

## Are You a Dialysis or Transplant Patient Who Lives in MI, MN, ND, SD, WI?

If you answered "yes" to this question, you should consider serving on the Renal Network 11 Consumer Committee. The Consumer Committee is made up of 13 ESRD consumers from the states of Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin. The members of this Committee help to support Network 11 in its mission to assess and improve the quality of care provided to individuals with End Stage Renal Disease (ESRD). The Consumer Committee provides input to the Executive Committee and Medical Review Committee, works on special projects, and helps to develop educational materials for ESRD patients. If you would like more details about serving on this important Committee, please call Renae Nelson at 1-800-973-3773.

### NKF News!!

Lunch and Learn—Saturday, November 15, 2008  
Patient/Family Education: Focal Segmental Glomerulosclerosis (FSGS) & Nephrotic Syndrome; Milwaukee, WI. Contact 1-866-NEPHCURE or email at [info@nephcure.org](mailto:info@nephcure.org).

## Medicare Prescription Drug Coverage

Click on to <http://www.medicare.gov/> to find information about Medicare Prescription Drug Coverage. To obtain general Medicare information, order booklets, and to learn about Medicare health plans, contact 1-800-MEDICARE (1-800-633-4227) 24 hours a day, 7 days a week for assistance. English and Spanish-speaking customer service representatives at this number can answer questions about the Original Medicare Plan and provide up-to-date information regarding the health plans available in your area.



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# Common

News and Information



# Concerns

For kidney patients and their families

## From the Committee Chair

Welcome to our fall edition of *Common Concerns*. This issue provides a summary of the Conditions for Coverage along with an article titled, "Ask the Pharmacist." We hope you find this newsletter informative and enjoyable.

Judith McLaughlin,  
Consumer Committee Chair

## New Conditions for Coverage Released by CMS

On April 15, 2008, the Centers for Medicare & Medicaid Services (CMS) published the long-awaited Conditions for Coverage (CfC) for end stage renal disease facilities. The CfC are the rules that dialysis facilities must abide by to qualify for Medicare Certification. These CfC replace the original rules that were published in 1976. Since 1976 there have been many advances and changes to the dialysis treatment process and to the methods used to evaluate the quality of care provided to dialysis patients. As a result, important changes have been made to the CfC.

The new CfC have been in development since the mid-1990's and have undergone a rigorous comment and review process by the renal community, including patient advocacy groups, since February 2005. Following are some of the important changes related to patient care.

### Patient Assessment and Care Planning

While the 1976 rules required a patient assessment and care planning process, the new CfC are more specific in defining this important process and its scope. The old regulations stated that patients should have input into the care planning process. Most dialysis units may have asked you to sign a care plan that had been developed for you. The new CfC are specific in stating that you, the dialysis patient, are a very important member of the care

planning team, and that you have the right to have a voice in your care. The dialysis team needs to make every effort to include you in the actual care planning process. Because of this clarification, you may now find that the dialysis staff invite you to attend the care planning meeting. You should make every effort to attend these meetings. Your input is vitally important.

### Expanded Assessments

The previous regulations required the dialysis team to do patient assessments, but they were not specific as to what needed to be included in that assessment. The new Conditions are much more specific as to what that assessment should contain and how often the patient should be assessed. For example, if you have been in the hospital, your health care team is likely to meet with you following your return, to assess whether or not changes need to be made to your care plan.

### Patient Care Technicians Training and Certification Now Required

Until now, there have been no specific federal rules regarding the training and certification for Patient Care Technicians (PCTs). The training has varied from dialysis unit to dialysis unit. Starting on October 14, 2008, federal regulations will require training and certification for all PCTs. Training includes classroom studies as well as practical skills. The new regulations clearly outline what needs to be in a PCT training program.

In addition to the formalized training, beginning October 14, 2008, all currently employed PCTs will have 18 months to become certified. This involves passing a national examination to demonstrate excellence in knowledge and skill level.

## Patient Rights

The former Conditions for Coverage outlined very specific rights for patients on dialysis. Those same patient rights are in the new Conditions and have been expanded. Network 11 is in the process of revising its patient rights document. The revised version will be distributed to all dialysis units, included in a future edition of *Common Concerns*, and posted at the Network 11 Web site. Your dialysis facility will be posting those patient rights along with information to assist you should you need to file a grievance with the facility, the State Survey Agency, or Network 11.

## Summary

The Centers for Medicare & Medicaid Services is committed to providing an oversight process that can help to assure that the care you receive in your dialysis unit is the best quality care available. These new regulations demonstrate that commitment. When you have concerns regarding your care, Network 11 encourages you to first talk with your health care team, but be assured that we are here to assist you as needed.

## Life as a Transplant Patient

by Ruth

I have been very fortunate to have had a successful kidney transplant for the last 27 years. Even though there have been other health problems along the way, my transplant has done very well over the years, and I still have good function. I feel that this has happened for several reasons.

