



HEARTLAND HEADLINES

A Quarterly Newsletter for ESRD Patients

July 2009

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POINTS TO REMEMBER

Adequate Dialysis Means:

- *Getting to dialysis on time*
- *Staying for your full treatment*
- *Maintaining fluid balance*
- *Following your renal diet*
- *Taking your medications*

Symptoms of Inadequate Dialysis:

- *Tiredness*
- *Weakness*
- *Nausea*
- *Poor appetite*
- *Losing body weight*

Who is the Heartland Kidney Network?

Do you know who we are and what we do? Heartland Kidney Network is a nonprofit organization that contracts with Center for Medicaid & Medicare Services (CMS) for End Stage Renal Disease (ESRD). Heartland Kidney Network is part of a national system of ESRD Networks established by Congress in 1976 to help dialysis and kidney transplant centers achieve high standards of care for kidney patients.

Heartland Kidney Network focuses on the Six Aims from Institute of Management (IOM, 2001) and promotes the following goals of patient care:

- Patient Centered
- Effective
- Safe
- Efficient
- Equity
- Timeliness

Heartland Kidney Network's mission is to promote and facilitate high quality care standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri and Nebraska. We are able to fulfill our mission daily by assisting patients and facilities in the following areas:

What Can We Do For You?

Patient Services (PS): The team provides technical assistance to patients, family members, facility staff, and the community. This department handles patients' complaints and grievances, identifies educational needs, develops educational resources and hosts patient focused educational meetings to meet the needs of the renal community. Other ESRD related education such as rehabilitation, treatment options and transplant education is provided. This department also facilitates the Patient Advisory Committee, (PAC), which acts as an advisory group and helps to promote issues of patients' rights and responsibilities.

Quality Improvement (QI): The team helps your dialysis facility with continuous quality improvement (CQI) activities. This is done by providing education to the staff, monitoring your facility's quality outcomes, collecting data and examining trends. This department watches specific measures to ensure your facility delivers quality care.

Information Management (IM): The team works with your healthcare provider in the collection and filing of Medicare eligibility forms. The IM staff is responsible for supplying forms, providing instruction, editing data, entering data, and transmitting information to CMS while monitoring facilities for compliance.

How Can You Get Involved?

You can be involved with the Heartland Kidney Network Board of Directors, Medical Review Board, or the Patient Advisory Committee. Your participation would involve making recommendations regarding patient health care messages, educational materials, and other patient focused activities. You can also join a patient support group or organize a patient support group in your dialysis clinic. You would do this by sharing knowledge and experience to increase the likelihood that all patients will receive quality care and improve ones sense of caring and understanding. Please call the Network office at (800)-444-9965 for more information.

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

H1N1 Influenza Virus (Swine Flu)

According to the Centers for Disease Control and Prevention (CDC), outbreaks of the H1N1 Flu continue to spread across the United States. It is expected to spread to all 50 states and may take a while before it even slows down. At this time, it appears to be a mild illness and there have been suspected cases but no confirmed cases in dialysis.

It is important that individuals with chronic illnesses such as kidney disease, protect themselves from possible H1N1 Flu infection, as well as other types of flu.

People with chronic kidney disease (CKD) and kidney transplant recipients are high-risk groups for influenza infection. If you get sick you should not skip dialysis. Please be sure to call your doctor and/or dialysis provider. They will assist you in getting tested and treated for the virus.

If you become sick, you will need to limit your contact with others to keep from infecting them. To best protect yourself and others:

- Washing your hands often helps protect you from germs.
- Avoid close contact with people who are sick. When you are sick, keep your distance from others and protect them from getting sick as well.
- Remember to always cover your mouth and nose with a tissue or your sleeves when coughing or sneezing.
- Considering that germs often spread when a person touches something that is contaminated with germs and then touches his or her eyes, nose or mouth, avoid touching those areas.
- To help prevent the spread of your illness when you are sick, stay home from work, school and errands if possible.
- Practice other good health habits. Eat nutritious food, be physically active, manage your stress, and get plenty of sleep.



