Quality of Life at the End of Life

May 14, 2019

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Welcome to the Community Action Network (CAN)

atom Alliance Partners

Multi-state alliance for powerful change composed of three nonprofit, healthcare quality improvement consulting companies

Qsource.

AQAF
THE BUSINESS OF QUALITY

IQH
Information & Quality HEALTHCARE

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Meet the CAN Team

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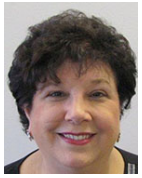
Mississippi		Mary Helen Conner	Mary.Conner@area-g.hcqis.org
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Please commit to being…

- Fully present and engaged
- Open-minded
- Collaborative and willing to participate
- Willing to share successes and challenges
- Ready to value each other's experiences

Housekeeping

- All lines are on mute today to preserve sound quality.
- If you have a question, pressing idea that you'd like to share, you can "raise your hand" by clicking the hand icon next to your name in the GoToWebinar Control Panel. We will un-mute your line at the next pause in our presentation.
- Please feel free to type in your questions or comments privately or with the entire audience in the "Questions" area of the Go To Webinar Control Panel. We will respond during the call
- We are recording today's call. The recording and the slide presentation will be located here: www.atomalliance.org/CAN
- After the presentation, please complete the post-event survey. It should take about 30 seconds and your feedback is priceless to us in planning future events, so many thanks in advance!

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Let's Celebrate Our Success!

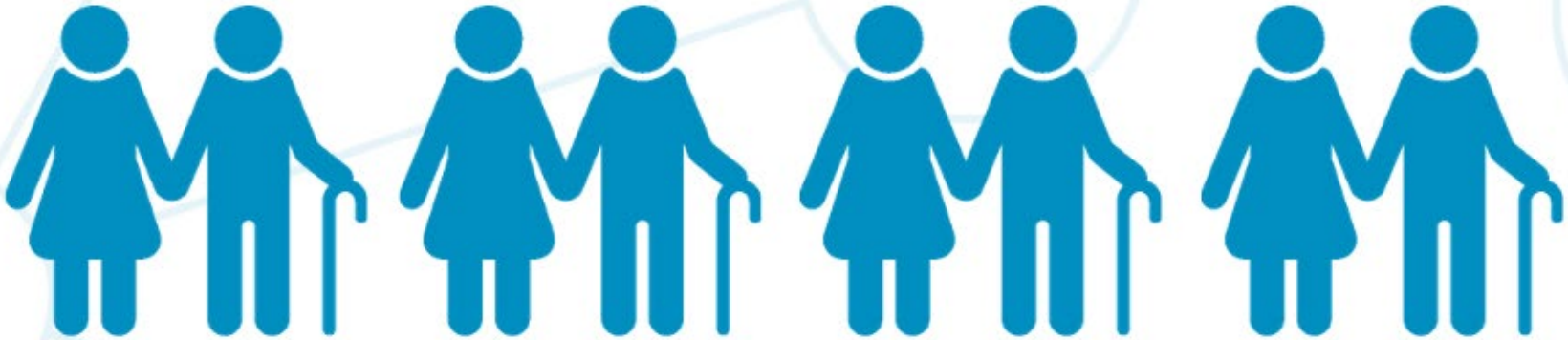
atom Alliance would like to thank everyone for participating in the Community Action Network, CAN, meetings and working with us for the past five years. Our communities will be extremely important in the future as additional work will be conducted at the community level.

Beginning in August 2019, work at the community level will include behavioral health, chronic kidney disease, antibiotic stewardship, reducing the burden of opioid use, reducing readmissions and additional interventions to impact the level of care in our communities.

We look forward to the great results that we can achieve together as we continue the journey to impact the quality of life and medical care for our Medicare beneficiaries.

Some of the work that has been accomplished over the past five years includes…

Our collaborative efforts impacted 2,251,846 people with Medicare, with 1,135,999 living in rural areas.



Our interventions helped avoid approximately 41,000 hospital admissions, saving $478 million.

