

Kidney End-of-Life Coalition Website (www.kidneyeol.org)

An Outline for Dialysis Facilities

The Kidney End-of Life Coalition's website offers a wealth of information for dialysis providers, patients and family members. Use the guide below to walk through the website and locate pertinent information for your staff and patients. If you have any questions about the website or its resources, please contact Samantha Dorr at (804) 794-3757 or sdorr@nw5.esrd.net.

Homepage: www.kidneyeol.org

- The homepage introduces the Kidney End-of-Life Coalition and provides links to recent, pertinent information elsewhere on the website
- As of May 2010, this page includes links to the end-of-life webinars that were held between January – April 2010
- “Search” box feature (listed on every page) can be used to find specific information on the website, using keywords or phrases

“What’s New” webpage: <http://www.kidneyeol.org/kidneynews.htm>

- This page shows a chronological archive of important Coalition news, including press releases

“Coalition History” webpage: <http://www.kidneyeol.org/history.htm>

- This page explains the Coalition's history and lists all of the Coalition's active and inactive workgroups and affiliated organizations

“Advance Care Planning” webpage: <http://www.kidneyeol.org/advanced.htm>

- This page offers an explanation of advance care planning and breaks out its resources into three (3) categories: tools for patients, resources for initiating end-of-life discussions and educational tools for staff
- Useful tools include:
 - o [ACP policy](#) template for dialysis facilities
 - o Links to [state-specific advance directive documents](#)
 - o [Order form](#) for the Coalition's *Advance Care Planning: For the Dialysis Patient and Their Family* brochure
 - o Mid-Atlantic Renal Coalition's [educational module](#) “Caring through the End” (in-service format for clinicians)

“End-of-Life Decisions in the Dialysis Unit” webpage: <http://www.kidneyeol.org/dialysis.htm>

- This page includes a brief explanation of the importance of establishing end-of-life decisions in the dialysis unit, including the establishment of a DNR policy, and lists beneficial tools for staff
- Useful tools include:
 - o [Model DNR policy](#) for the dialysis facility
 - o Robert Wood Johnson Foundation's ESRD Workgroup's [full report](#) on “Promoting Excellence in End-of-Life Care”
 - o [Personal death awareness exercises](#)
 - o NKF/CNSW's [1-page explanation](#) of the Medicare Hospice Benefit

“Palliative Care and Hospice” webpage: <http://www.kidneyeol.org/hospice.htm>

- This page defines and distinguishes the terms “palliative care” and “hospice care,” includes information about the Medicare Hospice Benefit and provides resources and presentations for dialysis and hospice providers
- Link to the [Medicare Hospice Benefit definition](#) on the CMS website (see page 35, section 50.6.1.4)
- Useful tools include:

- CMS's [Hospice Payment System Brochure](#)
- [Code of Federal Regulations](#) for hospice services
- PowerPoint slideshow "[Sustaining Hope, Providing Help: Case Studies in Advanced Illness.](#)" This presentation uses case studies to detail the benefits of palliative care and hospice for CKD and ESRD patients and is appropriate for hospice or dialysis clinicians
- PowerPoint slideshow "[Did this patient die in hospice? New questions in caring for patients with ESRD.](#)" This presentation includes critical elements for providing hospice care to ESRD patients and describes strategies for hospices to use when working with dialysis centers and nephrologists

"Patient and Family Education" webpage: <http://www.kidneyeol.org/education.htm>

- This page lists a patient-friendly definition of advance care planning for ESRD patients and includes information for patients/families in the following topic areas: advance directives, choosing not to start/choosing to stop dialysis, personal stories and additional links
- Useful tools include:
 - NKF's brochure "[Advance Directives: A Guide for Patients and Their Families](#)"
 - Section on choosing not to start or choosing to stop dialysis, including two (2) brochures developed by the NKF: "[If You Choose Not to Start Dialysis Treatment](#)" and "[When Stopping Dialysis Treatment is Your Choice: A Guide for Patients and Their Families](#)"
 - Personal, [first-hand account of hospice care](#) by Coalition member John J. Lombard, Jr.

"Physician/Clinician Education" webpage: <http://www.kidneyeol.org/physician.htm>

- This page explains of the important role that nephrologists play in end-of-life decision-making and includes educational resources and presentations for clinicians
- Useful tools include:
 - Link to RPA Guideline "[Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis](#)" (note: revised version set to be released in Oct. 2010)
 - Links to webinar presentations "[Pain Assessment and Management](#)" and "[Symptom Assessment and Management](#)" and related resources
 - The Coalition's pain management brochure entitled "[Clinical Algorithm & Preferred Medications to Treat Pain in Dialysis Patients](#)"
 - [Frequently Asked Questions](#) about end-of-life care for renal patients

"Presentations" webpage: <http://www.kidneyeol.org/presentations.htm>

- This page lists various presentations submitted by Coalition members
- Useful tool includes:
 - PowerPoint slideshow "[Hospice in ESRD: To Withdraw or Not to Withdraw](#)" developed by Dr. Rebecca Schmidt in October 2005 (note: this is the most downloaded presentation on the website)

"Professional Resources" webpage: <http://www.kidneyeol.org/resources.htm>

- This webpage includes multi-disciplinary resources in the following topic areas: legal issues (state and federal), cultural competency, education, death and dying; and lists related organizations and recommend reading
- Useful tools include:
 - Information on the Physician's Orders for Life-Sustaining Treatment or [POLST Paradigm](#)
 - Link to the website for NHPCO's [Hospice Action Network](#)
 - Bibliography of journal articles addressing end-of-life care for ESRD patients