





# FAMILY "TOOLS OF ENGAGEMENT" BEST PRACTICE 2

#### **BEST PRACTICE**

Provide support and resources to guide patients/families in patient centered advance care planning.

#### **HOW DO YOU ACHIEVE THIS BEST PRACTICE?**

- 1) Improve communication between patient/families and health care professionals
  - a) Assess readiness to learn about this topic and health literacy
  - b) Assess perceptions about dialysis and their quality of life
  - c) Encourage expression of fears, cultural beliefs, wishes and preferences
    - i) Gain insight into their understanding of ESRD and kidney replacement therapies
  - d) Assess families role in the decision making process and relationship with patient
  - e) Assess current knowledge and/or advance care planning activities that may have been completed
- 2) Empower the family to discuss advance care planning with the patient through education about the importance of advance care planning and the pros and cons of specific components, including:
  - a) Advance Directive (including Living Will, Durable Power of Attorney, and Surrogate)
  - b) Cardiopulmonary resuscitation
  - c) Hospice
  - d) Palliative Care
  - e) End-of-life care (e.g., symptom management, pain, and uremic symptoms)
  - f) Making decisions
    - i) Appreciate the level of difficulty in making choices
    - ii) Assess congruence between patient/family (surrogate) treatment preferences
    - iii) Ethical and legal issues
- 3) Encourage family to engage advance care planning activities with patient by providing psychosocial, spiritual, and cultural support
- 4) Respect the role of family/primary caregiver as part of the healthcare team by providing support and involving them in the decision making process
  - a) Understand what it means to be a caregiver
  - b) Provide emotional and spiritual comfort
  - c) Encourage and assist in the development of caregiver stress reduction strategies

FAMILY ENGAGEMENT BEST PRACTICE 2: TOOLS AND RESOURCES	
Web-Based Tools and Resources	
Advance Care Planning Information	Caring Connections <a href="http://www.caringinfo.org/PlanningAhead.htm">http://www.caringinfo.org/PlanningAhead.htm</a>
	The Maryland Commission of Kidney Disease <a href="http://dhmh.maryland.gov/mdckd/marc.html#adcare">http://dhmh.maryland.gov/mdckd/marc.html#adcare</a>
	National Hospice and Palliative Care Organization www.nhpco.org
Caring Connections	Caring Connections <a href="http://www.caringinfo.org/Home.htm">http://www.caringinfo.org/Home.htm</a>
Kidney End-of-Life Coalition	Kidney End-of-Life Coalition <a href="http://www.kidneyeol.org/">http://www.kidneyeol.org/</a>
Physician Orders for Life Sustaining Treatment Paradigm (POLST)	Physician Orders for Life Sustaining Treatment <a href="http://www.ohsu.edu/polst/">http://www.ohsu.edu/polst/</a>
Planning for End-of-Life Care Decisions	National Institute on Aging <a href="http://www.nia.nih.gov/HealthInformation/Publications/endoflife/08_planning.htm">http://www.nia.nih.gov/HealthInformation/Publications/endoflife/08_planning.htm</a>
Printed Tools and Resources	
Caregiver Booklet	Caring Connections <a href="http://www.caringinfo.org/userfiles/File/EOL_Caregiver_booklet.pdf">http://www.caringinfo.org/userfiles/File/EOL_Caregiver_booklet.pdf</a>
End of Life Decisions Booklet	Caring Connections <a href="http://www.caringinfo.org/userfiles/File/PDFs/End-of-Life_Decisions.pdf">http://www.caringinfo.org/userfiles/File/PDFs/End-of-Life_Decisions.pdf</a>
Five Wishes Booklet	Aging With Dignity <a href="http://www.agingwithdignity.org/five-wishes.php">http://www.agingwithdignity.org/five-wishes.php</a>
If You Choose Not to Start Dialysis Treatment	National Kidney Foundation <a href="http://www.kidney.org/atoz/pdf/lfYouChoose.pdf">http://www.kidney.org/atoz/pdf/lfYouChoose.pdf</a>
Initiation or Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team	National Kidney Foundation <a href="http://www.kidney.org/members/source/catalog/index.cfm?section=unknown&amp;task=3&amp;CATEGORY=P&amp;PRODUCT_TYPE=SALES&amp;SKU=12-10-0334">http://www.kidney.org/members/source/catalog/index.cfm?section=unknown&amp;task=3&amp;CATEGORY=P&amp;PRODUCT_TYPE=SALES&amp;SKU=12-10-0334</a> (Book; \$20.00 for non-members)
Myths and Facts about Health Care Advance Directives.	American Bar Association <a href="http://www.abanet.org/aging/pdfs/myths">http://www.abanet.org/aging/pdfs/myths</a> and fact ab <a href="http://www.abanet.org/aging/pdfs/myths">out HC AD.pdf</a>

## When Stopping Dialysis Treatment Is Your Choice: A Guide for Patients

National Kidney Foundation

 $\underline{\text{http://www.kidney.org/atoz/atozcopy.cfm?pdflink=Stop}}$ 

**Dialysis.pdf** 

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### **Supporting Literature:**

Mogg A, Bartlett A. **Refusal of treatment in a patient with fluctuating capacity: theory and practice.** *J Forens Psychiatry Psychol.* 2005 16(1):60-69. <a href="http://www.informaworld.com/smpp/1584559447-743/content">http://www.informaworld.com/smpp/1584559447-743/content</a> db=all~content=a713735089

Song MK, et al. Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. *Appl Nurs Res.* 2010 23:65-72.

http://linkinghub.elsevier.com/retrieve/pii/S0897189708000475

Werth JL, et al. **Psychosocial issues near the end of life.** *Aging Ment Health.* 2002 6(4):402-412. <a href="http://www.ncbi.nlm.nih.gov/pubmed/12425774">http://www.ncbi.nlm.nih.gov/pubmed/12425774</a>

All links last accessed on October 31, 2010