Nursing Instructions to Educate Caregivers in Palliative Care

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MODULE 0: HOW TO TEACH ADULTS

As a nurse – or a different healthcare provider –, you are participating in this training course to learn not only what to teach cancer patients and their caregivers in palliative care but also how to teach them. Therefore, it is important that you consider some concepts regarding how to be efficient in your role as facilitator and trainer.

As a trainer you have information to provide, and you also wish the participants to learn certain skills. You will have better results if you promote active participation: including the experience and knowledge of participants and being able to establish an open, safe, and nonjudgmental learning atmosphere.

The goal of this module is to provide information and methods for patients and caregivers to be able to implement/carry out what they are being taught regarding palliative care.

PRINCIPAL MESSAGE

Cancer patients and caregivers need to receive information that considers their characteristics as adult learners, carrying out a dynamic and interactive learning session to have better learning results and be benefitted by this palliative care basic course.

CONSIDER THE AUDIENCE

Adults learn differently than children. As a trainer, you must consider this difference when planning how to approach an adult audience.

- Adults want to know why they must learn.

Adults are motivated to learn if they understand the benefit of learning and what is required from them. Help your patients to identify the question: “What is there in this for me?”

- Adults want to be responsible.

Adults have a self-concept of overseeing their own lives. They wish to be perceived as capable of assuming responsibilities. However, many have the childhood experience of receiving passive learning. Support
them to have an active participation that leads to a self-assessment of their own learning.

- **Adults bring their own personal experiences to learning.**

Personal experience is a great resource for adult learning. Ask about their experience, respect and value this.

- **Adults are ready to learn according to their needs.**

Adults learn when they decide to learn and commit. They need to commit to understanding the utility of learning. Make sure your participants finish the session with some added value.

- **Adults focus on tasks.**

Education in children is often focused on a topic (for example, grammar). However adult education must be focused on carrying out tasks (for example, writing a letter). You must organize your learning in a practical manner, tasks, instead of theoretical content.

**KNOW THE ESSENTIAL INFORMATION**

This module presents information regarding how to teach adults, patients, and caregivers. Between 40% and 80% of medical information provided to patients is immediately forgotten, and as there is more shared information, there will be more of it forgotten.

Therefore, you must put into practice the teaching and learning theory to ensure that the efforts in teaching palliative care have a good result.

This module includes the following topics: Principles of adult education (memory and collection of information, active learning vs passive learning and psychoeducation), Preparation for the learning session (mentoring in needs, barriers for learning and handling learning challenges).

**PRINCIPLES OF ADULT EDUCATION**

Human beings enjoy learning. Young people learn in a natural manner through two methods: emulation and play. We see this process in a
baby copying the expressions and actions of its parents, all while smiling joyfully.

However, learning methods have been used for years without producing a real change in students; these have been focused on providing presentations with a wide range of information and little dynamic interaction.

Instead of using this approach, adult education principles collect the power of emulation and play through diverse methods: study cases, stories, role playing and debates in small groups, among others.

The interactive methods and examples of how to apply them in patients and caregivers are included in this unit.

**MEMORY AND COLLECTION OF INFORMATION**

When an adult learns something new, this information is transferred into a short memory. However, it must pass onto a long memory for it to be truly collected. An adult can collect up to three things in a long memory in an hour. To collect the information, adults must be alert and pay attention.

A person may pay attention to new information for only 10 minutes before needing a couple of minutes to rest and process the information. Overall, the skill of paying attention decreases after approximately 45 minutes.

**PASSIVE LEARNING VERSUS ACTIVE LEARNING**

**Passive learning** – This type of learning occurs when the participant does not take an active role. For example: reading, listening to a presentation, observing the interaction between the teacher and students. An advantage of passive learning is that a large quantity of information can be transferred. The disadvantage is that, although the student knows the information, he/she may not be able to understand how to apply it to solve a problem. This style has the following characteristics:

- The teacher or trainer decides what the students must learn.
- The teacher or trainer teaches in a one-way manner.
• There is not any space for experiences belonging to the student.

Active learning – This type of learning occurs when the information is analyzed, discussed, and connected to relevant activities or activities included within the current decisions. Adult students process and remember the information better when:

• They are able to do something with the information.
• They discuss the information with others.
• They ask questions about the information.
• They compare the information with their own experience.
• They have time to reflect on the information.
• They use the information and assess the results.

The active learning style has the following characteristics:

• The teacher or trainer and trainee negotiate what will be studied.
• The education is interactive; information is shared by the trainer and trainees.
• The education incorporates the trainee’s experience.

In essence, three methods can be considered to enhance education per adult patients and caregivers:

Focus on what is practical – The learning session should be related to a difficulty or problem that the patient or caregiver is facing.

Promote participation – Engage patients and/or their caregivers with the material and learning process.
**Acknowledging Barriers** – Understand that the patient and its caregiver have many priorities and pressure regarding time.

**Psychoeducation**

The concept of psychoeducation in cancer assistance assumes that fear and anxiety result in a lack of information and understanding. Therefore, this method combines learning and psychological interventions and provides information regarding palliative care; however, it also shows patients and caregivers some strategies used to have a better life with their illness even considering methods to deal with communication, behavior, and emotions.

The trainer serves as a facilitator, guiding the conversation, providing opportunities for reflection and summarizing learning points.

**Preparing for the Learning Session**

**Advisory of Needs**

You are teaching cancer patients and their caregivers. They arrive at the session with a variety of experiences, motivations and needs. You may ask some questions before starting the session. For example:

- *What would you like to know regarding how to take care of your patient when at home?*

The answers to this question will allow you to know the interest of the participants, whether they are familiar with the topic, to give a correct approach to their learning.

**Learning Barriers**

There may be some learning barriers to face:

- Lack of trust with the trainer or previous bad experiences when learning
- Anxiety of being seen as someone inferior or ashamed.
- Pending problems that occupy their minds.
- Being interested in the session but in a hurry or with other priorities.
• Personal barriers, for example fear of cancer, difficulty facing illness.

You may try to approach the needs of patients and caregivers, but you may not be able to adapt at the fullest to all of them. However, respect helps overcome barriers.

• Respect the independence, maturity, knowledge and previous experience of the patient and caregiver.

• Respect the cooperation: the trainer, patient and caregiver bring valuable information and perspectives.

• Respect and ask about the motivation of the patients and caregivers to learn.

• Respect the resistance to change; there may be an understandable reason for this.

HANDLING LEARNING CHALLENGES

Diverse experiences – It is important to consider the different experiences of potential participants throughout the scheduling of the learning sessions. Consider characteristics such as gender (women and men), cultural level, age, cancer type, cancer stage, role (patient and caregiver).

Silence – Silence may be interpreted as confusion of the participants and a need to clarify information. It may also be that the participants are thinking about how this information is relevant to their own experience. A strategy for this challenge is to ask certain specific questions:

• *What has been useful for you from what I have shared? What may you use?*

• *Do you wish to know more about the topic?*

• *How do you feel about what we have shared and how does this affect your situation?*
**Too much content** – Time is a limited resource. Therefore, you need to determine what is the most important content for the group instead of covering all the material.

**Talking too much** – You want to have a good conversation however the trainer also has the responsibility of having influence in the conversation for the group’s benefit. If there are one or two people dominating the discussion, you may say something such as:

- *We have not heard everyone yet. I would like everyone to have to opportunity to share their ideas and experiences. Does anybody else want to give their input regarding this topic?*

In case you stay in one topic and are not able to continue with others, you may say something such as:

- *This conversation shows the importance of this topic for us. However, there are other topics that we wish to discuss today. Is it ok if we continue with the following topic?*

**Conflicts among members** – Conflicts among participants or a group member show a lack of respect for each other; it is the facilitator’s responsibility to facilitate a communication of mutual respect. You may say something such as:

- *We are all people, and we are going to have different opinions. Nobody is right or wrong. We would like everyone to share their point of view.*

**A very sentimental participant** – The content of the learning session may cause a strong emotion in a participant. You may use the following strategies to handle this challenge:

- Acknowledge with the group that this demonstration of emotions is healthy.
- Request the support of a person to help the patient leave the session in case he/she is unable to continue.
- Give individual follow up to the participant once the group session has ended.
DYNAMIC ACTIVITIES

ACTIVITY 1: THE CASE OF MRS. JUANA AND HER DAUGHTER MARTA

Mrs. Juana is a 64-year-old woman with advanced cancer that has arrived at the palliative care service where you work at. Juana has not attended her last two appointments. Marta, a 40-year-old woman and daughter of Juana, has been to the service this week – outside of the appointment date -, requesting a prescription for her mother. Marta has explained that her mother stays home and gets very anxious when she goes outside. You believe Marta can benefit from the course provided by the “School for Caregivers” of INEN. What would you tell Martha to invite her to participate? What questions would you ask her? Explain how the concepts presented in this module may help in the conversation with Marta.

ACTIVITY 2: PRACTICE FACILITATING GROUPS

Form groups of 6 – 10 people, it is better if they hardly know each other. Choose a facilitator and a person that will report for the group. Choose a conversation topic, for example:

- What is the responsibility of the person in taking care of her health versus the responsibility of the state?

- Does a patient have the right to make decisions on their own that may result in being harmful for their health or, should the nurse avoid this? For example, a patient wants to stop eating but the nurse knows about the consequences that this may have in the patient. Does the nurse have the “right” of obligating the patient to eat?

- Sometimes the families do not want to tell the truth to the patient about their health condition. What should a nurse do when the family insists on the fact that telling the patient will harm her? How can a nurse know if this is true? Does the patient have a right to know?
The facilitator starts and guides the group discussion for 12 minutes. The group then has 2 minutes to analyze what worked well and what was difficult. The reporter has one minute to present the group’s analysis of the conversation to everyone.

**BIBLIOGRAPHY**


MODULE 1: GUIDANCE TO PALLIATIVE CARE

Nurses and other healthcare providers understand that cancer palliative care includes many topics, such as pain and other symptoms, facing emotions such as sadness and uncertainty up to the planning of the end of life. However, many patients and caregivers do not understand the objectives of cancer palliative care and what it means to be referred to this service.

This module provides a guide to teach patients and caregivers the concept of cancer palliative care, important information and documentation that will be needed within time, how to have access to services and what they can expect throughout the development of their illness.

The objective of this module is to ensure that patients and caregivers are informed about cancer palliative care to help them face a cancer illness.

PRINCIPAL MESSAGE

Cancer palliative care specializes in providing integrated assistance for people with advanced and terminal illness. This focuses on the relief of symptoms and stress caused by this type of illness. The objective is to improve the quality of life for the patient and the family.

CONSIDER THE AUDIENCE

This “Guidance to Cancer Palliative Care” module may be applied in a collective (group) context or individual manner. For any of these two options, patients and caregivers are recommended to attend and participate in the guidance together.

Given the social and cultural context of Peru, it is understandable that some patients do not wish to know the details about their illness or prefer to have a relative or caregiver handle all medical information. If
this were the case, both parties are recommended to participate in this first module to ensure that there is space to have a conversation and clarify the preferences of the patient before proceeding.

Consider the education level of the audience to ensure that an appropriate language is used. The flipchart images and text included in this program are tools used for this purpose.

**KNOW THE ESSENTIAL INFORMATION**

Many people do not know what palliative care is or what it is used for. The content of this module presents key points to be informed to the patient and caregiver regarding cancer palliative care. You may also use “support care” instead of “palliative care” if understood better. The topics presented in this module are what is palliative care and what is it used for, healthcare team, knowledge, expectations and preferences (of the patient and caregiver) and planning of the learning session.

**WHAT IS PALLIATIVE CARE AND WHAT IS IT USED FOR?**

The World Health Organization (WHO) defines Palliative Care (PC) as “the approach that improves the quality of life of patients and families that face problems associated to threatening illnesses, through the prevention and relief of suffering given by an early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.”

The objectives of palliative care are:

- To reaffirm the importance of life, considering death as a normal process.
- To establish a process that does not accelerate or postpone the arrival of death.
- To provide relief to pain and other distressing symptoms.
- To integrate all psychological and spiritual aspects of the patient’s treatment.
- To offer a support system to help patients have the most active life possible until death takes over.
• To offer a support system to the family for it to be able to face the patient’s illness and overcome the grieving period.

Cancer palliative care will consider the following problems in each patient:

**Physical problems** – Common physical symptoms are pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath and insomnia. Some symptoms may be a side effect of the treatment. Many of these symptoms can find relief with medication or other methods such as nutritional therapy, physiotherapy or breathing techniques. In addition, chemotherapy, radiotherapy, or surgery may be used to reduce the size of tumors that cause pain and other problems.

**Emotional and psychological problems** – Specialists in cancer palliative care may provide resources to help patients and families to face emotions that come with a cancer diagnosis and treatment. Depression, anxiety, and fear are some of the problems that may be treated with cancer palliative care. Experts may provide guidance, recommend support groups, carry out family meetings and make referrals to mental health professionals.

