.

WHO DEFINITION OF PALLIATIVE CARE

(<http://www.who.int/cancer/palliative/definition/en/>)

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

PALLIATIVE CARE:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

SUPPORTIVE CARE:

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy, radiation therapy, dialysis etc and includes those investigations needed to better understand and manage distressing clinical complications.

WHO DEFINITION OF PALLIATIVE CARE FOR CHILDREN

Palliative care for children represents a special, albeit closely related, field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows (the principles apply to other paediatric chronic disorders too):

- 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 illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach, which includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes

Screening Tool- Community Survey to identify patients in need of palliative care (BSMMU-IPM screening tool)

Number:

Name:

Address:

Name of respondent:

Question	Response	Score
How would you describe his/her <u>mobility level</u> during the last three months of life?	0. Full, like a person of his age 1. Reduced 2. Was usually mainly sitting or laying 3. Was mainly in bed 4. Was totally bed bound Not assessable	
How would you describe his/her <u>activity level</u> during the last three months of life?	0. Normal, like a person of his age 1. Normal with effort 2. Able only to do light work, or simple chores around the home 3. Unable to do any work at all Not assessable	
What would you say about his/her <u>ability to care for him/herself</u> during the last three months of life?	0. Could take full care of him/herself, like a person of his age 1. Needed occasional assistance 2. Needed assistance most of the time 3. Needed total care Not assessable	
How was he/she <u>eating and drinking</u> during the last three months of life?	0. Normally, like a person of his/her age 1. Had reduced intake or very little food 2. Had only a few sips of liquids or less by mouth or had a naso-gastric tube Not assessable	

How was his/her level of <u>consciousness</u> during the last three months of life?	0. Full, like a person of his/her age 1. Delirious 2. Drowsy 3. Comatose Not assessable	
Was he/she affected by <u>pain</u> during the last three months of life?	0. Not at all 1. Slightly 2. Moderately 3. Severely Not assessable	
Was he/she affected by <u>other symptoms</u> beside pain during the last three months of life?	0. Not at all 1. Slightly 2. Moderately 3. Severely Not assessable	
Was he/she feeling <u>anxious, depressed or worried</u> during the last three months of life?	0. Not at all 1. Occasionally 2. Most of the time 3. He/she was completely absorbed by worries and anxiety Not assessable	

Relationship to the patient:

Contact Number (if any):

Total Score:

Minimum score is 0 and maximum 24

Any patient with scores above 10 to be evaluated clinically for palliative care

Name of Data Collector:

Contact Number:

Date:



World Health Organization

(<http://www.who.int/ncds/management/palliative-care/pc-infographics/en/>)

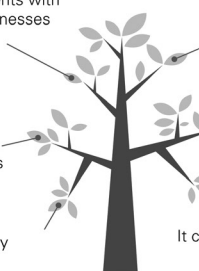
IMPROVING ACCESS TO PALLIATIVE CARE

WHAT IS PALLIATIVE CARE ?

It is care for patients with life-threatening illnesses & their families

It can be given in homes, health centres, hospitals and hospices

It improves quality of life

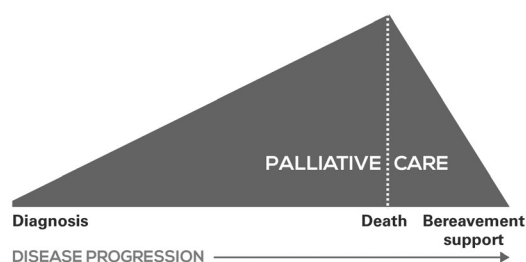


It benefits health systems by reducing unnecessary hospital admissions

It relieves physical, psychosocial & spiritual suffering

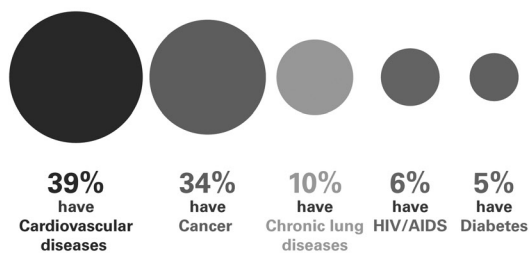
It can be done by many types of health professionals & volunteers

WHEN IS PALLIATIVE CARE NEEDED ?



WHO NEEDS IT ?

Of the **40 million** people who need palliative care each year:



86%
of people who need palliative care do not receive it



83%
of the world's population lack access to pain relief



98%
of children needing palliative care live in low and middle income countries

WHAT ARE THE BARRIERS ?



Poor public awareness of how palliative care can help



Cultural & social barriers, such as beliefs about pain and dying



Insufficient skills and capacities of health workers



Overly restrictive regulations for opioid pain relief

WHAT CAN COUNTRIES DO ?

Implement the 2014 World Health Assembly Resolution 67.19 on palliative care, by:

INTEGRATING PALLIATIVE CARE INTO NATIONAL HEALTH POLICIES



Revise laws & processes to improve access to opioid pain relief



Include palliative care in the training for health workers



Provide palliative care services, including through primary health care centres and homes

4

Community Participation in Palliative Care

(60 MINUTES)

INTRODUCTORY STATEMENT

Whatever be your background, whatever be your relationship with the patient, there is only one question to ask when you face a person with incurable illness. “How can I use my skills and knowledge to reduce his/her suffering?” In other words, “How can I be a compassionate presence to someone who is suffering?”

ACTIVITY

- Discuss the ways in which we can support a bedridden, elderly or dying patient and his/her family?
- How can we find likeminded people to do this?
- How can such people in an area work together?

(10 minutes for discussion, 10 minutes for reporting back)

SUMMARIZE (15 MINUTES)

1. Quality of care can improve when people with different background and skills participate in the care of the patients.

In every society, there are people who are interested in serving and helping patients. We only need to locate them, orient them and ensure their participation in patient care.

2. It will be good to prepare a list or map of the geographical area one can cover. Look out for community volunteers in these areas. Make a list of possible likeminded people/ groups/organizations.

3. Training programmes can be used to fill the gaps in skills and knowledge. For example, how to offer emotional support or how to prevent pressure sores, etc.
4. It will be good to establish a system of keeping in touch with each other and supporting each other.

POSSIBLE STEPS IN SETTING UP A COMMUNITY-BASED PALLIATIVE CARE UNIT

- **Step I: Sensitization:** In any region, there will be people interested in helping others. Many of them might already have been helping others in their individual capacities. The idea is to sensitize them to the problems of patients with incurable diseases and also to get as many of them together as possible. The first step is to get those who are likely to be interested to an awareness meeting/discussion. This will be the responsibility of the local lead. All of the groups/organizations involved in social reform or healthcare activities in the region are to be invited. This meeting should ideally be convened by a 'neutral' local group or institution to ensure participation from the different interest groups/organizations in the region. Explain the issue of incurably ill and bedridden patients in the region. Discuss possible way to help them. Register those who are willing to spend a couple of hours every week for such patients as volunteers. Sensitize healthcare workers in the region.
- **Step II:** Establish a homecare programme as a demonstration project in the region.
- **Step III:** Train those who are willing to get trained in basic nursing care, communication skills and/or emotional support. The training should be done locally and also at a time and venue convenient to the majority of the participants. Get the trained volunteers to document the problems of bedridden/incurably ill patients in their neighbourhood (use a proper form such as the community volunteers patient care protocol). It is important to have weekly review meetings of the new volunteers at this stage. These review meetings can be used to discuss solutions to the problems documented by the volunteers. Initiate a social support programme to support food for starving families, educational support to the patients' children, emotional support to patients and families by trained volunteers, and similar activities. Establish a contact point for giving and taking information. A space available with one of the new volunteers or well-wishers can be used (a local shop, public library premises, etc.). Start collecting money,

manpower and other resources. Link with the nearest palliative care unit if one is available. Train healthcare workers in the region.

- **Step IV:** Adding a nursing component to the programme is the next step. It may take 1–2 months for the local group to establish a stable social support system and to raise money to employ a part-time nurse. Getting the services of a nurse in the neighbourhood is the best option from the long-term point of view. Encourage the nurse to get trained in palliative care. Initiate nurse-led homecare programmes under supervision of the project team. In certain situations, help from the nurse from a nearby palliative care unit might be available. Use the nurses' protocol as guide to nurse-led homecare. Establishing a culture of meticulous documentation and review is important.
- **Step V:** Providing the medical component is very often the most difficult part due to 'scarcity' of trained doctors. One possible option is to get help from a local doctor in medical issues. Self-study by the doctor can be facilitated by regular supply of reading material and online materials. Thereby we can assure the availability of the doctor in the project team to guide. Encourage the doctor to get formal training in palliative care.
- **Step VI:** Once the homecare service starts getting established, there will be a need for a regular outpatient clinic. Availability of a trained doctor and nurse is a prerequisite. Remember that starting an institution (outpatient clinic/inpatient services) is more expensive than initiating a homecare programme. The facility can very often be linked to a local hospital.
- **Step VII:** Establish a system of regular review and evaluation. Any palliative care or supportive service usually generates good appreciation from the local people. It is important not to get carried away by the good words. Active attempts at identifying areas for improvement should always be there.
- **Step VIII:** Continue with steps I and II in a nearby area with the help of the team already established.

5

Ethical Issues

(150 MINUTES)

ACTIVITY 1

Words; Morality, Ethics, Law

What do you understand when you hear these words? Explain with examples

(General discussion 10 minutes)

SUMMARIZE (10 MINUTES)

ETHICAL PRINCIPLES WHILE LOOKING AFTER PATIENTS

(15 MINUTES)

- Autonomy: Principle of respect for autonomy
- Non-maleficence: Principle of avoiding harm to others
- Beneficence: Principle of doing good
- Justice: Principle of fairness and equality

ACTIVITY 2

Based on the ethical principles mentioned, discuss the dos and don'ts while caring for a patient. (15 minutes for discussion, 15 minutes for reporting)

SUMMARIZE (5 MINUTES)

RIGHT TO KNOW/ RESPONSIBILITY TO KNOW

ACTIVITY 3

Discussion in groups

- Do you think that the patient should know the diagnosis and prognosis? Why?
- Do you think that YOU should be told the diagnosis if YOU are diagnosed to have a major disease? Why?
- Do you think YOUR FAMILY MEMBER AND NOT YOU should be told the diagnosis? Why?
- Is it the responsibility of the patient to know the diagnosis and prognosis

(Discussion for 15 minutes. Reporting 15 minutes.)

SUMMARIZE (10 MINUTES)

Remember that when the patient is asking about the diagnosis or prognosis, the reason behind it need not always be the desire to get the facts. It can be a plea for reassurance, an expression of helplessness or cross checking some ideas/beliefs/facts. It is important to know what the patient really wants. Remember that being honest is an important way to foster trust and show respect for the patient. Patients may lose the trust in the carer if they discover or perceive lack of honesty. But harsh disclosure of truth can be brutal and damaging. When a request for information about the diagnosis or prognosis comes up from the patient during the course of a conversation, the carer can agree to discuss the issue with the treating doctor or to collect the necessary information from the healthcare professional and convey. Often families will ask to withhold a serious diagnosis or prognosis from the patient because they want to spare their loved one the potentially painful experience of hearing difficult or painful facts. A discussion with family members to allay these concerns is necessary in such situations.

In addition to fostering trust and demonstrating respect, collecting and giving truthful information to patients helps them to become informed participants in important health care decisions.

ACTIVITY 4

You are a volunteer carer looking after a 55-year-old man with advanced cancer. The patient's family also loves and respects you. During the course of conversation, the patient tells you about a relationship he had with another woman during his younger days, information he has not revealed to anyone else before. He says he feels guilty about the way he broke that relationship.

When you are about to leave, the patient's wife asks you what you were discussing. She was curious as she found the patient upset.

What will you tell her?

What should the volunteer do if the patient tells you something and asks you not to tell the doctor or nurse about it?

(Discussion in groups for 15 minutes, reporting 15 minutes)

SUMMARIZE (10 MINUTES)

Confidentiality:

A confidential relationship between the carer and patient is essential for the patient to share personal information relevant to care. Patients must be able to trust the carer. Only in a setting of trust can a patient share their private feelings and personal history. This will help the carer to get a holistic picture and decide on areas of possible intervention. Confidentiality is central to this trust. Confidentiality is not only an ethical issue but a legal obligation also. Always remember that a carer is entrusted with information about the patient solely to be of service to that patient.

