



Hospice Care

Prepared By Zainab Mahmoud Awali

Supervisor By Dr. Zainab Hussein

Head of Medical-Surgical Department

Objective

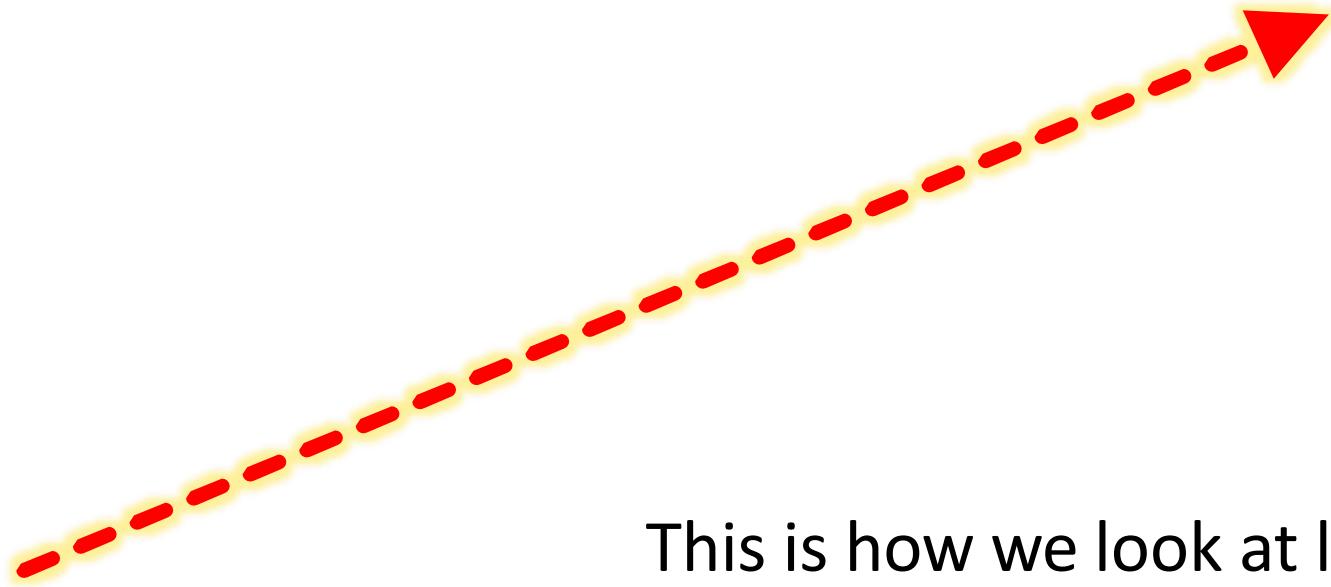
- Define the concept of palliative care.
- Define the concept of end life.
- Define the concept of hospice care
- Explain the hospice philosophy
- Discuss the history of hospice care .
- Explained the aim of Hospice Care
- Understand the Principles of hospice care
- Describe Impact of Hospice on patient & caregiver
- Learn how to apply hospice care
- Mention the Ethical consideration related to hospices care