**Spiritual problems** - When receiving a cancer diagnosis, patients and their families tend to look for the meaning of life in a deeper manner. For some patients, the illness gives them more faith; for others, it makes them doubt their faith while they fight to understand why they are suffering from this illness. An expert in cancer palliative care may help people to explore their beliefs and values to find peace or reach an acceptance level that is suitable for the situation.

**THE HEALTHCARE TEAM**

Cancer palliative care is provided by a trained team of doctors, nurses, psychologists, social workers and other specialists that work together in any stage of terminal illness; this care can be provided in any stage of cancer treatment.

It is important that patients ask who forms part of their team for them to know what their available resources and services are. A brief guidance to the patient and its caregiver regarding the roles of
different healthcare providers will help them know who to direct their questions, concerns, and problems to.

**Doctor:** The doctor examines each patient referred to cancer palliative care. He/she prescribes medication and other treatments that give the nurse the criteria and margin of discretion regarding the medication doses (for example, lorazepam 0,5 - 1,0 mg each 8-12 hours as needed due to anxiety). Each patient receives a package of different pain killers which may include morphine, lorazepam, haloperidol, prochlorperazine, senna and docusate.

**Nurse:** The nurse is a very active participant of the team. A nurse is available to answer the questions of family members through the telephone (with the support of a doctor). Nurses are experts in the administration of liquids and medications through IVs; administration of sub-cutaneous treatment; aiding for wounds and deciding what equipment is needed (for example, wheelchairs, hospital beds, chairs with urinal, etc.). They are trained to control most of the new symptoms and changes in existing symptoms such as pain, nausea, shortness of breath, anxiety, depression, constipation, itchiness, and delirium. They are also able to teach families comfort measures for the patient such as positioning and skin care.

**Social worker:** The social worker assesses the needs of the family, their economic situation and whether they need additional people to take care of the patient. They are experts when treating psychological problems such as anxiety and depression. In case there are conflicts in the family, the worker tries to solve these problems for the family to be united. The nurse and social worker cooperate to help the family during this mourning period.

**Psychologist:** The psychologist applies clinical psychology knowledge and tools to help people dealing with cancer. The type of help that cancer patients need varies from person to person and family to family. Most cancer patients do not have a mental illness or psychological disorder. However, cancer can create psychological problems such as anxiety or profound depression. It may also create problems in a marriage or family. Psychologists that treat cancer patients try to create a safe atmosphere of trust for patients to express their true emotions.

**Nurse technician:** The nurse technician cooperates with the healthcare staff in the execution of basic nursing procedures. These may vary from vital signs (temperature, pressure, and weight), taking blood samples
and assisting in the hygiene of patients. He/she may administrate medications with the supervision of a nurse.

**Support staff:** The hospital has other support professionals for cancer patients and their families: pharmacist, nutritionist, physical medicine and rehabilitation, volunteers, and spiritual counselling. A nurse trained in cancer palliative care shall guide the patient and its family regarding the services offered by this staff according to their needs.

**KNOWLEDGE, EXPECTATIONS AND PREFERENCES**

The knowledge, expectations and preferences of the patient and its caregiver are interrelated.

**Knowledge** regarding health has a great effect on cancer results: better knowledge may improve medical results. The knowledge that patients and their families have has an influence in their capacity to participate in decision making regarding medical assistance. Knowing about cancer allows a person to have reasonable expectations regarding what may happen.

**An expectation** is a strong belief that something will happen in the future. It can also by a belief that someone will or must achieve something. Patients with advanced stages of cancer usually have misunderstandings regarding the intentions of treatments and its general forecast. Many patients that receive palliative radiation or chemotherapy have expectations, yet somehow unrealistic, that their cancer will be cured by these therapies. They may also believe that if they receive assistance in palliative care, they will not receive any other type of assistance. The healthcare staff may speak with the patient about their expectations and provide information to develop a good assistance plan that everyone agrees with.

**The preferences** of patients serve as fundamental guidelines to provide efficient palliative care. We must know what “quality of life” means for the patient and what they want for their lives to provide support in a good quality of life. It is important to ask the patient what she wants and to listen to her answer. To assume of what is best for the patient and act based on this assumption without considering the patient’s opinion may create additional stress.
The following are key questions to help approach knowledge, expectations and preferences of cancer patients and caregivers:

**Knowledge:**

- What do you understand from cancer palliative care?
- Do you know what illness you have? Do you wish to know?
- What do you understand from what is going to happen with your illness throughout the following months?

**Expectations:**

- How do you anticipate that receiving cancer palliative care will assist you with these wishes, goals or hopes?
- What do you expect healthcare providers for cancer palliative care service to do for you?
- How frequently do you believe you may come to the hospital to receive follow up in cancer palliative care?

**Preferences:**

- What wishes, goals or hopes do you have for your life?
- Do you wish to learn how to take care of yourself at home? Does your caregiver wish the same?
- Do you wish to have the healthcare staff communicate directly with you or your caregiver?
- Do you wish to know the details of your illness, even the forecast?

**PLANNING THE LEARNING SESSION**

The text of the modules has been designed to be used as a guideline for your speech. The flipchart images have been designed as a dynamic form of presenting important information. Although the images complement the text, they do not include the complete text. The use of images assumes that you have dominated the content in these program modules.
One session may be offered in many environments. If time is limited, it can be focused on specific aspects of the program as a group workshop. For example, the content of one or more program modules can be presented according to what the healthcare professional has assessed as an interest of its target audience (patient and/or caregiver). The content may also be used in an individual manner. This will allow the information to be adapted for the cancer patient and/or caregiver, especially if it is about an intervention used to focus on an identified problem.

PREPARE THE MATERIAL
The material to be used is the following:

- A flipchart with images chosen according to the learning session.
- Hospital or institution formats; for example, a format for caregiver appointing, a format for medication prescribed for cancer palliative care, a consent for medication, a cancer palliative care service pamphlet.
- Markers, pens, pencils according to what is necessary for the chosen or planned dynamic activities.

INTRODUCTION
You should mention your name and title. You may also offer your contact information at the beginning or end of the presentation. You shall briefly explain your experience in cancer palliative care and the motivation that you must continue in this service. Make sure to request the names of the participants and a brief reason of why they are participating in the session.

PRESENTING THE TOPIC
You shall present the topic of the learning session by mentioning some general phrases regarding the main message of the session. State how long the session will approximately last for and the type of activities
that will be carried out. This may be a good time to mention the schedule and topics of the other sessions.

**EMPHASIZE THE OBJECTIVES**

You shall state the objectives of the learning session before presenting the flipchart to the participants. The following are examples of objectives that may be met in a learning session:

- Patients identify at least one personal wish or hope they have for their lives.
- Participants (patients and caregivers) may describe, in their own words, the benefit of cancer palliative care service.
- Patients define, or at least consider, who their main caregiver is and fill out the format to appoint the caregiver. Caregivers accept the role.
- Participants (patients and caregivers) start a conversation regarding the goals they have for their care.

**PRESENT THE MATERIAL**

The presentation of the material consists in using the flipchart, chosen activities and necessary formats. The recommendation is to hand out the formats to patients and caregivers when they need to be filled out. The suggestion is to have a 30 – 45-minute group learning session that includes an interactive presentation and dynamic activities.

**DYNAMIC ACTIVITIES**

**ACTIVITY 1: DEFINING PERSONAL WISHES AND HOPES**

The purpose of this activity is to facilitate a creative process in which the patient can identify and explain a wish or hope that she has in her life. Ask the participant to think about the wish or hope silently. Ask the participant to identify a personal object that represents this wish. Give her 2 – 3 minutes to consider this and explain that at the end, everyone may give a brief explanation about the object and wish to the group.
Other options to facilitate this creative process may be:

- Provide paper and pens for the patient to draw something that represents their wish.
- Offer magazine images to the participants; ask them to choose one that represents their wish.
- Provide a list of words from nature (sea, sun, mountain, river, butterfly, rain, etc.) and ask participants to choose one that may represent their wish.

**ACTIVITY: WHAT IS A GOOD LIFE?**

Using flipchart images for this session, request participants to “brainstorm” what a good life would mean for each person represented in the drawings. After this is done, ask each participant to take a moment with their caregiver and discuss what they define as a “good life” for them at this moment. Ask every person to explain what their partner explained to them in one phrase.

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MODULE 2: ROLE OF THE HOME-BASED CAREGIVER

The role of the home-based caregiver is critically important for cancer patients but may often pass unnoticed in the patient care system. Caregiving may be overwhelming and exhausting as the demand on the caregiver is coupled with their emotional reaction to the illness of their loved one. The purpose of this module is to guide the home-based caregiver in fulfilling their role with the aim of improving patient care and comfort. This module in particular focuses on what it means to be a caregiver, recognizing the many tasks and looking for ways to help caregivers improve both their coping to the new role, knowledge, and skills.

PRINCIPAL MESSAGE

The main message of the module is that it is important to acknowledge the emotional and physical effort that is required of caregivers. Caregiving is a role that requires many skills. Caregivers need support to care for themselves. If a caregiver learns to care for him or herself, he or she will be more likely to have the energy to take care and be kinder towards the patient and carry out the physical task of caregiving.

CONSIDER THE AUDIENCE

The target audiences of this module are caregivers of cancer patients. Participation in this learning session is an opportunity for caregivers to reflect on their role and experience as caregivers and to consider how to improve the quality of life for both their patients and them.

By developing this group session, caregivers will have the opportunity to offer and receive support from others in a similar situation and share experiences and lessons learned about how to provide care. When planning your presentation, consider which are the greatest areas of interest for your audience and tailor your presentation to these areas.

KNOW THE ESSENTIAL INFORMATION

There are three areas of essential information in this module: taking care of the caregiver, empathy as the essential caregiving skill and caring skills for the caregiver.
Home-based caregivers need information that helps them fulfill their role as part of the care team. Nurses and other medical staff are well positioned to provide emotional support and technical information to caregivers.

THE EFFECTS OF CAREGIVING ON THE CAREGIVER

Providing care and support to cancer patients is physically and emotionally demanding. It is important that caregivers are aware of their own feelings and limitations; and seek to avoid overextending themselves so much that they find the pressure and stress making it impossible to continue providing good care. The following are some signs that a caregiver may be feeling overwhelmed and need to take care of themselves:

- Finds that being with a patient or loved one is an exhausting task, possibly presenting a lack of interest.
- Experiences an increase in physical problems. The caregiver may feel exhausted or in pain: for example, having frequent headaches, stomach problems or alterations in sleep patterns.
- Is no longer able to relate to patients in a positive and supportive manner.
- Has less patience than usual, gets angry easily and takes offense at small things. Relationships may be affected.
- Experiences lack of confidence and loss of self-esteem. Feels they are not good at caregiving or that the patient does not like their care.
- It is always advisable to ask a caregiver or, preferably, a nurse trained in cancer palliative care if you are feeling very sad or depressed.

When a caregiver is overwhelmed, it may be difficult to carry out tasks of administering medication or arriving to appointments on time. If you notice this type of issues,
SELF CARE FOR THE CAREGIVER

Feelings of being overwhelmed can be avoided by recognizing signs and developing strategies of self-care. Self-care may include any of the following:

- Find ways to relax. This may mean finding a quiet place to sit, talking with a close friend or partner, reading, listening to the radio or music, or watching television.

- Hobbies and exercise may also help alleviate stress and give people pleasure. Take time to do things you enjoy.

- Take care of social relationships. It may be helpful to have a close friend or relative with whom a caregiver can talk, laugh and share good and bad experiences.

- Take some time if needed. Occasionally, it may be helpful to take some days to rest. Ask for other friends or family members for help in providing care to the patient.

There will be times when caregivers feel frustrated or helpless in their role in helping a patient. They will not be able to solve every problem and make everything better. However, being able to offer care and support to a cancer patient is vital and gratifying.

EMOTIONAL AFLICITION OF THE CAREGIVER

Family members or friends taking care of cancer patients usually have their own special needs during the patient’s illness.

Caregivers may experience emotions like the ones felt by the cancer patient. Fear, anxiety, sadness, and anger are some common emotional reactions to the fact that a loved one is ill.

Many caregivers will feel better if they know that they are doing a good job of keeping the patient as comfortable as possible. Teaching them how to provide supportive care may help them feel assured and satisfied that they are doing a good job.

Other ways that health teams for cancer palliative care may help caregivers are:

- Reminding them to make time for themselves so that they are able to relax for short periods of time without feeling guilty.
• Helping them plan on how to provide care and share tasks with others.
• Encouraging them to express their feelings and assuring them that their feelings are normal.

**EMPATHY: THE FUNDAMENTAL CAREGIVING SKILL**

Empathy is the ability to understand and share the feelings of the other person. It is the basis for all caregiving. As human beings, we all have life experiences, whether of joy or sadness, which gives us the ability to put ourselves in someone’s shoe.

