

# PALLIATIVE CARE IN THE CONGESTIVE HEART FAILURE PATIENT

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# DISCLOSURES

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- I have no significant financial disclosures ( sadly ).

# OBJECTIVES

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- Define comprehensive palliative care and how it differs from hospice.
- Explain emerging models for EOL care and what a palliative approach might look like in heart failure
- Discuss importance of advance care planning and designating a surrogate
- Discuss symptoms Palliative Care might address

# ON THE RISE

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- Number of American with CHF
  - 5.7 million people (2009-2012)
  - 6.5 million people (2011-2014)
  - 46% rise to 8 million in 2030 projected
    - Increase in incidence and prevalence

# COSTLY SYMPTOMS

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- Up to 20% of the CHF population has symptoms
- Accounts for 60% of the cost
- Often underestimated

# PALLIATIVE CARE

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- 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.
  - Often consistent with diseases that have no cure
- Palliative care fellows are taught to manage symptoms from patients suffering from any different disease processes.

# SIMPLER DEFINITION OF PALLIATIVE CARE

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- Active, total care of patients whose disease are not fully responsive to cure
  - Symptoms are prioritized
  - Achieve best quality of life for patient and family
  - Affirms life
  - Palliative care fellows are taught to manage symptoms from patients suffering from any different disease processes.

# PALLIATIVE TRAINING

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- Most fellowships ( including cardiology ) in the country have no formal training in either breaking bad news or discussing goals of care
  - Closest many programs had was “the consent form”
- “Focus about getting the device, etc versus what if you don’t”
- No set pathway for referral if patient says “no thanks”



# PALLIATIVE = HOSPICE, RIGHT? WRONG!

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- Palliative care services can be appropriate for anyone with a serious, complex illness, whether they are expected to recover fully, to live with chronic illness for an extended time, or to experience disease progression
- Hospice services and palliative care programs share similar goals of providing symptom relief and pain management

# PALLIATIVE=HOSPICE, RIGHT? WRONG!

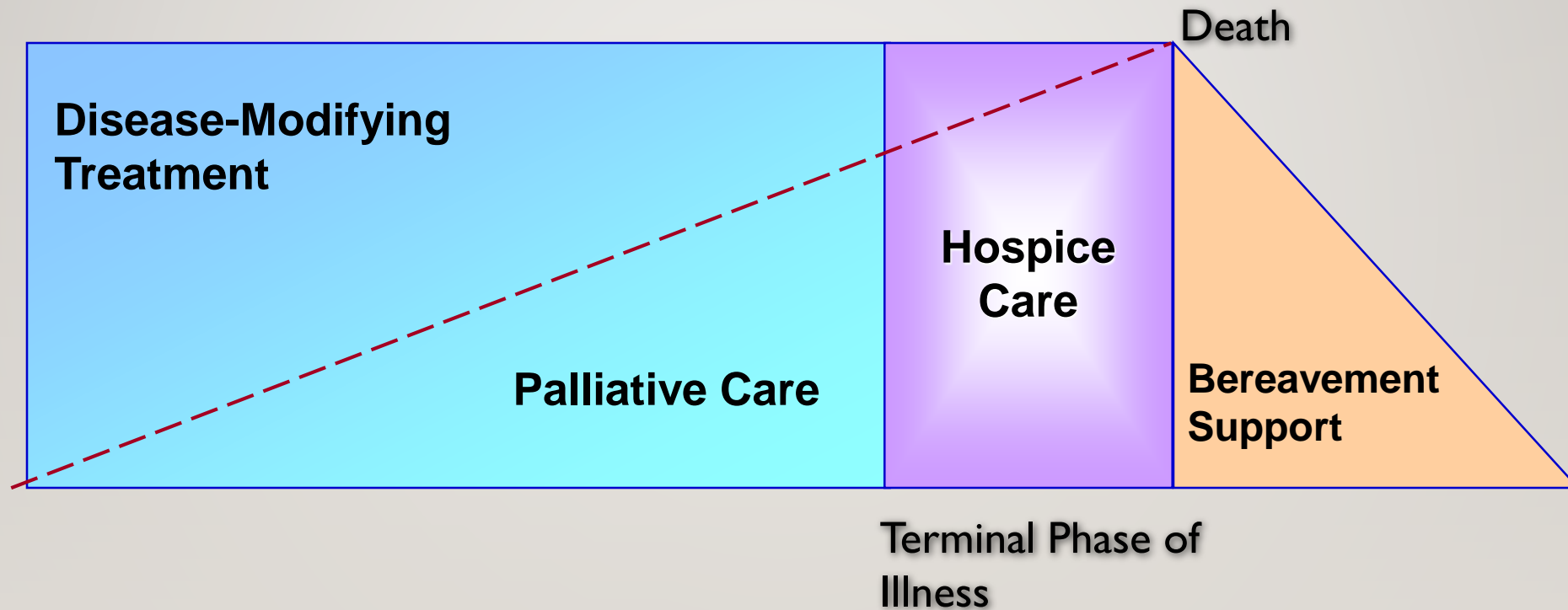
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- Hospice is a type of care involving palliation without curative intent. Used for people with no further options for curing their disease or in people who have decided not to pursue further options they view as having too burdensome a toll.
  - Put another way, hospice is a branch of palliative medicine, but it does not encompass all of palliative medicine