For more information regarding the H1N1 Flu, visit the websites listed below and talk to your treatment team at the dialysis unit.

- ◆ Centers for Disease Control (CDC) H1N1 flu information.
www.cdc.gov/h1n1flu
- ◆ Kidney Community Emergency Response (KCER). Coalition information specific to dialysis patients, including checklists and hotlines.
www.kcercoalition.org
- ◆ U.S. Government H1N1 Flu information.
www.pandemicflu.gov
- ◆ Heartland Kidney Network
www.heartlandkidney.org

The American Association of Kidney Patients (AAKP) is pleased to announce the 2009 Annual Convention will be held in Denver, Colorado September 3-5, 2009.

The official Annual Convention registration brochure is now available!

For questions about the AAKP Annual Convention, please call **(800) 749-AAKP**



aakp

Wondering How You Can Stay Active?

Have you thought about working, going to school, volunteering or taking part in a hobby? All these activities can improve your life and some cases, your health. Staying active can give you a sense of purpose and help keep your mind active as well as provide you with the support.

Most people have doubts and concerns about being able to work and/or return to work because they are not sure if they will lose their medical benefits, or they are afraid they may not have the energy they once had before starting dialysis.

Good News! There are government programs in place to allow you to test your ability to work. Some of these programs include:

- * Trial Work Period - for people on Social Security Disability Income (SSDI), you can receive your regular disability check for nine months regardless of how much you make as long as you report your work activity.
- * Plan to Achieve Self Support (PASS) - for those on supplemental Security Income (SSI), Social Security may allow you to keep some income and/or resources for a specified time for a work goal. For example, you can set aside money to pay expenses for education, job training, or start a business.
- * Medicare and Medicaid Coverage - for those on Medicare, you remain eligible as long as you are on dialysis and for a period of time after transplant. For people on Medicaid, you may be able to continue to receive your insurance benefits or possibly pay a small premium to keep it (it depends on which state you live in).

Options available to patients vary by state and situation. It is important that you understand the rules and your options before making any decision. Please talk to your dialysis or transplant Social Worker to help answer your questions and/or refer you to other rehabilitation programs. Remember, work is not an option for everyone. If you are unable to work, consider volunteering, going to school, or getting involved in a hobby. Remaining active is the key.

Source: This information was provided by www.lifeoptions.org

The Benefits of Volunteering

Most people on dialysis are no longer pursuing career opportunities. Some individuals long to work again but have found managing a job as well as dialysis to be simply too difficult and exhausting. Others may voluntarily remove themselves from the grind of the workday world, if financially feasible, in order to spend more time with family or attend to health issues. Many others are in retirement. Regardless of which reason applies, everyone whose employment has ended due to age, disability, or incompatibility with medical treatment regimens may face similar effects: the loss of feeling useful, lowered self-esteem, having too much time on one's hands, having fewer social outlets, loss of self-confidence, and perhaps depression. If this describes you or someone you know, please consider the benefits of volunteering.



Volunteering is when you give your time to help another person, group, or cause. There is a long list of possible advantages to those who volunteer. Author Allan Luks explores some of them in his book, *The Healing Power of Doing Good: The Health and Spiritual Benefits of Helping Others*. Some of the advantages he lists are:

- A more optimistic and happier outlook on life
- A heightened sense of well being
- An increase in energy
- A feeling of being healthy
- Decreased feelings of loneliness, depression, and helplessness
- A sense of connectedness with others
- A greater sense of calmness and relaxation
- An improvement in insomnia
- A stronger immune system
- A reduction in pain
- Speedier recovery from surgery

Volunteer activities also offer a meaningful way to interact in a world that may otherwise focus on the limits of people who are on dialysis instead of showcasing what they can do, not only for themselves, but also for others. Volunteering is a selfless way to “give back” and acknowledge one's own prosperities. It's a way to promote lifelong learning and also self-examination. Volunteering can add structure to one's daily life. Lastly, in some cases it's possible for a volunteer experience to result in a paid position. Whatever your motives, consider volunteering for the potential benefits it holds for you.