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We helped avoid more than 6,300 hospital readmissions, saving more than $81 million.

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Objectives

At the end of this webinar, attendees will be able to:

- Understand the difference between palliative care and curative directed therapy
- Be able to describe hospice care
- Understand the types of patients that may be classified as “end of life”
- Recognize the myths around hospice care
- Know the benefits of hospice care
- Be able to discuss symptom management strategies at the end of life

Advanced Illness and End of Life Care

Dustin Dillon MD
Hospice and Palliative Medicine Physician
Pediatrics and Adults

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The earlier you call, the more we can help.

Curative vs. Palliative Care

Curative Focus

- Physician-directed
- Focus on cure and Rehabilitation
- Length of Life
- Unit of care –
  - patient
- Illness is treated
- Medical Model

Palliative Focus

- Patient-directed
- Comfort and Symptom Management
- Quality of Life
- Unit of Care – Patient/Family/ Significant Others
- Person is treated
- Holistic Model

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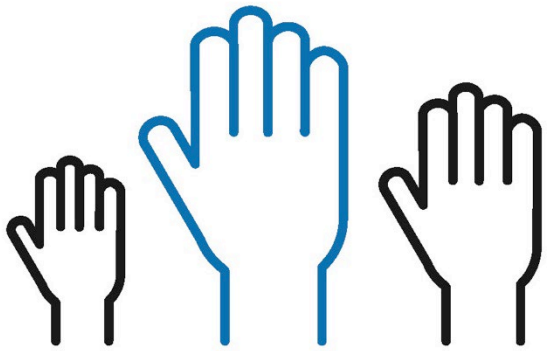
Polling Question #1

Do you know the difference between palliative care and hospice care?

- ❑ Yes
- ❑ No



What is hospice?

- Healthcare pertaining to people at the end of life
- Goal is palliative, not curative
- Relief of suffering while enhancing quality of life
- Not to hasten or delay death
- Utilizes a team approach to address physical, spiritual and emotional needs
- Small part of palliative medicine model