# Palliative Care & Hospice



# Continuum of care



# PALLIATIVE CARE AND HEART FAILURE

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- Fear of abandonment ( if they choose no further treatments)
  - Not completely irrational
    - Several authors ( Kubler-Ross, Saunders ) discuss that when curative or life prolonging therapies were not available, many patients were cut loose
    - 1960s. Surgical oncologist curious as to what happened to those patients who were no longer resectable
      - Horrified to find many of them abandoned by the system.
        - Too complex for PCP, no more therapies from specialists
      - Classic phrase to describe why palliative care was needed

# INTEGRATING PALLIATIVE CARE

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- Most physicians agreed with the idea that palliative care would be beneficial for patients for “months”
- However, the “average” patient gets 96 hours of palliative care before they die
- Palliative Care is not Hospice
  - In our history, horrible occurrence of the wrong expert being asked
  - May find the phrase “Supportive Care” in the future

# BENEFITS OF PALLIATIVE CARE IN CHF

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- Exploring patients' understanding about their illness
- Discussing prognosis
- Clarifying goals of care and applying to advanced directives
- Navigating treatment options and symptom management
- Coordinating care
- Planning end-of-life care including evaluation for hospice

# DEGREES OF PALLIATIVE CARE

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## PRIMARY PALLIATIVE CARE

- Initial symptoms
- Advanced directives
- Discussion of risks/ benefits

## SECONDARY PALLIATIVE CARE

- NYHA IV
- Comorbidities
- Major interventions
- Patient wants a change in status
- LVAD



# BENEFITS OF PALLIATIVE CARE IN CHF

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- Comprehensive management by interdisciplinary team
- Enhance comfort
- Inclusive of many therapies
- Continual, active, dynamic assessment of goals
- May have a survival benefit of having another set of eyes on the patient

# ANNUAL REVIEW

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- Characterization of clinical status
- Solicitation of patient values/goals/care preferences
- Estimation of prognosis
- Review therapies
- Advance care planning
- Documentation

# SYMPTOMS ADDRESSED BY PALLIATIVE CARE

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- Fatigue
- Insomnia
- Depression
- Anxiety
- Pain
- Nausea
- Itching
- Appetite
- Dyspnea

# BENEFITS OF PALLIATIVE CARE

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- Palliative Care in Heart Failure trial ( PAL-HF )
  - Randomized controlled single center study
  - Improvements in two quality of life measurement systems
  - Patient also improved depression, anxiety, spiritual well-being
- Social Worker-Aided Palliative Care Intervention ( SWAP-HF )
  - Intervention group more likely to do advanced directives and have “in line “ prognosis
- Can be a downside of “who is running what”
- On a systems level, palliative care shown to cut down unnecessary ICU stays and ER visits

# APPROACHES TO ADVANCE CARE PLANNING

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- Always better to “walk than run”
- Routine/Structured ACP
- Event driven/Triggered

# ADVANCED DIRECTIVES

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- An individual's written or verbal ( to a physician ) instruction that anticipates and directs the provision of healthcare
- Tells us how the patients wants to be cared for when they cannot tell us
- Can be viewed as a positive for patient's families so they know what the patient wants
- Tells us who they want to make decisions ( surrogate )

# WHO CAN MAKE DECISIONS?

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- 1) Patient
- 2) HCPOA, HC proxy, HC agent
- 3) Surrogate appointed by the patient or physician

# WHAT IS A SURROGATE?

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- Any individual who has been designated by the patient or the attending physician to make healthcare decisions for the patient if the patient becomes incapacitated and does not have an advanced directive
  - Must be willing
  - Must be available
- A surrogate authority is effective when the patient lacks capacity and healthcare proxy has not been documented or is not available
  - Always document if it was attempted to get a HCPOA



# WHO CAN BE A SURROGATE

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- Anyone ( 18 or older ) chosen by the patient
  - Patient must have capacity
  - The patient must designate to a physician or do it in writing
  - The surrogate cannot delegate their surrogacy
- Arkansas does not use a hierarchy
  - Be careful of your state of origin

