

Golden Rules for the Golden Years

Resources to Help Reduce Symptom Burden & Caregiver Burnout in Older Adults

The aging population...

- Average life span is increasing
- Many older adults will develop chronic illnesses that they will live with for years
- These years are often characterized by increasing
 - Physical discomfort and other symptoms
 - Psychological and social stress
 - Eventual need for caregiver support

Given these facts, what resources are available to make these years the true “Golden Years”?

Topics To Be Covered

- Palliative Care
- Caregiver Burnout
- Advance Directives
- Dementia

Case

- Mrs. A is an 83-year-old woman with Alzheimer's dementia whose primary caretaker is her husband. Mrs. A also has high blood pressure and osteoporosis. She has been hospitalized for three days with pneumonia.
- Her hospital course has been complicated by periods of confusion, moaning and agitation. Mrs. A has pulled out her IV three times requiring restraints. She was also found to have a vertebral fracture thought to be caused by coughing related to her pneumonia.

Palliative Care is...

- A medical specialty that aims
 - to relieve suffering
 - improve quality of life

for patients with serious illness and their families.

Domains of Palliative Care

- **Symptom management:** pain, shortness of breath, nausea, constipation, fatigue, etc.
- **Communication & goals of care clarification:** facilitate medical decision making and help match medical treatments with patient and family's goals of care
- **Psychosocial, religious, spiritual and practical support** for patients and families
- **Care of the actively dying patient**

The palliative care team includes:

- Physicians
- Nurses
- Social Workers
- Spiritual counselors
- Massage Therapists

Misconception.....

- *“I thought palliative care was what we do when there is nothing more the doctors can do”*
- **NO!** Palliative care is best if offered simultaneously with all other appropriate medical treatment, ideally at time of serious illness diagnosis, regardless of prognosis.

Misconception....

- “*I thought palliative care was the same as hospice care....*”
- **NO!** Palliative care extends beyond end of life care.
- Hospice provides end of life care for *terminally ill* patients through a team based approach.
- Any patient who has a terminal illness, is no longer seeking curative treatment, and whose life expectancy is approximately 6 months or less qualifies for hospice care.

Palliative Care vs. Hospice Care

PC can be provided at any time (best if started at time of diagnosis) along a patient's illness trajectory

Provides care to patients who are terminally ill (typically those patients who have a prognosis of 6 months or less)

Care that patients receive *at the same time* as efforts to cure or prolong life

Patients are no longer candidates for curative oriented therapy.

Expert care of pain and symptoms throughout illness

Expert care of pain and symptoms through end of life.

How can Palliative Care Help?

- **Improves patient quality of life**
 - Reduces distressing symptoms.
 - Improve communication helping you better understand your serious illness and the pros and cons of medical decisions.
 - Provides support.
- **Improves family satisfaction and well-being**
 - Reduces depression and prolonged grieving.
 - Provides practical support for family.

Wright, A, Zhang, MS, Ray, A, et al. Associations Between End –of- Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. *JAMA*. 2008; 300: 1665 – 1673.

How can Palliative Care Help?

- Randomly assigned patients with metastatic lung cancer to receive either standard oncologic care or standard care in addition to early palliative care.
- Patients receiving early palliative care had lower rates of depression, & better quality of life and mood scores.
- They also received less aggressive care at the end of life, but had longer survival than did patients receiving standard care alone.

Early Palliative Therapy in Advanced Lung Cancer
Temel et al. NEJM. 363 (8): 733-742

Can Palliative Care Help You?

- Congestive Heart Failure
- COPD
- Liver Failure
- Kidney Failure
- Dementia
- Cancer

Case cont.

- On day 3 of her hospitalization a palliative care consult is called to evaluate Mrs. A's moaning. The palliative care physician assesses that Mrs. A is experiencing a significant amount of pain related to her fracture.
- The palliative care physician prescribes a pain regimen and Mrs. A's moaning stops. Her confusion and agitation improve as they were likely related in part to her uncontrolled pain. She no longer requires restraints.
- The palliative care physician also orders a bowel regimen to prevent constipation. She tells Mr. and Mrs. A that more members of her team will return to meet them both.

Resources

- www.nhpc.org/learn-about-end-life-care
- www.getpalliativecare.org

Caregivers

- Caregivers are key in providing support to older adults, assist in care plan implementation, and help with daily activities.
- Care giving can be a very rewarding experience....as well as challenging!

· Adelman, RD, Tmanova, LL, et al. Caregiver Burden A Clinical Review. JAMA.311(10); 1052-1059; 2014.

Littrivis, E., Smith, C. Palliative Care: A Primer. Mount Sinai Journal of Medicine 78(4); 2011.

