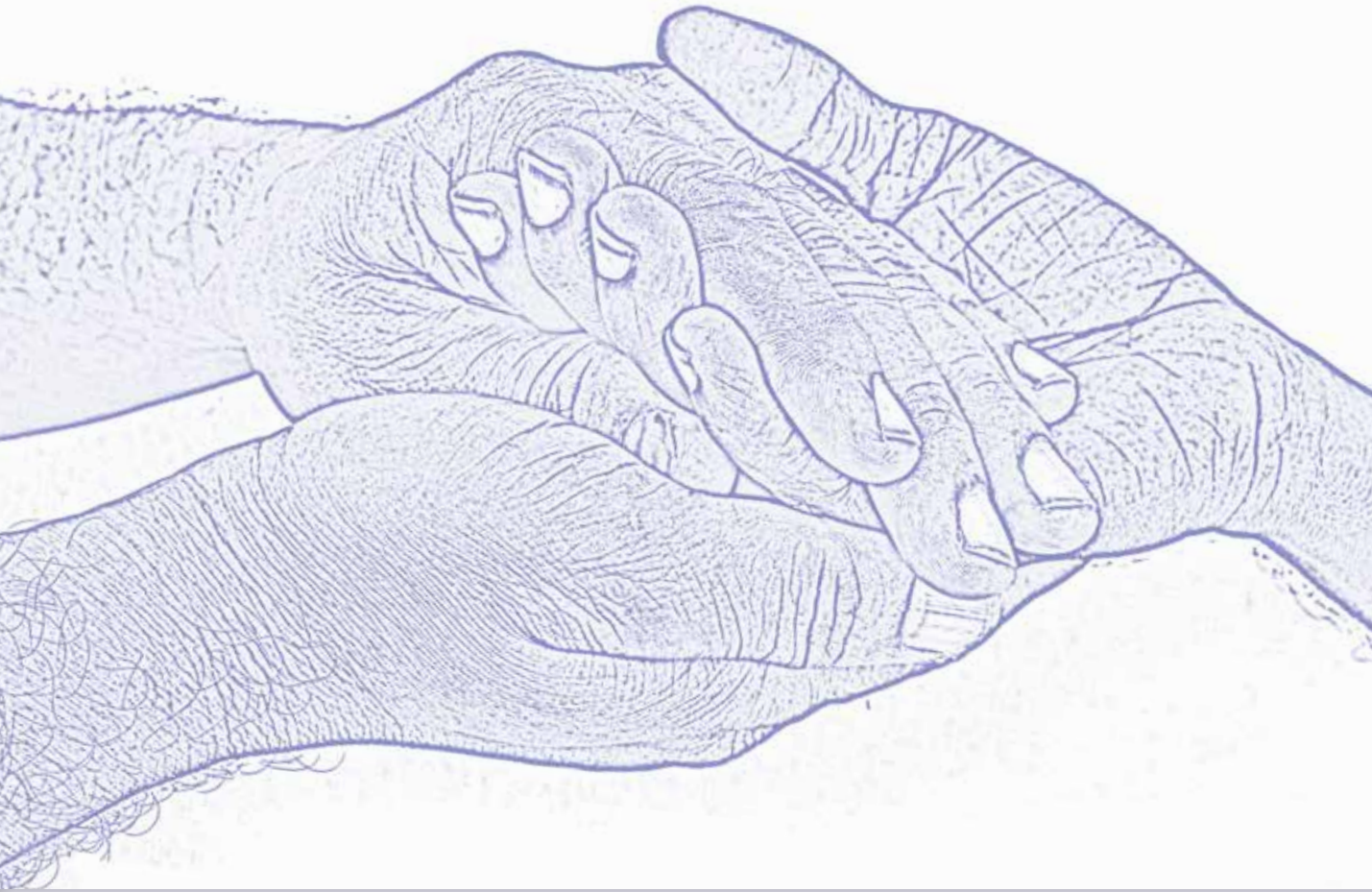


Palliative Care

A Workbook for Carers



**INSTITUTE OF
PALLIATIVE MEDICINE**



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



Sri Anubhava Society

SANJEEVAN

AN INTEGRAL APPROACH TO END-OF-LIFE CARE

Palliative Care

A Workbook for Carers



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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 Navajbai Ratan Tata Trust

Palliative Care—A Workbook for Carers

October 2017

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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 toward 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 16-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.



Dr Suresh Kumar

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

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Printing of this workbook was made possible by a grant to SANJEEVAN Palliative Care Project by Navajbai Ratan Tata 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 16-hour course or as a 1+3+12 hour series.