The most important thing is to talk to the patient and understand why he is insisting not to inform the doctor or Nurse.

Concepts

- **Ethics** is the study of how we decide what is wrong and what is right.
Terms Ethics and Morality are very often used synonymously
Ethics are followed because society has decided that it is the right course of action.
It is dependent on the prism of others
- **Morality** is seen from the perspective of an individual. It is followed because a person believes that it is the right course of action
- **Law** is conditions regulating behaviour of people, formulated and enforced by governments

6

Communication Skills

(180 MINUTES)

Ask one person in the group to narrate an experience in which a communication process went wrong (did not have the intended result or had the opposite result). Also, his/her thoughts now on why this happened. (10 minutes)

Communication is a process by which two or more people exchange ideas, facts, and feelings in a way that each gains a common understanding of the meaning, intent and use of a message.

Good communication with the patient serves many purposes. It helps in identifying the patient's concerns. Some of the concerns are expressed explicitly, but some are unexpressed and will come out only upon exploration. The process of communication should be helpful in building trust and reducing uncertainty.

Good communication skills can be learned. Communication can be verbal and non-verbal.

Ask the group for a few examples of non-verbal communication

VISITING PATIENTS

Almost everyone visits family members, friends, colleagues or neighbours with a serious illness. Usually people do this without any preparations.

ACTIVITY 1

Discuss the following:

1. Are there any preparations needed from our part when we visit a patient?
2. What do you talk about with the patient?
3. What are the dos and don'ts in such a conversation?
4. How do you conclude the conversation and take leave?

(Discussion in groups for 15 minutes, reporting 15 minutes)

SUMMARIZE (15 MINUTES)

- Remember that you are visiting basically to support the patient. Remember that your role will be to be a compassionate presence.
- Inquire what time would be convenient for the patient and family to visit.
- Inquire whether the patient is in the mood/mindset to talk before starting a conversation.
- Explore what is the topic that the patient wants to talk about.
- It's OK to admit if you do not know what to say or how to start.
- Do not mention or compare with other patients.
- Do not criticize the care/treatment the patient is currently getting.
- Do not offer premature reassurance.
- Do not destroy hope.
- Do not prevent the patient from asking difficult questions/saying uncomfortable things.
- Do not confuse the patient or family by suggesting other treatment methods/magic remedies.
- When you take leave, tell the patient and family if you plan to visit again. Check whether the date and time suggested will be convenient.

BARRIERS TO COMMUNICATION

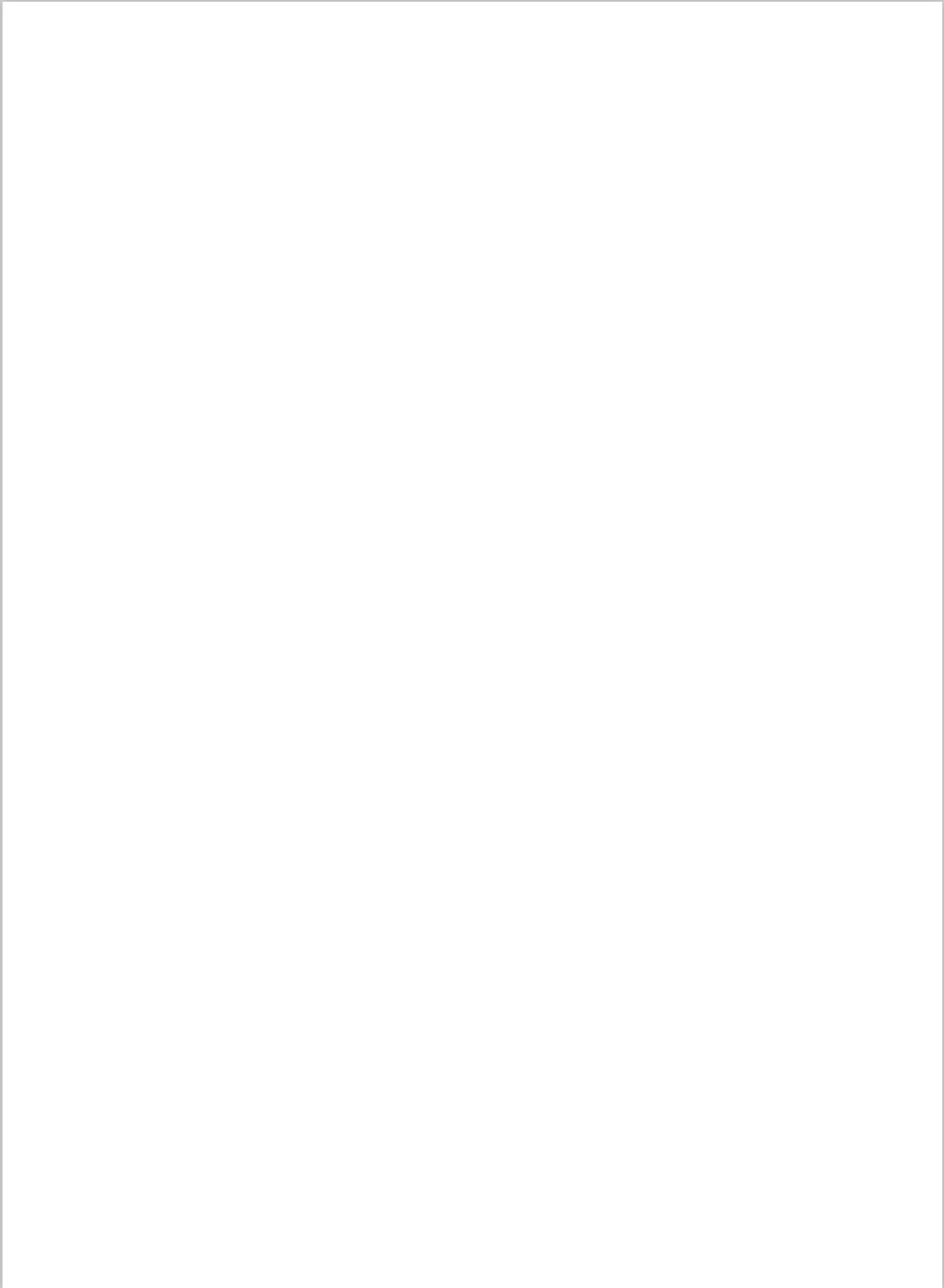
ACTIVITY 2

Discussion in groups

Difficulties in communication with patients: The difficulties can be due to individual factors (patient or carer) or social factors.

- Discuss your difficulties
- Generally, what are the barriers to proper communication with patients?

(Discussion for 15 minutes. Reporting 15 minutes.)



Summarize barriers to communication (5 minutes)

- Physical
 - Deafness or hearing loss
 - Blindness or impaired vision
 - Aphasia or speech disabilities
- Psychological attitudes and prejudice (of the carer, family, patient and society)
 - Prejudice
 - Attitudes
 - Personality
- Cultural diversity

ACTIVE LISTENING

ACTIVITY 3

Discussion in groups

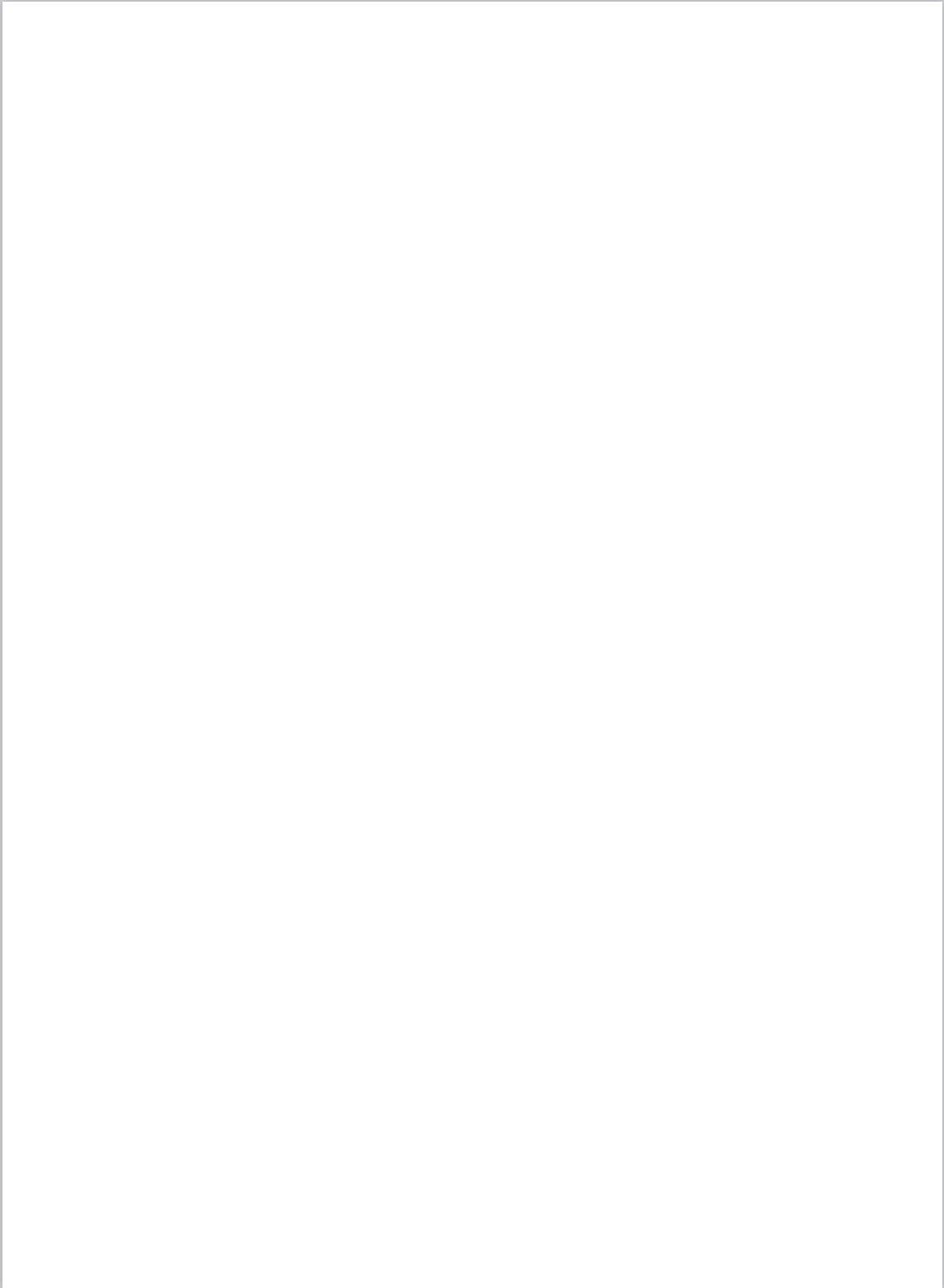
Group work: Attributes of good listener: How do you want the listener to listen when you talk to him/her? (Discussion in groups followed by reporting).

Group Work: Attributes of good speaker: How do you want the speaker to speak when he/ she talks to you? (Discussion in groups followed by reporting).

or

Group exercises should be carried out in pairs with an attentive listener versus an inattentive listener. A feedback is to be collected on what the speaker felt.

(15 minutes for group work, 15 minutes for reporting).



SUMMARIZE THE CONCEPT OF ACTIVE LISTENING

(15 MINUTES)

“Listening is different from hearing”: Hearing is merely noting that someone is speaking whereas listening is making sense of what is heard. This will mean that the listener pays constant attention, interprets, and remembers what is heard. Hearing is passive; listening is active.