Compassion comes from empathy as we use our understanding of feelings to find effective ways to be helpful. A key question to develop compassionate reactions is “How would I like to be treated if I were in this situation?”

Developing empathy and showing compassion helps achieve a sincere and successful interaction with a patient because this person will feel seen, heard, and accepted as a person. There are several methods to practice empathy:

• Approach and look at the person while speaking to him or her. Make eye contact, this shows that you are attentive and invites the patient to express him or herself.
• Call the person by his or her name; always speak in a respectful manner. Avoid using adjectives or nicknames (for example: grandpa, mommy, etc.).
• Be cautious when communicating information regarding illness.
• Use a low, calm voice. High pitched voices signal stress.
• Observe the body language of the patient. This can usually provide much more information about a person than their words.
• Acknowledge the person’s emotion and look for ways to express how you can relate to their emotion.

**Empathy is not feeling pity.** You feel sad or disappointed when feeling pity. Most cancer patients state they do not want to feel pity from their caregivers, they want to feel understood.
CARE SKILLS FOR THE CAREGIVER

Depending on their physical deterioration, patients with advanced cancer may need help to carry out their daily activities. One of the most concrete ways that caregivers can show their empathy (understanding of feeling and needs) and compassion (desire to help), is by helping with the physical care that patients need. This module divides physical care into three categories: 1) skin care, 2) patient mobility and 3) feeding.

SKIN CARE

Good skin care is fundamental for patients in cancer palliative care. Cancer and cancer treatment make the skin weaker and more easily damaged. Prevention and improvement of skin problems can be managed with hygiene, nutrition, and exercise.

BATHING

Bathing cleans and removes waste from the skin; it stimulates circulation of the blood and provides active and passive exercise for patients. Also, bathing provides a good time to observe signs of injuries in the skin particularly at the elbows, shoulder blades, tailbone, and heels (see section of Prevention of Pressure Ulcers). Bathing is also a very intimate way of helping a patient and it can be a time to express tenderness and care.

Depending on the individual needs of the patient, caregivers may help the patient by assisting with getting into and out of the tub or shower, washing hair, washing private parts, toweling dry and rubbing on lotion.

- It is important to maintain safety and comfort during bathing. It is also important to be careful with the skin and moisturize it adequately. Keep an organized, clean, ventilated, enlightened room, according to the needs of the patient, at a comfortable temperature and free from drafts.

- Use moderately warm water for bathing. Water should be just above normal body temperature or roughly 38 degrees Celsius.

- Use mild, unscented soaps such as glicerine or baby soap. Rinse the skin well. Pat it dry with a soft towel, do not rub.
• Do not use alcohol or alcohol pads, especially if undergoing chemotherapy or radiation.

• Moisturize the skin after bathing. Avoid the use of lotions that are scented or contain alcohol. Apply lotions in a smooth and circular motion.

• Be aware of the potential for falling. For example, use nonslip rugs in the bathroom. If possible, install handrails or use chairs in the bath and shower.

If the patient is bedbound, caregivers shall bathe him or her in the bed using a pan with warm water (38 C) and follow the suitable technique:

• Make sure the patient is covered with a small blanket or sheet to avoid chill and add privacy. Place a towel under the patient to avoid moistening sheets.

• Start with the face, use a soft wet cloth without soap. Use different parts of the cloth to clean different parts of the eyes and face. Make sure the face is dry. Rinse the cloth.

• Add a small quantity of soap to the cloth, move on to the arms and legs, then the chest and back. Rinse the cloth in the pan after completing each body part. Finish the bath with the private areas.

• Ensure that each body part is completely dry before moving on to the next body part.

ORAL CARE

Cancer treatment, particularly radiation and chemotherapy, can cause oral side effects that range from dry mouth to serious infections. Possible oral changes include redness, swelling, tenderness, and sores in the lining of the mouth, tongue, and lips. These changes may cause discomfort and make it difficult to swallow.

Good oral care helps prevent sores from forming and reduces the risk of infection. It also helps keep the mouth from becoming dry and cracked.
Elements of good oral care include brushing and flossing if the use of floss is permitted, rinsing and lip moisturizing:

- Brush teeth and tongue gently after each meal and at bedtime. Use a soft or super soft bristle toothbrush and change the toothbrush every 3 to 4 months.

- If using dentures or dental prosthesis, take them out and clean them as often as the mouth is cleaned.

- Floss with unwaxed dental floss once a day at bedtime. However, if the patient has not flossed regularly before treatment, do not start flossing as this can cause trauma to the gums.

- Rinse the mouth every 4 to 6 hours or more often if needed. Swish and gargle for 15 to 30 seconds, then spit out the rinse. Appropriate rinses include water, water with salt, water mixed with salt and baking soda, alcohol, and sugar free mouthwashes.

- Use of lip moisturizer after mouth care and reapply it periodically during the day.

- Check the mouth, gums, and teeth daily to look for bleeding and signs of infection. It is important to report these to the healthcare team.

**INCONTINENCE**

Some patients may require help using the toilet or may have lost control over his or her bladder. This can be a difficult part of caregiving but there are steps a caregiver can take to manage the situation.

- Remember incontinence may be very embarrassing for the person. Stay calm and reassure the patient that “it is ok”. Use a matter-of-fact approach, for example “Let me clean you and help you out of these wet clothing.”

- Help remind the patient to go to the bathroom on a frequent, scheduled basis (every 3 - 4 hours). This helps avoid urgency and rushing to the bathroom.
- Keep bedpans or urinals close for those patients who are bedbound or have trouble getting out of bed.

- Protect the mattress with plastic sheets. Cover it with a sheet to avoid sweating or injuries in the skin.

- Be aware that incontinence can be a trigger for skin breakdown. Pay extra attention to skin care and change soiled sheets immediately.

- Disposable diapers are an effective way of protecting the skin, clothing and bedding.

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**WOUNDS**

Cancer patients need to take care of all injuries in the skin; cancer patients have weakened immune systems that put them at risk of infection. In addition, cancer treatments can both cause wounds and weaken wound healing. Keep all wounds clean to prevent infection.

**Radiation injuries** may occur during treatment as intense exposure to radiation can damage skin tissue. These injuries may result in dryness, itching, swelling, redness or blistering; in fact, they often look very similar to sunburn. The prevention of radiation injuries should be discussed with your physician before treatment. When injuries do occur, they normally go away within weeks after the treatment. However, some injuries can result in scarring and changes in the skin color. Other injuries can lead to infection.

**Chemotherapy medication** can cause irritation in the skin and surrounding blood vessels. That irritation may cause short term pain, redness, or itchiness; it may also result in long term ulcers and tissue damage.

**Cancer Surgery** may be complex and result in one or more skin complications. Surgical injuries may lead to scars and infections.

Caregivers should focus on keeping injured skin and surrounding areas clean, dry, and moisturized:
- Use mild soap and water to clean the area being treated (avoid extreme water temperatures) (see section Bathing and Cleanliness for suggested soaps and water temperature). Use a soft cloth and be gentle with the skin when showering or bathing. Thoroughly pat dry instead of rubbing.

- Use loose fitting, cotton clothing to reduce skin irritation.

- Protect the skin from the sun — cover up and stay in the shade.

- Moisturize skin at least 2 times using non scented and alcohol-free lotion (see section Bathing and Cleanliness for suggested lotions).

- Do not use make up, perfumes, powders or aftershaves in areas being treated with chemotherapy or radiation. Do not shave skin that has been treated or place tape on treated skin and do not let treated skin come into contact with extreme temperatures.

When reviewing wounds, the caregiver should monitor for signs of infection and report these signs to the healthcare team.

- Signs of infection at the woundsite include swelling, heat, redness, and pain. Other signs include bad odor and puss discharge.

- If the infection is advanced, the patient may have fever, sweating or chills.

PREVENTION OF ULCERS

Pressure ulcers are wounds that develop when pressure on the skin stops the circulation of the blood to the tissues in this area. Areas such as the hips, knees, heels, elbows, and the area above the buttocks (sacrum) are at greater risk because they are support and prominent areas.

Look for areas of the body that remain red or dark for more than an hour and which do not turn white when pressed. Look for areas of the skin that feel warm or look shiny. These are early signs of poor blood
circulation. Take action to keep the damage from worsening and prevent an ulcer.

Blood must circulate adequately in the body to protect and heal damaged skin:

- Patients who move little are at risk of having pressure ulcers. Help the person to keep moving often. If the person cannot move him or herself, help reposition them in their bed or chair every 2 hours and move their arms or legs (passive exercises).

- Look at the surface the patient is sitting or lying on to make sure blood circulation is not affected. Smooth wrinkled sheets and move objects that may damage the skin.

- Wet skin is damaged more easily. Check for incontinence or sweat. Remove any dirty and wet sheets and help keep the skin dry and clean.

- Make sure the patient has enough food and water; eating and drinking help the patient keep blood moving and the skin healthy.

**PATIENT MOBILITY**

Patients may require help from their caregivers to move their body. This may range from assistance with balance or walking to being completely immobile in bed.

**POSITIONING IN BED**

When moving a patient who is unable to move by themselves, it is important to do so carefully to reduce friction and injuries. Injuries may occur when a patient is pulled across bedclothes, for example.

One of the most common position changes is moving a patient up in bed. The following steps must be followed to do this properly:

- Place a folded sheet beneath the patient, extending it from the shoulders to the thighs. You may need to roll the patient from one side to another to get the sheet under their body.
• Place a pillow between the head of the patient and the top of the bed to protect the head from any injuries.

• If possible, request help to move the patient so that there is one person positioned on each side of their body.

• Move the sheet closer to the patient and grasp it at the shoulders and hips.

• Use body mechanisms to move the patient up in bed (see the section of Ambulation Safety for Patients and Caregivers).

Pillows help support and maintain the patient in a specific position. For example, the caregiver may place several pillows behind the patient’s back for an upright position or put a pillow between the patient’s knees and ankles to avoid having them rubbing together.

The supine position (lying on the back) may provide comfort especially after the surgery. To support body alignment, place a pillow under the head and shoulders as well as under the back and thighs, this helps keep the knees slightly flexed. Pillows can be placed under the forearms to elevate the arms.

If the patient would like to rest in the side position to relieve the pressure on the sacrum (tailbone), place a pillow under the head and neck, another under the upper arm and another between the hips. This helps to keep the body properly aligned.

If the patient is bedbound, it is best to reposition them every 2 hours to prevent skin problems (see section on Prevention of Pressure Ulcers).

\\begin{footnote}{\textbf{AMBULATION SAFETY FOR PATIENTS AND CAREGIVERS}}\\Mobility can be dangerous for patients and caregivers. Patients may have physical limitations related to their illness treatment or medication that cause lack of balance, dizziness, or confusion; this creates a greater risk of having fall-related injuries or injuries.\\Caregivers are also at risk of having an injury when carrying out sudden movements and exaggerated physical efforts to help the patient.\\To accommodate the patient, hazards that may result in falls must be removed. The risk for falls may be reduced by ensuring the home is...\end{footnote}
well lit and removing possible hazards such as rugs, furniture and diverse objects that mean an obstacle in the way. Installing handrails in the tub or using a chair for the bathroom may also reduce the risk of falling in a bathroom. Overall, the patient must be familiarized with the distribution of the furniture and other potential hazards in the home. If the patient is walking or doing exercise, he/she must use shoes made for exercise.

Caring for another person is a physically demanding activity. When moving or lifting a patient, it is important for the caregiver to be aware of the appropriate posture and mobility technique and ask for help if needed:

- Do not lift the patient unless it is required. Use caution so as not to injure the skin.
- Use good body posture and mechanics. When lifting keep the back straight and abdominal muscles tight. Bend from the hips and knees, not the waist. Lift smoothly and not suddenly. Prepare the new destination for the patient beforehand.
- Maintain balance. Keep your feet apart and parallel to the shoulder width to provide a strong foundation.
- The caregiver should not twist his or her body when moving or lifting. Instead, they should turn their whole body when moving or lifting the patient. They should twist his or her whole body looking at the person to be lifted.

**PHYSICAL ACTIVITIES AND EXERCISE**

Cancer patients, particularly those in treatment, need physical activity for their mental and physical wellbeing to speed up recovery and improve long term health outcomes. Exercise helps reduce fatigue, it may increase muscle strength, flexibility, and general conditioning, which may be weakened by treatment. Exercise protects bones and improves heart function; it may also help improve depression symptoms. It also helps prevent pressure ulcers.
The exercise plan must include what works better for the patient as well as what is considered as safe, and it should include what the patient likes to do. An effective exercise program includes aerobic work, strength training and stretching.

- Aerobic exercises increase heart rate and respiration, getting oxygen to the whole body. Some examples may include a quick walk or jog. Gardening or house cleaning may also provide physical exercise; this may be done if the patient’s physical capacities allow them to do so.

- Strength training which may include weightlifting helps tone and form muscle, this may be done if the patient’s physical capacities allow them to do so.

- Stretching helps keep muscles and joints flexible.