# UNFRIENDED PATIENT

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- Patient without known family or friends
  - Designated after a reasonable search ( that is vague, we know )
- Patient with no willing agent
- Physician can designate a surrogate ( or make decisions themselves ) if :
  - Institution's ethics committee agrees
  - Obtains concurrence from a physician not involved in care nor in the “chain of command” of the physician
- One has to prove a chosen surrogate is a bad choice

# WHO SHOULD BE SURROGATE

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- Knows the patient's wishes
- Has shown evidence of care for the patient and will act in patient's interest
- Is readily available and willing to service
  - Must not be prohibited from making decisions ( i.e. court order )

# TYPES OF ADVANCED DIRECTIVES

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## LIVING WILL

- The patient's medical wishes about care if incapacitated
- Can direct one's care when they are unable to comment
- It goes into effect only if patient is incapacitated
- POLST and DNR form are mini-versions

## HEALTH CARE POWER OF ATTORNEY ( HCPOA )

- Individual whom a patient has designated to make decisions regarding medical care when the patient is incapacitated
- Does not go into effect unless patient is incapacitated

# ADVANCED DIRECTIVES

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- Document must be signed by patient or previously approved proxy
- Must be a witnessed signature
  - Two adults not part of the care team and not the proxy
  - One should be disinterested party
  - Or signature witnessed by Notary Public

# CAPACITY

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- The ability to understand and appreciate the nature and consequences of healthcare decisions, including the significant benefits and risks of and alternatives to any proposed healthcare, and to reach and communicate an informed decision
- Capacity is determined by the patient's attending physician
  - Does not need to be done by psychiatrist
  - Determination should be documented
- Incapacity may be temporary, wax and wane, or be permanent
- Competence is determined by a court of law

# THE PATIENT WITH THE ICD

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- ICD can be deactivated but pacemakers are recommended to stay on
- Judged to be “life sustaining measure”
- Ideally the criteria for deactivation should be done before implantation

# DOCUMENTATION FOR DEACTIVATION

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- Notify medical team
- Confirm patient/surrogate had requested deactivation
- Insure the right decision maker is determining the decision
- Confirm the device to be deactivated and the consequences



# DEVICE DEACTIVATION

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- DNR order
- Physician order for deactivation
- Contact cardiology or device rep
- IF ICD, locate magnet
- Be prepared for symptoms
- Document like a procedure

# IMPLANTED DEVICES

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- Pacemakers, ICD, and LVAD therapies prolong life and may improve quality of life
- Device therapy is increasing
  - LVAD implantation now requires a palliative consult per joint commission
- Defined as “life sustaining measures” when an advanced directives says “no life sustaining measures” ( pacemaker may be excluded )

# AICD DEACTIVATION

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- At one facility, of 55 devices deactivated for end of life, 52 were implanted in the last six months.
- Receiving an AICD should spark a GOC/advanced directive conversation

# WHEN TO ENROLL/CONSIDER HOSPICE

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- Common misconceptions
  - Don't have to forego other care
  - You can change your mind
  - Not forced to be at home ( however no round the clock nursing )
  - Cannot tell someone they “have to be DNR”
- Should document how the hospice was chosen ( Stark Law )

# WHEN TO ENROLL/CONSIDER HOSPICE

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- One year rule of thumb
- Prognosis less than 6 months to enter ( good faith )
- Individualized
- Based on goals of care: Patient "wants" and "spending the time left"
- Heart failure one of fourteen conditions with pre-listed guidelines
  - Patient is optimally treated or has refused treatment
  - NYHA class IV with added support ( but not required ) of EF <20
  - Embolism to brain from heart, arrhythmia, HIV, prior cardiac arrest, unexplained syncope

# WHEN TO ENROLL/CONSIDER HOSPICE

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- Benefits last for 13 months after patient dies
  - Support for family as well as patient
- Covered by Medicaid/Medicare
- May enroll, drop, re-enroll
- Six month periods of eligibility ( does not “run out“ )

# EVENT-DRIVEN TRIGGERING

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- Comorbidities or new diagnosis
- Initiation of inotropes ( be careful about starting then wanting hospice )
- First or recurrent ICD events
- Considering RRT ( dialysis )
- Symptomatic hypotension or azotemia
- Ever increasing medication requirements
- Increased symptoms/ Decreased QOL
- Functional changes ( ADLs, Falls )
- Recurrent hospitalizations