Suggestions for improving listening skills (*adapted from Baylor University’s Community Mentoring project*)

- Make eye contact with the speaker: Helps in focusing attention, reduces the chance of distraction and is encouraging to the speaker. Lack of eye contact may be interpreted as disinterest or disapproval.
- Show non-verbal signs of being interested: For example, affirmative nods and appropriate facial expressions.
- Avoid distracting actions or gestures: Actions and gestures such as attending phone calls, looking at other people, playing with pens or pencils, shuffling papers, etc., will make the speaker feel like the listener is not interested in what is being said.
- Ask questions: Questioning helps ensure clarification of what the speaker is saying, facilitates understanding, and lets the speaker know that the listener is engaged. Know the difference between open questions and closed questions and the role of each.
- Paraphrase: Paraphrasing means restating what the individual has said in different words. This technique allows the listener to verify that the message was received correctly.
- Avoid interrupting the speaker: Allow the speaker to complete his or her thought before responding, and do not anticipate what he/she will say.
- Do not talk too much: Talking is easier than listening intently to someone else. Recognize that it is impossible to talk and listen acutely at the same time.
- Summarize: Recount in a few words what you have understood at the end of conversation

These are 3 important steps to understand emotions:

1. **Empathize:** We try to see and hear the patient's feelings (e.g. sadness, joy, anger, anxiety, fear), by comparing them with our emotional experiences (emotions that we have experienced often). But sometimes the emotional state we perceive in the patient can be wrong. So we can understand the patient's response by saying, 'I think you're in a good mood / sad mood (which feeling we understood) to see what we assumed was right or wrong.'
2. **Validate:** Understand and accept that the patient has the right and full authority to experience any emotion. "It seems natural for you to feel this state of mind (sadness, fear, etc.), I am only trying to understand"
3. **Explore:** Find out the reasons behind the patient's emotions so that the patient's condition can be deeply understood. "It would be nice to know the most important things that cause you fear / sadness / anxiety"

Thoughts / Feelings: Often patients are reluctant to express their thoughts and feelings. If you can create an opportunity, a patient may express his/her feelings or thoughts. Ask appropriately, e.g. 'What are the most recent thoughts in your mind', 'What have you been thinking off lately?'

Introduction to Role play

(10 MINUTES)

Role play is a training program that creates an imaginary situation that helps to improve the ability to communicate empathetically. Role play presents the same problems that are encountered in real patient care. But instead of a patient or a caregiver, someone who participates in the training plays that part. Such situations are presented during training sessions. This will help in developing the ability of health workers, including volunteers, to respond appropriately to the social and psychological problems of the patient and family.

The following skills can be improved through role play

- Intervention in patient care beneficially
- Understand the patient's difficulties and circumstances
- Understand the positive aspects of their communication skills and the aspects that need to be improved

Presentation Rules

Role play generally has two characters:

- Someone presents the patient, or patient's family member
- Another is a health worker / volunteer

The trainer should explain how to play the role, and what the role of each member of the group is.

Both role players will be given a note explaining their situation (do not show it to each other. Ask the trainer if anything is not clear)

While two are characters, the others should be observers and analyze the presentation.

Presentation time will be 5 to 8 minutes and at the most 10 minutes. One of the observers should be instructed to stop the role play when the time is up.

Video recording may be helpful, but it should only be done with everyone's permission. When analyzing role play, you can display the video and watch and learn from it.

Points to observe during presentation:

Points to remember while playing the character of the patient / family member. The issue should be handled in a relevant manner without unnecessarily harassing the health worker / volunteer or making the situation too mild

The volunteer character should read and understand the explanatory note to begin the conversation with the patient (or family member). Must be aware of time constraints. Training should be seen as an opportunity to improve his/her skills. Playing a role with the understanding that he/she has no flaws in communication will be an obstacle in improving their skills.

After the presentation

1. First the patient character should tell about his/her experience. Comment on what felt good about the intervention on the part of the volunteers and what could have been improved.
2. Next, volunteer should tell about the experience, what he/she did well, and what he/she could have improved

3. Next is an opportunity for observers to comment. The feedback should be mainly about the involvement of the volunteer. Always comment on positive aspects of volunteer communication first and then what and how to improve. It is better to suggest how to avoid the flaws rather than to point out their mistakes.
4. The role play video can be displayed at any time during analysis. In general, it is effective to show the video first and then comment. Relevant parts can be re-displayed if there are any doubts during the discussion.

Things to consider when evaluating the role play

- First discuss the good parts of the presentation and then how to improve the shortcomings.
- It is more important to evaluate the communication of the volunteer than the character of the patient.
- Volunteer's behavior, expressions, gestures (non-verbal communication/body language); and the use of language and words (verbal communication) can be described separately.
- Acting skill in presentation is not important. A detailed assessment of how the potential problems were handled is important.

The following is an example of role play. Other situations like this can be created. It would be helpful if the trainer prepares more role plays like this.

Example:

(10 MINUTES)

case 1 : Patient

You are Raju and are 18 years old and studying for a first year degree (undergraduate). His family consists of father, mother and brother living with him. He played football well at a young age itself and wanted to become a professional football player. He is a big fan of Messi and the Barcelona team. He used to stay awake to watch football matches on TV.

You now have cancer and paralyzed below the waist and unable to walk and has been under palliative home care for some time.

You have a lot of problems both mentally and emotionally. Now you are in a state of not feeling any interest in anything. He has some worries and anxieties (can I walk anymore? Can I still play football? etc) about the future, and not watching football matches on TV as in the past. You have not shared these concerns with anyone. When you talk to a volunteer you can talk about it if you are interested in sharing, and leave it if you are not interested.

Volunteer

Raju is a patient you have known for some time. You have visited Raju's house many times before and talked to his parents. When you saw Raju's father on the way yesterday, he told you about Raju's present situation. He has not been watching TV for the last few days and he also lost interest in football. He is always thinking about something. Today you are going to see Raju, try to find out things from him and respond appropriately to what he says.

Discussion / Feed back (20 Minutes)

Start with "Raju" followed by other participants

- Good practices that you observed
- Communication issues that you observed
- Things which could have been improved

Summary (5 Minutes)

7

Physical Problems

(60 MINUTES)

This is an 'interactive lecture' on the role of carer in offering support and documenting symptoms.

PHYSICAL SYMPTOMS IN ADVANCED DISEASE

One or more of the following symptoms can be present in advanced diseases.

PAIN

Prolonged pain is a main problem faced by most of the patients with advanced diseases. This is particularly so in the case of individuals with cancer, 80% of whom suffer pain in various stages. Such severe pain is experienced also in peripheral vascular diseases and joint-related diseases. Patients bedridden due to age or stroke or advanced diseases experience generalized aches and pains during movement.

Acute pain that lasts for a short period of time is different from severe pain that lasts over a long duration. Such pain engulfs the whole person and affects the individual's personality and lifestyle. This pain also constantly reminds the patient that the illness persists. A feeling of isolation, disappointment, remorse and anxiety aggravate the pain.

It is not possible to measure the severity of a person's pain or compare it with another person's pain from the outside. One has to believe the patient and it is important not to make biased judgments. Since we can never be in the shoes of another person, our judgment of the patient's problem will be realistic only if we believe the patient.

Detecting the cause of pain and administering the required medication at proper intervals will help control the pain in most of the cases.

Apart from medicines, emotional support, expressions of empathy and love, sense of security of having helping hands around, and control of other symptoms will bring a lot of relief to the patient's pain.

FATIGUE

Persistent tiredness is the most prevalent symptom associated with advanced diseases. It affects both body and mind and can have a broad impact on physical, emotional, and social wellbeing.

Care

A doctor or nurse will be able to advice on correctible factors and sometimes medicines. Supportive measures include

- Plan rest periods to conserve energy for important activities/events
- Schedule necessary activities spread throughout the day rather than all at once
- Engage in light activities
- Get enough rest and sleep
- Eat a nutritious diet, including plenty of liquids

VOMITING

In an illness such as cancer, problems in the oesophagus (food pipe) and stomach/bowels often result in severe vomiting and nausea. Chemotherapy medicines used in cancer also causes vomiting. Vomiting is found in bedridden patients due to many other reasons too.

Care

- Try to provide care to the patient in a well-ventilated room.
- Avoid smells that cause nausea, for example, smell of cooking, smell of antiseptics etc.
- Give small portions of food at frequent intervals instead of big meals at one time.
- Try to make the patient sit up while eating and do not let him lie down immediately after food.
- Give the patient the food that he/she prefers.
- Make sure that the patient takes plenty of fluids.
- Make sure that medication prescribed for vomiting is taken in the proper dose at the proper time.
- Do consult the doctor or a nurse in case the vomiting is not settling down.

CONSTIPATION

Constipation is common in chronically ill patients, especially the bedridden. This happens generally due to decreased intake of food and water, lack of fibre in food, lack of exercise, etc. As the body weakens, the patient finds it difficult to go to the toilet and needs help. Lack of privacy also is an issue very often. In the case of cancer patients, certain medicines as well as problems in the bowel can cause constipation. Lack of bowel movement for a long time hardens the stool and may require removal by giving enema or even manually. Hence, one has to make the patient and family members understand the importance of taking the medicines for bowel movement regularly. Ensure privacy for the patient and provide a commode or bed pan, if required.

DIARRHOEA

Long-term and bedridden patients often suffer from diarrhoea from time to time. The patient, when given medicine after a few days of constipation, is bound to have a few loose stools. But sometimes the stool hardens and then liquefies to present as diarrhoea. The treatment is an enema. Diarrhoea is also caused through infection through food or water. Whatever be the cause, loose motions puts the patient and family in difficulty. If the patient becomes weak, arrange for a bed pan or commode. Give him lot of fluids for intake (tender coconut, oral hydration solution, etc.). Consult a doctor if the problem is not settled.

BREATHLESSNESS

Breathlessness is common among patients suffering from many long-term illnesses relating to lungs, heart, kidney and so on. While some of them continue walking or doing other daily activities, others are unable to sit or even lie down due to severe breathing difficulty.

Patients with breathing difficulty go through a lot of anxiety and fear, which aggravates their problem. At such times it is necessary to create a calm atmosphere and reassure them.

Care

- Provide care to the patient in a well-ventilated room.
- Fan should be switched on or use a hand fan.
- Loosen the garments worn.

- Make the patient sit or lie down in his most comfortable position.
- Make arrangements for him to lean comfortably when seated. Give water as and when required.
- Do not allow people to crowd in the patient's room.

EXPLORING AND DOCUMENTING PHYSICAL PROBLEMS

It is important to explore the following points when a patient complains of a symptom.

- What is the meaning of that symptom to the patient?
 - Of the symptoms that have been bothering the patient, which symptom bothers him/ her the most?
 - How do the symptoms affect him/her? How much do they interfere with his/ her life (e.g. sleep/daily activities/sense of well-being)?
 - What ideas does he/she have about the meaning of these symptoms?
 - Do they make him/her worry about health/illness? What are his/her concerns?
 - How are these symptoms affecting his/her family and friends?
- When did the symptom start?
- Where is it?
- Which all are the factors relieving and worsening the symptom?
- Is there any related factors/symptoms?
- How severe is it?

ADMINISTERING PRESCRIBED MEDICINES

The patient has to follow given instructions if the medicines are to be effective. Giving more than what is prescribed or less than what is prescribed can prove harmful.

Discuss the reasons for the patient not taking medicines as prescribed (elicit comments from the group).

Sometimes the patient is seen not taking medicines properly.

- Did not understand the instructions?
- Unable to afford the cost of medicine.
- Being fed up with prolonged treatment and / or large number of medicines
- Need to take medicines at short intervals.
- Side effects caused by the medicines
- Fear of getting addicted to the medicines.
- Dislike for the smell, colour or taste of the medicine.

WHAT CAN THE CARER DO?

- Find out the details about effect, dosage, etc., of each and every medicine.
- Where medicine is not taken as per instructions, find out the reason.
- Try and find out difficulties in taking the medicine.
- If you are aware, make the patient and family understand the effect and importance of each medicine, proper dosage and timing, etc.
- Teach the family members to take care that the medicines do not get mixed up.
- Also teach them to keep the medicines in a dry cool place (keep in an airtight container).
- Follow up on subsequent visits.

8

Spiritual Issues

(150-MINUTES)

INTRODUCTORY STATEMENT

Spirituality is a very fluid concept. People tend to define it in very different ways. Some associate it with their concept of God. Some do not.

ACTIVITY 1

1. Are all religious persons spiritual ? Can a non religious person be spiritual ?
2. Are all believers of God spiritual ? Can an atheist be spiritual ?
3. What do you consider as a spiritual issue? One example?

Brainstorm in small groups (15 minutes). Report back (15 minutes).

ACTIVITY 2

DEFINITION OF SPIRITUALITY

“Spirituality is a dynamic and intrinsic aspect of humanity through which persons seeks ultimate meaning, purpose and transcendence and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices.”

This is a definition of spirituality by an international consensus group. (DOI:10.1089/jpm.2014.9427)

Encourage one person in the group to read out the definition and explain. Facilitate a discussion (15 minutes).