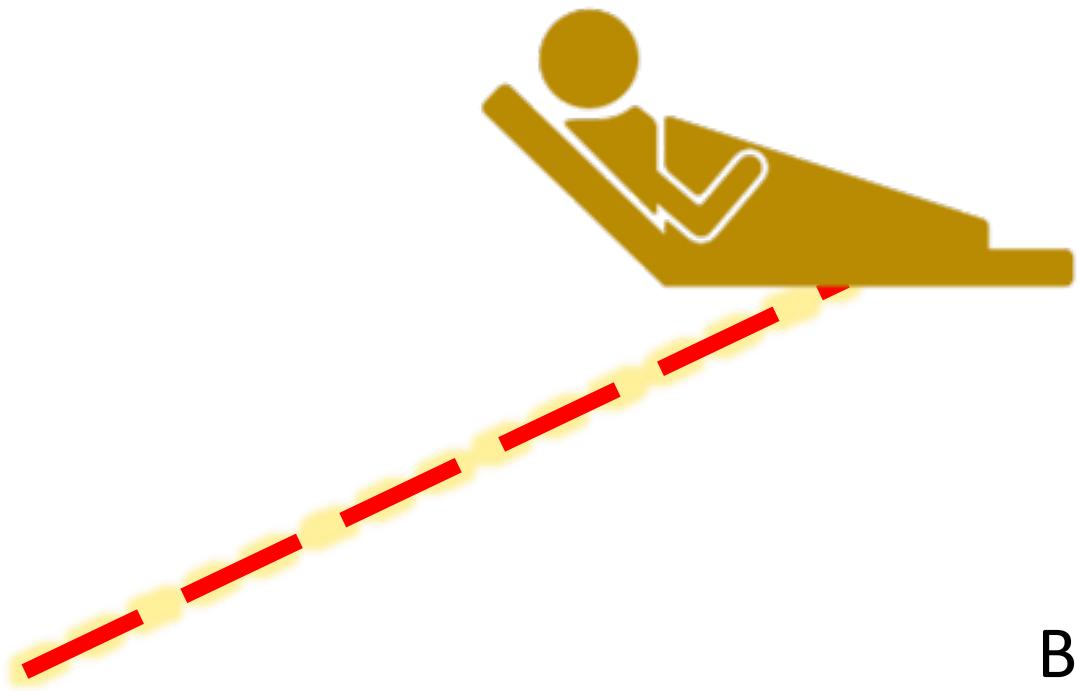
Outlines



- Introduction.
- Definitions.
- philosophy of hospice
- History of hospice care
- Aim of Hospice Care
- Principles of hospice care
- Impact of Hospice on patient & caregiver
- Application
- Ethical consideration



This is how we look at life. We expect it to
just go on and on.