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

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 16-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 16-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 in planning the training programmes. These are only for guidance as there may be variations in requirements between groups.

Broad outlines of suggested schedules of the 16-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-MINUTE SESSION)

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

WHO 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.



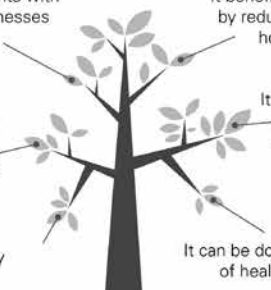
IMPROVING ACCESS TO PALLIATIVE CARE

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

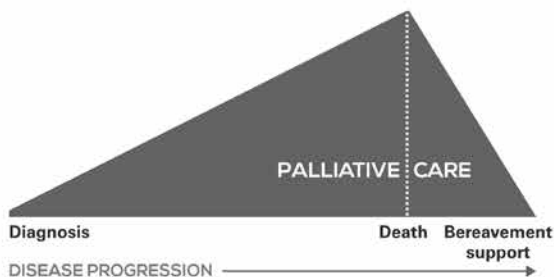


It benefits health systems by reducing unnecessary hospital admissions

It relieves physical, psychosocial & spiritual suffering

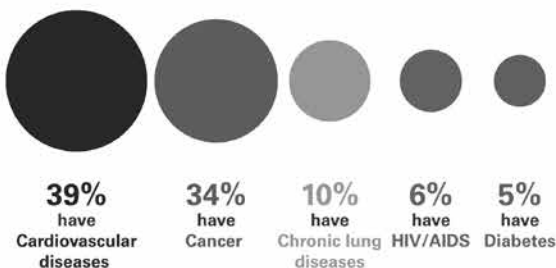
It can be done by many types of health professionals & volunteers

WHEN IS PALLIATIVE CARE NEEDED ?

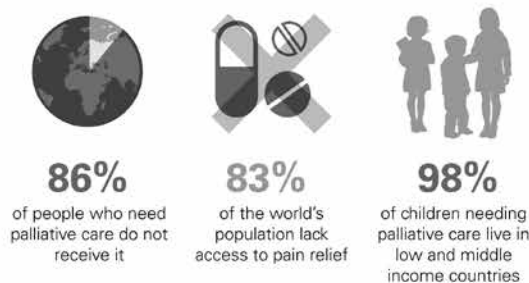


WHO NEEDS IT ?

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



WHAT ARE THE GAPS ?



WHAT ARE THE BARRIERS ?



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

90 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 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.

CARER'S RESPONSIBILITIES TO PATIENTS

CONFIDENTIALITY

ACTIVITY 2

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 is curious as she found the patient upset.

What will you tell her?

(Discussion in groups for 10 minutes, reporting 10 minutes)

SUMMARIZE (5 MINUTES)

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 the private feelings and personal history 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.

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 3

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)

5 Socioeconomic & emotional issues

(TWO HOURS)

ACTIVITY 1

Gopal, a 33-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

How can you help him?

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

ACTIVITY 2

Pool the details of government and non-government agencies in the area from which a patient/family can get medical/ social/financial support (discussion in groups 15 minutes; reporting 10 minutes). Develop this into a sharable resource list for the area.



LIFTING AND MOVING PATIENTS

(15 MINUTES INCLUDING DEMONSTRATION)

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.

ACTIVITY 3

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 (discussion in groups 5 minutes; reporting 5 minutes). Develop this into a sharable resource list for the area.

SEEKING PROFESSIONAL HELP

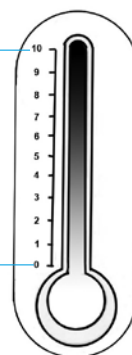
(10 MINUTES)

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

DISTRESS THERMOMETER

10 EXTREME DISTRESS

0 NO DISTRESS



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 in the upper right corner.

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	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I have felt calm and relaxed	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I have felt active and vigorous	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
I woke up feeling fresh and rested	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
My daily life has been filled with things that interest me	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

The raw score is calculated by totalling 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.

6 Physical problems

(ONE HOUR)

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 advise 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.

Sometimes the patient is seen not taking medicines properly.

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

- 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.

NOTES



7 Spiritual issues

(150-MINUTE SESSION)

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. How will you define spirituality?
2. What is its relationship with religion?
3. What do you consider as a spiritual issue? One example?

Brainstorm in small groups (15 minutes). Reflect on the responses and write down your response (10 minutes). Share with others (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. \(DOI:10.1089/jpm.2014.9427\)](https://doi.org/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

INTERACTIVE SESSION

A 30-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

SUMMARIZE (5 MINUTES)

8 Communication Skills

(THREE HOURS)

INTRODUCTORY STATEMENT

(10 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.

