END OF LIFE:
HOW TO MEET THE NEEDS OF PATIENTS
WHEN TREATMENT IS NO LONGER AN OPTION

CHANDANA BANERJEE, MD, MPA

Director & Designated Institutional Official
Graduate Medical Education
Assistant Clinical Professor
Department of Supportive Care Medicine
City of Hope National Medical Center

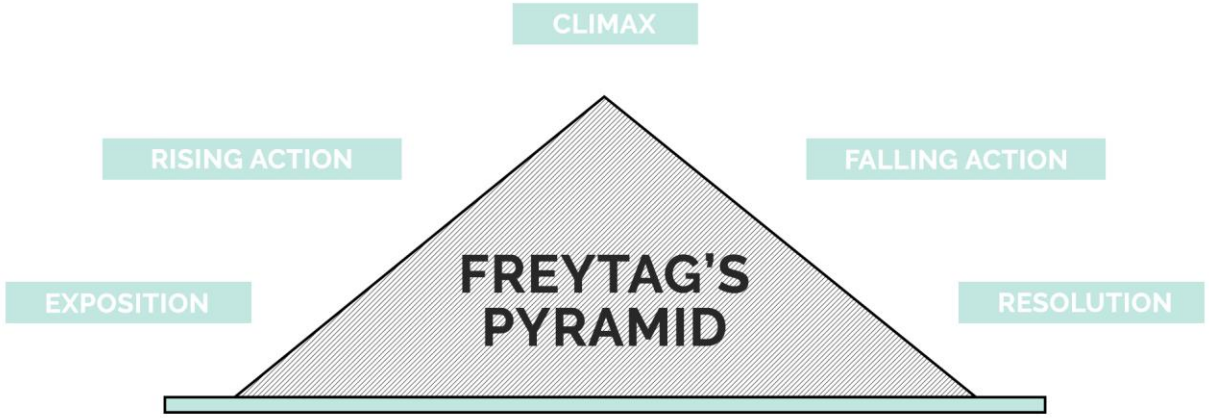
A NOVEL APPROACH

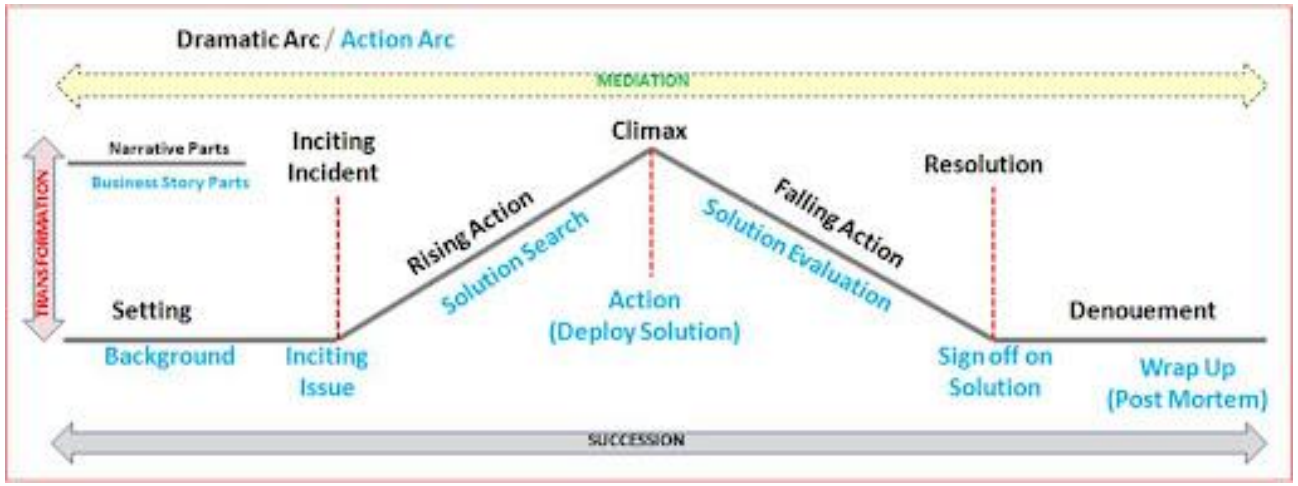
Disclosures

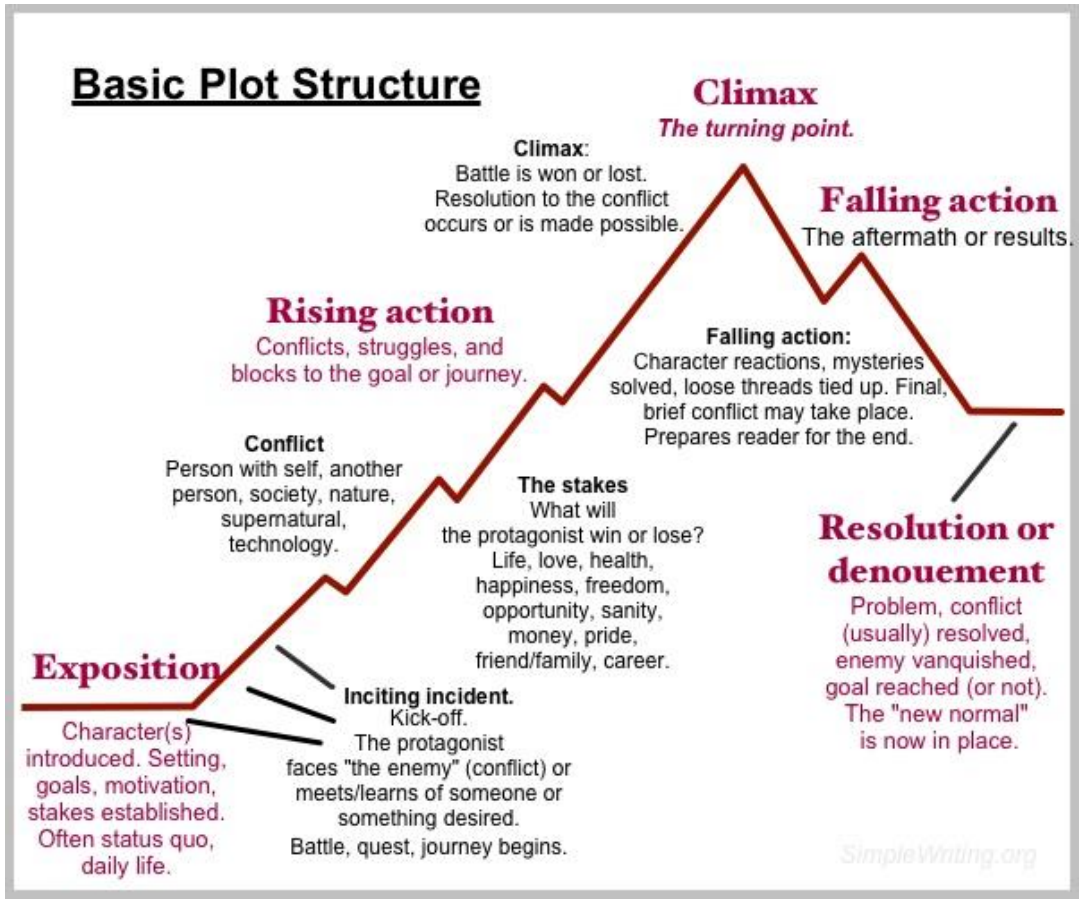
- Nothing to disclose.

THE NARRATIVE AROUND END-OF-LIFE CARE

Structure of a Novel







The Beginning

Planning for the end from the very beginning becomes extremely important when the disease is aggressive, inherently not curable, or progressively more rapidly than anticipated. Things of importance to consider at the beginning of the diagnosis or care plan

-- Establishing treatment options and plan of care
-- Discussing goals and objectives
-- Explaining anticipated disease course
-- Understanding the patient-family dynamics: who are the key characters?
-- Understanding the patients' beliefs, values and culture
-- Establishing trust
-- Introducing Advance Care Planning (ACP)
-- Possible introduction of Palliative Care Principles

The Middle

This is the part that can highly influence the ending of the narrative! The heart of the matter. The substance!

