



FAMILY “TOOLS OF ENGAGEMENT” BEST PRACTICE 4

BEST PRACTICE 4

Coach families, friends, and caregivers in the principles, techniques, and value of partnering with the patient and his or her inter-disciplinary health care team.

HOW DO YOU ACHIEVE THIS BEST PRACTICE?

- 1) Teach families and caregivers about the defining attributes of partnerships, including:
 - a) A genuine and trusting relationship
 - b) Honest and open communication and listening
 - c) Praise and encouragement
 - d) Reciprocity
 - e) Empathy
 - f) Respect for each other’s expertise
 - g) Working together with negotiation of goals, plans and boundaries
 - h) Participation and involvement
 - i) Support and advocacy
 - j) Willingness to share information
 - k) Commitment to “enable choice and equity” (Bidmead & Crowley, p.206)

- 2) Teach families and caregivers communication skills that allow them to effectively partner with the health care team and advocate for the patient. These skills include the ability to:
 - a) Negotiate
 - b) Share decisions
 - c) Collectively solve problems
 - d) Establish goals
 - e) Take action
 - f) Identify strengths and weaknesses
 - g) Clarify roles and responsibilities
 - h) Evaluate progress (refer to “New Health Partnerships” under Tools)

- 3) Help caregivers focus on coping skills and resources, including:
 - a) How to communicate with the patient
 - b) Where to find support services
 - c) How to be an advocate for the patient
 - d) How to recognize caregiver stress
 - e) The Importance of caring for self
 - f) How to develop individualized strategies to reduce stress

- 4) Teach families and caregivers how to optimize care-giving when they can't be there, including how to:
 - a) Assess the multi-faceted needs of the patient, from health care to living assistance
 - b) Develop a plan of care
 - c) Provide on-going support and education
 - d) Communicate with the healthcare team
 - e) Seek help from neighbors and friends
 - f) Use community resources for care
 - g) Seek out technologies that connect families to the patient and to health care providers (see Technologies under Tools)
 - h) Organize transportation, meals, recreation, etc.
 - i) Mobilize resources during an emergency
 - j) Choose professionals that specialize in Geriatrics
 - k) Manage documents, insurance, and legal matters
 - l) Care for themselves

- 5) Guide caregivers in partnering effectively with senior housing, home health care, assisted living, and nursing homes to ensure communication across all settings.

FAMILY ENGAGEMENT BEST PRACTICE 4: TOOLS AND RESOURCES

Web-Based Tools and Resources	
“Ask the Doctor”	National Kidney Foundation http://www.kidney.org/patients/Dr_SpryQ&A.cfm
Caregiving/Long-Distance Caregiving Resources	AARP http://assets.aarp.org/external_sites/caregiving/planAhead/long_distance_issues.html Long Distance Caregiving http://www.longdistancecaregiving.com/ National Family Caregiver Association http://www.nfcacares.org/caregiving_resources National Kidney Foundation http://www.kidney.org/patients/pfc/caregiver.cfm
Decreasing Patient-Provider Conflicts	National Forum of ESRD Networks http://esrdnetworks.org/special-projects/copy_of_decreasing-patient-provider-conflict-dpc
Emergency Patient Resources	Kidney Community Emergency Response Coalition http://www.kcercoalition.com/resources.htm
Health Literacy Information Translations	Ohio Health/Nationwide Children’s Hospital http://www.healthinfotranslations.org/
Partnering in Self-Management: A Toolkit for Clinicians	New Health Partnerships http://www.newhealthpartnerships.org
Partners in Care	Dialysis Patient Citizens http://www.dialysispatients.org/partners-in-care
SeniorHealth Videos	National Institutes of Health List of videos - http://nihseniorhealth.gov/videolist.html
Support/Education Network	Renal Support Network www.rsnhope.com
Your Dialysis Care Team	National Kidney Foundation http://www.kidney.org/atoz/content/dialcareteam.cfm

Printed Tools and Resources	
Caregiving/Long-Distance Caregiving Resources	<p>Caring from a Distance http://www.cfad.org/</p> <p>Family Caregiver Alliance http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2003_long_distance_handbook.pdf</p> <p>National Alliance for Caregiving http://www.nahu.org/consumer/MMISYCHiringIndependentCare07.pdf</p> <p>National Institute on Aging http://www.nia.nih.gov/So_Far_Away_FINAL707.pdf</p> <p>National Kidney Foundation Long-term Care Residence Chronic Kidney Disease Checklist</p> <p>Senior Housing Net http://www.seniorhousingnet.com/care-selection/glossary.aspx</p> <p>University of Missouri – Kansas City http://cas.umkc.edu/casww/ldcargvr.htm</p>
Telephonic, Audio, & Live Resources	
A Conversation with a Nurse (Podcast)	<p>Renal Support Network This program describes one nurse’s approach to taking time to listen to her patients, answer questions, resolve issues, and explain treatments. Play Now</p>
Patient Lifestyle Meetings	<p>Renal Support Network Hopeline - Call 1-800-579-1970</p>
People Like Us: Coffee House Conversations (Live, telephonic and/or pre-recorded web-based)	<p>National Kidney Foundation www.kidney.org/coffeehouse/</p>
Planning for Emergencies: A Guide for People with Chronic Kidney Disease	<p>National Kidney Foundation Call 1-800-622-9010</p>
Technologies to Connect Families to Patients and Providers	
Blogs/Forums/Social Networks	<p>DaVita, Inc. http://www.davita.com/forum/ http://www.davita.com/blogs/ http://www.kidneypostings.com/ http://kidneypostings.davitablogs.com/?p=99 (Caregiver Support)</p>

