



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

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

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

All links last accessed on August 19, 2010