If the patient has not been exercising, it is important to start and progress slowly. For example, it may be helpful to start with one or two simple daily stretches or a ten-minute walk before progressing to four or five stretches or a thirty-minute jog. Encourage the patient to listen to their body; if they are not feeling well (for example vomiting or in pain) or have a temperature, it is best not to exercise.

If the patient is bedbound, the caregiver will carry out passive bending and extension exercises to maintain muscular tone and flexibility of muscles and joints.

FEEDING

Patient feeding is often a concern for caregivers. This section looks to provide key information to help caregivers understand the needs of feeding, patient diet and nutrition as well as how to manage feeding problems that appear throughout the care of a cancer patient.

FEEDING CONCERNS FOR CANCER PATIENTS

It is common for cancer patients to feel less interested in eating food. They may have reduced appetite (anorexia) or problems with their bowels (constipation or diarrhea). They may feel nauseated or have bouts of vomiting and eating may increase these symptoms. The objective is to maintain hydration, control nausea and vomiting and preserve body weight.
• Fraction the food. Try eating 6 to 8 small portions or try eating every 1 to 2 hours. Eat food when hungry.

• At mealtime, focus on eating high calorie and high protein meals (meat, poultry, fish, dairy, nuts). Food with an easy digestion is recommended.

• Serve food that smells good. Avoid strong odors and maintain circulation of air in the kitchen and home.

• Modify the texture of food (blended, solid or liquid) and taste new meals and recipes.

• Avoid drinking liquids during meals.

• Encourage sitting up or keeping the upper part of the body raised for one hour after eating. This can help with nausea and heartburn.

• Make mealtimes social, convivial and enjoyable. Gently encourage eating; do not nag. Do NOT force foods.

For patients with mouth sores or infections: Eat soft foods that are easy to swallow such as gelatin, scrambled eggs, oatmeal, milkshakes, mashed potatoes, and bananas. Avoid citrus, spicy foods, salty foods, and dry foods. Use a blender to prepare vegetables and smooth meat. Cook food until soft and tender. If sores cause too much pain, numb the mouth with ice or popsicles before eating.

For patients with nausea: Rinse mouth with water before eating. Focus on foods that are soft and easy to digest instead of heavy meals. Eat food at a normal temperature, not too hot or cold. Suck on mint or lemon candies if your mouth has a bad taste.

For patients with diarrhea: Eat broth, soups, bananas, or fruits to replace lost salt and potassium. Try energy drinks. Ensure plenty of liquid throughout the day. Avoid greasy foods, caffeine, high fiber foods (such as beans, cabbage, and broccoli), and milk and dairy products until the episode has passed.
For patients with constipation: Eat more fiber rich foods (beans, grains, vegetables, and fruits), drink liquid throughout the day (water, prune juice, warm juice, and caffeine free tea) and try to get some exercise done. It may be useful to try taking some medication for constipation such as milk of magnesia or stool softeners.

PREVENT AND TREAT DEHYDRATION

Every cell and organ in the body depends on water to function correctly. Water eliminates waste and toxins. It transports nutrients, regulates body temperature, controls heart rate and blood pressure, protects organs and tissues and creates saliva.

People receiving cancer treatment are at a higher risk for dehydration due to side effects such as vomiting and diarrhea. Diarrhea may be caused by an infectious process presenting fever.

Caregivers may notice the following signs and symptoms for dehydration.

- Dry or sticky mouth with a swollen tongue or extreme thirst
- Fatigue or weakness
- Irritability, disorientation, and confusion
- Headaches, dizziness or lightheadedness
- Nausea or constipation
- Dry skin or sunken eyes
- Weight loss
- Dark urine or lack of urination

Caregivers may help prevent dehydration and treat it when it occurs:

- Do not wait for the patient to drink liquids only when feeling thirsty. Patients must try to drink liquids on a regular basis.
- Have them try small amounts of fluids throughout the day. These may be juice or water. Avoid caffeine drinks such as soda, tea, and coffee. Liquids at room temperature may be easier to take rather than hot or cold liquids.
• If the liquids are too difficult, try ice chips, popsicles, and gelatine.

• Have the patient drink most liquids between meals. Use a straw to drink liquids.

• The patient must eat foods with a high level of water such as lettuce, watermelon, broccoli, and yogurt.

• Always have a bottle of water available.

• Lubricate the lips to alleviate symptoms of a dry mouth.

• If the patient is vomiting or has diarrhea, have them drink at least one cup of liquid after each episode.

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**NUTRITION FOR CANCER PATIENTS**

Cancer can change the way the body uses food. Even when a patient seems to be eating enough, the body may not be able to absorb all nutrients from foods. In addition, cancer treatments may affect taste, smell, appetite as well as the ability to eat enough food, causing malnutrition. For this reason, eating habits for cancer patients may be different from healthy people.

Ensuring adequate nutrition before, during and after treatment can help the patient feel better and stronger. Having enough protein and calories is important for healing, fighting infection and having energy.

• Avoid carbonated drinks (such as sodas) and foods that cause gas (such as beans, peas, broccoli, cabbage, radishes and cucumber).

• Choose high protein and high calorie foods to increase energy and help wounds heal eggs, cheese, whole milk, ice cream, yogurt, nuts, peanut butter, and meat. Focus on eating breakfast with one third of the calories and proteins needed for this day.
• If constipated, increase fiber rich food and liquids. Fiber sources include whole grain cereal, beans, vegetables, fruits, and whole grain bread.

• Consider nutrition calorie supplement drinks between meals, especially if eating solid food is a problem: soups, milk, juice, or milkshakes.

Cancer patients often have weak immune systems, particularly if undergoing radiation or chemotherapy. The lack of food may increase the risk of infection. Preparing food in a meticulous manner, washing hands, and avoiding the use of food products out of date may reduce the risk for infection:

• Avoid raw eggs or fish, moldy vegetables or fruit and food sold in open containers.

• Carefully wash all fruits and vegetables before eating them.

• Wash your hands frequently to reduce the presence of bacteria.

• Cook all the meat, poultry and fish until well done.

• Refrigerate all leftover food within 2 hours of cooking and eat refrigerated food within 24 hours.

• Do not purchase food that is out of date.

BIBLIOGRAPHY
MODULE 3: PAIN MANAGEMENT, COMMON SYMPTOMS AND SIDE EFFECTS

A cancer patient may suffer several types of pain and a variety of symptoms and side effects caused by the illness. The pain is not only physical but also psychological (anxiety, depression, fear), spiritual (fear of losing themselves) and social (fear of losing family, friends, and social relationships).

This chapter is based on physical pain and ways of helping caregivers recognize and treat the most common discomforts, symptoms, and side effects of cancer patients. In addition, it focuses on non-pharmacological interventions where a nurse may teach a patient or caregiver to help alleviate the sources of pain and discomfort that the patient may be suffering.

The objective of this module is to ensure that nurses have a teaching reference for patients and caregivers to understand the common sources of pain and discomfort, how to manage these concerns at home and what signs or symptoms require the intervention of healthcare staff.

**PRINCIPAL MESSAGE**

If a person with cancer has pain or other discomforts related to cancer, he or she does not have to bear with it. Even though cancer pain cannot always be alleviated completely, there are ways of reducing this symptom for most patients.

A person may feel tired, depressed, angry, concerned, alone and stressed when the pain and other discomforts are not managed in a suitable manner.
On the contrary, if the pain and discomforts are managed in a suitable manner, the person may enjoy being active, sleeping better, enjoying their family and friends, improving their appetite, and preventing depression.

**KNOW THE ESSENTIAL INFORMATION**

The content of this module is based on the identification of types of physical pain, encouraging patients to speak about pain in order to carry out an assessment, management of the 7 most common physical challenges suffered by cancer patients and instructions for when caregivers contact the patient’s doctor and nurse.

Pain is a common symptom in cancer and cancer treatments. It is also one of the most distressing and feared symptoms for patients and caregivers. The understanding of the nature of pain and ways of controlling it may contribute to having a better life quality in a significant manner.

Module 4 details pharmacological pain management.

**PHYSICAL PAIN**

The quantity of pain that a person feels depends on many things such as the cancer’s location, the type of damage that causes the pain, types of treatment and medication taken by the person and how he or she experiments pain in their body. Every person is different.

**DISCUSS AND ASSESS PHYSICAL PAIN**

Patients must be encouraged to talk about their pain and discomfort with their caregivers, doctors, and nurses. Caregivers are usually people that help the patient to communicate their pain for which it is important that they know what key questions to ask their patients. Caregivers are usually people that help patients communicate the following:
Where does the patient have pain or discomfort?

What does he/she feel (for example: sharp, dull, throbbing, constant, burning, or stabbing pain)?

How long does it last for?

What reduces pain or discomfort or worsens it?

When does pain or discomfort occur (what time of the day, what does the person do or what is happening)?

Does pain or discomfort intervene in the development of daily activities?

How strong is the pain (for example: scale from 0 to 10 or choose a face that represents the pain)?

Some people may not be willing to or want to speak about their pain or physical discomfort. An attentive caregiver may also look for non-verbal signs of discomfort such as facial movements, restlessness, constant movements in bed, complaints, or moans, taking care of the area with pain or avoiding contact with the area.

TYPES OF PHYSICAL PAIN

Nurses and other medical staff may use the description of pain or discomfort of a patient to help identify what the cause of the problem is and what is the best way to alleviate it. There are two main categories of pain: 1) neuropathic pain and 2) nociceptive pain. Nociceptive pain may be categorized as somatic or visceral.

Neuropathic pain is harm caused to nerves, for example a lesion to the spinal cord or peripheral nerves. Nerves allow the brain to communicate with the skin, muscles, and organs. Patients normally describe neuropathic pain as burning, tingling, throbbing and itchy or a “pins and needles” sensation. Some people complain of a throbbing, sharp and cutting pain. This type of pain usually occurs within days, weeks or months of the lesion and it tends to happen in waves of frequency and intensity. Neuropathic pain is the most common and complex pain to treat.
**Nociceptive pain** is pain caused by harm made to body tissue and it is usually described by a sharp, throbbing or aching pain. This type of pain may be caused by tumor cancer cells that grow and extend to other parts of the body close to the cancer’s location. Nociceptive pain may be caused by the cancer being extended to the bones, muscles or joints or causes the blockage of an organ or blood vessels.

**Somatic pain** is the type of nociceptive pain related to the skin, bones, muscles or joints. Somatic pain caused by the activation of pain receptors in the body surface or musculoskeletal tissue is usually described as a sharp or achy pain and it is well located. Somatic pain is usually caused by the combination of factors such as swelling, trauma, excessive activity, vigorous stretching, and contractions. Overall, somatic pain is usually aggravated by the activity and is alleviated with rest.

**Visceral pain** is the type of nociceptive pain related to internal organs suffering harm or lesions. This type of pain is vague and not well located; it is usually described as a pressure or compression type, sharp or diffused pain. Visceral pain may be caused by problems with internal organs such as the stomach, kidney, gall bladder, bladder, and intestines. These problems include distension, perforation, swelling and retention or constipation and may cause symptoms such as nausea, fever, discomfort, and pain.

All types of pain may be sharp or chronic. Different types of pain can be felt at the same time, independently or at different moments and may respond in separate manners to treatment.

**PHYSICAL PAIN MANAGEMENT**

There are several key messages that nurses must share with their patients and caregivers regarding pain management. Sharing these key messages may help patients and caregivers to participate in their care and make it possible to have good pain management.

We will now present the following key pain messages for patients and caregivers:
• Pain can be managed and controlled as part of a cancer treatment plan.

• Speaking openly with your doctor and nurse will help control the pain and discomforts in a better way.

• Having a register of pain and discomfort will help the medical staff create a better control plan for the patient.

• The best way to control pain is stopping it before it begins or avoiding it from getting worse.

Module 4 will provide details regarding pain management medication.

Nevertheless, we present the following key messages for pain medication:

• There are many medications for pain management; each person has a different pain control plan.

• It is highly rare that people who take medication prescribed for cancer pain become addicted to it.

• The body does not become immune to pain medication. Stronger medication should not be saved for “later”.

It is important for patients to have access to pain medication. However, there are many non-pharmacological options for pain management that may be highly effective.