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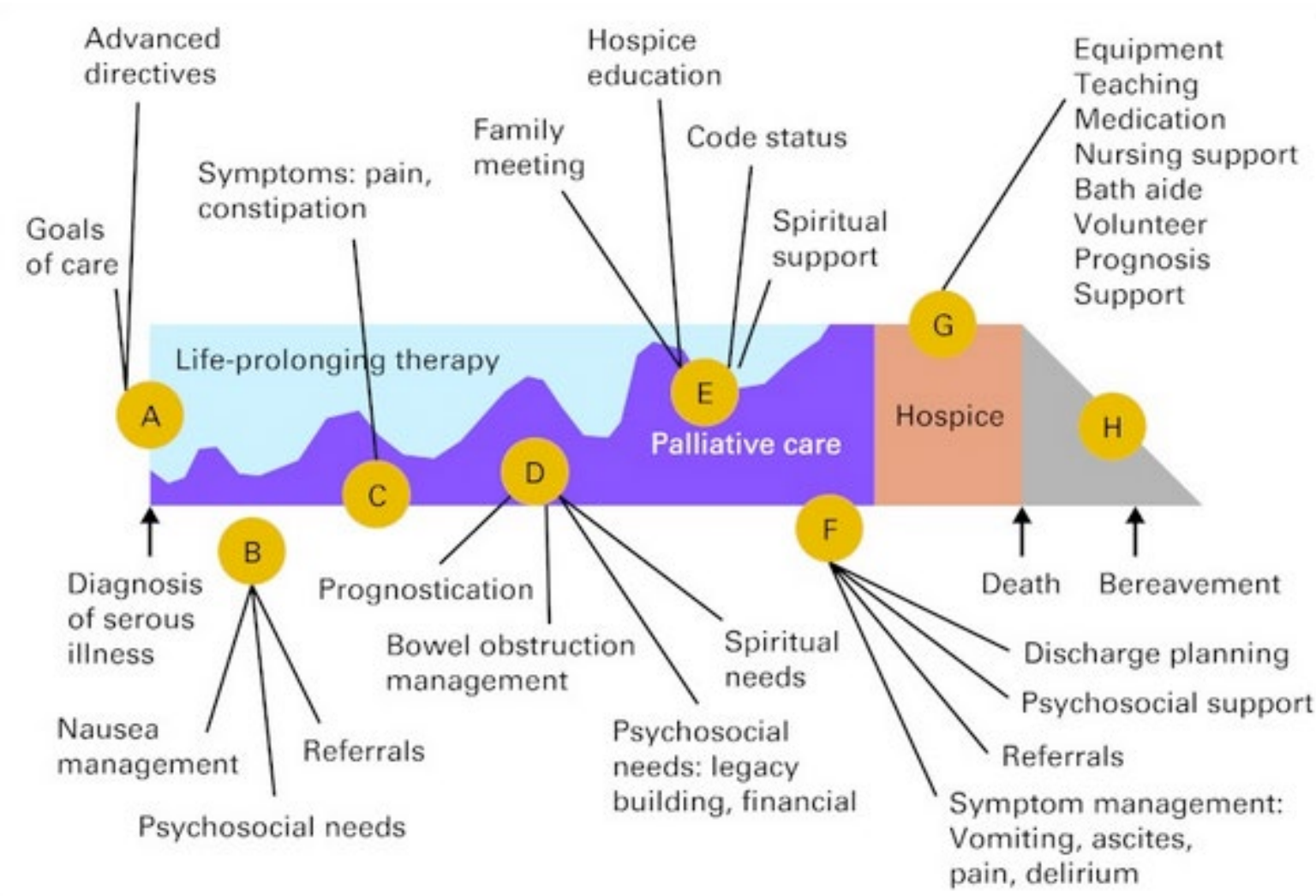
Advanced directives
Goals of care
Symptoms: pain, constipation
Family meeting
Hospice education
Code status
Spiritual support
Equipment
Teaching
Medication
Nursing support
Bath aide
Volunteer
Prognosis
Support
Life-prolonging therapy
A
B
C
D
E
F
G
H
Palliative care
Hospice
Diagnosis of serous illness
Nausea management
Referrals
Psychosocial needs
Prognostication
Bowel obstruction management
Psychosocial needs: legacy building, financial
Spiritual needs
Death
Bereavement
Discharge planning
Psychosocial support
Referrals
Symptom management: Vomiting, ascites, pain, delirium

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Hospice Philosophy

- **Hospice provides support and care for persons in the last phases of an incurable disease so that they may live as fully and as comfortably as possible.**
- **Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life.**
- **Hospice affirms life and neither hastens nor postpones death.**
  - National Hospice & Palliative Care Organization, www.nhpco.org

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History of Hospice Care

- The idea of hospice can be traced back to the medieval times
- Dame Cicely Saunders began work with terminally ill in 1948 in London
- 1967-Founded first modern hospice at St. Christopher's in the UK
- 1969-Kubler-Ross writes *On Death and Dying*, pleading for home care instead of institutional driven care

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History of Hospice Care

- 1974-Florence Wald founds 1st U.S hospice in Branford, Connecticut
- 1978-Hospice of Louisville/S. IN accepted their first patients.
- 1980-JCAHO establishes standards for accreditation
- 1983-Medicare Hospice Benefit

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MEDICARE HOSPICE BENEFIT

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Medicare Hospice Benefit

- Conditions of Participation (CoPS)-originally written in 1983 with very few changes to the benefit, despite multiple changes in the industry
- Revised in 2006 and 2008 by CMS
- Compliance required in order to maintain Medicare Certification
- All other insurances generally follow Medicare guidelines, with few minor changes

MHB Benefit Periods

- Initial period of 90 days
- Second benefit period of 90 days
- Unlimited number of 60 day benefit periods when continued certification made by the HMD

Hospice Services

- Skilled Nursing Care
- Certified Nursing Aide
- Medical Social Worker
- Chaplain
- Volunteers
- Grief Counselors/Bereavement Support
- Nurse Practitioner or Physician
- Medications, Medical Supplies, & Medical Equipment
- Wound Care, Physical, Occupational, Speech, & Nutritional Therapies

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WHO BELONGS IN HOSPICE?

