



HEARTLAND HEADLINES

A Quarterly Newsletter for ESRD Patients

DECEMBER 2008

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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*

Your Rights And Responsibilities in the ESRD Environment

As a dialysis patient, knowing your rights and responsibilities is an important part of your care. Observing them will contribute to more effective care and greater satisfaction for you and your health care team. Federal law CFR (494.70) protects your rights as an End Stage Renal Disease (ESRD) patient. Please take time to review them and make yourself familiar with every right and responsibility. You have the right and responsibility to the following:

You Have a Right To

1. Respect, dignity, and recognition of his or her individuality and personal needs, and sensitivity to his or her psychological needs and ability to cope with ESRD.
2. Receive all information in a way that he or she can understand.
3. Privacy and confidentiality in all aspects of treatment.
4. Privacy and confidentiality in personal medical records.
5. Be informed about and participate, if desired, in all aspects of his or her care, and be informed of the right to refuse treatment, to discontinue treatment, and to refuse to participate in experimental research.
6. Be informed about his or her right to execute advance directives, and facility's policy regarding advance directives.
7. Be informed about all treatment modalities and settings, including but not limited to, transplantation, home dialysis modalities (home hemodialysis, intermittent peritoneal dialysis, continuous ambulatory peritoneal dialysis, continuous cycling peritoneal dialysis), and in facility hemodialysis. The patient has the right to receive resource information for dialysis modalities not offered by the facility, including information about alternative scheduling options for working patients.

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

Your Rights Continued...

8. Be informed of facility policies regarding patient care, including, but not limited to, isolation of patients.
9. Be informed of facility policies regarding the reuse of dialysis supplies, including hemodialyzers.
10. Be informed by the physician, nurse practitioner, clinical nurse specialist, or physician's assistant treating the patient for ESRD of his or her own medical status as documented in the patient's medical record, unless the medical record contains a documented contraindication.
11. Be informed of services available in the facility and charges for services not covered under Medicare.
12. Receive the necessary services outlined in the patient plan of care described in §494.90.
13. Be informed of the rules and expectations of the facility regarding patient conduct and responsibilities.
14. Informed of the facility's internal grievance process.
15. Be informed of external grievance mechanisms and processes, including how to contact the ESRD Network and the State survey agency.
16. Be informed of his or her right to file internal grievance or external grievances or both without reprisal or denial of services.
17. Be informed that he or she may file internal or external grievances, personally, anonymously or through a representative of the patient's choosing.

It Is Your Responsibility

1. To be informed through learning as much as you can about your kidney disease and how it is treated and talk to your health care team about your concerns regarding your treatment.

2. To plan and follow a treatment program and find out about other services and referral recommended by your health care team.
3. To be on time for your scheduled dialysis and tell the dialysis facility ahead of time if you are unable to attend your next treatment date.
4. To follow facility policies and procedures that have been developed to provide safety and quality of care to all patients.
5. To be considerate and treat other patients and staff members with respect, dignity and consideration without threatening others, acting in a violent manner or cause physical harm.
6. To fulfill your financial obligations by making every effort to pay your bills, obtain Medicare Part B coverage or co-insurance through a private carrier and keep your facility informed.

The Basics of Medicare Prescription Coverage

What is Medicare prescription drug coverage?

Medicare prescription drug coverage is insurance that covers both brand-name and generic prescription drugs at participating pharmacies in your area. Medicare prescription drug coverage provides protection for people who have very high drug costs or from unexpected prescription drug bills in the future.

Who can get Medicare prescription drug coverage?

Everyone with Medicare is eligible for this coverage, regardless of their income and resources, health status, or current prescription expenses.

When can I get Medicare drug coverage?

You may sign up when you first become eligible for Medicare (three months before the month you turn age 65 until three months after you turn age 65). If you get Medicare due to a disability, you can join from three months before and three months after your 25th month of cash disability payments. If you don't sign up when you are first eligible, you may pay a penalty. If you didn't join when you were first eligible, your next opportunity to join will be from November 15, 2008 to December 31, 2008.

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The Basics of Medicare Prescription Coverage continued

How does Medicare prescription drug coverage work?

Your decision about Medicare prescription drug coverage depends on the kind of health care coverage you have now. There are two ways you can join Medicare prescription drug coverage. You can join a Medicare prescription drug coverage plan or you can join a Medicare Advantage Plan or other Medicare Health Plan that offers drug coverage.

When you join, you will generally pay a monthly premium, which varies by plan, and a yearly deductible. You will also pay a part of the cost of your prescription, including copayment or coinsurance. Cost will vary depending on which drug plan you choose. If you have limited resource an income, and you qualify for extra help, you may not have to pay a premium deductible. You can apply or get more information about extra help by calling Social Security at 1-800-772-1213 (TTY- 1-800-325-0778) or visit their website at www.socialsecurity.gov

Why should I get Medicare prescription drug coverage?

The plan provides greater peace of mind by protecting you from unexpected drug expenses. For most people, joining now means protection from unexpected prescription drug bills in the future.