-- Communicating progress or anticipated issues
-- Solicit patient understanding on how things are going
-- Soliciting patient feedback
-- Discussing prognostication based on disease progression
-- Reviewing expectations
-- Discussion of ACP
-- Discussing goals and objectives of treatment plans if new plans introduced
-- Introducing the What If options
-- Introducing Goals of Care
-- Involving Palliative Care Teams and principles

The End

This is when we know the the disease will continue and progress, eventually leading to death.

-- Everything that was discussed in the Middle plus…
-- Delivering difficult news
-- Discussing Goals of care in details
-- Reviewing ACP
-- Introducing/Getting POLST filled
-- Introducing Hospice Care
-- Discussing various End of Life Care models
-- Transitioning patient to end of life care teams

So now that we have established the idea of the Novel=Disease, let's get into details of some of these things

IMPORTANT CONCEPTS IN PALLIATIVE & END OF LIFE CARE

Palliative Care

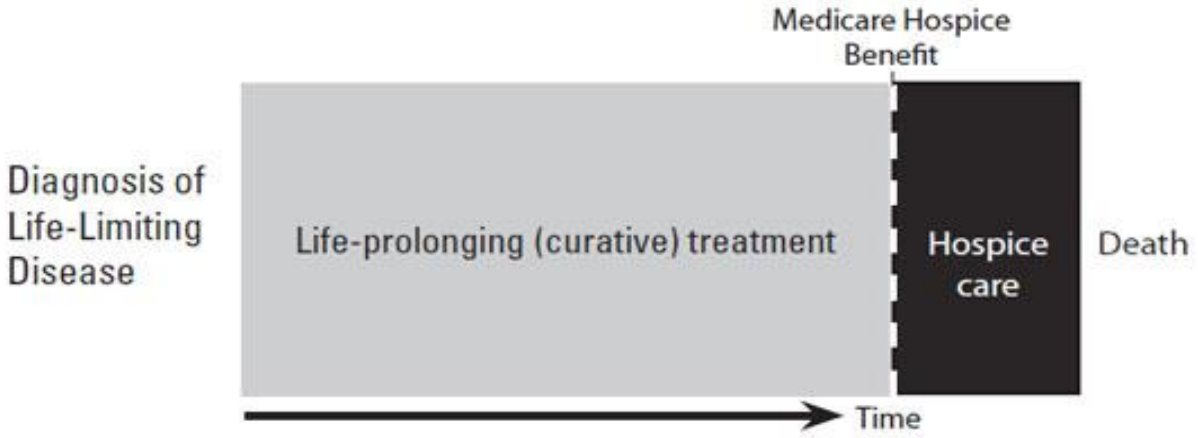
WHO Definition:

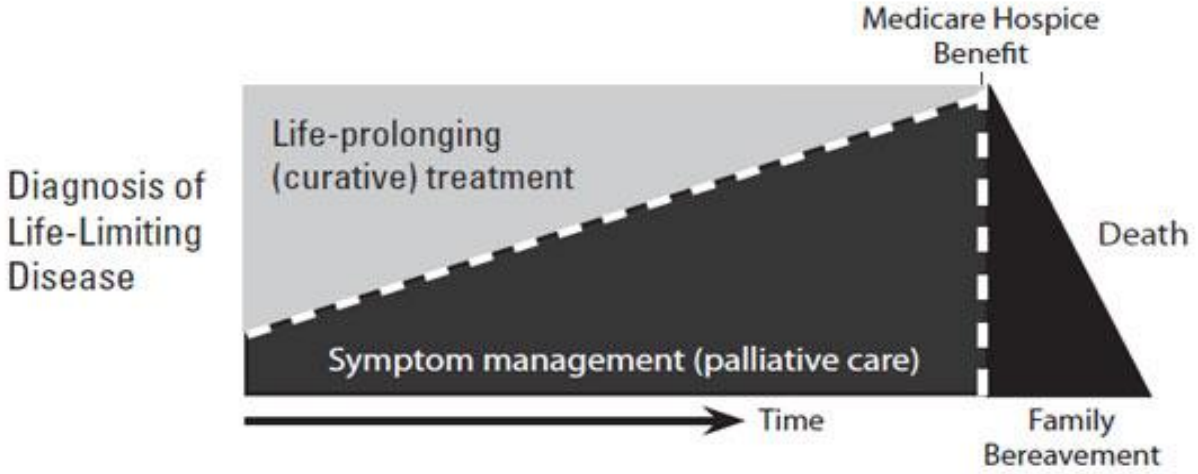
Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems,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

What does Palliative Care Involve?