Table: Non-pharmacological approaches for physical pain management
<table>
<thead>
<tr>
<th>Approach</th>
<th>Description</th>
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<tbody>
<tr>
<td>Physical Therapy</td>
<td>Exercises or methods used to help restore strength, increase muscle movements, and alleviate pain. Physical therapies may help with pain, neuropathy, lymphedema, fatigue, and vascular impairment.</td>
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<tr>
<td>Stretching and mild exercising</td>
<td>Stretching and posing system with a special focus on breathing. The purpose is to calm the nervous system and balance the body, mind, and spirit.</td>
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<tr>
<td>such as yoga or tai chi</td>
<td></td>
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<tr>
<td>Massages</td>
<td>A massage consists of pressing, rubbing, and rolling body parts using hands and special tools. A fixed circular movement may work in the best way for pain. A massage may reduce pain and anxiety, help with fatigue and stress as well as alleviate tension and increase blood flow. Deep or intense pressure shall not be used in cancer patients unless a doctor or nurse states it can be done.</td>
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<tr>
<td>Heat and cold therapy</td>
<td>Heat therapy (for example: a hot shower or bath) may alleviate muscle pain while cold therapy numbs the pain. The patient must ask its doctor or nurse whether it is safe to use some of them during treatment. Do not use them for more than 10 minutes at a time. Do not use heat or cold over an area in which there is poor circulation.</td>
</tr>
<tr>
<td>Relaxation</td>
<td>Relaxation reduces pain and avoids it from worsening by eliminating muscle tension. It may help improve sleep and energy and reduce anxiety and stress. The most common relaxation methods are visual concentration, breathing and muscle tension and slow breathing.</td>
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<tr>
<td>Hypnosis</td>
<td>Hypnosis is a trance state of relaxed and focused attention. Patients must be led by a person trained in hypnosis. It may be used to block pain awareness or help change pain sensation towards a more pleasurable one.</td>
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</tbody>
</table>
There are many ways of helping patients manage their pain at home. However, patients and caregivers also know they do not have to do this alone. The patient or caregiver must contact the hospital, doctor, or nurse if the pain is not being controlled in a suitable manner.

When to contact a doctor or nurse in reference to shortness of pain:

- The patient has uninterrupted pain (pain that continues even when feeling relieved after the normal intake of medication).
- The patient is unable to stand up or walk due to the pain.
- The patient is unable to sleep due to the pain.
- The patient is crying or gets upset due to the pain.
- The patient appears to be resistant to move or tightens the muscles when moving.

Pharmacological options for pain:

Patients may obtain some pain medication such as paracetamol or NSAIDs without a prescription. However, it is important that doctors provide information regarding the doses, side effects and interaction with other medications. Prescribed medication may include opioids, anticonvulsant medication, steroids, and antidepressant drugs.

**COMMON SYMPTOMS AND SIDE EFFECTS OF THE TREATMENT**

The illness process, as well as the radiation and chemotherapy treatment, may have symptoms and side effects that go beyond what may be understood as traditional “pain”. It is important to recognize these symptoms and side effects, many of them can be managed in a non-pharmacological manner at home.
Fatigue is the most common symptom in palliative care. Its treatment can improve life quality in a significant manner. However, it generally has multiple causes such as illness, medical treatment, malnutrition, interruption of normal sleeping patterns, depression, or pain. This may make it difficult for treatment.

To manage fatigue at home:

- Promote light to moderate exercise such as walking or swimming. It has been proven that exercise is quite useful to improve fatigue even when it can be inconsistent for many people.

- Be sure the patient has adequate sleep. Being able to identify and manage the underlying sleeping problems is crucial to help patients manage fatigue. Nurses can teach the patient and caregivers different approaches regarding sleep hygiene.

- Identify and reduce the exposure to stressful situations and events. Emotional stress may be particularly exhausting for a person that is ill.

- Promote the appropriate intake of nutritional food; the lack of calories and appropriate nutrients may contribute to fatigue.

When to contact a doctor or nurse in reference to shortness of breath:

- After the change of medication, if the fatigue or numbness is severe and it does not disappear after several days.

Pharmacological options for fatigue:

There are a limited number of pharmacological agents that have shown to be efficient in the treatment of fatigue in palliative care populations. Pharmacological treatment may help with fatigue because of an underlying problem such as anemia or deficiency of vitamins.
SHORTNESS OF BREATH (DYSPNEA)

At times, patients may feel they do not have enough air. This sensation may be caused by the lung’s inability to obtain enough oxygen or the heart’s difficulty to send oxygen to the body.

Patients must speak with their doctor or nurse as soon as possible when suffering a slight shortness of breath because this may be due to several reasons.

When patients suffer shortness of breath, this may make them feel anxiety which may later lead to them feeling worse. There are many things that can be done when a patient suffers from shortness of breath.

To manage shortness of breath at home:

• First, focus on relieving anxiety, encourage relaxation because anxiety may worsen the shortness of breath. A strategy is to recommend the patient to inhale in a slower manner.

• Open a window or use a fan to have air movement; the blocking of air towards the central face and nose (<15 cm) stimulates the nerves that help reduce the dyspnea sensation.

• Ask the patient to sit using additional pillows or a back support when laying down or sitting on a chair. This allows a better expansion of the lungs and better blood flow from and to the lungs.

• Plan resting periods within the activities; reduce the time for visits or speaking, if speaking causes shortness of breath.

If these techniques do not help with shortness of breath, patients and caregivers must be encouraged to contact their doctor or nurse.

When to contact a doctor or nurse in reference to shortness of breath:

• Shortness of breath with chest pain or changes in the mental function (changes in attention, memory, language)
• Severe shortness of breath that does not allow the patient to walk or eat; the patient has blue lips or nails.

**Pharmacological options for shortness of breath:**

Doctors look for a way of managing the underlying causes of shortness of breath and they may prescribe medication to treat this. In addition, the supply of oxygen through a tube or mask may help. Severe shortness of breath that does not find relief through these methods may be treated with morphine.

**SICKNESS AND VOMITING**

Many environmental and psychological factors may cause sickness and the treatment, such as for example chemotherapy, may leave the patient with sickness throughout the whole day. Some pain medications, such as opioids, may cause sickness and vomiting during the first days of intake.

**To manage sickness and vomiting at home:**

• If the nausea is related to medication, stay in bed after their intake.

• Prepare food that the patient enjoys and causes less sickness. Note that their preference in flavor may change with the illness.

• Offer healthy hydrating beverages that the patient enjoys such as water, juice or tea, drink slowly and more frequently.

• Offer smaller portions of food more frequently instead of larger portions of food.

• Prepare light non spicy meals such as soups, mashed potatoes, gelatin, and puddings.

• Take medications with food unless otherwise stated.

• When preparing meals, avoid cooking close to the patient; the smell might cause nausea.

• Overall, try to reduce odors and images that may increase nausea.
If these techniques do not help with sickness and vomiting, patients and caregivers must be encouraged to contact their doctor or nurse.

**When to contact a doctor or nurse in reference to sickness or vomiting:**

- When sickness or vomiting prevents the patient from taking medication.
- If vomiting lasts for more than one day and the patient urinates very little or complains of abdominal pain.
- If these develop any breathing problem.

**Pharmacological options for sickness and vomiting:**

There are many drugs that a doctor may prescribe for nausea. These include metoclopramide, levosupiride, dimenhydrinate, dexamethasone and hyoscine.

---

**LACK OF APETITE**

Patients frequently lose their appetite due to pain, the illness process and side effects of the medication. In fact, flavors may change due to illness. It is important to encourage the person to eat without making them eat. The body may not tolerate food and the person may vomit.

There are many ways of encouraging the intake of food; many of these recommendations are similar to those for vomiting and sickness.

**To manage lack of appetite at home:**

- Prepare food the patient enjoys.
- Encourage the intake of small meals at a higher frequency.
- If the patient does not eat due to the presence of mouth sores, the wounds must be healed first. In addition, treating vomit and nausea is a cause of anorexia.
If these techniques do not help with the lack of appetite, patients and caregivers must be encouraged to contact their doctor or nurse.

**When to contact a doctor or nurse in reference to lack of appetite:**

- If the caregiver or patient notices a quick weight loss.
- If the patient is constantly refusing to eat.
- If the patient is not able to swallow food.

**Pharmacological options for lack of appetite:**

First to be treated are the underlying causes of anorexia such as depression, nausea, and vomiting. If the anorexia is currently unsolved, the doctor may prescribe prednisone (an oral steroid) as appetite stimulation if the patient has suffered a severe weight loss. However, this medication is reserved for short-term use. In addition, dexamethasone (a low doses steroid) may be used to treat anorexia.

---

**CONSTIPATION**

Normal patterns vary among people and may be anywhere from once every two days to three times a day. However, treatments may cause constipation and the patient may have less frequent bowel movements or more pain.

**To manage constipation at home:**

- Increase the intake of liquids to help the bowels pass through the intestines.
- Increase the diet fiber to provide volume and stimulate going to the restroom.
- Participate in moderate exercise of muscles, sit ups and intestines.

If these techniques do not help with constipation, patients and caregivers must be encouraged to contact their doctor or nurse.

**When to contact a doctor or nurse in reference to constipation:**

- If the patient complains of abdominal pain and has not had a bowel movement in 3 or more days.
Pharmacological options for constipation:

In case there is constipation, the doctor and nurse may help treat this with laxatives such as lactulose, magnesium milk, sodium picosulphate, glycerin and enemas.

EDEMA

In advanced cancer patients, edema is usually due to multiple causes and may increase as the illness progresses. An edema in cancer patients may be caused by obstruction to the vein, immobility, liquid retention, and medication such as steroids. It can also be caused by a change in the lymphatic liquid flow due to surgery, radiation, or solid tumors. Patients with chronic edema may feel distressed or uncomfortable and may have reduced mobility.

To manage the edema at home:

- Elevate the affected limb to help with the circulation and the return of the liquid.

- Maintain good skin care; the edema increases the risk of lesions or infections in the skin.

- Test the use of compression socks and compression therapy to reduce swelling in case the patient tolerates this; otherwise avoid using tight clothing.

- Encourage moderate exercise and stretching, the movement of the muscle helps return the excess of liquid to circulation.

- Avoid standing for long periods of time or sitting with crossed legs.

- Minimize the amount of salt in the diet to reduce the liquid retention; make sure there is enough protein as little protein may contribute to the edema.

- Drink liquids continuously as normal (1-1.5 lts. a day) to maintain good hydration unless otherwise stated by the doctor or nurse.
If these techniques do not help with edema, there must be emphasis made on the fact that patients and caregivers contact their doctor or nurse.

**When to contact a doctor or nurse in reference to an edema:**

- If the patient gains 2.5 kilograms or more in a week.
- If the patient develops severe liquid retention or sudden pain.
- If the patient’s feet and hands feel cold, and the skin is firmer or with a shiny aspect.
- If the swelling seems to go to the arms and legs of the patient.

**Pharmacological options for edemas:**

Palliative chemotherapy and radiotherapy may be useful and necessary in the control of malignant edemas by reducing tumors in metastasis. Patients with severe edemas, for example ascites, may be treated with liquid draining, even though diuretics such as furosemide are not any good for patients with chronic benign lymphedema.

**CONFUSION OR DELIRIUM**

Delirium is a common complication within advanced cancer patients; it is characterized by restlessness, illusions and incoherent thoughts or speaking. Confusion or delirium may be a side effect of cancer treatment including drugs such as opioids. Patients with confusion may show one or more of the following signs: forgetfulness, lack of concentration, difficulty speaking or changing moods.

**To manage delirium at home:**

- Help the patient keep a regular schedule, awake during the day and asleep during the night.
- Maintain a familiar home and environment; keep all possessions in the same place and make sure they are easy to find and reach.
- Keep a clock and calendar nearby.
- Remove hazardous objects.
• Deliver drugs in a regular manner and keep a familiar pattern of physical activities.

• Keep a low level of noise, for example, noise made by a television set or radio.

• Speak in simple sentences and make sure only one person speaks at a time.

• Make sure family members or other familiar people are close.

When to contact a doctor or nurse in cases of confusion or delirium:

• If the patient experiences a sudden change in the ability to speak after starting to take a new drug.

• If the patient has new or more confusions.

• If there is a sudden change in the personality or physical functionality.

• If there is a sudden inability to speak.

Pharmacological options for confusion and delirium: Antipsychotic drugs such as haloperidol are frequently used to help manage deliriums in a patient.

URGENT SIGNS AND SYMPTOMS

There are certain signs and symptoms that state the need of professional help; if a cancer patient shows any of these signs, the patient or caregiver must contact the doctor or nurse immediately:

• Temperature of 38° C or more.

• Chills.

• Chest pain or increase in shortness of breath.

• Sudden confusion or disturbing hallucinations.

• Buzzing in ears.
• Severe headache with stiff neck.
• Heavy urine or urine with blood.
• Shaking or uncontrolled movements.
• Numbness or tingling in the legs.
• Sudden incontinence.
• Inability to urinate or have a bowel movement.
• Nausea and/or vomiting with relief.
• Hives/itchiness/rash/swelling.

In addition, patients and caregivers may contact their doctor or nurse in reference to other changes they wish to discuss such as something they may find to be abnormal for the patient or a general sensation of discomfort. The palliation of symptoms emphasizes the relief of discomforts according to what is defined through the experience of the patient and its symptoms.

DYNAMIC ACTIVITIES

PROGRESSIVE MUSCLE RELAXATION

Progressive muscle relaxation is a technique that relaxes the muscles of your body. It is a physiological method oriented towards rest and it has the following effects: reduce stress, reduce heart frequency, help control anxiety, reduce pain, feel more rested.