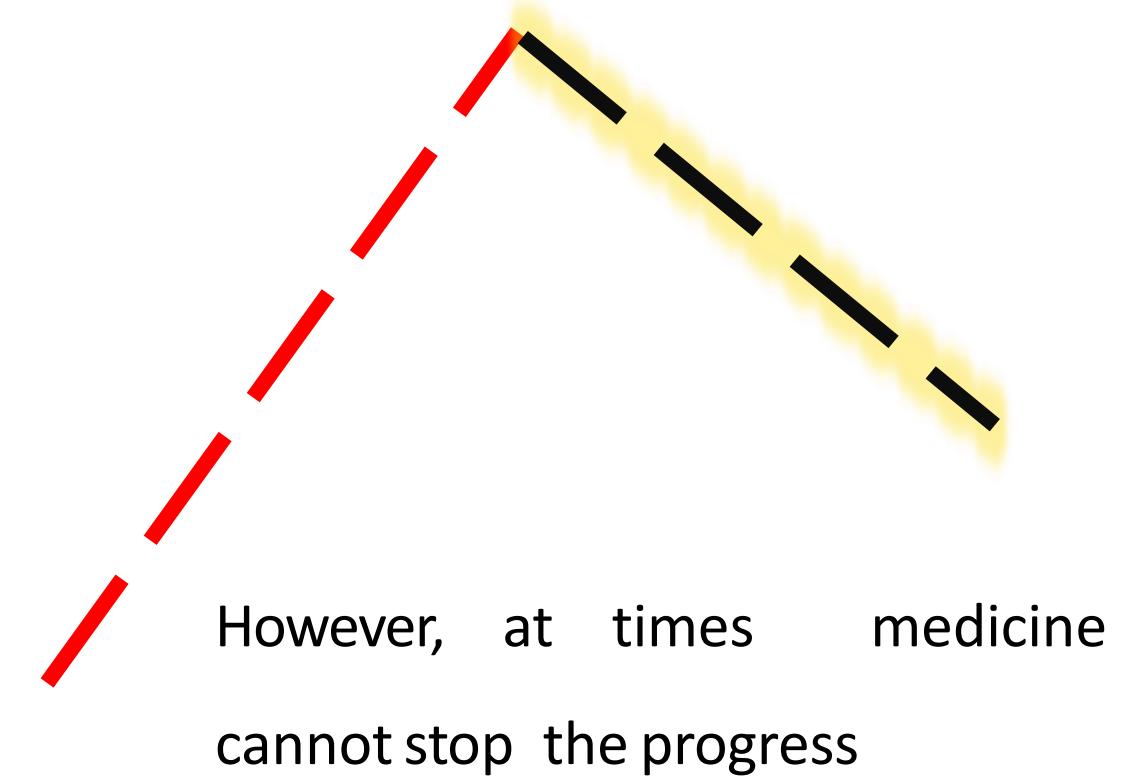


But...

what if there is a chronic disease?



Fortunately, medicine today can help us recover and keep us comfortable



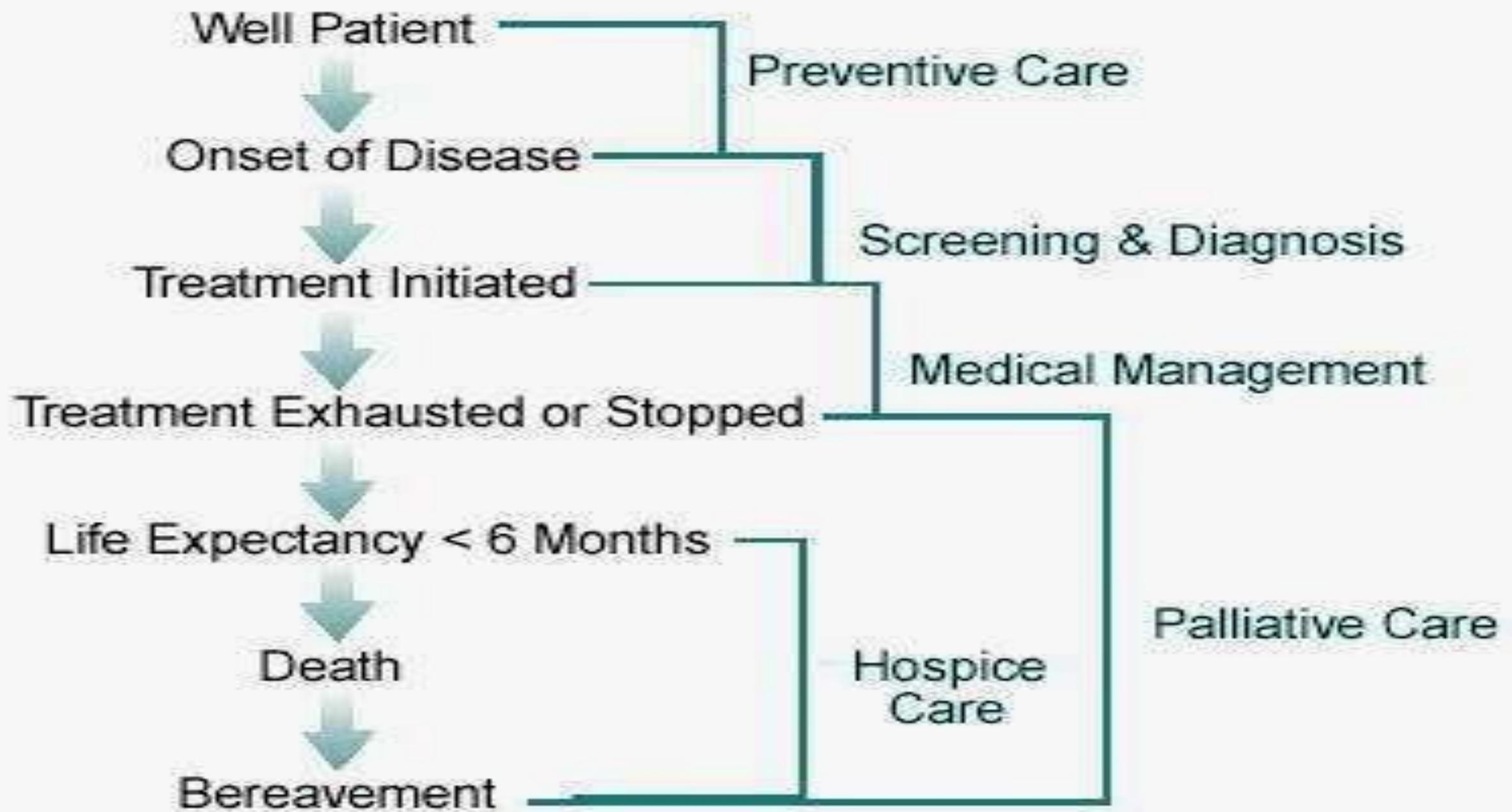
However, at times medicine cannot stop the progress

