



## **PATIENT “TOOLS OF ENGAGEMENT” BEST PRACTICE 2**

### **BEST PRACTICE 2**

***Enhance and maintain quality of life by incorporating an individual and holistic educational approach about the physical and psychosocial impact of dialysis on patient lives.***

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

1. Identify and provide learning opportunities in varying:
  - a. Formats
    - Written
    - Live
    - Telephonic
  - b. Delivery Vehicles
    - Telephonic
    - Audio
    - Video and DVD
    - Computer-based
    - Web-based
    - Radio
  - c. Settings
    - Home
    - Dialysis unit
    - Hospital
    - Other community providers
2. Assess patient’s perception of care and quality of life at initiation of dialysis with periodic re-evaluation and/or at the end of each treatment.

3. Develop qualitative assessment tool that is based in Story Theory.\*
4. Questions that could be asked by health care professionals include:
  - a. Tell me about the challenges you are facing as you begin dialysis.
  - b. What is most important to you right now?
  - c. Can you think of a past challenge or “difficult time” that you “got through”? Tell me about that time – what helped you get through it?
  - d. Tell me about your future hopes and dreams.
5. Questions that could be asked by the dialysis technician:
  - a. Can you tell me what is most important to you right now?
  - b. Is there anything I should know about you that you have not already told me?

BEST PRACTICE #2 PATIENT TOOLS AND RESOURCES	
<b>Audio/Video Pre-Recorded or Live Tools and Resources</b>	
<b>Patient Bulletin Boards and Podcasts, Support and Crisis Groups, KidneyTalk Podcast Radio Show, Written Materials, Videos</b>	Renal Support Network <a href="http://www.rsnHOPE.org">www.rsnHOPE.org</a>
<b>People Like Us: Coffee House Conversations</b> Live, telephonic and/or pre-recorded web-based	National Kidney Foundation <a href="http://www.kidney.org/coffeehouse/">www.kidney.org/coffeehouse/</a>
<b>Chronically Happy: Joyful Living</b> Author - Lori Hartwell, founder of RSN (audio and print)	Renal Support Network (RSN) <a href="http://www.rsnHOPE.org">www.rsnHOPE.org</a>
<b>Dialysis Information</b>	American Association of Kidney Patients (AAKP) <a href="http://www.AAKP.org/Dialysis-information">www.AAKP.org/Dialysis-information</a>
<b>Renalife</b> (patient magazine)	American Association of Kidney Patients (AAKP) <a href="http://www.aakp.org/newsletters/">www.aakp.org/newsletters/</a>
<b>Taking Control: Money Matters for People with Chronic Kidney Disease</b>	National Kidney Foundation <a href="http://www.kidney.org/patients/pfc/control.cfm">www.kidney.org/patients/pfc/control.cfm</a>
<b>Web-Based Tools and Resources</b>	
<b>Kidney School</b> 16 “live” self management modules; PDFs can be printed for patients without internet access	<a href="http://www.kidneyschool.org">www.kidneyschool.org</a>
<b>Patient Education about Home Dialysis, “Ask the Experts” Forums</b>	<a href="http://www.homedialysis.org">www.homedialysis.org</a>
<b>AAKP My Health</b> Web-based health record	American Association of Kidney Patients (AAKP) <a href="http://www.AAKP.org/my-health">www.AAKP.org/my-health</a>
<b>ESRD Patient Information</b>	DaVita <a href="http://www.davita.com/education/">www.davita.com/education/</a>
<b>Dialysis Information</b>	American Association of Kidney Patients (AAKP) <a href="http://www.AAKP.org/Dialysis-information">www.AAKP.org/Dialysis-information</a>

<b>KDQOL Complete</b> On-line quality of life survey tool	<a href="http://www.kdqol-complete.org">www.kdqol-complete.org</a> (purchase involved)
Booklets, podcasts, newsletters, Dialysis Answers, fact sheets are all available by downloading from this site	LifeOptions <a href="http://www.lifeoptions.org">www.lifeoptions.org</a>
List of resources, book on CD (purchase)	Dialysis Success <a href="http://www.dialysissuccess.com">www.dialysissuccess.com</a>
<b>Story Theory</b> (Liehr P. & Smith M.J. (2008) in M.J. Smith & P.R. Liehr (Eds.) <i>Middle Range Theory for Nursing, 2<sup>nd</sup> ed.</i> New York: Springer	<a href="http://www.amazon.com/Middle-Range-Theory-Nursing-Second/dp/0826119166/ref=sr_1_1?ie=UTF8&amp;s=books&amp;qid=1267216701&amp;sr=8-1">http://www.amazon.com/Middle-Range-Theory-Nursing-Second/dp/0826119166/ref=sr_1_1?ie=UTF8&amp;s=books&amp;qid=1267216701&amp;sr=8-1</a>
Hain D.J., Wands L.M., & Liehr P., <b>“Approaches used to resolve health challenges in a population of older adults undergoing hemodialysis,”</b> (in press),	<i>Research in Gerontological Nursing</i>
<b>Printed Tools and Resources</b>	
<b>A New “Normal”: Life on Dialysis – The First 90 Days</b>	National Kidney Foundation To order, follow the link or call 800.622.9010 <a href="http://www.kidney.org/professionals/KLS/anewnormal.cfm">www.kidney.org/professionals/KLS/anewnormal.cfm</a>
<b>Live &amp; Give Newsletter</b>	Renal Support Network <a href="http://www.rsnhope.org/newsletter/current_issue.php">http://www.rsnhope.org/newsletter/current_issue.php</a>
<b>Living Longer, Living Better</b> A heart healthy wellness program	National Kidney Foundation <a href="http://www.kidney.org/members/source/catalog/index.cfm?section=unknown&amp;task+3CATEGORY=P&amp;PRODUCT_TYPE+SALES&amp;SKU=12-10-2918">www.kidney.org/members/source/catalog/index.cfm?section=unknown&amp;task+3CATEGORY=P&amp;PRODUCT_TYPE+SALES&amp;SKU=12-10-2918</a>
<b>RightStart Patient Education Manual</b>	Fresenius Medical Care North America Resource Available for Fresenius Medicare Care patients only
<b>IMPACT Program</b>	DaVita, Inc. Resource Available for DaVita patients only
<b>Dialysis Answers</b> 1-2 page fact sheets for 0-3 months or 4 months+ on dialysis	LifeOptions <a href="http://www.lifeoptions.org/catalog/catalog.php?prodCat=pics">http://www.lifeoptions.org/catalog/catalog.php?prodCat=pics</a>
<b>Renalife (Patient Magazine)</b>	American Association of Kidney Patients (AAKP) <a href="http://www.aakp.org/newsletters/">www.aakp.org/newsletters/</a>
<b>Coping Effectively: A Guide for Patients and their Families</b>	National Kidney Foundation To order, follow the link or call 800.622.9010 <a href="http://www.kidney.org/atoz/atozcopy.cfm?pdfink=coping.pdf">http://www.kidney.org/atoz/atozcopy.cfm?pdfink=coping.pdf</a>
<b>Building Quality of Life: A Practical Guide to Renal Rehabilitation</b>	LifeOptions <a href="http://www.lifeoptions.org/catalog/catalog.php?prodCAT=booklets">www.lifeoptions.org/catalog/catalog.php?prodCAT=booklets</a>
<b>Satisfaction Surveys</b> Administered by dialysis organizations	