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Old vs The Not-So-Old Model of Palliative Care





Delivering Difficult News

- What does this mean for the patient?
- How are you going to do deliver it?
- And yes, you should deliver it yourself!
- Do you know how to deliver it?
- Multiple Models of Delivering Bad News
- Adopt them to suit your style and develop a model that works for you!

SPIKES & BREAKS Protocols

SPIKES protocol for delivering bad news	
Set the stage	• Arrange for a private, comfortable setting • Introduce patient/family & team members • Maintain eye contact & sit at the same level • Schedule appropriate time interval & minimize interruptions
Perception	• Use open-ended questions to assess the patient's/family's perception of the medical situation
Invitation	• Ask patient/family how much information they would like to know
Knowledge	• Warn the patient/family that bad news is coming • Speak in simple & straightforward terms • Stop & check for understanding • Remain cognizant of cultural, educational & religious issues
Empathy	• Express understanding & give support when responding to emotions
Summary & strategy	• Summarize & create follow-through plan, including end-of-life discussions if applicable

TABLE 2

BREAKS Protocol for Delivering Bad News

Background

Know the patient's background, clinical history, and family or support person.

Rapport

Build rapport, and allow time and space to understand the patient's concerns.

Explore

Determine the patient's understanding, and start from what the patient knows about the illness.

Announce

Preface the bad news with a warning; use nonmedical language. Avoid long explanations or stories of other patients. Give no more than three pieces of information at a time.

Kindle

Address emotions as they arise. Ask the patient to recount what you said. Be aware of denial.

Summarize

Summarize the bad news and the patient's concerns. Provide a written summary for the patient. Ensure patient safety (e.g., suicidality, ability to safely drive home) and provide follow-up options (e.g., on-call physician, help line, office appointment).

Information from reference 21.

Six step Protocol For breaking bad Application to the Patient with Cancer news:

SPIKES: A Six-Step Protocol for Breaking Bad News

Renato Lenzi, MD

SPIKES	Dos	Don'ts
Setting	Establish the right **Setting**: Allocate adequate time for the encounter. Ensure patient privacy. Review your communication plan before entering the room.	Interruptions
Perception	Find out what the patient's **Perception** and understanding of his or her condition is. Pay attention to the patient's words. Make a mental note of the discrepancies between medical facts and patient's perspective.	Assumptions
Invitation	Obtain a clear **Invitation** by the patient to give the information: "How would you like me to handle the information that we will obtain from these tests?"; "Are you the sort of person who wants all the details on their condition?"	Blunt disclosure
Knowledge	Use the patient's current understanding of his or her condition as a starting point to provide **Knowledge** and medical facts. Use the same level of language as the patient uses. Give the information in small chunks. Check for patient understanding at each step.	Medical jargon
Empathy	Be **Empathic**: "This must be very hard for you." Recognize that crying and anger are normal responses when receiving bad news. Provide realistic hope: "You will receive the best available treatment."	Destroying hope
Strategy	Explain your treatment **Strategy**. Encourage the patient's participation in decision-making. Summarize main points; answer questions. Negotiate next contact.	Ignoring patient input

1. Baile WF, Buckman R, Lenzi R, et al. Oncologist 5:302, 2000.

Kaye & ABCDE Protocols

Table 1: Peter Kaye's 10 Steps to Breaking Bad News
Preparation: be factual with clear objectives in a private setting
What does the person know?: ask for a narrative of events; "how did it all start?"
Is more information wanted?: "Would you like me to explain a bit more?"
Give a warning shot: "I'm afraid it looks rather serious" and allow the person to respond
Allow denial: denial is a defence, a way of coping. Allow the patient to control the amount of information
Explain: narrow the information gap. Detail will not be remembered but the way you explain will
Listen to concerns: what are your main concerns at the moment? Allow space and time for a response.
Encourage ventilation of feelings: this allows for empathy
Summary and plan: summarise concerns, refer on, give closure
Offer availability: offer further explanation, include other healthcare agencies, support groups and family support

TABLE 1

ABCDE Protocol for Delivering Bad News

Advanced preparation

Review the patient's history, mentally rehearse, and emotionally prepare. Arrange for a support person if the patient desires. Determine what the patient knows about his or her illness.