Tighten the muscles of each muscle group. Keep them tightened for 5 to 10 seconds. Relax the muscles for 15 to 20 seconds. Focus on the tension leaving your body. Repeat this for each muscle 2 or 3 times before passing onto the next muscle group.

Progressive muscle relaxation should not make you ill. Do not practice this if it is painful or uncomfortable. Deeply inhale and exhale to help relax your muscles. Maintain your muscles relaxed for a longer time than when they are tense. It is normal to feel heat and a tingling sensation.

Starting position: Close your eyes, sit on the sofa and lie down as comfortably as possible in order to relax your body to the fullest.
Phase 1: Tension-loosening:

Loosening of the face, neck, and shoulders in the following order: (repeat every exercise three times with some resting seconds in between):

- Forehead: Wrinkle for some seconds and loosen slowly.
- Eyes: Open widely and loosen slowly.
- Nose: Wrinkle for some seconds and loosen slowly.
- Mouth: Give a large smile, loosen slowly.
- Tongue: Press the tongue against the palate, loosen slowly.
- Jaw: Press the teeth noticing the tension in the lateral muscles of the face and temple, loosen slowly.
- Lips: Wrinkle them as wanting to give a kiss and loosen slowly.
- Neck and back of the neck: Bend it backwards, return to the starting position. Bend it forward, return to the starting position slowly.
- Shoulders and neck: Elevate the shoulders pressing them against the neck, return to the starting position slowly.

Loosening of arms and hands

- Tighten one arm without moving it and then tighten the other one with a closed fist, noticing the tension in arms, forearms, and hands. Relax slowly.

Loosening of legs

- Stretch one leg and then the other one by raising the foot in an upward position, noticing the tension on the legs: buttocks, thigh, knee, calf, and foot. Relax slowly.

Loosening of thorax, abdomen, and lumbar area (these exercises work better on a chair):
• Back: Arms in a crossed position and elbows positioned towards the back. You will notice the tension in the lower back and shoulders.

• Thorax: Inhale and retain air during some seconds in the lungs. Observe the tension in the chest. Exhale slowly.

• Stomach: Tighten your stomach, loosen slowly.

• Waist: Tighten your buttocks and thighs. Lift the buttocks from the chair.

Phase 2: Review:

Carry out a mental review of each one of the parts that we have tightened and loosened to prove that every part is still relaxed, continue relaxing each one of them.

Phase 3: Mental Relaxation:

Finally think about something pleasant, something you like, something relaxing; music, a landscape, etc. or leave your mind blank.

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MODULE 4: MEDICATION MANAGEMENT

Nurses, doctors, and other medical staff are familiarized with medication use and doses. However, medical management is frequently a new skill full of challenges for patients and caregivers. This challenge is greater due to the stress of being severely ill or having a loved one that is severely ill.

Teaching the adequate use and administration of medication is an important way of supporting patients and caregivers for patients to receive the complete benefit of their medication. This is extremely important in palliative care where the inadequate use of medication may leave patients with uncontrolled pain.

The objective of this module is not to form pharmacological medical staff in palliative care. This module assumes the staff has already received adequate training in pharmacology.

The purpose is to provide information, approaches and strategies for teaching patients and caregivers about management of medication prescribed for palliative care.

PRINCIPAL MESSAGE

It is fundamental to teach patients and caregivers the adequate management of medication in order to meet the objectives of palliative care. Both the information given to patients and caregivers and the way in which it is taught may improve the suitable compliance of medication intake.

Patients and caregivers need to know:

- What a medication is administrated for.
- What doses to use.
- How and when to administrate medication.
- What side effects to expect and how to manage them.
- How long will the treatment last.

When patients and caregivers do not completely understand the key points in medication management, it normally leads to inadequate use and deficient control of symptoms and pain. In addition, an inadequate education of medication management may contribute to the sense of frustration and distrust towards the medical staff and medical organizations.

CONSIDER THE PUBLIC
There are several reasons for which an adequate intake of medication is not done. Accessibility, lack of understanding the importance and unpleasant side effects are some examples that patients mention when they are asked why they do not take their medication as prescribed. When you teach a patient and caregiver about medication, it is fundamental to understand what barriers may be interfering with the adequate use of medication. Think about these barriers and take your time, be thorough when teaching patients and caregivers about medication and its administration.

**KNOW THE ESSENTIAL INFORMATION**

This module first includes basic information about key palliative care medication, their use and side effects. The text presents essential information for medication that is commonly used for palliative care, the important side effects and risks that patients and caregivers should know. Module 3 details the management of side effects. This module covers techniques to explain the doses and administration of medication as well as strategies to improve its adequate use.

**MEDICATION FOR PALLIATIVE CARE**

We will present basic information of essential medication for common use in palliative care based on a list that was created in 2013 by the WHO. Usually, it is recommended to begin with non-opioid pain medication and gradually progress towards stronger pain medication until the pain is alleviated. Most cancer pains can be controlled with oral pain medication. The objective is to alleviate pain and discomfort caused by the illness or treatment.

**NON-OPIOID MEDICATION**

These include paracetamol (acetaminophen), non-steroid anti-inflammatory drugs (NSAIDs) and complementary medication (co-analgesics).

Paracetamol (acetaminophen) is used as a primary analgesic or in combination with other medications, to treat light to moderate pain.

The NSAIDs may alleviate light to moderate pain, particularly those of somatic origin (for example, bone, muscle, skin pain). NSAIDs are especially useful for pain related to inflammation which is seen through pain, heat, redness, and swelling. In some situations, such as pain caused by cancer metastasis, NSAIDs may be a useful complement for opioid therapies.

**TABLE 1: NON OPIOID ANALGESICS**
Complementary analgesics are defined as medication that is not primarily designed to control pain but that may be used for some painful conditions on their own or in combination with other analgesics. Complementary medication includes corticosteroid, anticonvulsants, antidepressants, antispasmodic and bisphosphonates.

Antidepressants may help treat some painful conditions. This medication may affect the transmission of pain from the spinal cord to the brain. In addition, they may reduce depression and anxiety and help regulate sleep which influences pain; people that suffer depression, anxiety and insomnia have shown to have more severe and longer pain than other people.

Corticosteroids have analgesic properties to treat a variety of symptoms of cancer pain including bone and neuropathic pain as well as headaches; this is due to the increase of intracranial pressure, joint pain and pain caused by obstruction or distension of organs. They are also used to improve appetite, sickness, discomfort, and quality of life in general.

Anticonvulsants are frequently used for managing neuropathic pain, in other words pain caused by damage in the central and/or peripheral nervous system. Neuropathic pain syndromes can be related to cancer (for example, metastasis with a nerve lesion) and therapeutic intervention (for example, surgery, chemotherapy, radiotherapy).

Antispasmodics such as hyoscine (scopolamine) reduce motility and secretions in the gastrointestinal area. They are used for managing malignant intestinal obstruction and treating excessive respiratory secretions that are commonly associated with the end of life.

<table>
<thead>
<tr>
<th>Medication and Formulas</th>
<th>Use in palliative care</th>
</tr>
</thead>
</table>
| **Paracetamol** (acetaminophen): Tablets, injection | Light to moderate pain  
Complementary analgesics with opioids |
| **Ibuprofen** (NSAIDs): oral liquid, tablet | Light to moderate pain  
Complementary analgesics for moderate to severe pain |
| **Lidocaine 5%** (topical analgesic): patch | Postherpetic Neuralgia  
Neuropathic pain |

*WHO essential medication in palliative care*
<table>
<thead>
<tr>
<th>Complementary Analgesics</th>
<th>Opioid Analgesics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amitriptyline</strong>; <strong>Fluoxetine</strong>&lt;sup&gt;*&lt;/sup&gt; (antidepressant): tablet</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td><strong>Dexamethasone</strong>&lt;sup&gt;*&lt;/sup&gt; (corticosteroid) injection, oral liquid, tablet</td>
<td>Anorexia</td>
</tr>
<tr>
<td></td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td></td>
<td>Sickness and vomiting</td>
</tr>
<tr>
<td></td>
<td>Headache</td>
</tr>
<tr>
<td><strong>Gabapentine; Pregabaline; Carbamazepine</strong> (anticonvulsants): tablet</td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td><strong>Hyoscine</strong>&lt;sup&gt;*&lt;/sup&gt; (antispasmodic): tablet, oral liquid, injection</td>
<td>Visceral pain</td>
</tr>
<tr>
<td></td>
<td>Terminal respiratory congestion</td>
</tr>
</tbody>
</table>

**TABLE 2:**

*WHO essential medication in palliative care and/or national medication petition*

**Complementary Analgesics**

**Opioid Analgesics**

Opioids are characterized as weak or strong based on their strength. An oral 10mg dose of morphine is the strength it compares with to other opioids.

**Weak Opioids:** Codeine, tramadol.

**Strong Opioids:** Morphine, oxycodone, methadone, buprenorphine & fentanyl (transdermal patch).

Morphine, a strong opioid for palliative care according to the WHO, is the medication chosen for light to severe pain. Codeine and tramadol are usually medications chosen for moderate pain and it is usually 7 to 10 times less strong than morphine. Oxycodone is 2 times stronger than morphine and fentanyl, in a transdermal patch, may be 100 times stronger than morphine.

Transdermal opioids are useful for controlled pain, when strong oral opioids have intolerable side effects (sickness and vomiting, constipation, hallucinations), and for patients that cannot take oral medication.
**TABLE 3: OPIOID MEDICATION IN PALLIATIVE CARE**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Use in palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Codeine</strong>: tablet</td>
<td>Diarrhea</td>
</tr>
<tr>
<td></td>
<td>Cough</td>
</tr>
<tr>
<td></td>
<td>Moderate to severe pain</td>
</tr>
<tr>
<td><strong>Tramadol</strong>: tablet, capsule, oral liquid, injection</td>
<td>Moderate pain</td>
</tr>
<tr>
<td><strong>Morphine</strong>: tablet, oral liquid, injection</td>
<td>Dyspnea</td>
</tr>
<tr>
<td></td>
<td>Severe pain</td>
</tr>
<tr>
<td><strong>Oxycodone</strong>: tablet</td>
<td>Severe pain</td>
</tr>
<tr>
<td><strong>Methadone</strong>: tablet</td>
<td>Severe pain</td>
</tr>
<tr>
<td><strong>Buprenorphine</strong>: transdermal patch</td>
<td>Moderate to severe pain</td>
</tr>
<tr>
<td><strong>Fentanyl</strong>: transdermal pain</td>
<td>Severe pain</td>
</tr>
</tbody>
</table>

* WHO essential medication in palliative care

**OTHER MEDICATION IN PALLIATIVE CARE**

Table 4 shows other medications commonly used in palliative care.

**TABLE 4: MEDICATION FOR COMMON SYMPTOMS IN CANCER PATIENTS**

<table>
<thead>
<tr>
<th>Medication and Formulas</th>
<th>Use in palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Haloperydol</strong>: (antipsychotic): tablet, oral liquid, injection</td>
<td>Delirium</td>
</tr>
<tr>
<td></td>
<td>Sickness and vomiting</td>
</tr>
<tr>
<td></td>
<td>Terminal agitation</td>
</tr>
<tr>
<td><strong>Metoclopramide</strong>:; <strong>Levosulpiride</strong>; <strong>Dimenhydrinate</strong>: (antiemetic): injection, oral liquid, Tablet</td>
<td>Sickness and vomiting</td>
</tr>
<tr>
<td><strong>Ranitidine</strong></td>
<td>Gastric protector</td>
</tr>
<tr>
<td></td>
<td>Acid reflux</td>
</tr>
<tr>
<td><strong>Omeprazole</strong></td>
<td>Gastric protection</td>
</tr>
<tr>
<td></td>
<td>Acid reflux</td>
</tr>
<tr>
<td><strong>Loperamide</strong>: (antidiarrheal)</td>
<td>Diarrhea</td>
</tr>
</tbody>
</table>
**Furosemide; Spironolactone**
(diuretic): Edema

**Docusate Sodium*, Picosulphate Sodium*, Senna*, Lactulose, Magnesium Milks, Polyethylene Glycol, oral liquid; tablet Glycerin Suppository (laxative):** Constipation

**Midazolam, Alprazolam, Lorazepan** (sedatives): injection; Tablet
Anxiety
Insomnia
Terminal agitation (sedation)

*WHO essential medication in palliative care*

**SIDE EFFECTS OF MEDICATION**

Medication used in palliative care may have side effects. Patients and caregivers must know the possible side effects and when these are tolerable or require some kind of consultation to be made with the doctor.

**SIDE EFFECTS OF NON-OPIOID ANALGESICS**

Paracetamol: The doses in healthy people must be limited to no more than 4,000 mg every 24 hours to reduce the risk of liver damage.