INTERACTIVE SESSION ON SPIRITUAL ISSUES AT THE END OF LIFE

(5 MINUTES)

CONCEPT OF SUFFERING

Any experience in which we experience emotional pain can be suffering. We also get stuck in unpleasant emotions, in this difficult time in life, whether the cause is big or small. This also includes a lot of negative emotions. This might have happened to all of us in life at some point or other.

“Man is not destroyed by suffering; he is destroyed by suffering without meaning.”

~*Victor Frankl*

(Austrian neurologist & psychiatrist as well as a Holocaust survivor)

Frankl argues that suffering ceases to be suffering once we are able to find a meaning in life at that point. “What matters is not the meaning of life in general but rather the specific meaning of a person’s life at a given moment” (another quote by Frankl).

ACTIVITY 3

Look back on your life and reflect on an event or experience you consider as meaningful. Share with others if you feel so (2 minute for reflection; 8 minutes for sharing by those who volunteer).

INTERACTIVE SESSION ON SUFFERING AT THE END OF LIFE

(15 MINUTES)

There are a lot of unresolved issues which can cause spiritual pain in a person with advanced illness or old age. Typical examples are as follows:

- Physical symptoms
- Unfinished business
- Pain of leaving things behind (relationships, money, power, reputation, etc.)
- Loss of control on life and loss of dignity
- Feeling of being a burden
- Financial problems
- Broken relations in the past

ROLE OF CARER

The role of the carer is to encourage and help the patient to find meaning at the difficult given point in life. The carer is not expected to (and cannot) give a solution to the patient's spiritual problems as each individual is unique and the carer is a different person than the patient. This is so even when the patient and carer share similar or the same religious, political or social values. Sharing a similar value as the patient may nevertheless make the facilitation process easier.

It is important that the carer herself/himself is comfortable in his/her ability to help the patient. Being aware of one's own philosophy of life and death and one's own limitations is a prerequisite for effective facilitation.

ACTIVITY 4

Reflect on your strengths and weaknesses in each of the following areas. Write down two of your strengths and weaknesses in each area. Share with others if you feel so (10 minutes for reflection and writing down. (10 minute for sharing).

PHYSICAL

EMOTIONAL

SOCIAL

Interaction with the society outside including, but not limiting to, friends and family

SPIRITUAL

Meaning of life, values and beliefs and practice

ACTIVITY 5 (30 minutes)

How will you elicit the strengths and weaknesses of patients in all the above four areas? Suggest questions

INTERACTIVE SESSION

A 20-minute interactive session to discuss what can be done to support the patient in his/her spiritual journey at this difficult time.

SPIRITUAL CARE

The carer should be able to identify spiritual issues and to facilitate healing. Assessment requires a quiet, conducive environment. One has to express interest and ask specific questions (checklist given as appendix). Actively listen to patient's fears, hopes, pain, and dreams. Explore the meaning and values in the patient's personal life. How does he see the illness and its associated difficulties? Explore religious faith

Encourage the patient to explore meaningful moments in his/her life. Be aware of one's own beliefs and biases. Make sure that they do not distort the communication with the patient. Be a compassionate presence in the patient's life. Attentiveness to all (body, mind and spirit) dimensions of the patient and patient's family is important

9

Socioeconomic & Emotional Issues

(150 MINUTES)

ACTIVITY 1

Gopal, a 38-year-old manual labourer, had a fall from height, causing permanent damage to the spinal cord. He is now at home after getting discharged from the hospital. Both of his legs are paralyzed. He is on a catheter to pass urine. Gopal has two children, aged 8 and 4. His wife is also neither equipped nor trained to earn money.

Discuss how his present physical condition is going to affect his life and his family's life.

Discuss possible issues related to

- Mobility
- Activities of daily living
- Finance
- Personal relationships
- Social activities
- Health and social care: accessibility and quality
- Transport
- Work/capacity to work
- Home environment
- Carer issues
- Sexuality
- Emotional status

How can you help him?

Discussion in groups (30 minutes), Report back (15 minutes)

SUMMARIZE (15 MINUTES)

SOCIOECONOMIC AND EMOTIONAL PROBLEMS OF PEOPLE WITH PROGRESSIVE INCURABLE ILLNESS

Any physical illness psychologically affects the patient and family. In short-term diseases, the realization and hope that it will be cured, and the support from family and society, help them overcome the temporary difficulties. The situation is different for long term-diseases as those have no cure and get worse over time.

Problems related to the sickness, anxiety about the future, financial worry, fear about the family's future, and isolation together create a serious psychological condition troubling to the patient. These patients have a number of concerns related to their sickness.

- Will my sickness be cured?
- Is the treatment of any use?
- Is this leading to death?
- Are more problems in store for the future?
- How would my last days be?
- Why me?
- Is this due to any fault of mine?
- Will I turn into a burden for my family?

All these questions bother the patient and the severity is much more in the case of life-threatening diseases. These also result in feelings of guilt, disappointment, anxiety, fear, anger, despair and grief.

Most patients are well aware of the financial problems that bother their family due to their illness and treatment. The situation is all the more difficult for families with poor socioeconomic backgrounds.

Isolation, solitude, feeling of helplessness and despair build up pessimistic feelings in the patient. Self-hate, low morale and feeling down are common.

Concerns related to death and dying are also common. Reflections on the past life, feelings of regret, guilt, and sense of injustice also occur. Worries about the afterlife are not uncommon.

WHAT CAN BE DONE?

Very often a supportive conversation and a compassionate presence are helpful. The patient needs to realize that he/she is still wanted in this world, still deserves love and respect and under no circumstance will he/she ever be abandoned. A compassionate presence does not mean just words. Body language, touch, and proximity—everything has a role. Take care not to create any misunderstanding or lose confidence in the family members. The carer is there to listen to the patient, try and understand him/her and not to voice our opinions and force them upon him/her.

1. Listen attentively. Be a good listener.
2. Do not consider the patient's problems as insignificant.
3. Do not force your opinions/beliefs upon the patient.
4. Do not ignore the patient's queries.
5. Try to address the social issues that can be addressed.
6. Do not give any false hopes.
7. Ensure confidentiality.
8. Do not force the patient to talk.

SEXUALITY

Very often, in many cultures, carers find it difficult/embarrassing to explore sexual issues. Sexual issues can arise from various psychological and physical problems; some of which are:

1. Misunderstanding that the disease would spread.
2. Physical deformity caused by the disease that changes one's attitude about one's own body.
3. Deformities caused in sexual organs or other sexually important parts of the body.
4. Disease or treatment may bring about hormonal changes in the body thereby causing changes in the ability and interest in sexual life.
5. Frailty of the body.
6. Lack of privacy.
7. Colostomy, tracheostomy and so on.

WHAT CAN BE DONE?

1. Make sure that the patient gets the time and privacy to spend time with partner.
2. Encourage the patient to open up on his/her problems and needs.
3. In the case of patients with diseases that are transmitted sexually (AIDS/hepatitis) allow them to discuss with the doctor about safe methods of sexual intercourse.

Psychological reactions and difficulties associated with serious illness (20 MINUTES)

- Sadness, worries, anger, feeling fed up , hopelessness , fear, despair, frustration, inability to make decisions, confusion
- Forgetfulness / lack of attention, difficulty in sleeping and loss of appetite
- Thoughts and worries about illness, life problems and death

How can carers help?

- Gain the patient's trust so that you become a good listener and supporter to the patient
- Explore the doubts and questions that the patients has about illness and treatment. Make a note of it so that these can be raised with the Doctor / Nurse/ Healthcare professional .
- Help the patient and family in addressing social issues related to the disease and treatment . for eg : food, finances, travel facilities, and household needs. Interventions if any, should be attempted only with full knowledge and consent of the patient/ family
- Encourage the patient to reflect on resources that can help at the time of crisis. Such resources can be of two types:
 1. Internal resources: (e.g. experience of overcoming any crises, or dealing with difficulties in the past, spiritual beliefs, hobbies).
 2. External resources: (e.g. friends, relatives, acquaintances) – Patient might have got alienated from them due to illness. Explore if the patient is interested in re-establishing contact in such cases.

When to seek professional help for emotional difficulties


1. Abnormal changes in the patient's mental state or behavior (eg, irrelevant speech, delirium, hearing or seeing imaginary things, abnormal thought process, suicidal ideas /attempts, violent behavior.
2. Normal response to difficult situation persisting for long periods. Feelings, thoughts or behaviors that seem natural, if persisting for days/weeks. (e.g. persistent crying/ apprehension/anger/ suicidal ideas)
3. The patient feels temporarily relieved while talking to the carer, but keeps repeating the same behavior/talks distressfully on subsequent interactions.
4. Thoughts, feelings, and behaviors that interfering with the patient's care or treatment (eg behavior that completely negates the condition and neglects care)

If you notice any of the above:

- Ask the patient about it and try to understand how the patient views it (whether the patient sees it as a problem or trivializes it).
- Ask caregivers about it- Do they see it as an important problem or do they think there is nothing unusual about it? (This question should always be asked to caregivers who are with the patient most of the time and who knows the patient well)
- Ask the patient / caregiver to inform the doctor or nurse; Directly Inform the doctor / nurse only with the consent of the patient / caregiver
- Doctor or Nurse should be informed urgently if the patient shows suicidal ideas/ tendency

DISTRESS THERMOMETER

This is a screening tool for the carer to realize that professional help in psychosocial care is needed.

<p>First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.</p>	<p>Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.</p>	
	<p>YES NO Practical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Child Care</p> <p><input type="checkbox"/> <input type="checkbox"/> Housing</p> <p><input type="checkbox"/> <input type="checkbox"/> Insurance/financial</p> <p><input type="checkbox"/> <input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> <input type="checkbox"/> Work/school</p> <p>Family Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with children</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with partner</p> <p><input type="checkbox"/> <input type="checkbox"/> Dealing with close Friend/relative</p> <p>Emotional Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Depression</p> <p><input type="checkbox"/> <input type="checkbox"/> Fears</p> <p><input type="checkbox"/> <input type="checkbox"/> Nervousness</p> <p><input type="checkbox"/> <input type="checkbox"/> Sadness</p> <p><input type="checkbox"/> <input type="checkbox"/> Worry</p> <p><input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities</p> <p><input type="checkbox"/> <input type="checkbox"/> <u>Spiritual/religious concerns</u></p>	<p>YES NO Physical Problems</p> <p><input type="checkbox"/> <input type="checkbox"/> Appearance</p> <p><input type="checkbox"/> <input type="checkbox"/> Bathing/dressing</p> <p><input type="checkbox"/> <input type="checkbox"/> Breathing</p> <p><input type="checkbox"/> <input type="checkbox"/> Changes in urination</p> <p><input type="checkbox"/> <input type="checkbox"/> Constipation</p> <p><input type="checkbox"/> <input type="checkbox"/> Diarrhoea</p> <p><input type="checkbox"/> <input type="checkbox"/> Eating</p> <p><input type="checkbox"/> <input type="checkbox"/> Fatigue</p> <p><input type="checkbox"/> <input type="checkbox"/> Feeling Swollen</p> <p><input type="checkbox"/> <input type="checkbox"/> Fevers</p> <p><input type="checkbox"/> <input type="checkbox"/> Getting around</p> <p><input type="checkbox"/> <input type="checkbox"/> Indigestion</p> <p><input type="checkbox"/> <input type="checkbox"/> Memory/concentration</p> <p><input type="checkbox"/> <input type="checkbox"/> Mouth sores</p> <p><input type="checkbox"/> <input type="checkbox"/> Nausea</p> <p><input type="checkbox"/> <input type="checkbox"/> Nose dry/congested</p> <p><input type="checkbox"/> <input type="checkbox"/> Pain</p> <p><input type="checkbox"/> <input type="checkbox"/> Sexual</p> <p><input type="checkbox"/> <input type="checkbox"/> Skin dry itchy</p> <p><input type="checkbox"/> <input type="checkbox"/> Sleep</p> <p><input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet</p> <p><u>Other problems</u></p> <p>_____</p> <p>_____</p>

A persistent score of more than 5 may indicate a need to seek professional help

WHO 5 Wellbeing Index

(WORLD HEALTH ORGANIZATION, REGIONAL OFFICE FOR EUROPE, 1998)

Please indicate each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers means better well-being. Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3.

OVER THE LAST TWO WEEKS	ALL OF THE TIME	MOST OF THE TIME	MORE THAN HALF OF THE TIME	LESS THAN HALF OF THE TIME	SOME OF THE TIME	AT NO TIME
I have felt cheerful and in good spirits	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
I have felt calm and relaxed	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
I have felt active and vigorous	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
I woke up feeling fresh and rested	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
My daily life has been filled with things that interest me	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

The raw score is calculated by totaling the figures of the five answers.

