



MY INFORMATION: RESOURCES

The following is a list of resources that may be useful to you in finding more information about the topics covered in **“My Life, My Choices: Knowledge Is Power” My Kidney Kit**. The “My General Resources” section is a great place to look for information about all aspects of living with chronic kidney disease. The other resources are listed according to the topic that was discussed in the **My Kidney Kit** and can be used to further assist you. There are many resources out there that are available to you, so this list does not include them all. These resources are a helpful starting point when searching for more information.

Name of Resource	Contact information
My General Resources	
American Association of Kidney Patients (AAKP) —A national non-profit organization founded by kidney patients for kidney patients, striving to educate and improve the health and well-being of chronic kidney disease (CKD) patients	www.aakp.org 1-800-749-2257
American Kidney Fund (AKF) —Mission is to fight kidney disease through direct financial support to patients, health education, and prevention efforts	www.kidneyfund.org 1-800-638-8299
Dialysis Patient Citizens (DPC) —An independent organization of patients and families, led by patients, who provide education and advocacy for people affected by kidney disease	www.dialysispatients.org 1-866-877-4242
Kidney Patient News —Provided by the Renal Network (ESRD Network 4, 9, 10) helping kidney patients achieve optimal wellness with information and updates on chronic kidney disease, treatment, renal diet, and quality of care	http://www.kidneypatientnews.org/index.php

For more information or to file a grievance please contact the Heartland Kidney Network at: Heartland Kidney Network • 7306 NW Tiffany Springs Pkwy. • Suite 230 • Kansas City, MO 64153
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<p>Kidney School—A free online education program including 16 interactive modules with printable PDFs, pre- and post quizzes, and audio book chapters</p>	<p>www.kidneyschool.org</p>
<p>Life Options—Free research-based education materials including printable booklets, fact sheets, tips, message boards, and links, as well as a Helpline to call and talk to experts about your questions</p>	<p>www.lifeoptions.org 1-800-468-7777</p>
<p>National Kidney Disease Education Program—Improving understanding, detection, and management of kidney disease through education</p>	<p>www.nkdep.nih.gov 1-866-4-KIDNEY (1-866-454-3639)</p>
<p>National Kidney Foundation—Multiple resources and education materials related to living with kidney disease; Local offices:</p>	<p>www.kidney.org</p>
<p>NKF Serving Kansas & W. Missouri Regional Office</p>	<p>Phone: (913) 262-1551 Toll Free: (800) 596-7943 E-mail: nkfkswmo@kidney.org Web Site: www.kidneyksmo.org</p>
<p>NKF Serving E. Missouri & Metro East</p>	<p>Phone: (314) 961-2828 Toll Free: (800) 489-9585 E-mail: nkfemo@kidney.org Web Site: www.kidneyemo.org</p>

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<p align="center">NKF Serving Minnesota, Dakotas & Iowa Division Office</p>	<p>Phone: (651) 636-7300 Toll Free: (800) 596-7943 E-mail: nkfmdi@kidney.org Web Site: www.nkfmdi.org</p>
<p>Renal Support Network—A patient-focused, patient-run organization that provides many resources including patient newsletters, podcasts, and the HOPEline Peer Support phone line which allows you to connect with another person who is living successfully with chronic kidney disease</p>	<p align="center">www.rsnhope.org HOPEline: 1-800-579-1970</p>
MY LIFE	
Coping with Dialysis	
<p>Depression (PDF)—A publication of the National Institute of Mental Health providing an overview of depression including different forms, signs and symptoms, treatment, and how you can help yourself if you are depressed</p>	<p align="center">http://www.nimh.nih.gov/health/publications/depression/depression-booklet.pdf</p>
<p>National Alliance on Mental Illness—Works across the country raising awareness and providing essential and free education, advocacy, and support group programs for those affected by mental illness</p>	<p align="center">www.nami.org 1-800-950-NAMI (6294)</p>
<p>National Institute of Mental Health—Website includes publications, health and education resources, and outreach information on mental health</p>	<p align="center">http://www.nimh.nih.gov</p>
<p>Talking to Your Family About Kidney Disease (fact sheet)—Resource provided by the Quality Insights Renal Network 3 website</p>	<p align="center">www.qirn3.org/Files/Education/October2012-(2).aspx</p>

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We're Here For You.