What if I have Limited income and resources?

There is extra help for people with limited income and resources. If you qualify for extra help, Medicare will pay for almost all of your prescription drug costs. You can apply or get more information about the extra help by calling Social Security at 1-800-772-1213 (TTY- 1-800-325-0778) or visit their website at www.socialsecurity.gov

Source: www.medicare.gov



Important Dates to note:

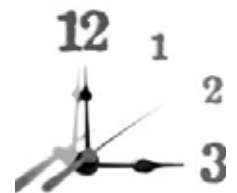
- October 1, 2008: Medicare Part D prescription Drug plan marketing Activities can begin-At this time you will gain information and evaluate the various Part D plan alternatives
- November 15 to December 31, 2008 Annual Coordinated Election Period- Here is a chance for you to join a Medicare Part D plan for 2009. If you already have a plan in place, it's time to decide whether to keep or change. There is no enrollment required to renew your present coverage.
- January 1 2009: Medicare Part D plan becomes effective and you will be able to start using your Part D benefits.
- January 1 to March 31, 2009: Coordinating Special Enrollment Period (SEP). This period is made available for those who enrolled into a Medicare Advantage Plan with prescription drug coverage (MA-PDs) and wish to dis-enroll back to the original Medicare coverage and prescription drug plan.

This information was obtained from www.medicarepartd.com

Are You Shortening Your Dialysis Treatment Time?

The hemodialysis treatments you are receiving replace only a small part (less than 15%) of the normal function of your kidneys. This is far below the 100% of normal kidney function. If you do not receive enough dialysis, your blood will retain too much of the body's waste products and you will always feel sick. If you are being under-dialyzed you can expect to experience many of the following symptoms:

- Feelings of weakness and tiredness all the time
- Loss of real weight
- Poor appetite
- Nausea
- Taste of ammonia in your mouth
- Yellow skin color
- Inflammation of the heart (Uremic pericarditis)



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also be placing yourself at higher risk for infection and prolonged bleeding. ON the other hand, most patients who are well dialyzed will experience the following:

- A sense of feeling good and feeling like dialysis is not necessary when the next treatment day arrives
- Good appetite with normal weight
- Reduction of yellow skin

You should recognize that your health depends on you receiving the right “dose” of treatment. This dose may include having a large enough dialyzer, a high enough blood flow, a well functioning vascular access and enough time on dialysis. There could be other factors



that may affect or interfere with your specific situation and prevent you from receiving the right dose of treatment. However, don't let shortening your dialysis time be one of these reasons.

It is easy to believe disconnecting from dialysis early a few times won't matter and to think, “It won't hurt me”. A request to shorten treatment becomes a habit, nor a one-time event. It may occur once a week, several times a month, or even with each session. Shortened dialysis time will eventually harm your body and you may experience the symptoms described earlier in this article. It puts additional stress on an already weakened body, and leads to a shorter life expectancy.

This is why your dialysis staff encourages you to remain on dialysis for your entire prescribed time, and why they remind you to arrive on time so that you can get your full dose of treatment. This is for your benefit, not that of your healthcare providers.

A well-dialyzed patient should be able to enjoy a lifestyle similar to the one lived before the renal disease occurred.

Source: This resource was reprinted from the ESRD Network 4 News.

This is a continuation of “ are you getting enough dialysis?”

Table showing the correlation between lost treatment time in minutes, hours, days and weeks. Based on three times a week dialysis treatments.

Reducing treatment by	Means lost time by week	And lost time by month	And lost time by year	It all adds up to weeks lost per year
5 Minutes	15 Minutes	65 Minutes (1 hour and 5 minutes)	780 Minutes (13 hours)	1 Week
10 Minutes	30 Minutes	130 Minutes (2 hours and 10 minutes)	1,560 Minutes (26 hours) (1 day and 2 hours)	2 Weeks
15 Minutes	45 Minutes	195 Minutes (3 hours and 15 minutes)	2,340 Minutes (39 hours) (1 day and 15 minutes)	3 Weeks
20 Minutes	60 Minutes (1 hour)	260 Minutes (4 hours and 20 minutes)	3,120 Minutes (52 hours) (2 days and 4 hours)	4 Weeks
25 Minutes	75 Minutes (1 hour and 15 minutes)	325 Minutes (5 hours and 25 minutes)	3,900 Minutes (65 hours) (2 days and 17 minutes)	7 Weeks
30 Minutes	90 Minutes (1 hour and 30 minutes)	390 Minutes (6 hours and 30 minutes)	4,680 Minutes (78 hours) (3 days and 6 hours)	8 Weeks

Be Informed about Immunization and Vaccinations

For the dialysis patient, receiving annual protection against influenza, pneumococcal disease and Hepatitis B is an important part of your healthcare. Infections are a major cause of death in end-stage renal disease (ESRD) patients, second only to cardiovascular disease, and also contribute to significant morbidity in patients with earlier stages of chronic kidney disease (CKD). Vaccines are a strategy to attempt to reduce morbidity related to infections. Despite the benefits, the current rates of immunizations for influenza, pneumococcal and hepatitis B immunizations are low. Some patients may say, "I've never had a flu shot in my life." The simple truth is that kidney disease places the dialysis patient and patients

with the earlier stages of CKD at a higher risk for infections. Flu season lasts from October to April. So if you have never had a flu shot, this year is the right time to start.