Source: Reprinted with permission from the ESRD Network 7.

Your Hemodialysis Vascular Access

There are two types of permanent access available. Arteriovenous Fistula (AVF) and Arteriovenous Graft (AVG). The AVF is created through a connection between your own artery and vein. It is considered the best vascular access because of the low rate of infections and its predictable performance (once it's matured.)

The AVG is created by implanting a synthetic material that forms the connection between your artery and vein. This access offers predictable performance without having to wait for it to mature. For this reason it can be used sooner than the AVF. Problems with the AVG include infections and clotting.

There is one temporary access available, the Central Venous Catheter (CVC). The CVC is a “Y” shaped catheter with the “Y” end used to connect to the blood lines of the dialysis machine. The other end, threaded through the jugular vein in your neck, rests in your heart. Part of the CVC is tunneled under the skin, leaving an exit site for the “Y” portion. This temporary access can be readily inserted and is often used for immediate, emergency treatment. The CVC does not provide predictable or reliable performance so there can be poor toxin removal (Low clearance). Other problems include higher infection and death rates than with either the AVF or AVG.

Since hemodialysis access failure is listed as the most frequent cause of hospitalization for patients on dialysis, CMS has included vascular access monitoring and surveillance requirements in the new Conditions for Coverage (federal regulations). Vascular access is one of the areas to be addressed in the patient's plan of care. The Interdisciplinary Team, of which the patient is a part, must provide monitoring and appropriate referrals to achieve and sustain vascular access. There needs to be a plan in place to address why a patient doesn't have a vascular access or has a catheter longer than 90 days.

Monitoring means someone physically examines your access starting at the incision site and following the veins as far as possible. This is done by looking at the access, feeling the entire length, and listening to the bruit.

Monitoring your vascular access is also your responsibility as a patient. You should know how it normally looks especially if there are lumps or bumps present. You should know how it feels for its entire length. You should know how and where to feel for the bruit. If you don't know how to do this, ask staff at your dialysis unit to show you.

For additional information on access options and caring for your access, contact the Network at our toll free patient number 1-800-444-9965.

Source: Reprinted with permission from the ESRD Network 5.

Dialysis Facility Compare

Did you know that there is a website that will give you information about Medicare-certified dialysis facilities? Did you know that you could use this information to assist you when choosing a dialysis facility? The website is called Dialysis Facility Compare. It is hosted by the Centers for Medicare & Medicaid Services (CMS) and provides characteristics as well as quality measures for each facility. Criteria is updated monthly and include the following:

- Address and phone number
- Date of initial Medicare certification
- Whether or not there are shifts starting after 5:00pm
- Number of treatment stations
- Types of dialysis offered (hemodialysis, peritoneal dialysis, home hemodialysis)
- Type of facility ownership (profit or nonprofit; corporate or independent)

We encourage you to utilize this information when you are planning transient treatments or a permanent move.

Visit: <http://esrdncc.org/index/information-for-esrd-patients>

"A Message from Your Patient Services Coordinator; Anne Karanja"

For those of you who are not aware, Heartland Kidney Network routinely provides patients educational meetings in select locations in Iowa, Kansas, Missouri and Nebraska. The first Modality Awareness Day was hosted in Kansas City, MO in May. The meeting provided patients with various dialysis treatment options available to you and how to select a treatment method of your choice. These meetings will provide you an opportunity to interact with other patients and also learn a lot of information relating to your care. Patients and family members have an opportunity to offer comments on their thoughts regarding the meeting as well. Heartland Kidney Network encourages you to attend and take advantage of the information. Details are provided to your Social Worker. Please check with him/her for the next meeting in your area.

It's Not All In Your Head

Living with Chronic Kidney Disease (CKD) touches nearly every aspect of a person's life. Unfortunately, CKD may place you at a greater risk of experiencing depression. Depression is very common. It affects nearly one in ten American adults each year (American Psychiatric Association, 2005). If you are on dialysis, those rates soar to between 20-30% (Cukor et al., 2006).