In fall 2020, my 94-years, father was discharged from a hospital with orders for hospice Care. I didn't know what to expect. Although over three months, his appetite had diminished along with the strength in his legs, I avoided researching end-of-life care. It turns out I'm not alone.



Introduction

Unfortunately, the confusion and misconceptions surrounding hospice can keep a family from seeking the service for a loved one and cause them to suffer needlessly. Knowing what to expect and when to begin hospice can help alleviate the anxiety and uncertainty surrounding end-of-life care.



Palliative Care Definition

- The World Health Organization (WHO) describes palliative care as services designed to prevent and relieve suffering for patients and families facing life-threatening illness, through early management of pain and other physical, psychosocial, and spiritual problems (Palliative & National, 2018) .
- Planning for palliative care should begin early in the patient's journey of serious illness regardless if the patient was in primary, secondary, or tertiary level of care

End of Life Care

- Is the care for people with advanced disease once they have reached a point of rapid physical decline, typically the last few weeks or months before an inevitable death as a natural result of a disease.

Definition of Hospice Care

Hospice, as part of the palliative care continuum, is a special program of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments. Hospice addresses all symptoms of a disease with a special emphasis on controlling a patient's pain and discomfort.



Hospice Philosophy

- The hospice philosophy accepts death as the final stage of life: it affirms life but does not try to hasten or postpone death. Hospice care treats the person and symptoms of the disease, rather than treating the disease itself.
- A team of professionals work together to manage symptoms so that a person's last days may be spent with dignity and quality, surrounded by their loved ones. Hospice care is also family-centered – it includes the patient and the family in making decisions.

Hospice falls under the umbrella
of palliative care



- Hospice focuses on maximizing the patient's quality of life using all treatments necessary to relieve the symptoms of a terminal illness, including:
- Physical (such as pain, nausea and shortness of breath).
- Psychosocial (anxiety, depression and insomnia).
- Spiritual Needs.

History of Hospice care

Hospice movement came into being in 1967 when Dame Cicely Saunders founded St Christopher's House in London. However, hospice care goes back to the mid-1800s.



In 1843, as a young widower and bereaved mother, Mme Jeanne Garnier, along with others in a similar situation, founded the Dames de Calaire in Lyon, France, to provide care for the dying. At that time death was seen as a failure by the medical system and consequently the focus of hospitals was on curative treatment - the dying was not welcomed.



- Palliative care was established in Saudi Arabia in 1992 at the King Faisal Specialist Hospital & Research Center.

Is Hospice the Same as Home Health Nursing?

Two primary differences between ***hospice care and home health nursing:***

- Any patient with a skilled medical care need is qualified to receive home health nursing care. Hospice care, on the other hand, is **limited to persons with a terminal illness, with a life expectancy of six months or less, and with a focus on palliation not cure.**
- Patients in home health care receive visits primarily from a nurse while patients in hospice care receive the services of an entire interdisciplinary team whose area of expertise is end-of-life care.