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

Discussion in groups

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?

(20 minutes for discussion in groups. 20 minutes for reporting.)

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 when you plan to visit again 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)

- Deafness or hearing loss
 - 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

(10 MINUTES)

“Listening is different from hearing”: Hearing is merely noting that someone is speaking where as 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

ACTIVITY 4

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?

(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.

The three key points in a strategy to address emotions during conversations with the patient is

1. being empathetic to the person;
2. validating the emotion expressed; and
3. exploring further the worries/concerns behind it.

9 Nursing issues

(TWO HOURS)

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)

PREVENTION AND MANAGEMENT OF PRESSURE SORES:

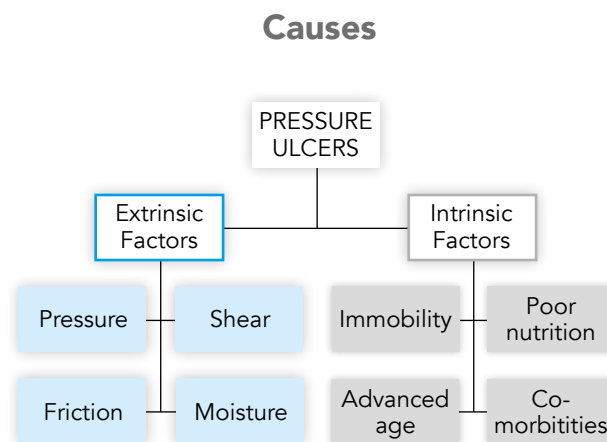
(40 MINUTES)

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.”

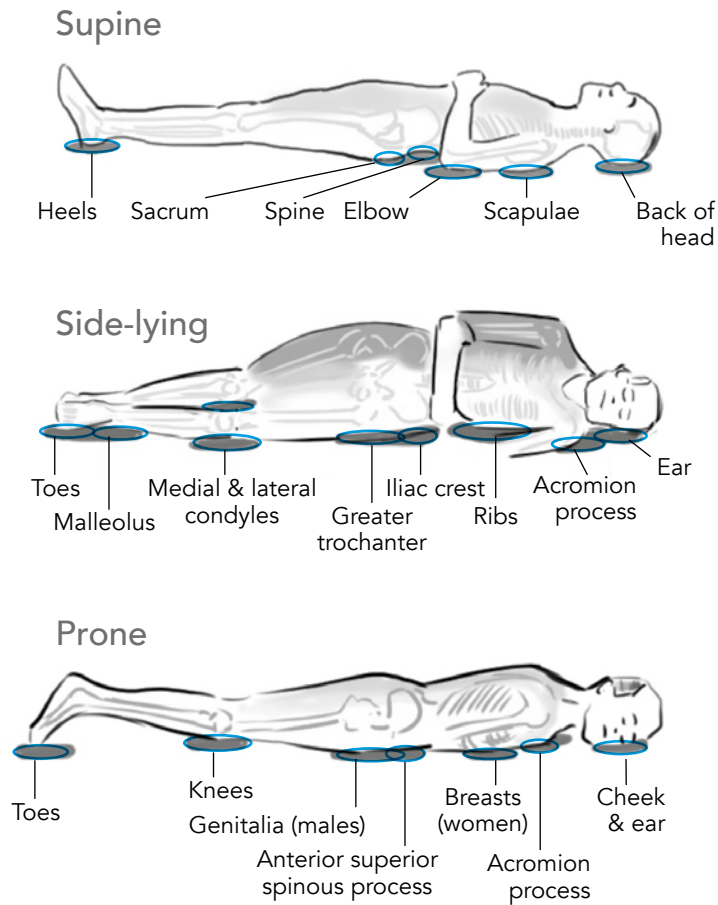
~ Florence Nightingale



Risk Factors for Pressure Ulcers

1. 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.



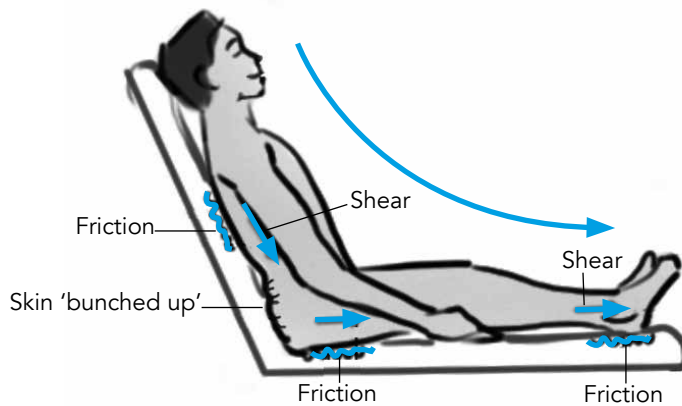
Pressure Points over Bony Points in Different Lying Postures

2. 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.