Depression is serious. If left untreated, it not only affects how you feel, but can also have an impact on your physical health, which can be fatal. Fortunately, depression is very treatable.

What Causes Depression?

Depression is not a sign of personal weakness. There are a number of factors that may lead to depression such as medical trauma or other traumatic life event; chronic stress; certain medications; changes in lifestyle; chemical imbalances in the brain; and continuous exposure to violence, neglect, abuse, and/or poverty.

Treatment and Prevention

Like many illnesses, patients can do things to prevent and treat depression.

- Take control - Learn about kidney disease and its treatment options. It is easier to cope with something if you understand it and feel more in control.
- Balance your thoughts - Positive thoughts and statements can influence your mood and physical health. Watch out for negative statements, such as "I never feel good." Statements such as these will put you at higher risk for depression and may negatively affect your health in other ways. Instead, use statements to purposely improve your mood and health, such as "I do have good days." You may want to make a list of positive statements and post them where you can see them. It may help to repeat the statements out loud. This exercise may seem silly at first, but it has been shown to help.
- Keep working or consider volunteering - It has been found that dialysis patients who work or volunteer often feel better and have fewer problems with depression.
- Consider your treatment options - Does your current treatment

fit your lifestyle and needs? Would home dialysis work better for you?

- Avoid drugs and alcohol - While you may feel better initially, drug and alcohol use will ultimately make you feel worse.
- Exercise - Physical activity releases natural chemicals that improve your energy level and overall mood.
- Accept the support of family and friends - Let your friends and family support you. Many people hide their coping problems and depression out of shame. If you ask for support, you will likely receive it. Make specific requests so that others know what you need from them. (Example: "I have been staying in bed every morning; can we meet on Friday mornings for coffee so that I have a reason to get out of bed?")
- Take time for yourself - People often get very busy with appointments and treatments. It is important for you to find time to do the things you enjoy. This will give you the necessary energy and strength to cope with your kidney disease.
- Counseling - Coping with a chronic medical problem is very difficult. Living with it every day can impact you in many ways. Counselors may be able to offer support by finding new ways of coping. There are many different kinds of counselors. Talk with your doctor and/or social worker if you need a referral.
- Medication - Antidepressants help restore the natural balance of chemicals (called neurotransmitters) in the brain. These chemicals affect a person's mood. Antidepressants are not addictive or habit-forming and they do not produce a "high." Contrary to popular belief, antidepressants will not change your personality. People usually start to feel better in 2-6 weeks. Side effects are usually mild, but care should be taken when starting any new medication. You should ask your doctor what to expect and what to do if you should experience any side effects.
- Ask to speak with your social worker - Your Social Worker will help you figure out if you are experiencing depression, and may suggest treatments you may not be aware of.
- Tell your doctor about your symptoms - Your doctor will want to rule out other medical problems and may refer you to a specialist or recommend medication.

Source: Reprinted with permission from Aaron Herold, LICSW - Patient Services Coordinator, ESRD Network 16

New Patients Welcome Booklet

New patients need to know a great deal of information on a variety of topics in a timely manner in order to reduce the stress caused by starting dialysis and worry about the unknown. The Network New Patient Welcome Booklet is a resource which provides new patients with a link to the Network at the start of their dialysis journey.

Please remember to let us know if this booklet was helpful to you by tearing and mailing back the "Tell Us What You Think" card. If you started dialysis and did not receive a copy of the Welcome Booklet, feel free to call the Network patient toll free line at (800)-444-9965 to request for a copy of the booklet. Be sure to update your mailing address with your facility staff whenever you move. This will help us keep an updated list for future mailings.

Questions/Comments?