Build a therapeutic environment/relationship

Ensure adequate time and privacy. Provide seating for everyone. Maintain eye contact and sit close enough to touch the patient, if appropriate.

Communicate well

Avoid medical jargon, and use plain language. Allow for silence, and move at the patient's pace.

Deal with patient and family reactions

Address emotions as they arise. Actively listen, explore feelings, and express empathy.

Encourage and validate emotions

Correct misinformation. Explore what the bad news means to the patient. Be cognizant of your emotions and those of your staff.

Adapted with permission from Rabow MW, McPhee SJ. Beyond breaking bad news: how to help patients who suffer. West J Med. *1999;171(4):261.*

Advance Care Planning

- “Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know -- both your family and your health care providers -- about your preferences.

- These preferences are often put into an *advance directive*, a legal document that goes into effect only if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury -- no matter how old you are. It helps others know what type of medical care you want.

- An advance directive also allows you to express your values and desires related to end-of-life care. You might think of it as a living document -- one that you can adjust as your situation changes because of new information or a change in your health”

Types of Advance Care Planning Decisions

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding) and artificial hydration (IV, or intravenous, fluids)
- Comfort Care

POLST: Physician Orders for Life Sustaining Treatment

At the national level, it is simply called POLST: Portable Medical Orders, or POLST for short. Portable means that the order is valid outside the clinic or doctor's office.

POLST is many things, including:

- A process: Part of advance care planning, which helps you live the best life possible
- Conversation: A good talk with your provider about your medical condition, treatment options, and what you want
- A medical order form that travels with you
- POLST communicates your wishes as medical orders
- POLST is for the seriously ill or frail
- POLST gives seriously ill or frail people more specific direction over their health care treatments compared to advance directives and more options than Do Not Resuscitate (DNR) orders

TRANSITIONING TO END-OF-LIFE TEAMS

Hospice Care

- Medical care to help someone with a terminal illness live as well as possible for as long as possible, increasing quality of life.
- An interdisciplinary team of professionals who address physical, psychosocial, and spiritual distress focused on both the dying person and their entire family.
- Care that addresses symptom management, coordination of care, communication and decision making, clarification of goals of care, and quality of life.

When is a patient eligible for Hospice Care?

- The patient has 6 months or less to live, according to a physician.
- The patient is rapidly declining despite medical treatment (weight loss, mental status decline, inability perform activities of daily living).
- The patient is ready to live more comfortably and forego treatments aimed at prolonging life.

Hospice Coverage Includes:

- Time and services of the care team, including visits to the patient's location by the hospice physician, nurse, medical social worker, home-health aide and chaplain/spiritual adviser
- Medication for symptom control or pain relief
- Medical equipment like wheelchairs or walkers and medical supplies like bandages and catheters
- Physical and occupational therapy
- Speech-language pathology services
- Dietary counseling
- Any other Medicare-covered services needed to manage pain and other symptoms related to the terminal illness, as recommended by the hospice team
- Short-term inpatient care
- Short-term respite care
- Grief and loss counseling for patient and loved ones

What is NOT covered on Hospice

- Treatment intended to cure your terminal illness or unrelated to that illness
- Prescription drugs to cure your illness or unrelated to that illness
- Room and board in a nursing home or hospice residential facility
- Care in an emergency room, inpatient facility care or ambulance transportation, unless it is either arranged by the hospice team or is unrelated to the terminal illness

OTHER END OF LIFE CARE CHOICES

- Comfort Care
- Palliative Sedation
- Compassionate/Terminal Extubation
- VSED (Voluntary Stopping of Eating & Drinking)
- Medical Aid in Dying

THANK YOU!