Caregivers

- 1/4 of caregivers stop working to provide care
- 1/3 lose majority of finances
- Family caregivers are at increased risk for heart attacks and overall mortality, especially those who report stress.

Plonk, WM Jr, Arnold, RM. Terminal care: the last weeks of life. *J Palliat Med* 2005;8: 1042 – 1054.

Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 1999; 282: 2215 – 2219.

Lee s, Colditz GA, Berkman LG, et al. Caregiving and risk of coronary heart disease in U.S, women: a prospective study. *Am J Prev Med* 2003; 24: 113 – 119.

Caregiver Burnout

- The stress that providing care for someone with a chronic illness places on an individual
 - Depression
 - Anxiety
 - Sleeping difficulties
 - Appetite changes
 - Loss of interest in activities
 - Self injurious thoughts
 - Change in care patterns

Who is at Risk?

- Spousal caregivers tend to face greater stress as compared to adult children caring for aging parents.
- Additional risk factors
 - female sex
 - living with the individual receiving care
 - social isolation
 - lower education level
 - increased care giving hours
 - no choice in the role

Capistrant BD, Moon JR, Berkman LF, GlymourMM. Current and long-term spousal caregiving and the onset of cardiovascular disease. J Epidemiol Community Health. Online publication 2011.

Adelman, RD, Tmanova, LL, et al. Caregiver Burden A Clinical Review. JAMA.311(10); 1052- 1059; 2014.

Support for Caregivers

- Self care
- Support groups
- Educational sessions
- Family help

Adelman, RD, Tmanova, LL, et al. Caregiver Burden A Clinical Review. JAMA.311(10); 1052-1059; 2014.

Saas K, et al. Coping by the carers of dementia sufferers. Age Aging. 1995; 24: 495 – 498.

Support for Caregivers

- Social work referral for home support
- Respite care
- Prayer
- Symptom relief for the care recipient

Adelman, RD, Tmanova, LL, et al. Caregiver Burden A Clinical Review. JAMA.311(10); 1052- 1059; 2014.

Saas K, et al. Coping by the carers of dementia sufferers. Age Aging. 1995; 24: 495 – 498.

Support for caregivers

- Through an interdisciplinary approach, *palliative care clinicians* are trained to recognize caregiver stress and have been shown to improve caregiver well-being and family satisfaction

Casarett D, Pickard A, Bailey FA, et al. Do palliative consultations improve patient outcomes? J Amer Geriatr Soc 2008; 56: 593 – 599.

Case cont.

- The palliative care nurse, social worker and chaplain return to check on Mrs. A and to meet Mr. A. Mrs. A is improving from her pneumonia and appears comfortable. She has however become weak during this hospital stay and can no longer get out of bed unassisted.
- On assessing needs for home care, the team suspects Mr. A is experiencing caregiver burnout. He, himself has several medical conditions including asthma and heart disease and it is becoming harder for him to care for Mrs. A.
- Mr. A cries when he shares with the team that he is worried about Mrs. A's new care needs. The palliative care team refer Mrs. A for evaluation for rehabilitation and home care services. They also refer Mr. A to caregiver support groups.

Resources

- www.caregiver.org
- www.eldercare.gov

Advance Directives

- *Oral or written* instructions that describe what treatment preferences an individual desires in the event that he or she loses decision making capacity.
- Informs decision makers and health care community of an individual's preferences for medical treatment.

Written Advance Directives

- Living Wills
- Health Care Proxy or Durable Power of Attorney for Health Care
- Combination Document

What is a Living Will?

- A form of a written advance directive that acts as a guideline for the type of treatment one would like to receive in the event that one loses decision making capacity.
- Important to complete a living will early in disease course.

What is a Health Care Proxy?

- An individual appointed to make medical decisions on one's behalf in the event one loses decision making capacity.
- Your HCP should be someone.....
 - you trust to make serious decisions
 - who clearly understands and has had discussions with you about your wishes
 - willing to accept the responsibility

Why complete an advance directive?

- Ensures you will receive the type of treatments you want at end of life.
- Choices at end of life can be very overwhelming and complex. Your loved ones want to respect your wishes, but may not know them.
- Serves as a guideline for health care agents or surrogate decision makers in the event of a serious illness, helping reduce stress.

Health Care Decisions that may be included in an Advance Directive

- Do Not Resuscitate Orders
- Wishes regarding life support
- Wishes regarding artificial nutrition & hydration
- Treatment choices regarding antibiotics
- Organ donation
- Funeral arrangements

And after....

- Review the contents of the AD regularly.
- Encourage the accessibility of the documents.
- Make copies.