Please contact: Anne Karanja, MPH,
Patient Services Coordinator, Heartland Kidney Network

Office Tel: 816-880-1709

Email: akaranja@nw12.esrd.net

Patient Services

Toll Free: 1-800-444-9965

Kidney Transplantation: Frequently Asked Questions

Considering whether or not kidney transplantation is right for you is a very personal decision that patients and their families must consider carefully. There are many members of your local healthcare team that can support you through the decision making process. Once you've decided to pursue renal transplant as a treatment for your kidney failure, your transplant team will join your local healthcare team in providing additional support specific to transplant. The following are commonly asked questions and answers you might consider as you pursue transplantation:

- 1. Does my insurance require a "special" referral for me to be evaluated for a kidney transplant?** Some insurance DOES require your Nephrologist to obtain a referral BEFORE any appointments for evaluation are made. Check with your insurance directly or speak with someone at your employer's Human Resources office.
- 2. Can I choose which transplant center I go to?** Yes, unless your insurance requires your transplant evaluation and surgery occur at a particular center. Again, it's important to contact your insurance company directly or speak to a representative in your HR department about the specifics of your coverage. Some insurance companies will assign you a special transplant case manager and this individual can be very helpful in addressing these and other transplant related insurance issues.
- 3. When will my medical records be sent to the transplant center for review and consideration for evaluation?** How long before I know whether or not I can be evaluated? Your Nephrologist and dialysis staff can tell you the status of the "paperwork" that goes to the transplant center. They also have experience with the various transplant centers in your area and can give you a reasonable estimate of when you might know something. They can also provide you with a contact at the transplant center if you want to personally confirm your paperwork was received.
- 4. Are there educational opportunities I can access before beginning the transplant medical evaluation?** Your dialysis staff, social worker and Nephrologist can help provide you with a variety of resources about transplantation. The transplant center you have been referred to also has resources such as written material, videos and or patient classes to help you through the learning process. There's lots of information to be learned, and no one expects patients to learn it all at once. If you obtain information from the internet it is wise to carefully consider the source. If in doubt, the dialysis staff, Nephrologist and transplant center can verify sources for you.
- 5. What is the time frame to complete the transplant evaluation for a patient with a diagnosis similar to mine?** Your transplant center will be able to provide an overview of what you might expect during your evaluation, including the actual testing to be done and the implications of various results, i.e. whether additional testing required, what would exclude you as a recipient, etc.
- 6. When will I know my evaluation testing is complete and what the outcome is?** Your transplant center will have the final word on when your evaluation is complete and whether or not you have been cleared to proceed with transplant surgery or listing for a deceased donor transplant.
- 7. If I have possible donors how and when can they find out if they can donate to me?** The live donor evaluation process begins with identifying those individuals who are willing to consider donation. Very basic requirements include that they be in good overall health and of a compatible blood type. Your transplant center will provide potential donors with detailed information about the donor evaluation and donor surgery. A separate healthcare team will care for the potential donor throughout the process.
- 8. If I do not have a live donor and have to be on the waiting list for a deceased donor is there anything I should know while waiting?** Stay in contact with your transplant center on a regular basis. Let them know if you have any changes in your health, undergo surgeries, have a change in type of dialysis your receiving, change in insurance coverage or change in your contact information.
- 9. How long is the transplant evaluation good for?** Does it ever expire? Evaluations or portions of it are typically good for a year to eighteen months. The evaluation will need to be updated periodically based on your current medical diagnosis and any new medical issues that may arise. When and how your evaluation will be updated may also depend on recommendations from the transplant team and your local Nephrologist.
- 10. Do I have to have a transplant just because that's what everyone says I should do?** No, the final decision to proceed with transplant is a choice you have to make for yourself. It is a treatment just as dialysis is a treatment and has the potential for good outcomes, as experienced by many who choose transplant. There are also risks that must be considered carefully. Your Nephrologist, dialysis staff and the transplant center will support you regardless of the decision you make.

The medical evaluation and general process leading to transplant is very similar between adults and children. Developmental, cognitive, growth and nutritional considerations along with the psycho-social impact for families can be the most challenging for this patient group. Children with renal disease require active involvement across various interdisciplinary care providers.