Depression is considered as a possibility if the raw score is below 13 or if the patient has answered 0 to 1 to any of the five items.

Social Support

People incapacitated with severe physical or mental illness are in need of social support. Support is usually needed in different areas of life including work , daily activities of living social and learning environments to compensate for compromised function and to improve quality of life

Effective support from other members of society will improve patient's self esteem , functionality and trust in others. The process involves listening to the patient and family, exploring gaps in relationships, functionality and emotional wellbeing .

Patient and family should be free to express their views. The feeling of being accepted by the carer encourages the patient to open up.

Possible Interventions include mobilizing resources for financial support, education of children, transport , necessary gadgets etc.

Leisure time activities such as listening to music, watching movies, and talking about topics of interest can be helpful in the case of some of the patients.

Comprehensive psychosocial support is an important component of palliative care, which begins with an early assessment of the strengths and weaknesses of the patient and family. Gaps identified need to be addressed in consultation with patient and family

Guidelines for home visits for psychosocial support

- Introduce yourself during the home visit.
- Be aware that establishing a good relationship with the patient and family may take time.
- If the patient is in a mood to talk encouraging him / her to narrate his/her stories can help in building a rapport .
- Go for open-ended questions preferably.
- Explore the strengths and weakness of the family with the aim of facilitating interventions in the areas of weakness and boosting areas of strength.
- It will be helpful to categorize patients' problems into physical, social, economic, and spiritual. This can be useful in analyzing and finding appropriate approach.
- Discuss possible interventions with the patient and family.
- Prepare an action plan.
- Liaise with experts in the required field if necessary.
- Follow-up , review and modify the action plan from time to time

10

Mobilising Local Resources

(75 MINUTES)

To explore locally available resources to support the patient

ACTIVITY 1

RELIEF FROM DIFFICULT SYMPTOMS

Who can help? How can we facilitate it?

Discuss the details, availability and limits of the healthcare facilities in the neighbourhood. Generate a data sheet.

(10 minutes for preparation, 10 minutes for reporting).

ACTIVITY 2

EMOTIONAL SUPPORT

Who can help? How can we facilitate it?

Generate guidelines for a carer willing to offer companionship to a patient. What sort of training will he/she need? (Refer also to the session on communication to patients.)

Generate a data sheet with details of professional psychologists/counsellors in the area (10 minutes for preparation, 10 minutes for reporting.)

ACTIVITY 3

SOCIAL SUPPORT

Help with daily living, better social interactions, financial support. Who can help?
How can we facilitate it?

- Discuss ways of improving the social interactions of the patient. Make a note.
- Generate a data sheet with details of possible government and non-government programmes/agencies that can help/details of local philanthropists who may help.
- Which transport facilities are available for patients in the area? Pool the details of government and non-government agencies in the area which can help with transportation.

Develop this into a sharable resource list for the area.

(15 minutes for discussion/15 minutes for reporting.)

11

Nursing Care

(120 MINUTES)

Nursing care is basically an area of professional care. A patient's comfort and wellbeing depends a lot on the carer's involvement in this area.

INTERACTIVE CLASSROOM SESSION:

(10 MINUTES)

ORAL HYGIENE:

- Brush and rinse mouth at every 12-hour interval (more frequently if the patient is bedridden). Use a soft brush.
- Soak dentures overnight if the patient is using dentures.
- Apply Vaseline or coconut oil to cracked lips.

SKIN CARE

- Maintain daily hygiene (e.g. sponge bath, shower, wash, hair care, shave, trim nails).
- Maintain clean environment (e.g. clean clothing, well-lit and fresh surroundings and sterile bed linen).
- Assess skin integrity, especially pressure points (e.g. sacrum, hips, heels, ankles, ribs, vertebrae, spine, shoulders, elbows, ears). (Details are given below.)
- A patient with poor mobility needs 2–4 hourly change of position.
- Pad bony prominences for protection and use water bed or air mattress.
- Be aware of friction and shearing forces while moving the patient.

DEMONSTRATION

1. Demonstrate bed making.
2. Demonstrate changing the position of a patient with poor mobility.

3. Demonstrate changing bed sheets of a bedridden patient avoiding friction and shearing forces.

4. Demonstrate how to fill up a waterbed.

(30 MINUTES)



LIFTING AND MOVING PATIENTS

It may be very often necessary to lift and move bedridden patients. Unless done in the proper way, this manoeuvre can be damaging both to the patient and carer.

It is important to keep some key points in mind while shifting patients. Mechanical devices are available to help with this activity. But very often they are not affordable to many patients at home.

1. Consider the weight of the patient.
2. Identify the need for help before lifting. Do not attempt to lift the patient by yourself. Get one partner.
3. Communicate with partner.
4. Have a plan.
5. Use your legs to lift.
6. Have feet positioned properly.
7. Keep weight close to body.
8. Lift without twisting.

PREVENTION AND MANAGEMENT OF PRESSURE SORES:

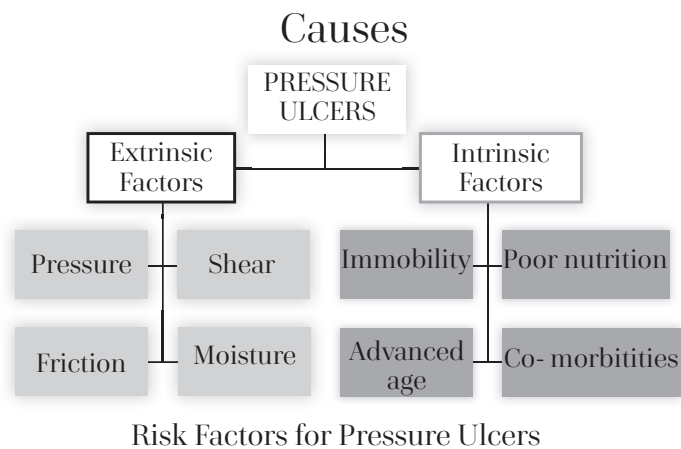
(40 MINUTES)

WHAT IS A PRESSURE ULCER?

Through the ages, this entity was known by several names like ‘bed sore’, decubitus ulcer, pressure sore, pressure necrosis or ischemic ulcer. However, by definition, all these terms refer to “an area of localized soft tissue necrosis caused by prolonged pressure higher than capillary pressure with or without shear and friction, related to posture, usually occurring over bony prominences”. Such ulcers become a nuisance as well as a matter of grave concern for the care givers when it occurs in an otherwise sick patient.

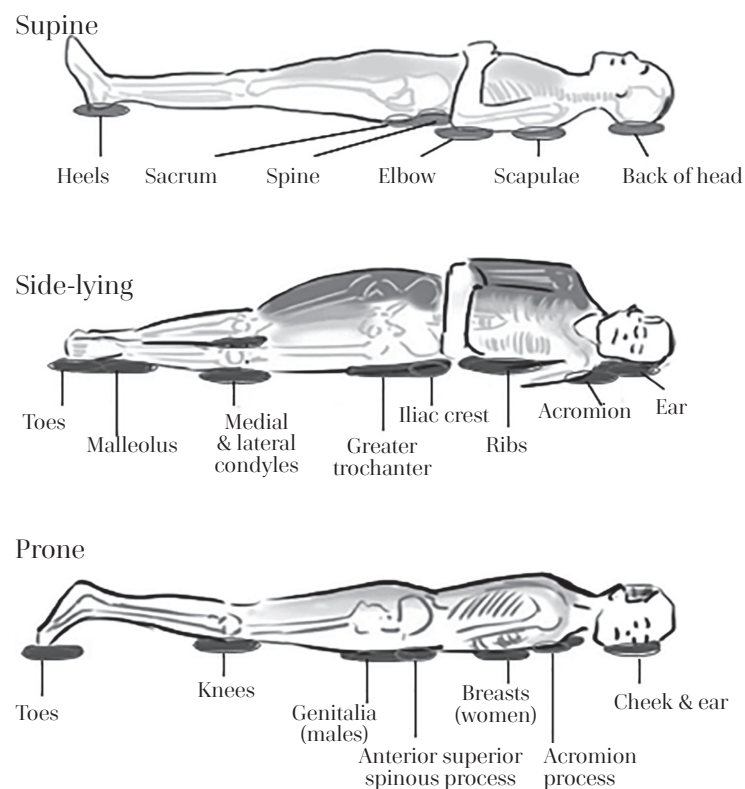
“If he (the patient) has a bedsore, it’s generally not the fault of the disease, but of the nursing.”

~ Florence Nightingale



PRESSURE

Pressure is the primary factor responsible for the development of the ulcer. It varies with body weight and surface area of skin contact. When the incident pressure exceeds the normal capillary pressure for a critical duration of time, blood circulation to tissue is compromised leading to cell death and eventually to skin ulceration.



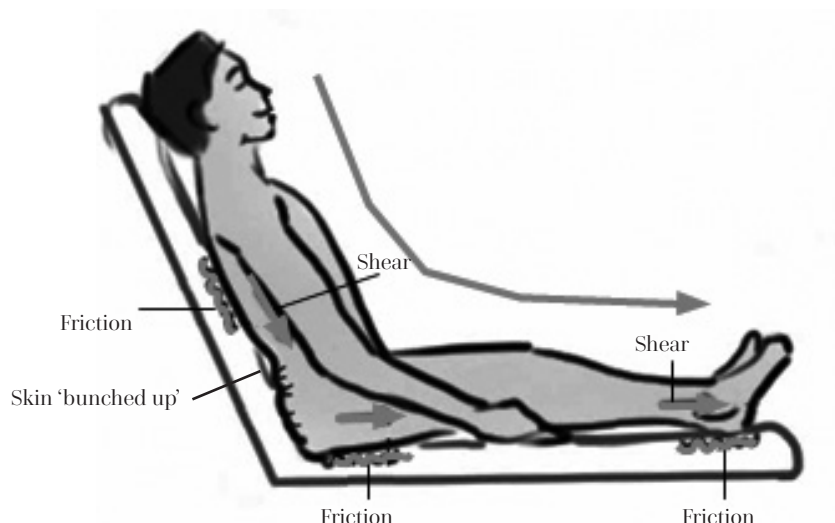
Pressure Points over Bony Points in Different Lying Postures

1. SHEARING

When the body of a propped-up patient tends to glide with gravity over a rough surface, skin and subcutaneous tissue remain stationary and in contact with the surface whereas the deeper tissues slide down. This differential movement will stretch and tear blood vessels to skin and cause ischemia and ulceration.

2. FRICTION

Friction occurs between skin and stationary surfaces such as a bed. A trivial breach in the epidermis of skin by friction causes loss of the protective barrier against infections leading to ulceration. Forceful pulls on bed sheets or clothes also lead to friction. Friction occurs together with shearing.



3. MOISTURE

Perspiration, discharges from wounds, urine or faeces due to incontinence all lead to skin maceration, blistering and eventual breakdown and ulcer. The excess moisture also weakens the skin barrier increasing the susceptibility to pressure, shearing, friction forces and infection.

4. ABNORMAL POSTURE

Pressure points vary in sitting, supine, lateral and prone postures and take the brunt of pressure. Tissues get squeezed between the skeleton and supports such as beds, chairs, shoes, prosthesis or surgical appliances, causing pressure ulcers. A 'hammocking' effect of an unsupported wheelchair, presence of contractures and spasticity will increase the propensity for pressure ulcers.

5. IMMOBILITY

Change of posture in normal individuals is a function of the unconscious mind. This function is impaired in sedated, comatose or neurologically compromised individuals. Unremitting pressure in such patients who sit or lie in the same position for prolonged periods cause pressure ulcers in susceptible areas.