Patients prescribed with SNAIDs for more than a week should also take a proton pump inhibitor (for example, omeprazole) to prevent gastric discomfort. SNAIDs may be contraindicated with gastrointestinal, kidney, cardiovascular and liver illnesses.
TABLE 5: SIDE EFFECTS OF NON-OPIOID ANALGESICS

<table>
<thead>
<tr>
<th>Medication Group</th>
<th>Side Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminophen/ Paracetamol</td>
<td>Large doses may generate liver damage. It may cause liver damage if the patient consumes 3 or more alcoholic beverages a day.</td>
</tr>
<tr>
<td>Reduces pain and fever</td>
<td></td>
</tr>
<tr>
<td>NSAIDs (aspirin, ibuprofen, naproxen)</td>
<td>It may cause stomach discomfort. It may cause mucous bleeding in the stomach, especially if the patient drinks alcohol. It may cause kidney problems, especially in elderly people and those with kidney illnesses. It may cause cardiac problems (except aspirin), especially for people that have a cardiac illness. Avoid this medication if the patient is under blood thinners.</td>
</tr>
<tr>
<td>Reduces pain, inflammation, (swelling) and fever</td>
<td></td>
</tr>
</tbody>
</table>

SIDE EFFECTS OF OPIOIDS

Opioid medication has several known side effects:

**Constipation:** Constipation is a side effect of opioid and it may be frequently reduced by increasing the amount of liquid, diet fiber and practicing moderate exercise (with the recommendations of a doctor and/or nurse). If there is constipation, adding laxatives or stool softeners may help start gastrointestinal movement. It is common to prescribe laxatives with opioids to avoid constipation in patients that do not have diarrhea.

**Nausea:** The patient may sometimes have nausea or vomiting during the first or second day of medication use. Advise this to your nurse or doctor. The doctor may prescribe anti sickness therapies to control these side effects.

**Sedation, Drowsiness or Confusion:** Opioids may sometimes cause sedation, drowsiness or numbness when taken for the first time or during approximately one day after the increase in dose. Some people feel confused or disoriented after taking an opioid analgesic. In case these side effects increase, contact your doctor immediately. The doctor can modify the dose or add a complementary medication.

**Slow breathing:** Opioids may reduce breathing, especially when taken in high doses. This can usually be solved as the body gets used to the medication. Breathing and other vital signs are monitored during a hospital stay. However, contact your palliative care team if the breathing causes discomfort. Complementary medication can be prescribed to treat this.
TEACHING ABOUT MEDICATION

Good teaching and education for patients and caregivers is fundamental for palliative care. It is more likely to comply with the pain management plan if the patient and/or caregiver have a good relationship with the healthcare professional and obtain positive feedback from them.

The noncompliance of the management plan may be the result of a lack of knowledge of the illness or condition, a lack of understanding of the reason for which the medication was prescribed, an inadequate follow-up and/or medication cost. Therefore, we know that telling the patients and caregivers what to do is not enough to have a good compliance. Good teachers also need to have communication with patients and caregivers to assess the comprehension and manage their concerns.

It is important to consider the things that may make it difficult for patients or caregivers to manage or administrate medication in a suitable manner, such as:

- Low literacy.
- Multiple steps to remember.
- Multiple professionals and medication.
- Deficient sight and/or limited motor skills.

What is the difference between positive and negative feedback? How are these problems managed when the patients or caregivers use the medication in an inadequate manner?
MODULE 5: END OF LIFE

Dying is a normal part of life. However, it is frequently treated as an illness. People usually spend their final days and hours in a hospital, where they may be alone and in pain. As we have already emphasized in this program, the main purpose for palliative care is improving the life quality of the patient. This includes improving the quality of life during the agony process. The end of life is part of life.

Teaching regarding what to expect at the end of life is probably the most recent form of navigation for the patient. Although we must all pass through this process, it is unknown territory for the person in agony and usually a new experience for the family and loved ones, saying "goodbye".

Nurses may help patients and families when the patient is close to the end of life. It is trustworthy medical staff that usually spends the most amount of time with the patient and their families. Nurses may help understand the medical forecast of the patient, explain the process and the end of the illness. They, with their important role and experience, are key pieces to help patients and their families to decide what they want and help them have the necessary care based on the patient’s wishes.

Physical, mental/psychological, emotional, and spiritual issues are an important part of the agony process. Patients and their families choose how to adapt to these problems and the nurse may provide information to help them deal with this important moment in their lives. Preventive Guidance at the end of life is a fundamental element of navigation of the patient for the palliative care nurse.

CONSIDER THE PUBLIC

Nurses that participate in end-of-life care have a significant challenge when considering the perspectives, expectations, and preferences of their patients. Some of these may seem to conflict with the goals of the end-of-life palliative care, which leads to ethical problems for the nurse regarding what actions should be taken.

For example, the traditional medical model is a healing one. This means it focuses on healing an illness. This approach may lead to aggressive treatments and a delay in pain management, comfort, and concerns for the end of life. Patients and family members under medical care may expect their medical staff to be focused on the treatment and healing process even when treatments no longer work, and healing is not a possibility.
In addition, in traditional western bioethics, the main key for autonomy requires adults to make their own decisions regarding medical treatment they want and do not want. However, we know that people and cultures vary regarding how they wish to share health information such as diagnosis and forecast of a cancer patient.

Many people also believe that death appears in a sudden and unexpected manner. However, there are many people that can feel/believe when death is near. Over 90% of all people will die after a long illness and not in an unexpected manner. The denial of death expectation may cause pain or hurt the patient when interfering with their desire of solving issues such as offering apologies, being forgiven, recognizing remorse, and saying goodbye to family and friends.

This course will not try to solve these dilemmas but nurses that participate in end-of-life care must try and consider the potentially ethical perspectives and courses of action based on moral principles.

Given the fact that this program does not cover a detailed revision of bioethics, we ask nurses and nurse leaders interested in learning more about bioethics, to look for additional information opportunities such as programs and online courses. A resource for those interested may be found in the Bioetic Foundation with headquarters in Cordoba, Spain: http://www.bioeticacs.org/

**KNOW FUNDAMENTAL INFORMATION**

Patients and their families experiment death in different manners. People have a range of differences and expectations regarding death. However, there are many experiences and common questions that a nurse may help respond to. Some of these questions are:

- Does my loved one feel pain? How do we know?
- Are we starving him/her?
- What should we expect? When will we know there is little time left?
- Should I/we stay at his/her bedside?
- Can my loved one hear what we are saying?
- What will we do after the death?

The content of this chapter shows a summary of key topics that will help a nurse guide their patient and family to respond to this and other questions regarding the end of life. These topics include cancer forecast, agony as a process, psychosocial and emotional support, common symptoms, and treatments during the final hours of life and mourning. It is expected that these topics only provide a basic description of the topics that may be discussed by a palliative care nurse. With experience and passing of time, it is expected that professionals have more nursing skills for this stage in life.
CANCER FORECAST

Many patients would want to know “how much time” they have left. There are several scales that may help a doctor determine a forecast. However, there is not a unique method that works for all patients.

A simple method used to assess the functional skill of asking patients: “What do you do with your time? How much time do you spend sitting in a chair or laying down?” If the answer is >50% of the time and this increases within time, one may estimate the forecast in approximately 3 months. Survival time tends to reduce more with the increase of physical symptoms, especially dyspnea, if these symptoms are related to the diagnosis of cancer. Although this is not a guaranteed manner of knowing how much time a person would live, it would be a good guideline to help nurses anticipate the needs of a patient and guide them in reference to what they should expect.

Nurses may not be sure of the information they may provide to the patient. Instead of simply telling the patient and their family to speak to their doctor, the nurse has the opportunity of interceding for the patient with the doctor and being an information channel. Nurses help communicate and explain information and feelings throughout the agony process.

Even when the patient’s doctor has the function of giving news to the patient and their family, such as when the first forecast was given, nurses may explain this technical information and guide family members towards the end of life.

Together with doctors, nurses should use the following steps to guide patients and their family towards the forecast:

1. Confirm that the patient and/or family member is ready to listen or talk about the forecast.
2. Present information using a range: some days to weeks; 2 to 4 months, etc.
3. Allow time for silence after giving information; respond to emotions.
4. Use the information to look for end of life patient’s goals.
AGONY AS A PROCESS

Agony is a psychological, social, and physical process. In the case of cancer, people usually have time to reflect about the fact that death is near. Family members may want to know what to expect, what they can do for their loved ones and when they should contact a doctor.

Providing preventive guidance regarding what to expect during this process will help patients and their family to make decisions during this important moment. Having this information may be comforting for many and makes this moment less stressful and confusing.

PSYCHOLOGICAL PROCESS

Dr. Elisabeth Kubler-Ross, psychiatrist, developed a mourning process model for people that face a terminal illness. This model has five points or “stages”, in other words 5 common answers among people that face death. It may be useful to understand what patients and family members suffer and their reactions and behavior.

However, nurses must understand that not everyone is going to experience the five answers. Crying our own death is not a linear process which means we should not expect people to pass from one answer to another in an ordered and progressive manner. There is not a “correct” way of agonizing and dying.

Nevertheless, the five stages are useful as conceptual tools if these are not applied in a teaching manner or are considered as potential answers.

The 5 “stages” are:

**Denial:** “I feel well”; “There must be a mistake.” During this response, people believe there is a mistake in the diagnosis and hang on to a preferable and false reality. Denial is only a temporary defense for the person.

**Anger:** “Why me? It is not fair!” Once people get a response to their anger, they recognize they can no longer remain in denial. During this response, the person may be frustrated with the people closest to them and it is frequently difficult to take care of them.

**Negotiation:** “If only... then l...” In the negotiation response, the person looks for a way of postponing the unavoidable, death. The usual way of having dialogue is negotiating the extension of life in exchange for a reformed lifestyle.

**Depression:** “What for? I am still going to die.” During this response, the person in agony starts to understand the certainty of death and desolation. They may reject medication/treatments or visits. Some people remain in silence and/or cry all the time. It is not recommended to try to lift the patient’s spirit during this time since depression allows a person to disconnect from other people and feelings.

“I am more than these five stages. And so are you.”

– Elisabeth Kubler-Ross
Acceptance: “Everything will be ok. I am ready to die.” During this response, the person starts to accept their mortality or the one of a loved one. This response normally comes with a retrospective and calmed view as well as a stable condition of emotions. However, not every person gets to this stage. Some people continue dealing with death until the end. In addition, the person in agony may have this response before their family members.

SOCIAL PROCESS

People with terminal illnesses change their daily functions as death is near in different manners. Family members play a particular role in helping a patient because their regular social life is changing. We will present some useful responses to teach family members regarding how to support patients throughout these changes.

Isolation from family and friends: People frequently focus on themselves during the final weeks of life. This does not have to mean that they are angry, depressed or do not like their caregivers. This change may be due to the lower amount of oxygen in the brain, lower blood flow and/or mental preparation for their agony. They may lose interest in things they used to enjoy such as television programs, friends, and pets.

Caregivers may let their patients know that they are here to support them. The person may be conscious and may listen even if they are not able to respond. Experts suggest that it may be useful to give them permission to become “free”. If they feel the need to speak, they may want to remember moments of joy and sorrow or tie loose ends.

Changes in sleep: People may be drowsy, sleepier, have interrupted sleep or confusion when waking up. Concerns may make patients unable to sleep during the night. Caregivers may ask them if they wish to have them stay in their room while they fall asleep. Patients may sleep more with the passing of time.

Caregivers must continue speaking to them even when they are no longer conscious because patients can still listen.

Growing weakness: Weakness and fatigue will increase within time. The patient may have good and bad days for which they will need more help with personal care and daily displacement.

Caregivers may help patients save energy for things that are more important for them.

Changes of appetite: While the body is naturally turning off, the person with cancer is going to need and want less food. The loss of appetite is caused by the body’s need to conserve energy and its skill of needing less food and liquid in a suitable manner.
Patients should be allowed to choose if they want to eat or drink and how to do it. Caregivers may offer small quantities of food that patients enjoy. Patients need energy to chew for which the caregiver could prepare mashed potatoes. If the patient has difficulty swallowing, one can offer liquid and use a straw if they are unable to sit. If the person cannot swallow, offer ice chips. Maintain the lips moist with lip balm and the mouth clean with a soft and moist cloth.

**Consciousness:** People frequently have episodes of confusion, restlessness, and hallucinations close to the end of life. They may be confused regarding time, place, and the identity of their loved ones.

Caregivers may gently remind the patient where they are and who they are with. They must be calm and quiet. If the patient is agitated, you should not try to control them physically. Speak to the doctor if the agitation occurs frequently, there are pharmacological treatments that help control or revert this.

There are times in which patients say they have heard or seen a deceased loved one. They may speak about travelling, seeing lights, butterflies, or other symbols of reality that we cannot see. If this is not disturbing for the patient, caregivers may ask them to tell them more. Allow them to share their visions and dreams without trying to tell them that what they see is not real.