<p>eCommunication Technologies</p>	<p>MSN - http://windowlive.com/desktop/messenger</p> <p>Skype - http://www.skype.com/intl/en-us/home</p> <ul style="list-style-type: none"> BDP: UCSF partners with Skype to connect patients with family and friends - http://news.ucsf.edu/releases/UCSF-partners-with-Skype-to-connect-patients-with-family-friends/ <p>Vizuphone - http://www.vizuphone.com/</p> <ul style="list-style-type: none"> Best Demonstrated Practice (BDP), UC Davis Medical Center: Connecting pediatric patients and their families - http://www.ucdmc.ucdavis.edu/cht/services/telemedicine/family.html <p>Yahoo - http://messenger.yahoo.com/</p>
<p>Facebook</p>	<p>Davita on Facebook http://www.facebook.com/davitakidneycare?utm_source=davidadotcom&utm_medium=socialmedia_textlink&utm_campaign=facebook_fan</p> <p>People Like Us on Facebook - National Kidney Foundation http://www.facebook.com/home.php?#!/group.php?gid=417996565113</p> <p>Renal Support Network Facebook Page http://www.facebook.com/pages/Renal-Support-Network/174580037735?ref=ts</p>
<p>Home Dialysis Information</p>	<p>http://www.davita.com/home/</p> <p>http://www.ultracare-dialysis.com/engine/renderpage.asp?pid=s0015</p>
<p>Patient Travel Services and Resources</p>	<p>http://www.dialysisfinder.com/</p> <p>http://www.ultracare-dialysis.com/engine/renderpage.asp?pid=s0018</p> <p>http://www.davita.com/dialysis-travel/</p>
<p>Personal and Private Websites/Blogs for People and Families with Health Care Challenges</p>	<p>Caringbridge www.caringbridge.org</p> <p>CarePages http://www.carepages.com/search?search%5Bterms%5D=kidney</p>

<p>Twitter</p>	<p>DaVita on Twitter http://twitter.com/davita?utm_source=davitadotcom&utm_medium=socialmedia_textlink&utm_campaign=twitter_follow</p> <p>People Like Us on Twitter - National Kidney Foundation http://twitter.com/NKFPeopleLikeUs</p>
<p>Use of Personal Health Record (PHR) for Connecting Families w/ Patient's Health Information</p>	<p>Benefits of PHR http://healthit.ahrq.gov/portal/server.pt?CommunityID=666&spaceID=399&parentname=&control=SetCommunity&parentid=&PageID=0&space=CommunityPage&in_tx_query=Benefits+of+PHRs&Submit.x=19&Submit.y=10</p> <ul style="list-style-type: none"> • BDP: My PHRs help me care for two elderly family members - http://www.myphr.com/index.php/phr_success_stories/article/2196/
<p>Supporting Literature</p>	
<p>Bidmead C and Cowle, S. A concept analysis of partnership with clients. <i>J Community Pract.</i> 2005 78(6):203-208. http://www.ncbi.nlm.nih.gov/pubmed/15984559</p>	
<p>Wiggins M. The partnership care delivery model. <i>J Nurs Adm.</i> 2006 36(7/8):341-345. http://journals.lww.com/jonajournal/Abstract/2006/07000/The_Partnership_Care_Delivery_Model.2.aspx</p>	
<p>Wiggins M. The partnership care delivery model: An examination of the core concept and the need for a new model of care. <i>J Nurs Manag.</i> 2008 16:629-638. http://www3.interscience.wiley.com/journal/120087738/abstract</p>	
<p>Wooton R, et al. Home telehealth: Connecting care within the community. 2006. http://books.google.com/books?hl=en&lr=&id=ccRC6ykyKBYC&oi=fnd&pg=PR9&dq=connecting+patient+families&ots=WyM0PFXWgl&sig=pvgTIMfYyIfSkzZ1H0Q_skPQjIQ#v=onepage&q&f=false (Book available to purchase from site.)</p>	

All links last accessed on December 4, 2010