6. NEUROLOGIC FACTORS

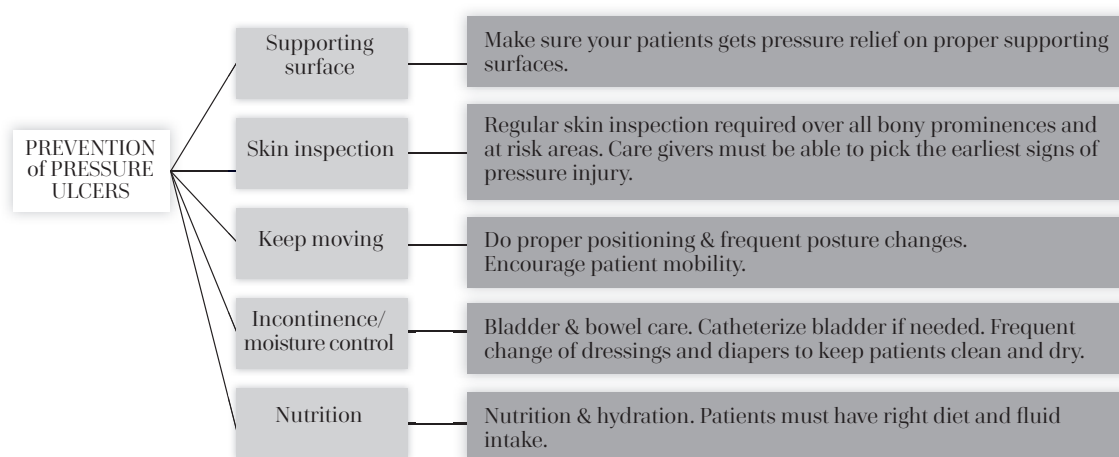
Any abnormality affecting the sensorimotor feedback system between the brain and peripheral senses as in muscle paralysis, impaired pain and pressure sensibility or coma can make a patient prone to develop pressure ulcers.

7. NUTRITIONAL FACTORS

Patients with rapid weight loss need closer observation. Poor nutrition will make a patient prone for pressure ulcers by loss of subcutaneous fat padding. Haemoglobin level is an important indicator of nutritional status. Anaemic patients with reduced oxygen-carrying capacity of blood are more prone to tissue hypoxia and ulceration. Blood transfusions in such patients would increase wound healing.

8. OEDEMA

Soft tissue oedema causes detrimental effects on tissues by decreasing tissue oxygenation, increasing interstitial fluid pressure and reducing blood flow. Hence areas of oedema are prone for pressure sores.



Preventive Measures for Pressure Ulcers

a. Pressure relief

Pressure-relieving mechanisms to reduce ambient pressure on the body by support surfaces and overlays must be used. There are several low-tech or high-tech devices available. These can be static surfaces such as air cushions, water bed or foam bed or gel or silicone cushions or even simple water-filled gloves. Dynamic surfaces offer very good pressure relief but are expensive and need an electric power source. Pneumatic ripple bed overlays or low air loss (LAL) beds use alternating air pressure for pressure relief. Air fluidized mattresses have warm air circulating through ceramic beads which keep the patient-mattress interface warm and dry.

b. Regular inspection

Careful inspection of pressure points of the body by the trained caregivers twice a day or more frequently in higher-risk individuals is required. This will help in detection of pressure ulcers at early stages and prevent their progression to more severe grades.

c. Positioning

- Nursing on pressure relief mattresses and cushions
- Pressure relief of at-risk areas by padding or silicone gel supports
- Careful handling of patients to avoid shear and friction
- Regular repositioning and turning every 2 hours or earlier in high-risk patients
- Alternate lying-down postures: right side, the back and left side
- Use 30-degree side lying position
- Off-loading of the heel
- Special care for patients sitting in wheelchair:
 - Use alternating air pressure cushions (avoid doughnut cushions).
 - Support the feet in wheelchair on a padded surface.
 - Avoid 'hammocking' of wheelchair seat.
 - Encourage patient to hoist himself on elbows at 15-minute intervals.
 - Never allow patient to sit in wheelchair continuously for more than 60 minutes.

d. Nutrition

Restoring nutrition and hydration, a positive nitrogen balance, replenishing trace elements, zinc and vitamin C are all essential prerequisites in pressure ulcer management. Recommended energy intake is 30–35 Kcal/kg/day and protein intake of 1.25–1.5 g/kg/day. Patient weight, mid-arm circumference and skin fold thickness must be charted at regular intervals by the care givers. Haematocrit values must be kept corrected to improve oxygen-carrying capacity of blood. Serum albumin values of 3.5–5 mg/dL or pre-albumin values of 16–35 mg/dL have to be maintained to ensure proper wound healing.

Points Below should be kept in mind while feeding through Nasogastric Tube:

1. Hands hygiene : Wash hands before feeding
2. Patient should be in an inclined position while feeding and should remain like that at least 30 minutes after the food.
3. The food should be given in a liquid or semi liquid form.
4. A small amount (30 ml) of boiled warm water should be given through the tube before and after feeding.
5. Ensure that air bubbles do not get into the tube , air can cause blockage
6. Feed prescribed quantity of food at prescribed intervals
7. Seek Doctors or Nurses help in case of any displacement/suspected displacement of the tube
8. Ensure oral hygiene
9. If the patient is conscious, patient can be allowed to taste the food before tube feeding

e. Wound care

If left uncared, pressure ulcers are capable of progressive involvement and destruction of underlying bones, joints and deeper structures. A patient can lose his life to spreading infection and septicaemia. Most pressure ulcers, however, heal with pressure relief, wound care and attention to general health of the patients.

Preparation of saline for cleaning and dressing at home:

- One pinch of salt in one glass of water or 2 teaspoon salt in 1 litre of water.

- Boil the solution.
- Keep this water in a clean, closed container for it can be used as needed.

Preparation of sterile dressing material at home:

Old cotton cloths that have been washed well with soap and water and dried in sunlight can be used. Cut the clean cloth into small pieces and steam for half an hour and store in a clean, airtight container (pressure cooker/idli cooker). Dry in sun and keep in clean dry containers.

CLEANING AND DRESSING

- Hands should be washed before and after dressing. Use gloves/small plastic bags to cover hands while cleaning and dressing.
- Waste materials should be properly disposed.

PATIENT WITH A URINARY CATHETER

Demonstrate catheter (Foleys and Condom) and urobag/Demonstrate how to empty urobags and reinforce the following points (20 minutes)

1. Observe if urine is draining freely.
2. Empty bag when it is three-fourth full.
3. Cap the urobag after draining urine.
4. Milking of the catheter (outer portion) prevents block.
5. Secure the urobag to the waist while walking.
6. Remember to arrange change of catheter as suggested by the doctor/nurse or when it is blocked.

12 Carers Issues

(45 MINUTES)

Introduction

Carers looking after patients with chronic illness very often have physical psychosocial and spiritual problems related to carer status .

ACTIVITY 1

Ashraf, 35, has been lying paralyzed below the waist for the last 10 years. The family consists of a wife and two children. Wife is the only carer. What are the potential problems she must be going through? Discuss and present all physical, mental, social, financial and spiritual issues.

(10 minutes discussion, 10 minutes presentation)

The following points are likely to be raised during the discussion:

- Physical issues : Pain, Fatigue , Sleep disorder etc
- Work related issues : Household work (cleaning ,cooking etc) , Personal needs (self care)
- Social issues: children's education, entertaining guests, getting stuck at home etc
- Financial issues
- Emotional issues : Fault finding by others, feeling of helplessness, getting fed up etc

ACTIVITY 2

How will you address the issues of caregivers mentioned above?

(10 minutes discussion, 10 minutes presentation)

SUMMARIZE (5 MINUTES)

13 Death and Dying

(60 MINUTES)

ACTIVITY 1

“We all will die one day. But most of us have concerns related to one’s own death. Why is death and dying distressing to people most of the time? What are your concerns about YOUR DEATH if it can happen in near future?”

(DISCUSSION FOR 10 MINUTES. REPORTING 10 MINUTES.)

Summarize (10 minutes)

- Since nobody can escape death, the health care professional need to realise that many of the concerns the patient has about death and dying can also be one's own concerns
- Concerns around death can generally be grouped into three broad categories
 - a. Fear of leaving 'things' behind

Worries about leaving the family, relationships, things that are enjoyed in life, wealth, power, good reputation etc behind
 - b. Fear of the process of death (Fear of facing death)

Worries about where, how etc including end of life symptoms, dependency on others.
 - c. Fear of the unknown after life

Worries about what will happen after death

Death has been a key subject of many religious texts. There have been books / chapters specifically addressing this issue

ACTIVITY 2

What would you consider as a good death? How do you prefer to die ?

One volunteer compiles the responses

(DISCUSSION FOR 10 MINUTES. REPORTING 10 MINUTES.)

SUMMARIZE (10 MINUTES)

I. Preconditions of Good Death currently available in literature

What Do Patients with Serious Illnesses Want? (Singer et al. JAMA 1999;281(2):163-168)

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

II. Summarizes with the generally agreed points on the concept of good death

- Communication. The dying person is allowed to ask questions and get honest and supportive responses
- Symptom relief
- Autonomy.

The dying person is allowed to take decisions about the care he/ she is to be provided

Completing unfinished business

Optimal treatment (not to hasten or prolong death)

14

Grief and Bereavement

(60 MINUTES)

ACTIVITY 1

How do people react when their loved ones die?

How long do people take to recover?

What can we do to help them?

(DISCUSSION FOR 15 MINUTES. REPORTING 10 MINUTES.)

INTERACTIVE CLASSROOM SESSION

(35 MINUTES)

Grief is the natural response to losing something or someone which they hold or feel dear. Bereavement is the state of this loss. It affects the physical, social, spiritual, emotional states of a person. Grief in palliative care setting can be the response of the patient over his loss of mobility or employment; it can be due to the social isolation felt by the patient due to his disease condition. Grief as a response to the death of a loved one is to be critically handled and is thereby explained in detail in this chapter.

Grief is naturally expressed by mourning (i.e., crying or talking about the loss). Understanding the process of grieving will help us to better handle it. There is no apt process of grieving or reacting to bereavement. It is dependent on a lot of variables such as personality, nature of the relation, situational conditions and social supports available. The support for grief should be ideally initiated before death. Grief cannot be suppressed by any pharmacological intervention. A loss of a person with whom you have had a lot of memories will create a void which cannot be filled, leading to a lot of pain. This will be showcased in a lot of different ways.

Points to remember: It takes time to accept the loss after which the person undergoes depression and slowly recovers. The depression phase can be really troubling and the person grieving can even have suicidal tendencies or may feel as if he is going crazy.

The mere presence of a person would be a considerable support for the family. The time required for support may vary considerably from few days to years. The foundation for supporting a person in grief is to listen. Listening rather than speaking can help the person recover. The caregiver should be aware of critical dates like birthdays and anniversaries when the need of support is higher.

The best way to support would be for the caregiver to motivate the grieving person to talk more about the death, enquiring about his or her feelings. This would help them in accepting the loss and pain of bereavement. Never compare their losses with yours and avoid trite remarks or platitudes. Simple pamphlets explaining grief and available counselling services and self-care will go a long way in providing support.

Major changes in sleeping patterns, considerable changes in weight (loss or gain), feeling confused, not being able to concentrate, and being unable to stop crying are all associated with grief. If the person recognizes these problems and is able to talk about it, it is likely that she/he will be able to recover in time.

Persistence of these symptoms for more than a few months, suicidal thoughts, thoughts of harming oneself or others, uncontrollable anger, or worries about one's own behaviour all indicate the need for professional help.

Appendix 1

Reporting format for community volunteers

PALLIATIVE CARE UNIT

(.....)

Report by community volunteer

Details of disease and treatment:

What type of disease?

.....

Duration:

Details of treatment so far:

.....

.....

.....

.....

How much did the treatment cost so far?

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What is he/she getting as treatment now?

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.....

.....

How much does the present treatment cost per month?

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.....
.....

How does he/she meet the treatment expenses?

Is there any help from any local organization or group?

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.....

Is there any help from the government? Details:

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.....
.....

Present status of the patient (Including physical, emotional & social problems)

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.....
.....

Patient's/ family insight about the disease

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.....
.....
.....

List of things that can be done for the patient and family:

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.....

.....