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Considerations around eligibility

- Disease Specific Criteria
  - Cancer
  - Non-cancer
- Functional Decline
- Goals of care

General hospice criteria

- Terminal condition-as defined by MD
- Patient/family aware of terminality of disease
- Patient/family desire a palliative focus of care
- Supportive criteria include:
  - Ongoing disease progression
  - Recurrent ER or Hospital visits
  - **PPS** 50% or less
  - Dependence in ADLs
  - Weight loss of >10% over the last 6 months

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Palliative Performance Scale

PALLIATIVE PERFORMANCE SCORE

%	AMBULATION	ACTIVITY AND EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUS LEVEL
100	Full	Normal activity and work No evidence of disease	Full	Normal	Full
90	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal job / work Significant evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby / house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance necessary	Normal or reduced	Full or confusion
40	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy ± confusion
30	Totally Bed Bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy ± confusion
20	As Above	As Above	Total care	Minimal sips	Full or drowsy ± confusion
10	As Above	As Above	Total care	Mouth care only	Drowsy or coma ± confusion
0	Death				

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DISEASE SPECIFIC CRITERIA

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Cancer

- Stage of disease-distant at diagnosis
- Clinical signs/symptoms
- Functional status
  - Usually PPS 60% or less
  - Generally shouldn't be working a full time job
- Complications of disease
- Weight loss

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Karnofsky or ECOG

- Karnofsky < 40 or ECOG > 3 ~ 3month survival
- Question= "How much time do you spend in chair or lying down"
  - > 50% can estimate prognosis less than 3 months

Karnofsky Status	Karnofsky Grade	ECOG Grade	ECOG Status
Normal, no complaints	100	0	Fully active, able to carry on all pre-disease performance without restriction
Able to carry on normal activities. Minor signs or symptoms of disease	90	1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
Normal activity with effort	80	1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
Care for self. Unable to carry on normal activity or to do active work	70	2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
Requires occasional assistance, but able to care for most of his needs	60	2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
Requires considerable assistance and frequent medical care	50	3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
Disabled. Requires special care and assistance	40	3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
Severly disabled. Hospitalisation indicated though death nonimminent	30	4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
Very sick. Hospitalisation necessary. Active supportive treatment necessary	20	4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
Moribund	10	4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
Dead	0	5	Dead