Case cont.

- The palliative care physician returns to check on Mrs. A.
- Mr. A shares that upon arrival to the hospital, the doctor had asked him if he knew what his wife's "code status" preference was, as Mrs. A was delirious. Mr. A was overwhelmed at the time and could not answer the doctor. On returning home, he found legal documents Mrs. A had completed upon receiving her diagnosis of dementia.
- He shows the palliative care physician the document and asks if that is what the doctor needed. On receiving Mrs. A's consent, the palliative care physician sits down with both Mr. and Mrs. A and reviews her living will and HCP with them. It names Mr. A as her primary HCP, and her niece Angela as alternate agent. Mrs. A acknowledges that her wishes remain the same. Mr. A feels relieved he is aware of Mrs. A's wishes regarding her future care....

Resources

- www.caringinfo.org
- www.aarp.org

Dementia

- Approximately 5 million Americans are affected with dementia
- 1 in 3 older adults die with dementia
- Projections for 2025, estimate a 40% increase in older adults with Alzheimer's

What is dementia?

- Dementia is an irreversible decline in one's mental abilities that **affects one's ability to carry out daily activities.**
- Caused by damage to brain cells that affects their ability to communicate, leading to deficits in more than just memory!

“Isn’t it all just aging?”

- Age related memory decline occurs, but does not affect daily functioning.
- Dementia is not a normal aging process!

What is dementia?

- Can affect
 - *new information acquisition*
 - *visual spatial abilities*
 - *language*

Dementia can affect....

- *reasoning and judgment*
- *personality & behavior*
- *orientation*

Examples of types of dementia

- Alzheimer's (most common)
- Vascular
- Lewy Body
- Frontotemporal

Prevention

- Maintain cardiovascular health
- Physical activity
- Mediterranean diet

Get a checkup!

- Rule out reversible causes (vitamin deficiencies, thyroid dysfunction, structural brain disorders)
- History
- Examination including memory & mental testing.
- May include brain scan
- Laboratory testing

Get a checkup!

- Family doctor or general internist may refer you to a specialist for initial or further testing.
- Geriatrician
- Neurologist
- Neuropsychiatrist

Stages

- Early – lapses in recent memories, learning new information is challenging, difficulty with independent activities of daily living (paying bills), getting lost in familiar places, personality changes
- Middle – lapses develop in older memories, difficulty recognizing family members & friends, challenges in basic activities of daily living (toileting, dressing), wandering, personality changes
- Late / End-stage – assistance required for activities of daily living, swallowing issues, loss of language, increase risk for infections

Patient and Caregiver Through the Stages....

Early

Patient: greatest importance lies in future planning (advance directives & financial), regular medical follow — ups, memory aids

Caregiver: supportive, assistance with chores, home safety measures

Through the Stages....

Middle

Patient: medical follow – up

Caregiver: safety aids (medical alert bracelet, home safety)
seek out resources, support groups, and help from
family, take time to formulate comprehensive medical
care plans with doctor & learn about behavioral changes,
routines become more important, take time to care for
oneself

Through the Stages....

Late

Patient: focus on maintaining quality of life

Caregiver: care needs increase, may need to decide on location of care or increase resources for home care, ensure that advance directives have been reviewed and discussed with PMD, continue to follow up with support groups and take time to care for oneself

Management

- Early evaluation can help by ensuring support and future care.
- Two drug classes are FDA approved for Alzheimer's dementia. These drugs will not reverse or stop disease progression, but may stabilize symptom burden for a period of time.

Future Directions

- Increase education and support to caregivers.
- Further progress in understanding brain function and dementia.
- Clinical trials underway for potential new drugs.

Case

- Mrs. A is scheduled to see the palliative care nurse in the outpatient palliative care practice for follow-up, after her rehabilitation stay. She is accompanied by Mr. A. They brought Mrs. A's living will and HCP documentation, and copies are made for her medical records.
- Mrs. A tells you she is feeling much better and denies pain. She no longer requires pain medicine, and she benefitted from her rehabilitation stay.
- Mr. A also reports feeling better since home care services have been implemented. His niece Angela also visits twice a week to drop off groceries and has been helping with light housekeeping.

Resources

- www.alz.org
- www.alzheimers.gov
- www.nia.nih.gov/alzheimers

Take Home Points

- Palliative care teams can help patients and families facing serious illness based on need, regardless of prognosis.
- Caregivers can provide the best care to recipients if they take time to also care for themselves, and by working together with health care teams to seek out resources to prevent burnout.
- Completing advance directives can help honor your wishes for the types of medical care you desire at end of life.
- Dementia is a progressive, chronic disease that is not just normal aging.