

# *Best Practices for End of Life Care for Dialysis Patients*

**Speaker:  
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**TUESDAY, JULY 13, 2010, 8:30AM-9:30AM CST**

**THIS WEBINAR WILL BEGIN MOMENTARILY**

**LINES WILL BE ON MUTE DURING THE PRESENTATION & WILL BE OPENED THEREAFTER FOR Q & A**



# Best Practices Defined

- **Best way to do something:** the most effective or efficient method of achieving an objective or completing a task
  - Encarta World English Dictionary
- A **best practice** is a technique, method, process, activity, incentive, or reward that is believed to be more effective at delivering a particular outcome than any other technique, method, process, etc. when applied to a particular condition or circumstance. The idea is that with proper processes, checks, and testing, a desired outcome can be delivered with fewer problems and unforeseen complications.
  - Wikipedia

# Best Practices and End of Life Care: Four Components

- **Policy:** provide guidelines, boundaries, accountability, legal requirements
- **Research:** provides information on gaps, what has been found to work well
- **Practice/Experience:** relies on our professional experiences/personal development and integration of EOL planning into daily interactions with patients
- **Resources:** provides helpful tools

# Policy: Patient Self-Determination Act

- Passed by Congress 1990: Patients are given written notice upon admission to the health care facility of their decision-making rights, and policies regarding advance health care directives in their state and in the institution to which they have been admitted. Patient rights include:
  - The right to facilitate their own health care decisions
  - The right to accept or refuse medical treatment
  - The right to make an advance health care directive

# Policy: Patient Self-Determination Act

- Facilities must inquire as to whether the patient already has an advance health care directive, and make note of this in their medical records.
- Facilities must provide education to their staff and affiliates about advance health care directives.
- Health care providers are not allowed to discriminately admit or treat patients based on whether or not they have an advance health care directive.

# Policy: Current Medicare Hospice Benefit

- CMS provides hospice benefit for ESRD
- Withdrawal from dialysis not prerequisite
- Individual hospice entities have option NOT to accept ESRD patients
- Non-ESRD diagnosis required for ESRD patients choosing to continue dialysis and retain ESRD benefit (unless hospice pays for ESRD-related services)

# Explanation of Hospice Benefit

- When beneficiary with ESRD has terminal diagnosis other than ESRD, beneficiary may elect hospice benefit and continue dialysis for palliative reasons.
- Examples of acceptable diagnoses for hospice coverage:
  - adult failure to thrive
  - cancer
  - AIDS,
  - chronic obstructive pulmonary disease (COPD)

# Explanation of Hospice Benefit

- ESRD beneficiaries with non-ESRD terminal diagnosis who elect hospice benefit but wish to continue dialysis may be covered under both hospice benefit and ESRD benefit.
  - Services related to terminal (non-ESRD) diagnosis would be covered under hospice benefit.
  - Services related to ESRD (eg. dialysis) would be covered under ESRD benefit.

# Explanation of Hospice Benefit

- When beneficiary with non-renal diagnosis for terminal illness elects to continue dialysis, dialysis facility would continue to bill under ESRD benefit and hospice would bill for terminal illness under hospice benefit.
- ESRD beneficiaries may elect to use hospice benefit under diagnosis of ESRD as terminal diagnosis. If so, hospice provider must be responsible for all dialysis and supplies as part of care for terminal diagnosis and palliation.

# Bottom Line



- Two government benefits cannot pay for same illness/condition in one beneficiary.
- Two government agencies can pay for two different illnesses/conditions in one beneficiary.

# Case Examples

- Patient with cancer diagnosis wants to continue dialysis. Is patient eligible for both hospice and ESRD Medicare benefits?
- Patient with no other terminal diagnosis wants to begin hospice but also continue dialysis. Is patient eligible for both hospice and ESRD Medicare benefits?