During the final days and hours of life, it is important that caregivers are prepared to manage their needs and the ones of the patient. The following points are good recommendations for families that are getting prepared for the death of a loved one:

- Having a patient in a place that allows them to have privacy and intimacy.
- Creating a family environment.
- Understanding what medication, equipment and articles may be required.
- Knowing that the patient may be conscious even when they are unable to respond:
  - Assume that the patient can hear everything.
  - Include the patient in the conversation.
  - Give the patient permission to die.
  - Touch the patient.
During the final hours of life of a cancer patient, caregivers should focus on making them feel as comfortable as possible. The patient should not be alone at these times; many people are afraid of being alone when death arrives. Make sure the family is close by and that someone is sitting when speaking about the person in agony. Sitting with the person, holding their hand, praying with them and their family may bring peace to their family and those that care for the patient. It is very important to explain this to the family of the patient and the caregiver for them to know what to expect and how to provide the best care possible.

**PHYSICAL PROCESS**

Cancer patients tend to have a constant functional reaction within a terminal phase. Preventive guidance may help people know where they are within the agony process and prepare them for the common physical needs of a person in agony. It may also comply to respond to the informative needs of the family.

**ACTIVE AGONY**

Almost all patients in agony go through a stereotype of symptoms and signs during the days before their death. This path is commonly known as “active agony” or “imminent death”. This section will describe the typical stages in a process of active agony.

The period necessary to develop all stages may be from 24 hours to 14 days or more; the course of time is unpredictable. There are the following stages of active agony: early, medium, and final stage.

- **Early stage**: In bed, loss of interest and/or ability to drink/eat, cognitive change (increase of time sleeping and/or in delirium).

- **Medium stage**: Further deterioration of the mental state (slowness when waking up with stimulation, only brief periods of wakefulness).

- **Final stage**: Death Rattle (oral secretions accumulated that are not eliminated due to the loss of automatic action of swallowing), decrease of stimulus of coughing or increase in the density of secretions, in a coma, with fever (tumor, pneumonia), altered breathing patterns (periods of apnea, hyper apnea or irregular breathing), cold limbs, distal or peripheral cyanosis or clotting alterations (violet spots).

A normal progression towards death goes from drowsiness, to lethargy, difficulty to wake up, which leads to a coma state. Some people may suffer a difficult progression with agitation and confusion to hallucinations, delirium, and seizures.

**PHYSICAL NEEDS**
• **Pain:** As the illness progresses, it may be more difficult to control the pain. It is important to provide pain medication on a regular basis. Caregivers must have close contact with their doctor and nurse to know which is the medication and correct doses. Palliative sedation uses special medication called sedatives to alleviate extreme suffering by making the patient calm and conscious; the objective is to alleviate suffering not to rush death. It may be useful to explore other control methods such as massages and relaxation techniques.

• **Intestines and Bladder:** There may be a loss of control in the intestines and bladder due to the relaxation of pelvis muscles. Caregivers must continue providing hygiene care, maintaining bedding and personal clothing dry and clean. The patient may start using diapers. In addition, there may be a reduction in the amount of urine due to a slower kidney function and/or reduced intake of liquids. Urine may be dark, or it may have a strong odor.

• **Breathing Patterns:** The breathing speed may increase or decrease in cycles (Cheynes-Stokes). The patient may not notice it, but caregivers must speak to the doctor or nurse if they are worried about the changes. There may be sounds of vibration or gurgles caused by the saliva or liquids accumulated in the throat and upper ways. This may be uncomfortable for caregivers and the patient. It may be easier to breathe if the body is turned towards the side and pillows are placed behind the back and under the head. In addition, caregivers may ask the doctor or nurse from the palliative care team regarding the use of a dehumidifier or external source of oxygen to make it easier for the patient to breathe if the patient has difficulty doing so.

• **Skin:** The skin may turn blue and feel cold as the blood flow reduces. Caregivers must avoid covering the patient with electric blankets or hot water bottles because these may cause burns. However, you may cover the patient with a quilt that is not heavy.

**CAUSES OF DEATH**

Patients and family members may understand what cancer is and what it is doing to their body. The nurse must assess the preferences and needs of the patient and family for this technical information.

During these final cancer stages, there are problems presented in many parts of the body.

• **Digestive System:** If the cancer is found in the digestive system (for example, the stomach, pancreas, or colon), the food or waste does not pass, and this may cause inflammation, sickness, or vomiting. If cancer prevents food from being digested or absorbed, the patients may suffer from malnutrition.
• **Lungs:** If there is little healthy lung tissue or the cancer is blocking a part of the lung, the person may have difficulty breathing or obtaining enough oxygen. If the lung collapses, it may get infected and that would be too difficult to overcome for a person with cancer.

• **Bones:** If the cancer gets to the bones, a large amount of calcium may be entering the blood flow which may cause the loss of consciousness and death. Bones with tumors may break and not heal.

• **Liver:** The liver eliminates toxins from the blood; it helps digest food and turns food into substances that are necessary to live. If there is not enough healthy liver tissue, the chemical balance of the body is affected. The person may eventually fall into a coma.

• **Bone marrow:** When the cancer is in the bone marrow, the body is not able to produce enough healthy blood cells. The lack of red cells will cause anemia and the body will not have enough oxygen in the blood. A low number of white cells will make it difficult to fight an infection. A decrease in platelets will prevent the blood from clotting and make it difficult to control abnormal bleeding.

• **Brain:** A large tumor in the brain may cause memory and balance problems, bleeding in the brain or loss of functions in other parts of the body which will eventually lead to a coma.

In some cases, the exact cause is not determined, and patients simply start to become weaker and weaker until they give up cancer.

**SIGNS OF DEATH**

The following items are physical signs of death:

- The person is no longer breathing and does not have a pulse.
- Their eyes are not moving or blinking, and the pupils are dilated (enlarged). The eyelids may be slightly opened.
- The jaw is relaxed, and the mouth is slightly opened.
- The body releases the contents of the bladder and intestine.
- The person does not respond to touch or words.
- The person’s skin is pale and cold at touch because the blood settles and the pressure drop.
Now that we have considered death as a process, we may consider specific ways with which nurses may provide active support during this process. Nurses may assess the psychosocial needs (mental, emotional, social, and spiritual needs) of patients and family members and guide them to find additional resources when necessary.

PSYCHOSOCIAL ASSESSMENT

Nurses may use therapeutic information to help patients maintain relationships, find the meaning of an agony process, and find a sense of equanimity to facing and preparing for death. Open questions are a fundamental part of therapeutic communication. Other therapeutic techniques include active listening, sharing observations, hope, humor, and feelings, using touch and silence, providing information, clarification, focus, making relevant questions and paraphrasing or summarizing. Sharing personal experiences is also a therapeutic communication technique if it is focused on the patient and caregiver.

The following chart presents several open questions to help assess the psychological needs of patients and caregivers.

<table>
<thead>
<tr>
<th>Assessment of Psychosocial Needs</th>
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<td>Meaning of the illness</td>
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<td>Adaptation style</td>
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<td>Stress Factors</td>
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<td>Spiritual Resources</td>
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</table>
| Psychiatric Vulnerabilities | “Have you suffered any periods of depression, anxiety, drug abuse or other significant difficulties during your adaptation to the illness?”
|                           | “What types of treatment have you had, and which have you found to be useful?”
| Economic Circumstances     | “How much do financial problems worry you?”
| Patient – Doctor Relationship | “How do you want me to help you with this situation? How can we work together in the best way possible?”
| Doctor – Nurse Relationship |

Rome et al. 2011

**PSYCHOSOCIAL SUPPORT**

People around the patient may be lost regarding what they should say or do. While every person has different needs, we will present some of the concerns that people normally have at the end of their life:

- Fear of being abandoned.
- Fear of becoming a burden for others
- Fear of losing their dignity
- Fear of losing control

Caregivers may approach some of these concerns with the following actions:

- Keep the patient company by speaking to them, watching tv/movies, or simply sitting next to them.
- Allow the patient to express their fears and concerns regarding death. Listen.
- Avoid the retention of information. Be sure that the patient is included in conversations about them and their care if they wish to be included.
• Reassure the patient that you will honor their wishes regarding their care and after their death.

• Ask if something can be done for the patient.

• Respect the need for privacy.

• Be open to remembering the patient’s life. During this period, it is possible for a patient to remember and reflect on their life, legacy, and loved ones. Caregivers may explore this using the following questions:
  - Which were the happiest or saddest moments that we have shared together?
  - What are the decisive or most important moments in our life together?
  - What makes us the proudest?
  - What have we taught each other? Support the spirituality of the person by speaking about their faith or arranging visits with spiritual leaders if necessary.

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**SPIRITUAL ISSUES**

When a person dies, religious and spiritual beliefs may serve as refuge, but they are also a source of questions and doubts. The person may have thoughts and doubts about their life and what will happen when they pass away; they may also think about why it is important to be in peace with their God or do certain things for their spirit or soul to be safe after death.

It is important to respect and answer in a positive manner to spiritual beliefs that the patient or caregivers may have. There are many things that can be done to help a person with a terminal illness find spiritual peace, offer a certain degree of comfort, and help them accept death. The patient may know someone in the community whose spiritual advice and wisdom may help them find peace; they may need this person to spend time with them. There may also be groups in the community such as women in their church that may help them find spiritual peace. It is possible that some people do not wish to speak to a religious person but may wish to discuss spiritual matters with someone they respect. It would be helpful to find someone, such as a member of the church or community, which may offer their help.

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**FEELING OF GUILT**

A person with cancer may feel guilty if they believe they have done something wrong that may have caused the cancer or that someone has cursed them. They may also feel guilty for other people having to take care of them or because their illness makes things more difficult for the people around them. For example, they may feel bad for the lack of money and because their medical needs consume the family resources.
In some cases, the patient may feel guilty for damage they may have caused to someone recently or in the past. This may be a good opportunity to apologize for the bad actions or tough words that may cause this feeling of guilt. This may help everyone feel better.

The patient and caregivers may require to be given trust and support, so they do not feel overwhelmed with guilt feelings. They must be constantly reassured that, nevertheless their great effort, every life cycle ends in death.

**COMMON SYMPTOMS AND TREATMENT**

Common symptoms and treatments for cancer and cancer symptoms have been developed in other modules of this program. Here, we will focus on the most common physical symptoms of the end of life and the key conversation topics with caregivers:

**PAIN**

- It is one of the most common end of life symptoms.
- A source of suffering for patients and families.
- It may worsen other symptoms.
- It is usually treated with opioid pain killers: the fear of the family of rushing a death due to breathing depression is a barrier for its use.

**DISPNEA (DIFFICULTY TO BREATHE)**

- A subjective sensation of lack of air.
- It may worsen due to the excess of liquid infusion.
- It may be easier to breathe if the patient’s body is placed in a lateral position towards the side and pillows are placed behind the back and head.
- It is commonly treated with opioids and benzodiazepines (for example midazolane), intravenous administration may be used if the patient is suffering, and the doses may increase based on a medical assessment.
- Caregivers may also ask their doctor or nurse regarding the use of a dehumidifier or external source of oxygen for the patient to be able to breathe easier.

**Delirium and Agitation**

- It is usually characterized by distress (spiritual, emotional, or physical distress), anxiety, agitation, and cognitive failure.
• It affects cognition, attention, sleeping cycle, humor, and speech.
• It has an acute beginning which distinguishes it from dementia.
• The treatment for terminal delirium usually requires the use of benzodiazepines and/or antipsychotics.

“The Death Rattle”

• This is caused by secretions accumulated in the throat that the patient is unable to eliminate.
• A profound aspiration is not recommended; this may cause discomfort or suffering which leads to agitation and increases the production of secretion.
• Anticholinergics, such as scopolamine, may help with secretions.

**MOURNING**

Mourning is the process of accepting death. This starts once the person becomes ill and the family notices the patient is dying. This process may involve very strong emotions. These feelings can sometimes be so overwhelming that people are unable to continue with their normal life, a person that goes through this may have a great sadness that causes depression.

The support received by other people is very important during this situation. This may remind the people going through this that these feelings are normal and that there are still many good things to experience in life. The simple fact of listening and holding the hand of a person may help.

**AFTER DEATH**

Place the body on its back with a pillow under the head. If necessary, the caregivers or family may place dentures or other artificial parts of the person in their place.

Contact suitable authorities according to local regulations. Contact the doctor and funeral home. Call relatives, friends, and church members when the family is ready to do so.

The family may need support making funeral arrangements. Every family has rituals and customs regarding how to prepare and show the body of a deceased person, this must be respected. Show the family support and listen to them if they wish to speak of their loved one, this may comfort them.

Once several days have passed, it is a good idea to visit caregivers and families to see how they are dealing with the death of their loved one. It will be very important to find out how they feel and contact them with support groups that may offer social, emotional, and spiritual help.
Family members and those that have taken care of the person may feel depressed during a long period of time after the death of a loved one. This is a normal part of the process of dealing with a loss. Most family members will accept the loss of a loved one and will recover from the depression within time. Sometimes people providing care may feel depressed and may require support or treatment.

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