I feel that I have been blessed to have received a kidney from my sister. Thankfully, she was an excellent match. Also, I am thankful to God for His blessings over the years in keeping my kidney strong. I know that many other patients have not had the good fortune that I have had and I am very grateful for His loving hand of protection on my kidney.

I also have tried to take all of my medications as prescribed each day. I have created a system whereby I take some medicines in the morning, at supper, and at bedtime. If I know that I will not be at home during supper time, I always bring my medications with me so that I can take them at the correct time. This takes a little planning, but it seems to work for me.

My doctors have all stressed that it is important to take your medications each day

as prescribed. I encourage all renal patients to work out a daily system for taking the medications prescribed by your doctors on a daily basis. You will benefit from this and will feel much better. Try it and see if it doesn't work for you too.

## Care Conference—It's All About You!

by Barbara

The care conference is your opportunity to meet with your physician, nurse, social worker, and dietician. It is the time for you and your family or caregiver to ask questions and get answers. Use it as an opportunity to improve your quality of life.

What questions should you ask? If the goal is to improve your quality of life, then start with that. What can I do to improve the outcome of my dialysis? Here are a few considerations:



- Review your detailed monthly lab report with your team and be sure that you understand the results and purpose of each test.
- Should any medications be adjusted? Be sure to understand the specific reasons for each change to medication or to dosage.
- What changes can be made to diet to improve nutrition, reduce excess fluid, or keep potassium and phosphorus under control, and how will that improve my dialysis results?
- What exercise can you recommend and how will it benefit me?
- What resources are available to assist with housing, finances, medication expenses, insurance? Your Social Worker can be an invaluable resource for these and any psycho-social needs you may have. Your Social Worker can assist with issues relating to vocational rehabilitation. Are you having trouble returning to work or to school? Don't be afraid to ask. Your Social Worker has access to many resources.

- Ask to have your dialysis machine settings explained to you. Do not be intimidated. This is very intricate and complicated information and will most likely take several conversations. You or your caregiver should understand that machine settings are unique to each patient and subtle changes can have an effect on how you feel.
- Be sure to ask about what can be done both with diet and with the dialysis machine to avoid cramps!
- What about modality? Do you understand your options? Have you had any discussions about the various home dialysis options vs. in-unit hemodialysis? Are you a candidate for transplant?
- Do you have an Advanced Directive? If you want to discuss end of life decisions, your care conference may be a good time to talk about this with your nephrologist and available team members.
- Do you notice any physical changes in your body? If you have questions about your medical condition, talk to your health care team.

Your team is there for you. Tell them of your concerns and do not feel rushed. Each subject is a complex issue unto itself. You deserve and are entitled to detailed explanations, non-rushed discussion and the time needed to absorb all that you learn.

Successful dialysis is a team effort. Take a moment to let your team know that you appreciate their expertise, concern and care.

## Ask the Pharmacist....Curt Johnson, D. Pharm

### **1. What is the difference between generic and brand name drugs? Is there ever a time when I should request a brand name drug over a generic drug?**

The first company to develop a NEW drug has patent protection for selling the product as a "brand" name drug. Upon expiration of the patent, other companies can produce an equivalent product and sell it as a generic substitute. All brand name and generic drugs must be approved by the FDA. In nearly all cases, an approved generic drug can be used in lieu of a brand name product, usually at a considerably lower cost. If a consumer is concerned about switching from one product to another, the prescriber or pharmacist is a good source of further information.

### **2. What does it mean when I see a listing of side effects for a particular medication?**

Pharmacists and prescribers should provide patients information regarding potential side effects of a drug. Drug manufacturers are required to provide side effect information to pharmacists and prescribers, and such information is readily available in books and on the Internet. Unfortunately, the amount of information can be almost overwhelming, leaving the patient with a need for some assistance in sorting through the often lengthy list of potential side effects. Once again, your pharmacist or prescriber are good sources of additional information to identify the side effects that are most likely to occur or that are potentially hazardous.

### **3. Are there dangers in mixing different medications? How can I prevent this from happening?**

Drugs can interact with each other and with non-prescription items such as natural or herbal products. Sometimes these interactions can be harmful. The most important thing you can do is to obtain your prescriptions from a single pharmacy so the pharmacist has a complete record of the medications you are taking. You can also minimize the risk of drug interactions by reporting all the medications, including over-the-counter products, you are taking every time you receive a new prescription. Some potential drug interactions can be safely managed, while others should be avoided.

### **4. Does it matter what time of day I take my medicines? Can I take my medicine with food?**

The answer to this question depends on the specific medicine you are taking. Some medications should be taken at specific times of the day; for others it does not matter. Some medications should be taken with food; others should be taken on an empty stomach. You should ask your pharmacist about how to take every prescription you have. Failure to take medications at the right times or with or without food may adversely impact the benefit of the treatment.

#### **Consumer Committee Tip of the Month**

*Check with your pharmacy to see if they offer any programs for discounted drugs.*