Signature of community volunteer :

Name of community volunteer:

Appendix 2

Proposed modules for sensitization and training programmes

INTERACTIVE TRAINING PROGRAMME FOR CARERS INCLUDING VOLUNTEER CARERS (20 HOURS)

1. What is palliative care?
 - a. A brief 15-minute presentation on what is palliative care, focusing on issues relevant locally.
 - b. Sharing of experiences with incurable illness in the family/friend circle, etc., by 3–4 participants.
2. Carer's responsibilities to patients/community participation in palliative care
3. Knowing about the patient's biomedical, psycho-social and spiritual status

Interactive sessions on problems faced by advanced, chronically bedridden and terminal patients and possible areas of interventions

- i. Socioeconomic issues: Knowledge, skills and attitude
 1. Dependence & issues related to dependence:
 - a. Mobility /lifting and moving
 - b. Activities of daily living
 - c. Financial
 2. Personal relationships—Importance
 3. Social activities—Importance/how to organize?
 4. Social support—Importance/What is possible?
 5. Health and social care—Accessibility and quality
 - a. Description of healthcare and formal social support systems: What is available? How to access?
 6. Transport
 - a. Description of transport systems: What is available? How to access?
 7. Work/capacity to work
 8. Home environment
 - a. Disruptions due to disease

- b. Carer issues
 - c. How to evaluate? How to intervene?
- 9. Sexuality
- ii. Physical Issues: knowledge, skills and attitude
 - 1. Energy and fatigue: Issues/assessment/principles of non-medical interventions
 - 2. Pain: Discomfort and other symptoms
 - a. Symptom/assessment/tips for non-medical interventions until professional help is available
 - 3. Sleep and rest: Issues/assessment/principles of non-medical interventions
 - 4. Prognosis:
 - 5. Know how to administer medicines prescribed:
- iii. Emotional Issues: Knowledge, skills and attitude
 - 1. Feelings: Negative and positive/attitude to the world
 - 2. Distress/assessing distress:
 - 3. Body image and appearance:
 - 4. Self-esteem:
 - 5. Thinking, learning, memory and concentration:
 - 6. When to seek professional help?
 - a. Psychiatric disorders associated with advanced illness
- iv. Spiritual Issues: Knowledge, skills and attitude
 - 1. Spirituality/definition/concepts/ religion and spirituality/spirituality as part of life
 - 2. Taking a spiritual history/assessment of spiritual pain
 - 3. Death and dying/being mortal
 - 4. Knowing how to communicate to the patient in a supportive way
 - a. What are the skills and knowledge that a carer in palliative care needs? (Brainstorming to create a first list of skills/ knowledge. To be prioritized by the mentor explaining the reasons for prioritisation.)
 - b. The carer should know how to communicate to the person in a supportive way
 - i. Discussion following the 'empathy' video
 - c. Barriers to communication (Group work on what are the barriers to proper communication to patients?)

d. Importance of listening skills?

- i. Group work: Attributes of good listener: (each group with 5–6 people) How do you want the listener to listen when you talk to him/her? (Discussion in groups followed by reporting.)
- ii. Group work: Attributes of good speaker: (each group with 5–6 people) How do you want the speaker to speak when he/she talks to you? (Discussion in groups followed by reporting.)

OR

- iii. Group exercises: In pairs with an attentive listener vs. an inattentive listener. (Feedback on what the speaker felt.)

- e. The process of visiting patients/dos and don'ts in communication with patients. (Discussion after showing a video on a badly done visit.)
- f. Exercises on exploring one's own communication style

5. Know the basics of nursing care

- a. Prevention of pressure sores
- b. Sterilization, asepsis, universal precautions
- c. Cleaning and dressing of wounds
- d. Stoma care

6. Know when and where to seek help, for the patient and also oneself

- a. Coping with illness/distress/ distress thermometer
- b. Helpful agencies in the neighbourhood
- c. Self-care
 - i. Need for self-care
 - ii. Knowing one's own strengths and weaknesses

7. Practical issues (Discussions to generate locally relevant information)

- a. Relief from difficult symptoms
 - i. Who can help? How can we facilitate it?
- b. Emotional support
 - i. Someone to talk/listen to
 1. Who can help? How can we facilitate it?
- c. Social support
 - i. Help with daily living, better social interactions, financial support
 1. Who can help? How can we facilitate it?

- d. Spiritual support
 - i. Meaning of life, religious issues
 - 1. Who can help? How can we facilitate it?
- 8. Grief and bereavement (30 minute presentation followed by discussions)

SENSITIZATION PROGRAMME (1 HOUR)

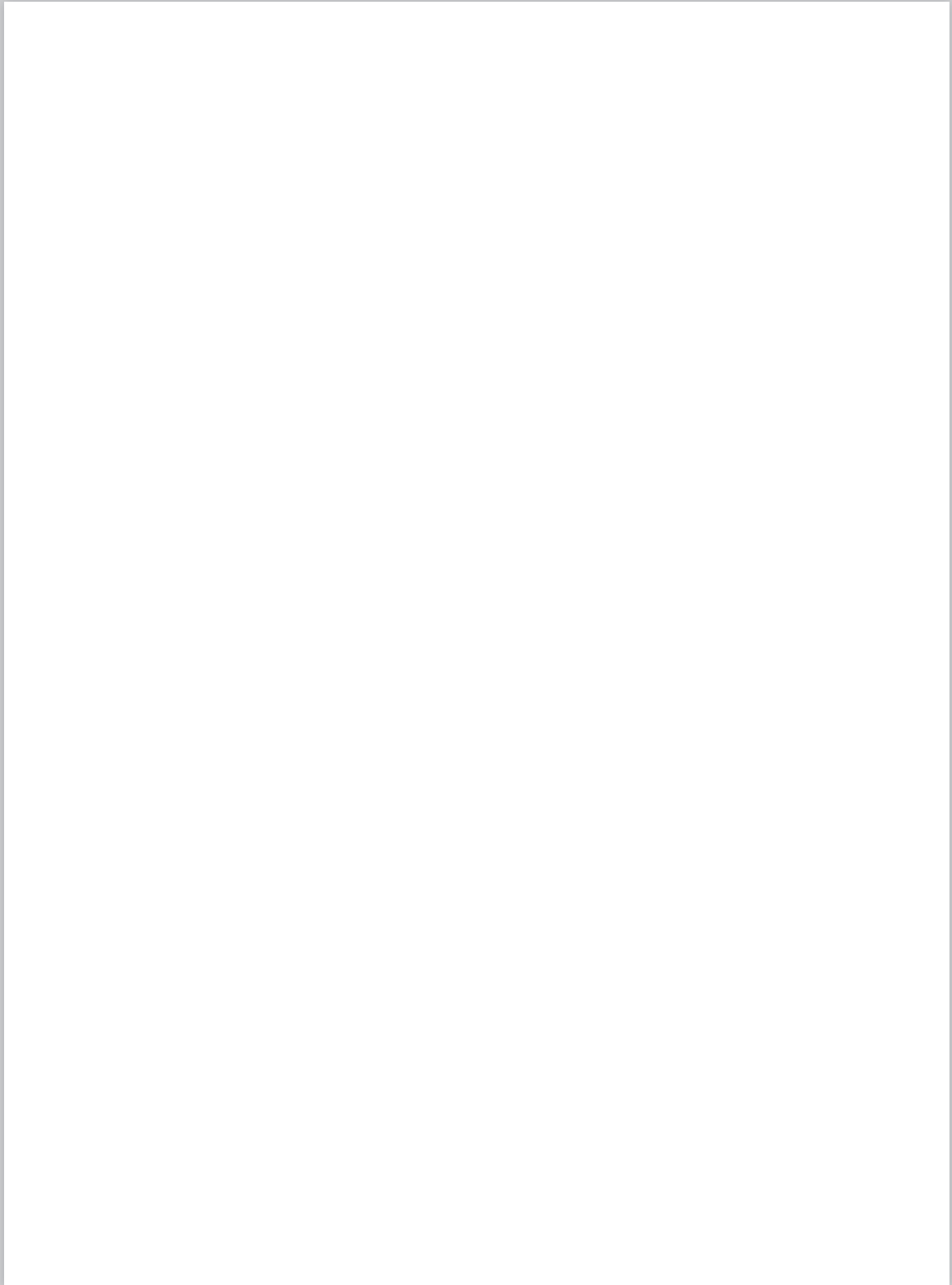
What is palliative care?

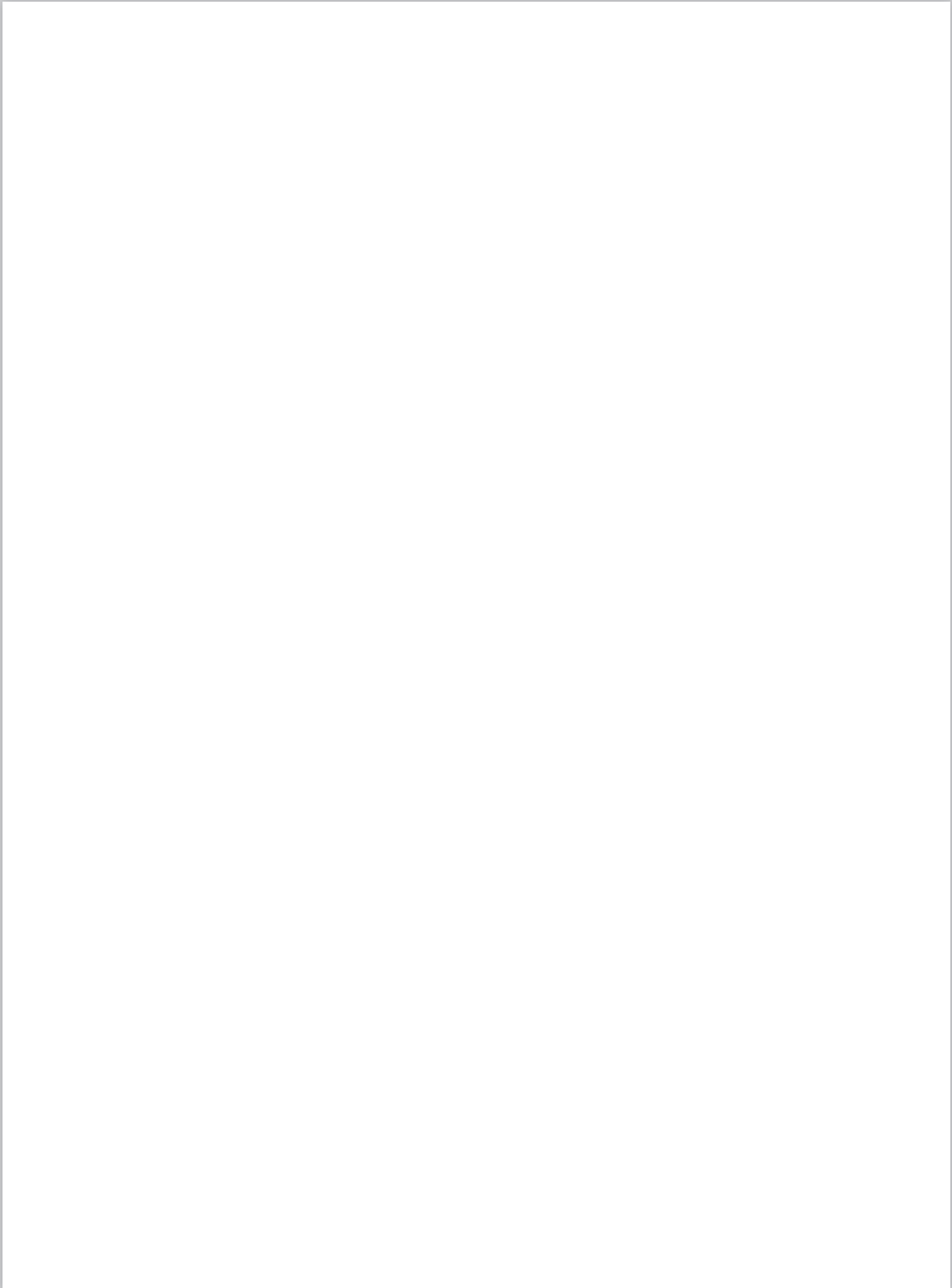
- a. A brief 15-minute presentation on what is palliative care, focusing on issues relevant locally.
- b. Sharing of experiences with incurable illness in the family/friend circle, etc, by 3-4 participants.
- c. What can we do as individuals? (Discussion 20 minutes)
- d. Summarizing/giving details about further training programmes. (10 minutes)

