

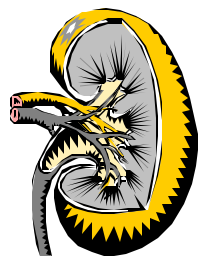
# ESRD Network # 12 Patient Newsletter

*Providing kidney patients and their families information on diet, health, and kidney disease.*

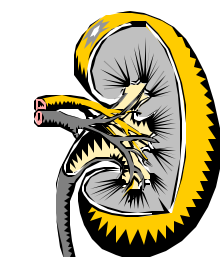
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## Weighing the Options



## Making the Choice

We are faced with complex choices every day. The following information is provided to assist you with informed choices about your healthcare. This newsletter will address patient safety, vocational rehabilitation, emergency preparations, and frequently asked questions.

There is a growing national interest in patient safety. Dialysis, both hemo and peritoneal, is a procedure that requires very specific technical skills and reliable performance of the same routine. The chances of a mistake being made increases the more often someone performs the same routine. Below are a few suggestions to consider to keep yourself safe while at the hospital or dialysis center:

- ☞ Ask questions of your healthcare team
- ☞ Seek more than one opinion
- ☞ Read information on your illness, options and treatment possibilities
- ☞ Keep a list of your current medications in your purse or wallet
- ☞ Write down your medical history, including allergies, diet, illnesses, type of dialysis access and recent hospitalizations
- ☞ Keep a list of your doctor's names and phone numbers in your purse or wallet

Nephron News is a patient centered newsletter distributed by Network #12 in accordance with the Centers for Medicare & Medicaid Services contract number 500-00-NW12. Network #12 proudly serves the renal community in Iowa, Nebraska, Missouri, and Kansas. Any questions regarding the newsletter, or suggestions for future topics may be forwarded to: Patient Services Department, 7505 NW Tiffany Springs Pkwy, Suite 230, Kansas City, MO 64153, or by calling 1-800-444-9965, Monday – Friday from 7 a.m. to 5 p.m.

☞ **Work with your doctor and other healthcare professionals as a team**

- ☞ Share up-to-date information with the team after hospitalizations
- ☞ Talk about concerns with your healthcare team
- ☞ If something doesn't seem right, point it out to your healthcare team.

☞ **Involve a friend or family member in your care**

- ☞ Ask family or friends to accompany you on appointments, take notes, or help you ask questions
- ☞ Family can assist you in communicating your preferences

☞ **Follow your doctor's directions**

- ☞ Ask for instructions in writing, ask for verbal explanations, and ask questions before you leave your appointment
- ☞ Take your medications *EXACTLY* as prescribed
- ☞ Report anything unusual to your doctor

The National Patient Safety Foundation provided the above information. For more information please write to: 515 North State Street, Chicago Illinois, 60610, or they can be reached @ 312-464-4848, or on the web at [www.npsf.org](http://www.npsf.org).



The following information was developed by Federal agencies in the Quality Interagency Coordination Task Force (QuIC) working with other health care purchasers and providers. The QuIC and its public-and private-sector partners are all working together to make the U.S. health care system safer for patients and the public. For more information please see <http://www.ahrq.gov/consumer/5steps.htm>

“Patient safety is one of the Nation’s most pressing health care challenges. A recent report by the Institute of Medicine estimates that as many as 44,000 to 98,000 people die in U.S. hospitals each year as the result of lapses in patient safety.”

<http://www.ahrq.gov/consumer/5steps.htm>

The following page lists five steps you can take to safer health care.

# 5 Steps to Safer Health Care

1. Speak up if you have questions or concerns. Choose a doctor who you feel comfortable talking to about your health and treatment. Take a relative or friend with you if this will help you ask questions and understand the answers. It's okay to ask questions and to expect answers you can understand.
2. Keep a list of all the medicines you take. Tell your doctor and pharmacist about the medicines that you take, including over-the-counter medicines such as aspirin, ibuprofen and dietary supplements like vitamins and herbals. Tell them about any drug allergies you have

Ask the pharmacist about side effects and what foods or other things to avoid while taking the medicine. When you get your medicine, read the label, including warnings. Make sure it is what your doctor ordered and you know how to use it. If the medicine looks different than you expected, ask the pharmacist about it.

3. Make sure you get the results of any test or procedure. Ask your doctor or nurse when and how you will get the results of tests or procedures. If you do not get them when expected – ask in person, on the phone, or in the mail – don't assume the results are fine. Call your doctor and ask for them. Ask what the results mean for your care.
4. Talk with your doctor and health care team about your options if you need hospital care. If you have more than one hospital to choose from, ask your doctor which one has the best care and results for your condition. Hospitals do a good job of treating a wide range of problems. However, for some procedures (such as heart bypass surgery), research shows results often are better at hospitals doing a lot of these procedures. Also, before you leave the hospital, be sure to ask about follow-up care, and be sure you understand the instructions.
5. Make sure you understand what will happen if you need surgery. Ask your doctor or surgeon: "Who will take charge of my care while I'm in the hospital, exactly what will you be doing, how long will it take, what will happen after the surgery, how can I expect to feel during recovery?"

# Vocational Rehabilitation

Every state has a Rehabilitation Council. Network #12 serves the ESRD Community in Iowa, Kansas, Missouri and Nebraska. For more information on vocational rehabilitation or if you are interested in returning to work, the social worker at your facility is an excellent resource for assisting you with this goal.