# Resources

- Education/Information:
  - <http://www.cms.gov/center/hospice.asp>
- Intermediary Carrier Directory:
  - <http://www.cms.hhs.gov/contacts/incardir.asp>

# Conditions for Coverage

- Sec. 494.70 Condition:  
Patients' rights.
  - (5) Be informed about and participate, if desired, in all aspects of his or her care, and be informed of the right to refuse treatment, to discontinue treatment, and to refuse to participate in experimental research;
  - (6) Be informed about his or her right to execute advance directives, and the facility's policy regarding advance directives;

# Research: Advance Directives Survey of Patients

- 80 chronic dialysis patients were asked why they had not executed advance directives.
  - 55 responders (69%) agreed that advance directives were a good idea, but only 35% had completed an advance directive.
  - Only 14% had discussed their wishes for life-sustaining therapy with their nephrologist.
  - 67% had discussed their wishes with their family.
  - Most who had not executed an advance directive said they had not done so because their family knew their wishes.

Holley, J.L., et al., "Factors Influencing Dialysis patients' Completion of Advance Directives," *Am. J. Kid. Disease*, 1997, vol. 30:356-360.

# *NKF Family Focus* Communication Survey

2003, N = 474

- 12% discussed end-of-life issues with physician
- 12% discussed end-of-life issues with social worker
- 58% had no discussion about end-of-life issues
- Out of 16 topics end-of-life was least likely to be discussed with health care team

# National Consensus Project for Quality Palliative Care Recommendations

- **Structure and process of care:** care plan, assessing cognitive capacity, assessing the team's readiness and ability to provide EOL care.
- **Physical aspects of care:** pain, symptoms, side effects
- **Psychological aspects of care:** assess and manage psychiatric co-morbidities.
- **Social aspects of care:** identify social needs of patients/families.

# National Consensus Project for Quality Palliative Care Recommendations

- **Spiritual aspects of care:** refer to pastoral/clergy care. Provide care that support's patient's cultural and/or religious values.
- **Cultural aspects of care:** be respectful of cultural preferences.
- **Care of imminently dying:** recognize signs/symptoms, refer to hospice, revise care plan
- **Ethical and legal aspects of care:** provide care within limits of applicable laws, be mindful of informed consent, decision-making capacity, self-determination

# Practice/Experience: When to talk about end of life issues

- Case example: Patient A
  - Discussed end of life issues at first visit in the hospital
  - Patient concerned about guilt, things he had done wrong in his life
  - Conversation focused on forgiveness of self
- Assess the impact of “life-sustaining treatment” on patients’ thoughts about end of life issues when conducting initial assessment.

# Practice/Experience: DNR discussions



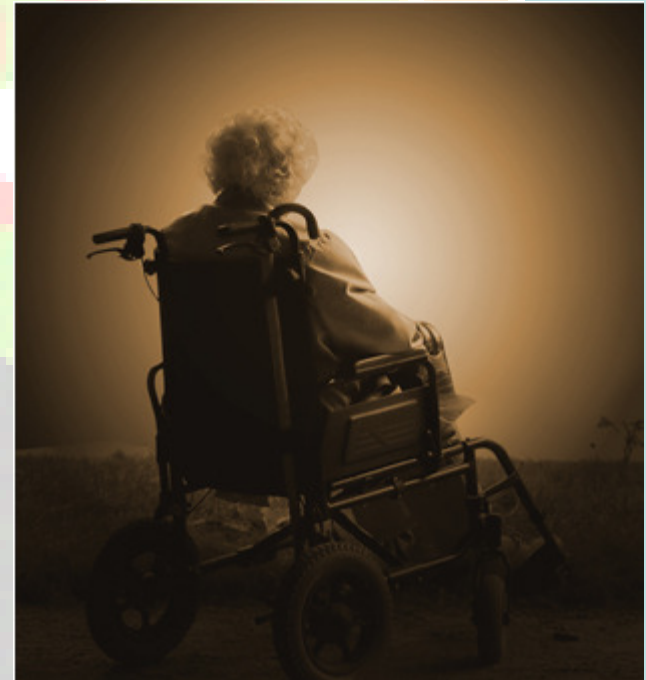
- Case example: Patient B
  - First DNR at dialysis facility
  - No code experience
  - Affect on staff and other patients
  - Lessons learned
- Assess DNR status at time of admission to dialysis facility.