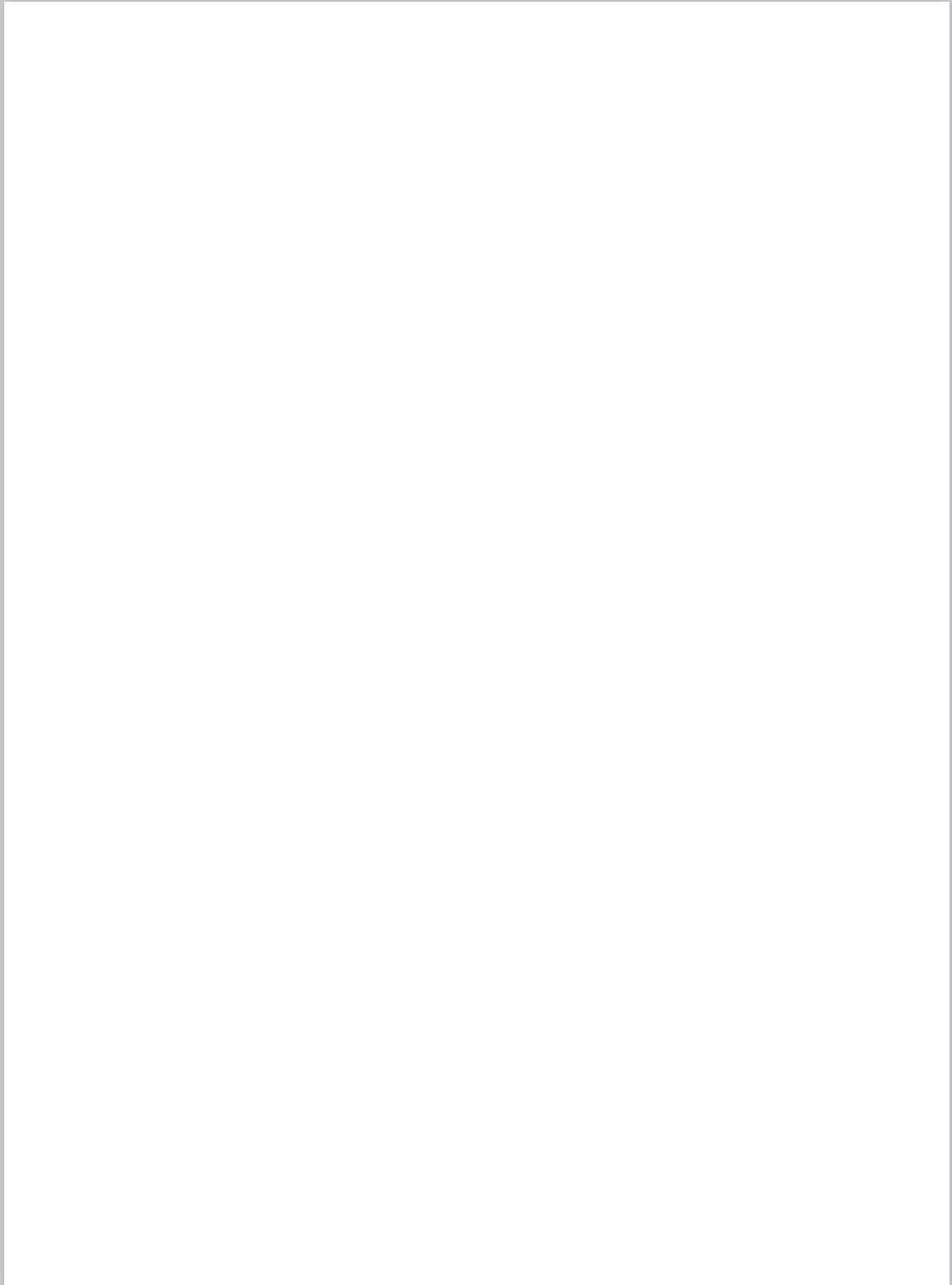
INTRODUCTORY TRAINING (3 HOURS)

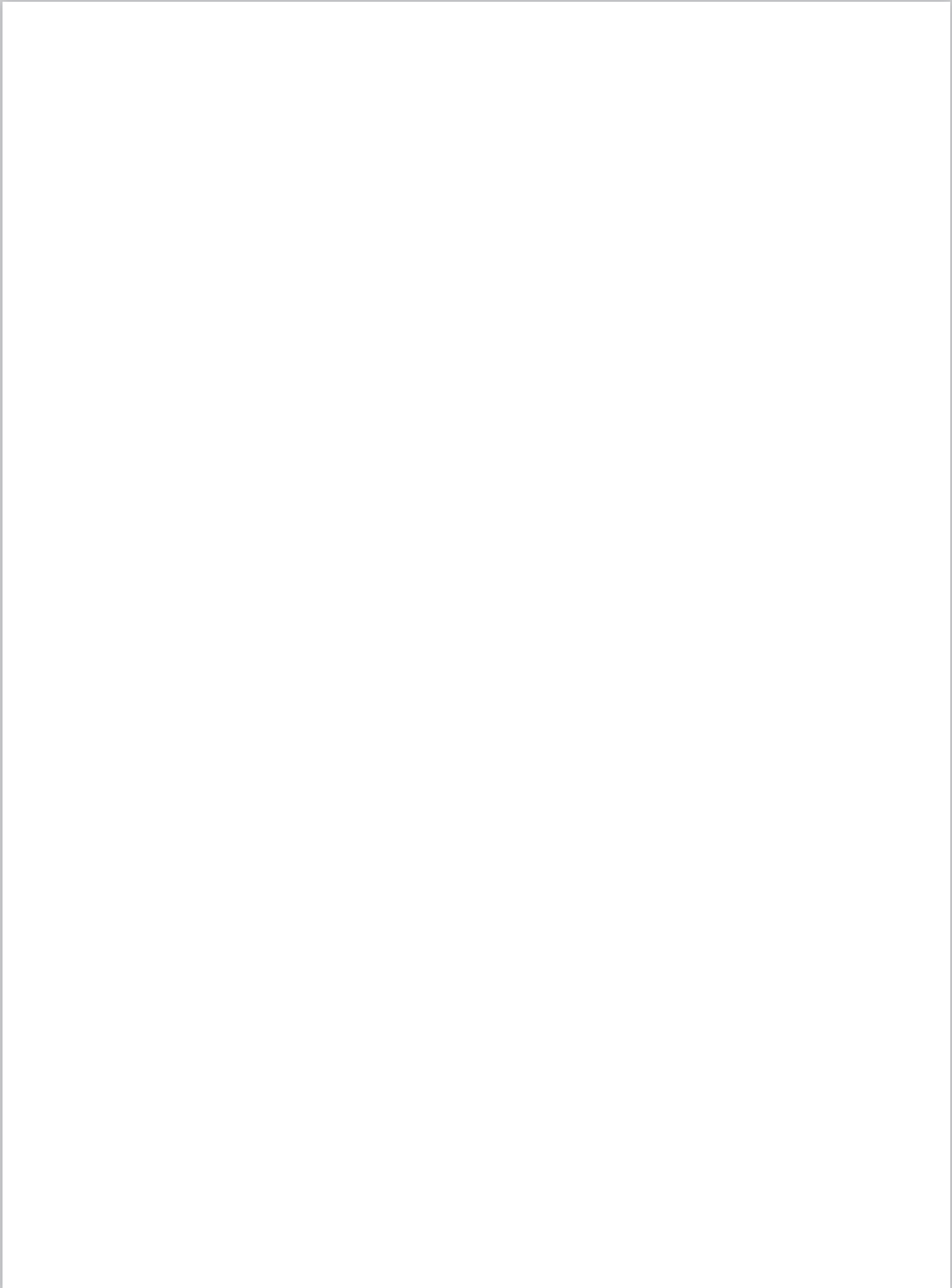
- 1. What is palliative care? (30 minutes)
 - a. A brief 15-minute presentation on what is palliative care, focusing on issues relevant locally, followed by discussion
- 2. Carer's responsibilities to patients/community participation in palliative care (60 minutes)
- 3. Knowing how to communicate to the patient in a supportive way (90 minutes)
 - a. What are the skills and knowledge that a carer in palliative care needs?
 - b. Barriers to communication
 - c. Importance of listening skills
 - d. The process of visiting patients/dos and don'ts in communication with patients

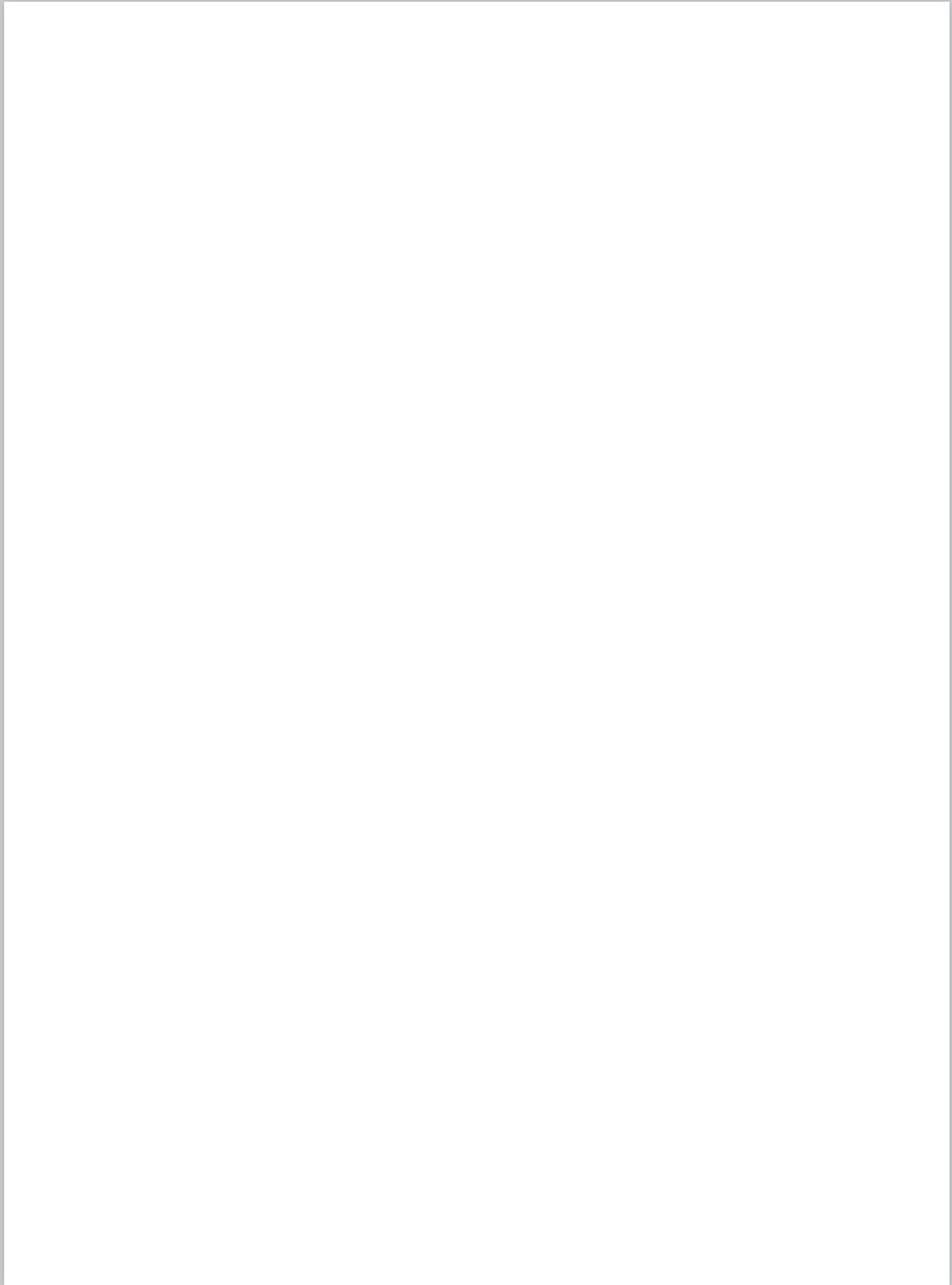
NOTES














Palliative Care - A Workbook for Carers is for palliative care/primary healthcare groups to train family carers/community volunteers in home-based care for people with advanced diseases, the chronically bedridden, elderly and the terminally ill. This has been developed through a series of workshops drawing on the experience of Institute of Palliative Medicine, the World Health Organization Collaborating Centre for Community Participation in Palliative Care and Long Term Care in community-based palliative care activities. The workshops for the generation of the workbook were supported by SANJEEVAN Palliative Care Project, Puducherry, which is a joint venture between Sri Aurobindo Society and Institute of Palliative Medicine.

This is the supporting document for a structured 20-hour training for carers in the community in line with the WHO guidelines in the area of community-based palliative care. This will serve as a useful resource to training programmes for family carers and community volunteers.

Copies available at

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<http://www.aurosociety.org/focus-area/special-initiatives.aspx>