



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

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