## **IOWA'S MISSION STATEMENT**

Our mission is to work for and with individuals with disabilities to achieve their employment, independence, and economic goals. Economic independence and more and better jobs are what we are about for Iowans with disabilities. To contact the Division of Vocational Rehabilitation in Iowa you may write to 510 E. 12th Street, Des Moines, IA 50319-0240 or call 515-281-4211. They can also be located on the web at: <http://www.dvrs.state.ia.us/>

## **KANSAS' MISSION AND VISION STATEMENT**

Our Mission: To protect children and promote adult self-sufficiency. Our Vision: Partnering to connect Kansans with supports and services to improve lives. To contact the Kansas Department of Social and Rehabilitation Services you may write to 915 SW Harrison Street, Topeka, KS 66612 or call 785-296-3959. They can also be located on the web at: <http://www.srskansas.org/>

## **MISSOURI'S MISSION AND VISION STATEMENT**

Making a positive difference through education and service. We provide leadership and promote excellence and promise to greatly exceed our customers' expectations. Vocational Rehabilitation 3024 W. Truman Blvd. Jefferson City, MO 65109-0525 573/751-3251 (voice) 573/751-0881 (TDD)

## **NEBRASKA'S MISSION AND GOAL STATEMENT**

Vocational Rehabilitation is an employment program for people with disabilities. We help people with disabilities make career plans, learn job skills, get and keep a job. Our goal is to prepare people for jobs where they can make a living wage and have access to medical insurance. To contact the Nebraska Department of Education-Vocational Rehabilitation you may call toll free 1-877-637-3422 (1-877-NE REHAB) or they can also be located on the web at <http://www.vocrehab.state.ne.us/>

# Emergency Preparations

The following excerpt is from the Medicare and You publication; a collaborative effort with Network 17, "Preparing for Emergencies: A Guide for People on Dialysis". For more information or to obtain a complete booklet, please call 1-800-444-9965 ext. 18.

This information has broad tips on how to prepare for an emergency if you have end stage renal disease. These tips will **not** work for every patient or in every emergency situation. You may have special health problems or face unique conditions that make a different answer better for you. Please contact your doctor for medical advice or treatment. **Do NOT rely on this guide for treatment or medical advice.**

## The 3-day Emergency Diet Plan

When dialysis is unavailable, your survival will depend on your ability to follow a limited diet. This information will help you prepare and manage an emergency diet plan. If you are able to communicate with your doctor at this time, he/she will be able to help you manage. If you are on CAPD and cannot get your supplies to do your exchanges, this plan will also apply to you.

The basis of this diet is 2 cups of fluid per 24 hours. The Northern California Council on Renal Nutrition developed the plan. It is stricter than the renal diet you normally follow to keep poisons from building up in your blood.

Bread/cereal.....	5-6 servings per day
Fruits/vegetables.....	2-4 servings per day
Meat/protein .....	3 ounces per day
Milk .....	½ cup per day
Fats.....	6 or more teaspoons per day
Sweets.....	as desired (except for diabetics)

Please speak with the Dietitian at your facility to determine the best emergency diet plan for you. Your healthcare team is the best resource for your individual needs and requirements as a patient.

# You Asked... We Answered

Q. Why does the doctor keep increasing the time I am on the dialysis machine?

A. The doctor, along with your healthcare team, attempts to remove toxins and fluid from your body during treatment. Sometimes patients gain weight, have access problems, or have decreasing urinary function. When these situations occur it can decrease the amount of toxins removed from your body. One way to increase the amount of toxins removed is to increase the amount of time you spend on dialysis.

Q. Why do I need a permanent vascular access?

A. A permanent vascular access (fistula or graft) has less chance of infection than a catheter. A fistula or graft allows more toxins and fluid to be removed during dialysis by increasing the flow of blood to the dialysis machine, and they have fewer long-term complications.

Q. Before I started dialysis I wasn't supposed to eat much meat, now that I am on dialysis everyone says "eat meat," "eat meat." Why?

A. Protein is needed to repair tissues and perform other body functions. To be used by the body, it first must be broken down. During protein breakdown, wastes – such as urea are produced. To keep urea from building up in your body, your healthcare team encouraged you to limit the amount of protein you were eating. Once dialysis was initiated, the artificial kidney removes urea from your bloodstream. Additionally, small amounts of albumin – a blood protein – are lost every treatment. Research has shown that patients live longer when their albumin level is adequate. For more information see - <http://www.scienceblog.com/community/article430.html>

Q. Why am I receiving iron during some treatments and not others?

A. Adequate amounts of iron are needed for you to have a stable blood count. Iron is both available and in storage in your body. Your healthcare team evaluates these levels and can determine if you need additional iron.

Q. How do I arrange dialysis if I want to go on vacation?

A. Speak with the Social Worker at your dialysis unit or you can visit the Dialysis Facility Compare website at <http://www.medicare.gov/Dialysis/Home.asp>. Once there, you can begin a dialysis facility search, select the state you would like to visit, then choose an option to search by - (city, county, entire state, etc.), select any or all of the units that are displayed and view their quality measures or facility characteristics.

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 CONSIDERATION  
 REQUEST  
 EVALUATES  
 PLANNING

Name \_\_\_\_\_ Facility Number \_\_\_\_\_

A request was made that the back of the puzzle be left blank, so when sent in, the newsletter remains complete.