<p>The Depression and Bipolar Support Alliance—Created for and led by individuals with mood disorders, the DBSA mission is to provide hope, help, support, and education to improve the lives of people who have mood disorders</p>	<p>www.dbsalliance.org 1-800-826-3632</p>
<p>Healthy Lifestyle Choices</p>	
<p>Dining Out With Confidence: A Guide for Patients With Kidney Disease (PDF)— Created by the National Kidney Foundation, this guide gives ideas for making your dining experience fun—even with your special diet</p>	<p>http://www.kidney.org/atoz/pdf/diningout.pdf</p>
<p>Exercise: A Guide for the People on Dialysis (PDF)— Resource developed by the Life Options Rehabilitation Program</p>	<p>http://lifeoptions.org/catalog/pdfs/booklets/exercise.pdf</p>
<p>USDA National Nutrient Database—Find nutrient information for over 8,000 foods</p>	<p>www.ndb.nal.usda.gov</p>
<p>Occupation</p>	
<p>A Practical Guide for People with Disabilities Who Want to Go to College (PDF)—Resource provided by the Western Pacific Renal Network (Network 17) website</p>	<p>http://www.esrdnet17.org/Pt%20Services/voc%20rehab/Guide for People %20who want to go to college%20(2).pdf</p>
<p>Building Quality of Life: A Practical Guide to Renal Rehabilitation (PDF)— Developed by the Life Options Rehabilitation Program, this resource covers the “5 E’s” of renal rehabilitation: Encouragement, Education, Exercise, Employment, and Evaluation</p>	<p>http://lifeoptions.org/catalog/pdfs/booklets/qualoflife.pdf</p>
<p>Employment: A Kidney Patient’s Guide to Working and Paying for Treatment (PDF)—Resource developed by the Life Options Rehabilitation Program</p>	<p>http://lifeoptions.org/catalog/pdfs/booklets/employment.pdf</p>

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Missouri Kidney Program —Financial help for eligible Missouri residents	www.som.missouri.edu/mokp/PatientAssistance.htm
Vocational Rehabilitation Services —Help with training or finding a job, listed by state	See state by state below
Kansas:	www.dcf.ks.gov/services/RS/Pages/Employment-Services.aspx 1-888-369-4777
Missouri:	www.dese.mo.gov/vr/vocrehab.htm 1-877-222-8963
Nebraska:	www.vocrehab.state.ne.us 1-800-474-3382
Iowa:	www.ivrs.iowa.gov/ 1-800-532-1486
Working with Chronic Kidney Disease (PDF) —Resource created by the National Kidney Foundation	http://nkf.worksmartsuite.com/GetThumbnail.aspx?assetid=521
MY CHOICES	
Kidney Transplant	
American Organ Transplant Association (AOTA) —Helping patients since 1986 with free transportation to and from their transplant center, as well as provide transplantation resources	www.aotaonline.org