Aim of Hospice Care

- Improve the quality of life rather than its length(patient center care)
- Prepare patients and their families for the end of life by :
- Meeting the needs of terminally ill patients through expert symptom management.
- Facilitation of caregiver support (family center care)
- Involve the patient and family in making decision
- Promote the dignity of terminally ill person

Principles Underlying of Hospice

- Death must be accepted.
- The patient's total care is best managed by an interdisciplinary team whose members communicate regularly with each other.
- Pain and other symptoms of terminal illness must be managed.
- The patient and the family should be viewed as a single unit of care.
- Home care of the dying is necessary.
- Bereavement care must be provided to family members.
- Patient and family beliefs, values, and culture should be respected and taken into consideration in developing plans of care.

Myths and realities of Hospice

- A place.
- Only for people with cancer.
- Only for old people.
- Only for dying people.
- Can help only when family members are able to provide care.
- About 80% of hospice care takes place in the home.
- Hospices are increasingly serving people with the end-stages of chronic diseases.
- Hospices serve people of all ages.
- Hospice focuses as much on the grieving family as on the dying patients.
- Alternative locations or resources may be available.



How hospice works?

- Hospice care can be provided onsite at some **hospitals, nursing homes, and other health care facilities**, although in most cases hospice is provided in the patient's own home. With the support of hospice staff, family and loved ones are able to focus more fully on enjoying the time remaining with the patient.
- When hospice care is provided at home, a family member acts as the primary caregiver, supervised by the patient's doctor and hospice medical staff.



Impact of Hospice Care on Patients

- Providing care to the patient.
- Medical care to relieve pain and other symptoms arising from a life-limiting illness.
- Basic needs of daily living.
- Counseling.
- Assisting the patient with unfinished legal or financial business and in making funeral arrangements.
- Religious care.

Impact of Hospice Care on Family Member

- Counseling services..
- Health Education.
- Practical assistance.
- Arrangements and with funeral/memorial services.
- Bereavement care.

The background of the image is a detailed fractal pattern, likely a Mandelbrot set, rendered in shades of blue, purple, and white. The fractal has a complex, organic structure with many spirals and intricate details. A semi-transparent dark gray rectangular box is centered over the fractal, containing the text.

