



Performance Excellence and  
Accountability in Kidney Care



## **FAMILY “TOOLS OF ENGAGEMENT”**

### **BEST PRACTICE 1**

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***Offer hope, courage, and support to families, friends, and caregivers in supporting their patient/family member toward health and wellness.***

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

1. Designate a family-engagement advocate (ideally a social worker) within the unit, who will:
  - a. Establish, with the family, the purpose of their involvement and their role in treatment
  - b. Foster respect and empathy for family members among the rest of the unit
  - c. Help the family to cope with the fear of losing a loved one or any other concerns
  - d. Connect the family with the unit dietician to learn about nutritious, renal-friendly meals
  - e. Seek to understand the family's past experiences, current situation, concerns, and strengths
2. Help staff recognize cultural diversity and provide care that considers individual cultural beliefs and preferences. (See forthcoming best practice on cultural diversity for additional information.)
3. Empower interested families to become leaders and advocates for patients through role-modeling, ongoing support, training, and advocacy.
4. Link families with peer-to-peer networks and resources, including telephonic, face-to-face (e.g., spousal support groups), printed, web-based, or multi-media domains.
5. Encourage hope by providing success stories and tools to help families communicate with providers.
6. Create strategies for the health care team that proactively encourage families to develop and sustain a positive attitude during the family member's course of treatment.
7. Promote spiritual well-being by making staff and families aware of community resources, such as faith-based and cultural organizations.
8. Explain facility visiting policies to the families of new patients (particularly those with children) to prevent infection and possible conflict between staff and family members.
9. Embrace family members as partners in the patient's care.
10. Respond to a family's need to be involved, understanding that the loss they are experiencing may be further complicated by issues like financial security or maintaining health insurance. Support their involvement in dealing with these issues.

## FAMILY ENGAGEMENT BEST PRACTICE 1: TOOLS AND RESOURCES

Web-Based Tools and Resources	
<b>Caregiver Survival Resources</b>	Today's Caregiver <a href="http://www.caregiver911.com">http://www.caregiver911.com</a>
<b>Caregiver Information/Advocacy</b>	National Family Caregivers Association <a href="http://www.nfcacares.org">www.nfcacares.org</a>
<b>Decreasing Patient-Provider Conflicts</b>	National Forum of ESRD Networks <a href="http://esrdnetworks.org/special-projects/copy_of_decreasing-patient-provider-conflict-dpc">http://esrdnetworks.org/special-projects/copy_of_decreasing-patient-provider-conflict-dpc</a>
<b>ESRD Patient Information</b>	Davita, Inc. <a href="http://www.davita.com/education">www.davita.com/education</a>
<b>KidneyTimes: Patient Stories</b>	Renal Support Network <a href="http://www.kidneytimes.com/subcatbrowse.php?Criteria=Hope&amp;subcat=Creative%20Studio">http://www.kidneytimes.com/subcatbrowse.php?Criteria=Hope&amp;subcat=Creative%20Studio</a>
<b>ESRD Network Forum</b>	National Forum of ESRD Networks <a href="http://www.esrdnetworks.org/">www.esrdnetworks.org/</a>
<b>Online Advocacy</b>	Dialysis Patient Citizens <a href="http://www.dialysispatients.org/advocacy">http://www.dialysispatients.org/advocacy</a>
<b>Partners in Care Online Membership Application</b>	Dialysis Patient Citizens <a href="http://www.dialysispatients.org/partners-in-care">http://www.dialysispatients.org/partners-in-care</a>
<b>Patient and Family Council</b>	National Kidney Foundation <a href="http://www.kidney.org/patients/pfc/index.cfm">http://www.kidney.org/patients/pfc/index.cfm</a>
<b>Patient and Family Council Message Boards</b>	National Kidney Foundation <a href="http://www.kidney.org/nkfmb/forums.cfm?conferenceid=DD4F2231-17A4-8D04-9499C70E025BB8C5">http://www.kidney.org/nkfmb/forums.cfm?conferenceid=DD4F2231-17A4-8D04-9499C70E025BB8C5</a>
<b>Spiritual Support</b>	Daily Strength <a href="http://www.dailystrength.org/c/Dialysis/support-group">http://www.dailystrength.org/c/Dialysis/support-group</a>
<b>Support Group for Patients with Polycystic Kidney Disease</b>	MDJunction <a href="http://www.mdjunction.com/polycystic-kidney-disease-">http://www.mdjunction.com/polycystic-kidney-disease-</a>
<b>Wellness for Caregivers</b>	<a href="http://www.caregiving.com/council-of-caregivers-tackles-your-conundums/">http://www.caregiving.com/council-of-caregivers-tackles-your-conundums/</a>
Printed Tools and Resources	
<b>Advocating for a Family Member</b>	Renal Support Network <a href="http://www.kidneytimes.com/article.php?id=20090730163148">http://www.kidneytimes.com/article.php?id=20090730163148</a>

<b>Chronically Happy: Joyful Living</b> (book; also available as audio)	By Lori Hartwell, Founder of Renal Support Network <a href="http://www.chronicallyhappy.com/">http://www.chronicallyhappy.com/</a> Call to order - 800-579-1970
<b>Hope, Sprinkled with a Generous Dose of Humor, is How My Husband Dealt with Kidney Failure</b>	Renal Support Network <a href="http://www.kidneytimes.com/article.php?id=20070207133752">http://www.kidneytimes.com/article.php?id=20070207133752</a>
<b>Living Well with Kidney Disease: A Resource for Patients and Their Families.</b>	National Kidney Foundation Order through link— <a href="http://www.kidney.org/site/504/book_order.cfm?ch=504">http://www.kidney.org/site/504/book_order.cfm?ch=504</a>
<b>Managing Stress: What Kidney Patients, Family Members, and Caregivers Need to Know</b>	Renal Support Network <a href="http://www.kidneytimes.com/article.php?id=20071015192333">http://www.kidneytimes.com/article.php?id=20071015192333</a>
<b>The Real Miracle of Family</b>	Renal Support Network <a href="http://www.kidneytimes.com/article.php?id=20070703190330">http://www.kidneytimes.com/article.php?id=20070703190330</a>
<b>Support Group Guidebook</b>	Association of Kidney Patients (AAKP) <a href="http://www.aakp.org/outreach/development/guide/index.cfm">http://www.aakp.org/outreach/development/guide/index.cfm</a>
<b>Telephonic, Audio, &amp; Video Resources</b>	
<b>Caregivers: Who Loves Ya, Baby?</b> A look at the importance of caregivers in patients' lives. Also presents key tips for caregivers to take care of themselves.	Renal Support Network (Podcast) <a href="#">Play Now</a>
<b>Communication Prescription for the Renal Care Professional</b>	Renal Support Network <a href="http://www.rsnhope.org/resources/comm_prescrip.php">www.rsnhope.org/resources/comm_prescrip.php</a>
<b>Chronically Happy: Joyful Living</b> (audio; also available in print)	Renal Support Network <a href="http://www.chronicallyhappy.com">http://www.chronicallyhappy.com</a>
<b>Family Focus</b>	National Kidney Foundation 800-622-9010
<b>Family Ties</b> (podcast)	Renal Support Network <a href="http://rsnhope.org/programs/kidneytalkshows/Martinlow_Spalding/index.php">http://rsnhope.org/programs/kidneytalkshows/Martinlow_Spalding/index.php</a>
<b>Hopeline</b>	Renal Support Network 800-579-1970

All links last accessed on August 19, 2010