# Practice/Experience: Integrating EOL conversation in care plan

- Case Example: Patient C
  - “my end of life project”
  - Care plan meeting discussion
  - Family involvement
- Integrate EOL discussions in the care plan meeting

# Practice/Experience: Managing multiple agencies

- Case Example: Patient D
  - Care planning with nursing home, dialysis facility, hospice agency
  - Coordinating care
  - Respecting privacy and confidentiality
- Recognize other agencies' roles in EOL care of dialysis patients and coordinate with them.



# Practice/Experience: Choosing your time to die

- Patient E
  - Diagnosed with pancreatic cancer
  - Allergic to morphine
  - Discontinued dialysis and died from kidney failure
- Recognize when discontinuing dialysis may ease the burden for dying patients. Develop a pain management care plan. Orient care plan to helping patients manage dying rather than prolonging death.



# Practice/Experience: helping to find peace

- Patient F
  - Stopped dialysis due to dependence caused by blindness
  - No family support
  - Attempted resolution at family issues
  - Discontinued dialysis
- Recognize the role the dialysis care team has in finding peace, emotional health prior to death.



# Resources: Kidney End of Life Coalition

Mission: To promote effective interchange between patients, families, caregivers, payers, and providers in support of integrated patient-centered end-of-life care for chronic kidney disease (CKD) patients.

# Coalition: Organizations Represented

**Mid-Atlantic Renal Coalition**

**National Hospice & Palliative  
Care Organization (NHPCO)**

**Centers for Medicare & Medicaid  
Services (CMS)**

**American Nephrology Nurses'  
Association (ANNA)**

**Forum of ESRD Networks**

**West Virginia University**

**American Kidney Fund (AKF)**

**American Association of Kidney  
Patients (AAKP)**

**Renal Physicians' Association  
(RPA)**

**National Renal Administrators'  
Association (NRAA)**

**National Kidney Foundation  
(NKF)**

**DaVita**

**Fresenius Medical Care**

**Dialysis Clinics, Inc.**

**VistaCare**

**Miscellaneous Members**

# Kidney EOL Coalition Resources

- Webinars
- Algorithm on pain management
- Template: advance care planning policy
- Model DNR policy
- CPR patient education
- Memorial service ideas
- Providing support to staff
- Links to state specific advance directive documents
- [www.kidneyeol.org](http://www.kidneyeol.org)

# Heartland Kidney Network Resources

- Advance Directives brochure:
  - <http://www.heartlandkidneynetwork.org/community/download/Advance%20Directives.pdf>
- Discussing Death & Dying newsletter:  
(with state specific forms for IA, KS, NE, and MO)
  - [http://www.heartlandkidneynetwork.org/community/pat\\_newsletters.html](http://www.heartlandkidneynetwork.org/community/pat_newsletters.html)

# NKF Resources

- Advance Directives: A Guide for Patients and Their Families
- If You Choose Not to Start Dialysis Treatment
- When Stopping Dialysis Treatment Is Your Choice: A Guide for Patients and Their Families
- [http://www.kidney.org/atoz/atozTopic\\_Brochures.cfm](http://www.kidney.org/atoz/atozTopic_Brochures.cfm)

# ANNA Resource: End-of-Life Decision-Making and the Role of the Nephrology Nurse

- [www.annanurse.org](http://www.annanurse.org) CEU activity
  - *Module 1: Techniques to Facilitate Discussion for Advanced Care Planning (ACP)*
  - *Module 2: Ethical and Legal Aspects of Advanced Care Planning (ACP)*
  - *Module 3: Cultural Diversity: Different Cultures, Different Solutions*

# Thank You!

- Wendy Funk Schrag, LMSW, ACSW
- [Wendy.schrag@fmc-na.com](mailto:Wendy.schrag@fmc-na.com)
- Certificate of attendance to be issued to all participants. Please forward your email if you did not sign in at the beginning of the session to;
- Anne Karanja ([akaranja@nw12.esrd.net](mailto:akaranja@nw12.esrd.net)) or call 816.880.1709
- Thank you for completing the survey!