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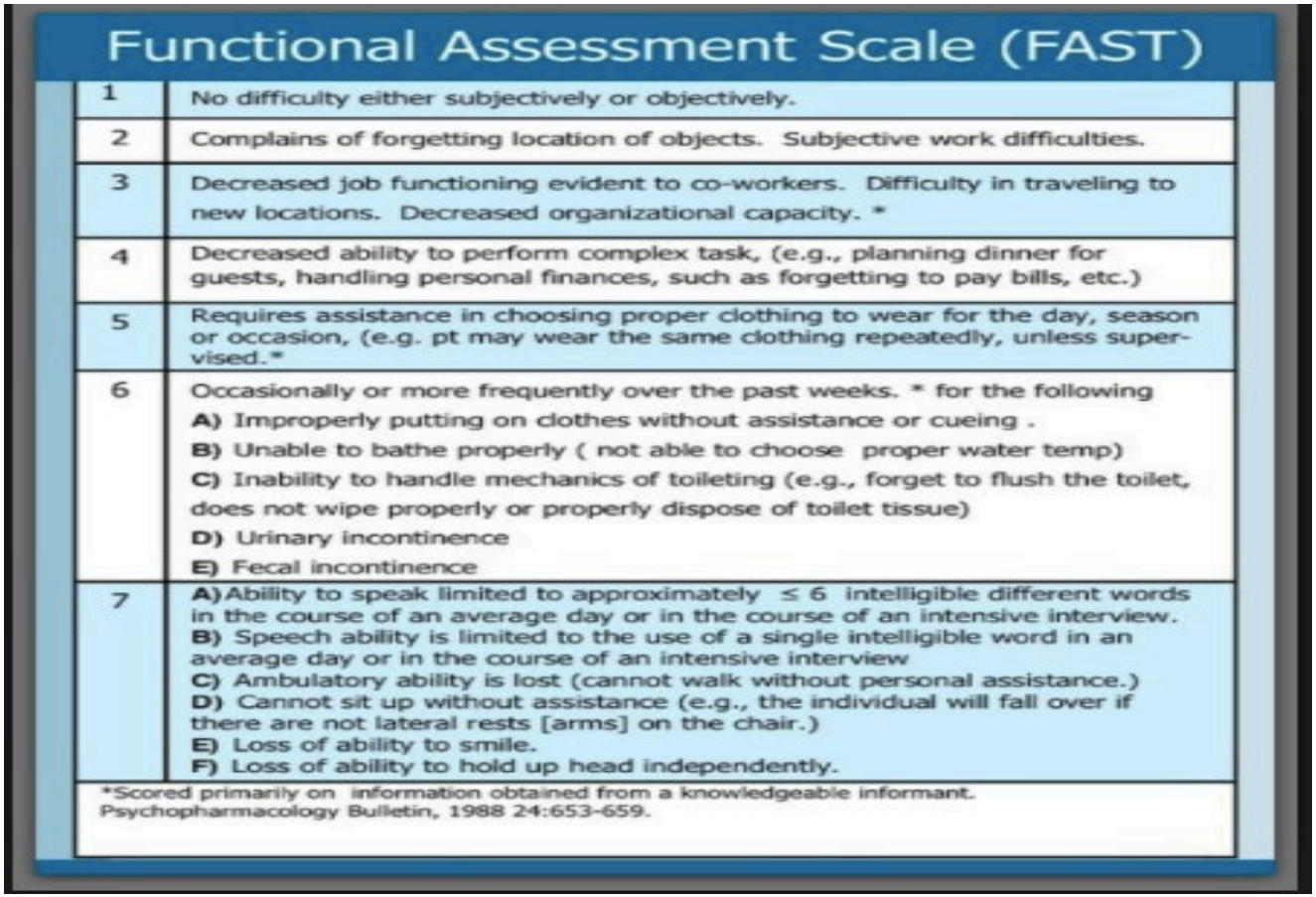
Prognostic Data

Malignant Hypercalcemia	**8 weeks**
Malignant Pericardial Effusion	**8-12 weeks**
Meningeal Carcinomatosis	**8-12 weeks**
Brain Metastases without XRT	**4-8 weeks**
Brain Metastases WITH XRT	**12-24 weeks**
Malignant Pleural Effusion	**3-6 months**

Alzheimer's Dementia and FAST Score



Functional Assessment Scale (FAST)	
1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following **A)** Improperly putting on clothes without assistance or cueing . **B)** Unable to bathe properly (not able to choose proper water temp) **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) **D)** Urinary incontinence **E)** Fecal incontinence
7	**A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview **C)** Ambulatory ability is lost (cannot walk without personal assistance.) **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.
*Scored primarily on information obtained from a knowledgeable informant. Psychopharmacology Bulletin, 1988 24:653-659.	

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Alzheimer's Dementia

- MUST BE FAST 7A or higher
  - If we are admitting for 6e looking for…
    - Recurrent fevers despite antibiotics
    - Weight loss of >10% in 6 months
    - Recurrent aspiration PNA or UTIs
    - Significant skin breakdown with stage III or IV ulcers

Clinical Course of Dementia

- Six month mortality..
  - Pneumonia-46.7%
  - Febrile episode-44.5%
  - Dysphagia-38.6%
  - Hip fracture-50%

Evidence of Functional Decline

- Decline in PPS
- Unintentional weight loss
- Low BMI-defined as less than 22
- Sarcopenia-measured by MUA circumference
- Low serum albumin levels

Polling Question #2

Which of these are common misconceptions of hospice care?