3. 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.



Mechanism of Friction and Shear

4. 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.

5. 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.

6. 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.

7. NEUROLOGIC FACTORS

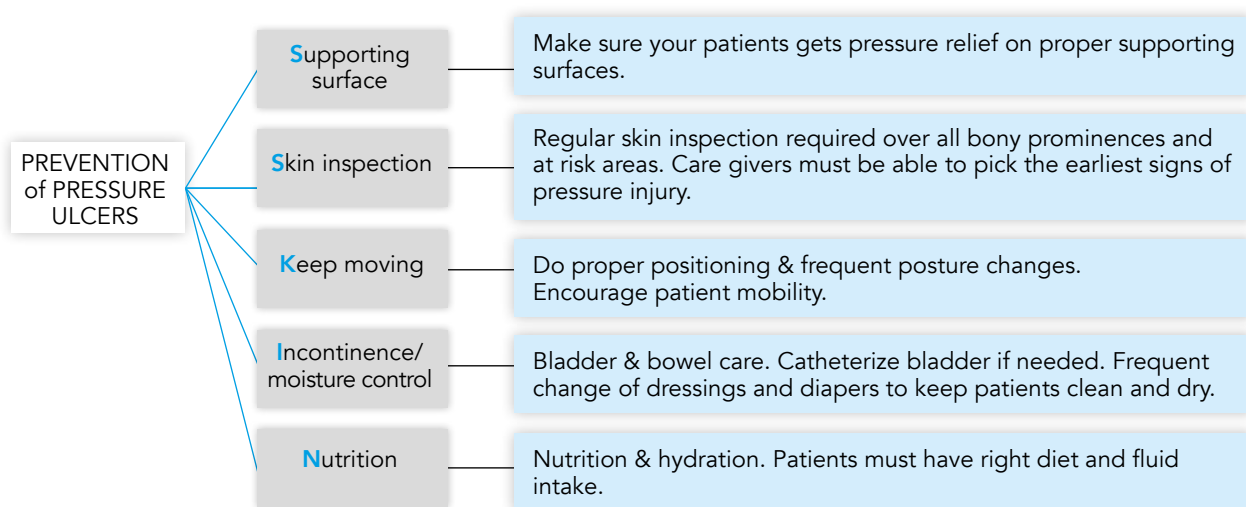
Any abnormality affecting the sensorimotor feedback system between the brain and peripheral senses as in muscle paralysis, impaired pain and pressure sensibility or coma can make a patient prone to develop pressure ulcers.

8. 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.

9. 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.

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.

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.

WOUND CARE

(20 MINUTES)

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 for half an hour.
- 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 stored 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.

10 Grief and bereavement

(ONE HOUR)

ACTIVITY

1. How do people react when their loved ones die?
2. How long do people take to recover?
3. 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.

11 Local resources

75 MINUTES

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.

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



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

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.

(15 minutes for discussion/10 minutes for reporting.)

Reporting format for community volunteers

PALLIATIVE CARE UNIT

(.....)

Report by community volunteer

Reg no: _____

Patient's name: _____

Age: _____ M/F _____

Address: _____

Phone: _____

Community volunteer address _____

Phone No _____

Route to the patient's house: _____

Details of family (members, job, source of income, illness, etc.): _____

Details of disease and treatment: _____

What type of disease? _____

Duration: _____

Details of treatment so far: _____

How much did the treatment cost so far? _____

What is he/she getting as treatment now? _____

How much does the present treatment cost per month? _____

How does he/she meet the treatment expenses? _____

Is there any help from any local organization or group? _____

Is there any help from the government? Details: _____

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

Patient's/ family insight about the disease _____

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

Signature of community volunteer _____

Name of community volunteer: _____

13 Proposed modules for sensitization and training programmes

INTERACTIVE TRAINING PROGRAMME FOR CARERS INCLUDING VOLUNTEER CARERS

(16 HOURS)

1. What is palliative care? (1 hour)
 - 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 (90 minutes)
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 hour)
 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 hour)
 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 hour)
 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 (2.5 hours)
 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 (3 hours)
 - 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 (2 hours)
 - 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 (1 hour)
 - 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) (1 hour)
 - 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) (1 hour)

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

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 16-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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