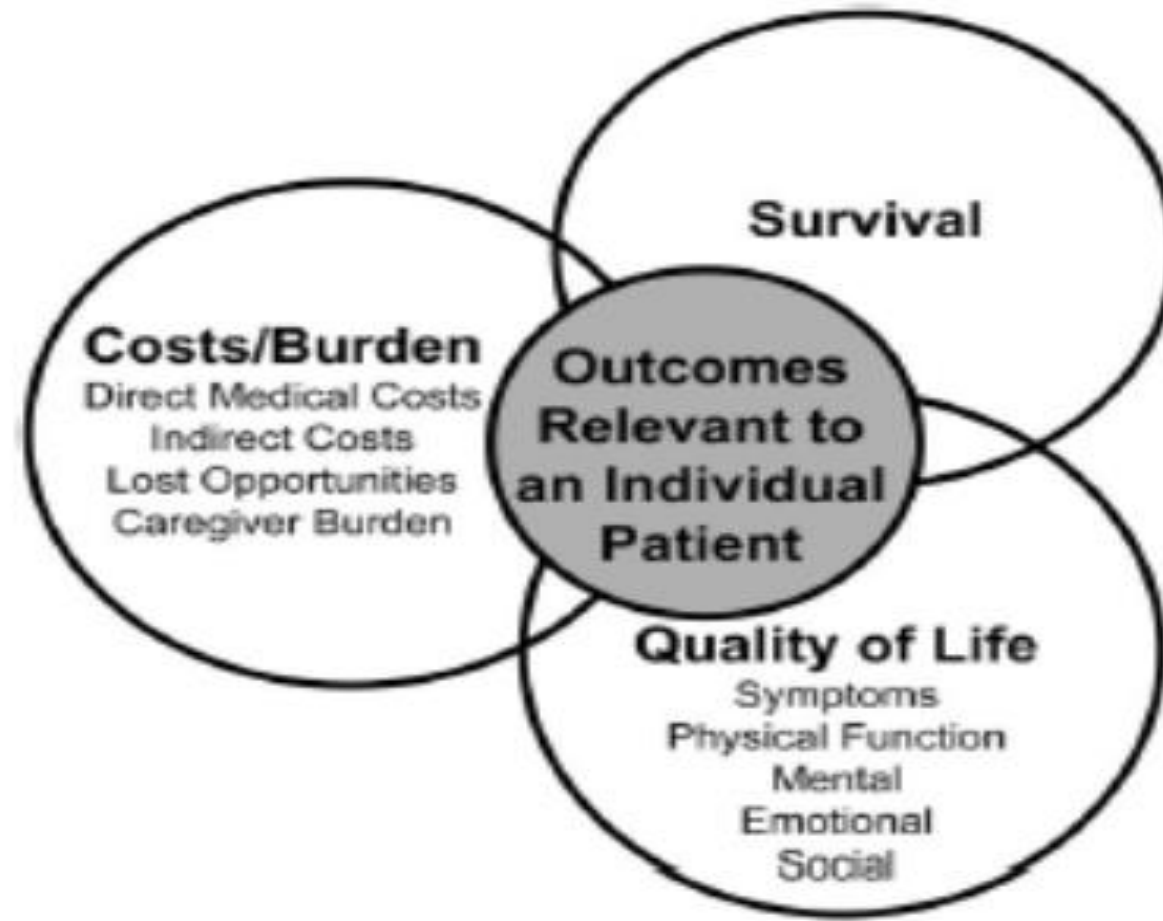
# GOALS OF CARE

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- Discussing goals of care is separate from discussing prognosis or breaking bad news
  - What does the patient want and how does that align with the care the physician can provide
    - Can also include the context of advanced directives
    - Best done early as compared to being done in the context of emergency
- Should not focus on how the patient wants to die but how they want to live
- These discussions should be frame in terms of being an individual and having personal goals



# Patient-centered Outcomes: Determining the Goals of Care



# CONDUCTING THE DISCUSSION

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- Advanced directives
  - Multiple studies show they do not upset or depress the patient to discuss advanced directives
- Pitfalls....what we are trying to avoid
  - Starting too late
  - Expecting too much too soon
  - Goals and prognosis in one sitting
- Patients usually want their main provider to conduct meeting
  - Sense of abandonment or inability to have questions answered
  - Fear they disappointed the physician

# CONDUCTING THE DISCUSSION

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- The basics ( in an ideal world )
  - Family present if desired
  - Having other care partners present if desired
  - Comfortable space that stops interruptions
  - “No page zone”
  - Tissue paper
- If you are having another provider discuss for you, then you have to let them have “freedom of movement”

# SUMMARY

- Patients do not mind discussing advanced directives
- Goals of care should be done in addition to discussion of prognosis
- Palliative care may be helpful in lessening the burden of symptom or in preparation for the possible consequences of severe illness
- Palliative care does not equal hospice

# THANK YOU!

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