A. It prolongs life.
B. It decreases the patient's quality of life.
C. It hastens death.
D. None of the above.
E. All of the above.

MISCONCEPTIONS OF HOSPICE CARE

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Hospice Myths

MYTH	FACT
Hospice care hastens death.	Hospice care neither prolongs life nor hastens death.
Hospice care is only for cancer patients.	About half of our patients have a diagnosis of cancer.
Using hospice care means giving up.	Hospice care offers hope for freedom from the fears of isolation, abandonment, loneliness, loss of control and physical pain; and hope that the family will be nurtured and supported.

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Hospice Myths

MYTH	FACT
Hospice care is only for the last two weeks of life.	Hospice care is available to all patients with a life expectancy of six months or less.
Hospice care is expensive.	Medicare, Medicaid, and many insurance plans cover 100% of charges for hospice services.

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Comparing survival between hospice and non-hospice patients

- Connor et al published a study in JPSM
  - Medicare beneficiaries with dx of
    - CHF
    - Lung cancer
    - Pancreatic cancer
    - Colon cancer
    - Breast cancer
    - Prostate cancer

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Comparing survival between hospice and non-hospice patients

- 4493 Medicare beneficiaries reviewed
  - Majority with primary dx of lung cancer
  - Survival significantly longer for CHF, lung cancer, pancreatic cancer
  - Average increase in survival of 29 days
  - Largest difference in survival was among CHF, which has the smallest cohort

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Study conclusions

- Patients avoid the risk of overtreatment when pursuing hospice
- Patients receive increased monitoring and assessment of problems, leading management changes
- Psychosocial support prolongs survival

SYMPTOM MANAGEMENT

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Common Symptoms in EOL

- Pain
  - *Total Pain*
- Dyspnea
  - *Total Dyspnea*
- Nausea and vomiting
- Agitation/Restlessness/Delirium
  - Think of reversible causes
- Increased Oropharyngeal secretions
  - "Death Rattle"

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How to Manage EOL Symptoms

- Education!!!!!!
  - Changes in Temperature
  - Changes in Breathing Pattern
  - Changes in Circulation
  - Changes In Alertness
  - Skin Changes
  - Changes in Secretions

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Opioid Analgesics

- Major class of drugs used in moderate to severe pain as well as refractory dyspnea
- Dose titration is often limited by side effects
- Addiction vs. Dependence vs. Tolerance

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Management of Dyspnea

- IV Steroids
- Nebulizer treatments
- Opioids **(APPROPRIATE DOSING DOES NOT CAUSE RESPIRATORY DEPRESSION)**
- Benzodiazepines if high anxiety related to SOA
- Thoracentesis as indicated
- Hand held fan to face (easy)
- Supplemental oxygen if patient is hypoxemic

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Terminal Restlessness

- Phenomenon in the last weeks of life
- Likely represents patient's level of distress
  - Can be physical, emotional, spiritual or combination of above
  - Will appear as inability to relax
  - Constant movement/restlessness
  - Common to hallucinate

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Terminal Restlessness

- Mainstay of treatment is benzodiazepines (e.g. lorazepam) or anti-psychotics (e.g. haloperidol)
- Can be dramatic and require significant symptom management to help patient relax
- If in last days to weeks of life, benzodiazepines are first-line treatment

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Audible Oropharyngeal secretions

- Commonly referred to as the “death rattle”
- Best is recovery position (postural drainage)
- Other medications to consider
  - Atropine drops (eye drops)
  - Hyosciamine
  - Glycopyrrolate
  - Education that this is NOT distressing to the patient

Final Thoughts

- Refer early
  - If you feel patient may be eligible, feel free to call for evaluation
- Call your local hospice for recommendations with symptom management issues should they arise

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QUESTIONS???

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The earlier you call, the more we can help.

Thank You For Joining Us

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- Please provide feedback in the post-event survey!

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