- It is important that dialysis and CKD patients discuss immunizations and vaccinations with their nephrologist.
- Make sure to find out the type of vaccine are recommended, when they should be given and at what dosage.
- Make an appointment and discuss how you can make vaccinations a routine part of your treatment plan.

This valuable resource can be found on the Web at:

http://www.cdc.gov/vaccines/pubs/downloads/b_dialysis_guide.pdf

Fistula First

What is a fistula?

Your body uses arteries and veins to carry the nutrients to your cells and the waste products away from your cells.

- Your surgeon will make a small opening in a vein and an artery.
- These openings will then be joined together during the operation.
- Over time the vein will get large enough for hemodialysis. The enlarged vein is called a Fistula.

How do you get the blood out of the fistula?

During your dialysis treatment two needles are inserted into this new blood vessel. One needle will take a small amount of your blood out of your body. This blood goes through the dialyzer. The other needle is used to put the blood Back into your body again. After each hemodialysis treatment, the needles are removed.

Do I need to do anything special to take care of this fistula?

- Avoid wearing anything tight on the limb that you have had your operation.
- You should not have a blood pressure taken or a blood test from the limb that you have had your operation.
- Check your blood access every day to make sure it is working and doesn't have an infection
- You may be asked to do some exercises to help your fistula grow.

What do I do to protect my Access?

- For safety reasons, your access needs to be visible at all times.
- Keep your vascular access clean.
- Learn how to take care of your access.
- If in doubt ask questions when staff cannulates your access.

What Does An AV Fistula Mean For You?

- Improved quality of life.
- Better dialysis treatment.
- Lower chance of death.
- Dramatically reduced chance of Infection.
- Fewer trips to the hospital.
- Most reliable and durable type of access.

Patient Advisory Committee

The Patient Advisory Committee is a group of patients from around the four Network state regions (Iowa, Kansas, Missouri, and Nebraska) who give feedback to the Network staff and the Medical Review Board about issues that affect the care and quality of patients. To see the complete list of PAC members and the regions they cover, please visit our website at www.heartlandkidney.org

The Heartland Kidney Network Patient Advisory Committee (PAC) has been working to empower our patients to become an active part of their healthcare team. The more involved you are with your care, the more freedom you gain and control over your care. The PAC members will be putting together a poster with the newly revised Center for Medicaid & Medicare Services (CMS) guidelines on Patients Rights and Responsibilities. This resource will be made available at your facility in December, 2008 and it will be in form of a poster. Please look out for it and be sure to familiarize yourself with your rights and responsibilities as a dialysis patient. Feel free to talk to your facility staff if you have any questions regarding your rights and responsibilities.

PLEASE MARK YOUR CALENDER

- **Kansas City, MO & KS**

Missouri Kidney Program / Patient Educational Classes on You can live a good life with kidney disease. For more information, contact Beth Witten, Coordinator at (913) 642-0269, toll free (888) 642-0269 or email: beth@wittenllc.com

January 24-25, 2009

May 16-17, 2009

March 7-8, 2009

July 11-12, 2009

- The National Kidney Foundation is offering a series of FREE monthly interactive telephone discussions called *Coffee House Conversations* "Your Safety on Dialysis Treatment: In-Center and at Home" for more information, please email: CoffeeHouse@Kidney.org

- **Springfield, MO**

Missouri Kidney Program Center for Chronic Kidney Disease is offering Patient Educational classes. For more information, contact Valerie Goodnight, Coordinator at (417) 882 0474, or email goodnightv@health.missouri.edu

March 21 & 22, 2009

September 12 & 13, 2009

June 20 & 21, 2009

December 12 & 13, 2009

- **Wichita, KS**

Heartland Kidney network to host Modality Awareness Day. February 22, 2009. For more information, contact Anne at (816) 880-9990, patient line (800) 444-9965 or email: akaranja@nw12.esrd.net

- 2009 NKF Serving KS & Western MO to host the Springfield Walk in May 30, 2009 at Phelps Grove Park. For more information, contact Keri Robinson at 417-881-8602 or email: keri.robinson@kidney.org
- January 1 2009: Medicare Part D plan becomes effective and you will be able to start using your Part D benefits. For more information go to www.medicarepartd.com
- January 1 to March 31, 2009: Coordinating Special Enrollment Period (SEP). This period is made available for those who enrolled into a Medicare Advantage Plan with prescription drug coverage (MA-PDs) and wish to dis-enroll back to the original Medicare coverage and prescription drug plan. For more information go to www.medicarepartd.com