Case Study Application

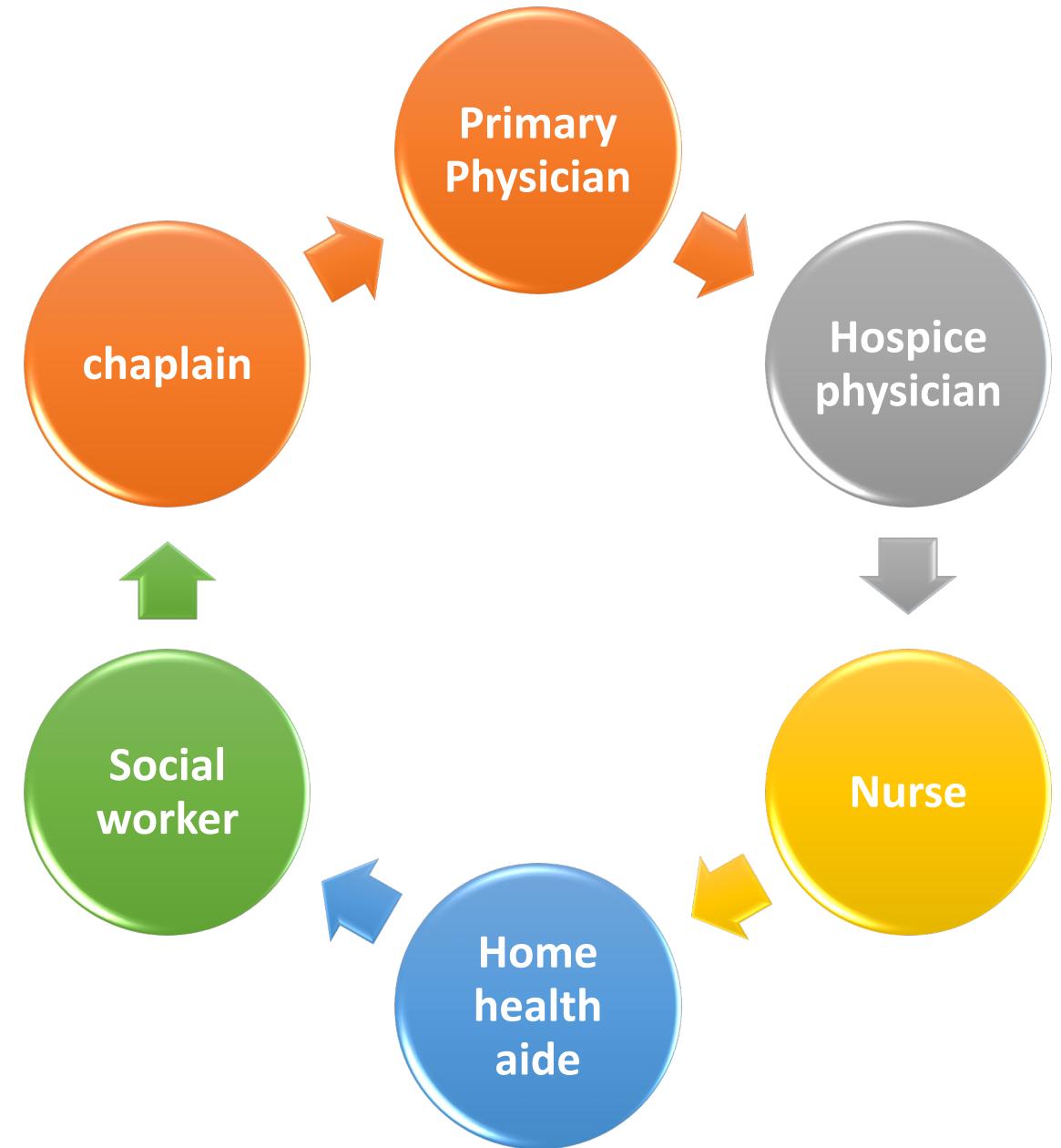
Case Study

- Mrs. R is a 42-year mother of two who has been married for 17 years. She was diagnosed with ovarian cancer 2 years ago. After the initial diagnosis she had a total hysterectomy with salpingo-oophorectomy. For the last 2 years she has undergone intensive chemotherapy and radiation. Despite treatment, the ovarian cancer progressed to the late stage and metastasized to the lungs and bones. She start to feel profound weakness , lost of appetite, drowsiness , depressed ad anxious.
- After collaborating with her healthcare providers, she has decided to pursue Hospice care.

Aim of intervention

- Relieve symptoms burden.
- Improve quality of life by providing specialized knowledge and skill.
- Ensure psychological , spiritual and bereavement.
- Facilitating communication about illness and prognosis with patient, family, caregiver and team member to coordinator the resources.

Members of the interdisciplinary Hospice Team



Primary Physician

- Provides the hospice team with medical history.
- Oversees medical care through regular communication with the hospice team.
- Provides orders for medications and tests.
- Determines his or her level of involvement on a case-by-case basis with the hospice medical director.

Role of the Physician

- Provides expertise in pain and symptom control at the end of life.
- Works closely with the hospice team and primary physician to determine appropriate medical interventions.
- Makes home visits on as needed basis.
- May oversee the plan of care, write orders, and consult with patient and family regarding disease progression and appropriate medical interventions on a case-by-case basis..
- **The primary goal of supporting patients' quality of life is the management of illness and/or treatment of related symptoms**



Role of the Nurse

- Visits patient and family in the home or nursing home on regular basis.
- May provide on-call services.
- Assesses pain, symptoms, nutritional status, bowel functions, safety, and psychosocial - spiritual concerns.
- Educates patient and family.
- Educates and supervises nursing assistants.
- Provides emotional and spiritual support to patient and family.

Role of Nurses in Communication

Skilled and empathetic communication is essential in providing excellent care. Nurses are trained in communication skills that allow them to discuss prognosis, goals of care, advance care planning clinical options, and medical decisions with patients and caregivers.