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<p>The Road to Receiving a Kidney Transplant (fact sheet, English/Spanish)—Resource provided by the Quality Insights Renal Network 3 website</p>	<p>www.qirn3.org/Files/Education/082011-2Transplant.aspx</p>
<p>Transplant Living—Everything related to transplant, from preparation to healthy living afterwards</p>	<p>http://transplantliving.org</p>
<p>United Network for Organ Sharing (UNOS)—A private, non-profit organization that manages the nation’s organ transplant system under contract with the federal government</p>	<p>www.unos.org Patient info: 1-888-894-6361</p>
<p>Peritoneal Dialysis</p>	
<p>Treatment Methods for Kidney Failure: Peritoneal Dialysis (PDF)— A publication by the National Institute of Diabetes and Digestive and Kidney Diseases</p>	<p>http://kidney.niddk.nih.gov/kudiseases/pubs/pdf/peritoneal.pdf</p>
<p>Self Cannulation</p>	
<p>Using the Buttonhole Technique for Your AV Fistula (brochure)—Resource provided by the Northwest Renal Network website</p>	<p>www.nwrenalnetwork.org/Fist1st/ButtonholeBrochureForPatients1.pdf</p>
<p>Types of Hemodialysis</p>	
<p>Home Dialysis Central—Everything you need to know about doing dialysis at home</p>	<p>www.homedialysis.org</p>
<p>Kidney Failure: Choosing a Treatment That’s Right for You (PDF)— A publication by the National Institute of Diabetes and Digestive and Kidney Diseases, NIH Publication No. 08-2412 November 2007</p>	<p>http://kidney.niddk.nih.gov/KUDiseases/pubs/choosingtreatment/choosingtreatment_508.pdf</p>

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What I Should Know about Fistulas	
Fistula First —Everything you need to know about an AV fistula including planning ahead, creating, and monitoring your AV fistula	www.fistulafirst.org/patients
Conquering Your Fistula Fear (fact sheet)—Resource provided by the Intermountain ESRD Network 15 website	www.esrdnet15.org/QI/FFconquer.pdf
MY TREATMENT	
Albumin	
Eat 6-9 Ounces of Protein Every Day (fact sheet)—Resource provided by the Intermountain ESRD Network 15 website	http://www.esrdnet15.org/images/magnet.pdf
Am I Getting Enough Dialysis	
Taking a Vacation from Treatment=Inadequate Dialysis (fact sheet)—Resource provided by the Intermountain ESRD Network 15 website	http://www.esrdnet15.org/Patient%20Resources/Vacation%20from%20tx.pdf
Anemia	
Understanding Anemia in Kidney Disease (PDF)—Resource provided by the American Association of Kidney Patients	http://www.aakp.org/library/attachments/Anemia%20Brochure.pdf
The Iron Story (PDF)—Resource provided by the American Association of Kidney Patients explaining how iron prevents anemia with patients with kidney disease	http://www.aakp.org/userfiles/file/the%20iron%20story.pdf

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Knowing My Lab Numbers	
Understanding High Phosphorus and Your Treatment Options (PDF) —Resource provided by the American Association of Kidney Patients	http://www.aakp.org/library/attachments/Understanding%20High%20Phosphorus.pdf
MY PLAN	
How Do I Control My Fluid Gains?	
Let's Talk About...Fluids (mini movie)—3 minute video to help patients understand why it is so important to manage fluids, provided by the Intermountain ESRD Network 15 website	http://www.esrdnet15.org/web_recording/mov3eng/mei_fluids_wb.swf
Pleasoning Gourmet Seasoning —Low-sodium seasonings that still have a lot of flavor	www.pleasoning.com
Quench gum —Chewing gum that helps get rid of thirst	www.quenchgum.com
Making My Wishes Known	
Caring Conversations —Workbook designed to guide you, your family, and your friends through the process of advance care planning	http://practicalbioethics.org/resources/caring-conversations.html

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End-Stage Renal Disease (ESRD) #12 Network Coordinating Council, Inc. dba Heartland Kidney Network. This resource was (created, developed, compiled, etc.) while under contract with Center for Medicare and Medicaid Services, Baltimore, Maryland.
Contract #HHSM-500-2010-NW012C. The contents presented do not necessarily reflect CMS policy.



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Medicare Part D	
Medicare.gov —The official U.S. government site for Medicare	www.medicare.gov 1-800-MEDICARE 1-800-633-4227
Partnership for Prescription Assistance —Database of drug assistance programs to help pay for medications	www.pparx.org
State Health Insurance Programs —Free counseling and one-on-one help with Medicare and other insurance concerns	MO: www.missouriclaim.org KS: www.aging.ks.gov/SHICK/SHICKIndex.htm NE: www.doi.ne.gov/shiip/ IA: www.shiip.state.ia.us/

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