Source: Reprinted with permission by Lynn W. McCoy RN, CNN, Pediatric Nephrology Care Coordinator, ESRD Network 6

Complaint and Grievance Process

Under the Federal Medicare Law, End Stage Renal Disease (ESRD) Networks are authorized to implement procedures for evaluating and resolving patient complaints and/or grievances about the quality or adequacy of the care you receive in your dialysis facility. In Iowa, Kansas, Missouri and Nebraska, your ESRD Network is:

Heartland Kidney Network
7505 NW Tiffany Springs Pkwy, Suite 230
Kansas City, Missouri
Telephone: (816) 880-9990 Fax :(816) 880-9088
Patient Toll Free Number (800) 444-9965
www.heartlandkidney.org

If you have a complaint or grievance about the quality or adequacy of care you are receiving, your *first step* should be to discuss your problem with your physician, nurse or facility administrator. Such discussions with your caregivers may resolve your concern.

If such discussion does not address your problem, the Network can assist you in resolving your complaint or grievance by providing an impartial review. However, you have the right to file a formal grievance with the Network as the first step if necessary.

Should you need more information about how the Network complaint and grievance process works, talk with your Social Worker and review the grievance poster at your facility provided by the Network. Feel free to call the Network at (800) 444-9965.

Patient Safety Tips to Help Prevent Medication Errors

Medical errors happen when something that was planned as part of medical care does not work out, or when the wrong plan was used in the first place. Errors can occur when doctors and their patients have problems communicating. As a patient, what can you do?

- Be involved with your health care. Take part in every decision about your health care for better results.
- Make sure that all of your doctors know about every medication you are taking.
- Make sure your doctor knows about any allergies and adverse reactions you have had to medicines.
- When your doctor writes you a prescription, make sure you can read it.
- Ask for information about your medicines in terms you can understand-both when your medicines are prescribed and when you receive them.
- When you pick your medicine from the pharmacy, make sure you ask any questions you might have about the directions on your medicine labels.
- Ask for written information about the side effects your medicine could cause.

A Federal Report on medical errors can be accessed online at <http://www.ahrg.gov/gual/errorsix.htm> Internet Citation: 20 Tips to help Prevent Medical Errors. Patient Fact Sheet. AHRQ Publication NO. 00-po38, February 2000. Agency of Healthcare Research and Quality, Rockville, MD.

Calendar of Upcoming Events

IOWA

- July 12, 2009 Renal Support Network .Davenport Patient Lifestyle Meeting. Davenport, IA. For more information call (866)-903-1728 or visit RSNhope.org

MISSOURI

- July 11-12, 2009, September 12-13, 2009 and November 7-8, 2009: Missouri Kidney Program/Patient Educational Classes in Kansas City. For more information, contact Beth Witten, Coordinator at (913) 642-0269, toll free (888) 642-0269 or email: beth@wittenllc.com
- October 24, 2009: National Kidney Foundation of Kansas and Western Missouri will host the 2009 Kidney Walk in Independence, MO. For more information contact Molly Kennedy at (913) 262-1551 or email molly.kennedy@kidney.org
- September 12 & 13, 2009, December 12-13, 2009: Missouri Kidney Program Center for Chronic Kidney Disease will offer Patient Educational classes in Springfield, MO. For more information, contact Valerie Goodnight, Coordinator at (417) 882-0474 or email: goodnightv@health.missouri.edu

NEBRASKA

- October 3, 2009: The National Kidney Foundation of Nebraska wil host a KEEP Screening in Omaha, NE. For more information call (402) 613-8458.

OTHER EVENTS

- Coffee House Conversations. National Kidney Foundation. FREE monthly interactive telephone discussions. For more information email CoffeeHouse@Kidney.org
- September 3-5, 2009. Annual Convention hosted by The American Association of Kidney Patients (AAKP) in Denver, Colorado. For questions call (800) 749-AAKP or email: info@aakp.org
- The American Association of Kidney Patients (AAKP) hosts FREE Health Line patient educational conference calls. For dates and to register for upcoming events, call (800) 749-AAKP.