Nurses can facilitate sensitive conversations in a supportive, non-threatening manner incorporating caregivers' concerns and values into conversations about treatment options and goals

Advocacy

- Nurses are well positioned to advocate for and promote the use of palliative & Hospices care within various healthcare settings.
- Nurses are trained advocates, collaborating within the interdisciplinary team to share patients' perspectives and priorities; these skills are particularly needed when the patient has a serious illness.



Role of Home Health Aide

- Assists patient with activities of daily living.
- Provides a variety of other services depending on assessment of need.



Role Social Worker

- Attends to both practical needs and counseling needs of patient and family.
- Arranges for durable medical equipment, discharge planning, funeral/burial arrangements
- Serves as liaison with community agencies.
- Assist family in finding services to address financial needs and legal matters.
- Provides counseling.
- Assesses patient and family anxiety, depression, role changes, caregiver stress.
- Provides general grief counseling.

Role of Chaplain

- Provides patient and family with spiritual counseling.
- Assists patient and family in sustaining their religious practice /spiritual beliefs.
- Ensures that patient and family religious or spiritual beliefs and practices are respected by the hospice team.
- serves as a liaison with the patient/family faith, community.
- May conduct funeral and memorial services.
- Provides hospice staff with spiritual care and counseling.

Volunteer

- Provides respite care to family members
- May assist with light housekeeping or grocery shopping.
- Helps patients stay connected with community groups and activities.
- Facilitates special projects.
- provide community education and outreach.
- May assist with office work.



Ethical Concerns in End-of-Life Care

Respect for Autonomy

- This principle is described as an agreement to respect another's right to self-determine a course of action and to support another's independent decision making .
- It can be difficult to see a patient make a decision about their health that the nurse does not personally agree with or that the nurse does not feel is the best decision for that patient's individual circumstances. As nurses, we must support and advocate for our patients' rights, including their right to make decisions.

Beneficence

The principle of beneficence is a moral obligation to act for the benefit of others. There are two aspects of beneficence:

- Providing benefits
- Balancing benefits and risks/harms.

Nonmaleficence

- It is the principle of refraining from causing unnecessary harm. Although some of the interventions that patients receive might cause pain or some harm, nonmaleficence refers to the moral justification behind why the harm is caused.

Justice

- Justice is the principle that governs social fairness. It involves determining whether someone should receive or is entitled to receive a resource. The Code of Ethics for Nurses (ANA, 2015) states that nurses' commitment is to patients regardless of their "social or economic status."

References

- Greer, J. A., Jacobs, J. M., El-Jawahri, A., Nipp, R. D., Gallagher, E. R., Pirl, W. F., ... Temel, J. S. (2018). Role of patient coping strategies in understanding the effects of early palliative care on quality of life and mood. *Journal of Clinical Oncology*, 36(1), 53–60. <https://doi.org/10.1200/JCO.2017.73.7221>
- Palliative, S., & National, C. (2018). Saudi Palliative Care National Clinical Guideline for Oncology.
- Greer, J. A., Applebaum, A. J., Jacobsen, J. C., Temel, J. S., & Jackson, V. A. (2020). Understanding and addressing the role of coping in palliative care for patients with advanced cancer. *Journal of Clinical Oncology*, 38(9), 915–925. <https://doi.org/10.1200/JCO.19.00013>

References

- History of the hospice movement. History of the Hospice Movement:: The Hospice Income Generation Network. (n.d.). Retrieved March 21, 2023, from <https://www.hospice-ign.org.uk/hospice-income-generation-network/history-of-the-hospice-movement>
- Hagan, T. L., Xu, J., Lopez, R. P., & Bressler, T. (2018). Nursing's role in leading palliative care: A call to action. *Nurse Education Today*, 61, 216–219. <https://doi.org/10.1016/j.nedt.2017.11.037>



**“as the body
becomes weaker,
so the spirit
becomes stronger”**

Thank you