

NETWORK NEWS

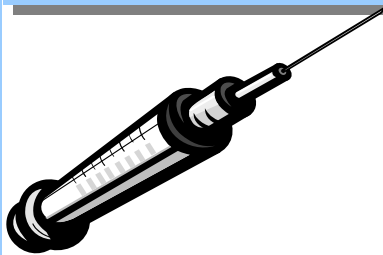
*Information For Northwest Renal Network
(ESRD Network 16)
Facilities and Providers*

4702 42nd Ave. SW
Seattle, WA 98116
(206) 923-0714
Fax: (206) 923-0716

**Alaska Idaho Montana
Oregon Washington
Spring 2007**



IMMUNIZATION INFORMATION



Maintaining high immunization rates for dialysis patients and staff will not only protect individuals in the clinic but also the community in general.

For Medicare patients, the costs of influenza and pneumococcal vaccines are covered when administered by certified providers. All dialysis clinics with a Medicare provider number are Medicare certified. Medicare beneficiary co-insurance or co-payment applies and the beneficiary does not have to meet his or her deductible to receive either vaccine. The co-insurance and yearly deductible does apply for Hepatitis B vaccination however.

For all persons 65 or older, and those with kidney disease, the Advisory Committee on Immunization Practice (ACIP) and other leading authorities recommended a lifetime vaccination against pneumococcal disease plus one booster five years later, and an annual vaccination against influenza. This advisory applies to all ESRD patients with no age limitations as they are an at risk group for influenza and pneumonia. The dialysis staff should also receive the influenza vaccine since they are in close contact with susceptible patients.

CMS has developed a variety of educational products and resources to help healthcare professionals and their staff become familiar with coding and reimbursement. For products to share with your patients visit www.medicare.gov and www.cdc.gov on the Web.

Northwest Renal Network would like to acknowledge the CMS Provider Communications Group and ESRD Networks 1, 5, 7 & 15 for information excerpted from their publications for this newsletter.

Inside this issue:

<i>Advance Care Planning</i>	2
<i>Helping Patients Understand Home Dialysis Options</i>	3
<i>Vocational Rehabilitation Assessment and Referral</i>	4
<i>Dialysis Facility Compare</i>	5
<i>E-Bulletin News</i>	5
<i>Beyond the Body (The Importance of Quality of Life Indicators)</i>	6
<i>Timely Assessment and Appropriate Transplant Referral</i>	7
<i>What's New at the Network?</i>	8
<i>Patient Advisory Committee</i>	8
<i>Network Contact Information</i>	8

INPUT IS WELCOME!

If you have suggestions for future topics to include in this newsletter, please contact Christie Hurley at churley@nw16.esrd.net (206) 923-0714

ADVANCE CARE PLANNING

Patients with kidney disease might consider preparing a legal document to guide loved ones, doctors and other healthcare professionals in providing treatment in a time of crisis. The **Patient Self-Determination Act** gives adults with the capacity to make medical decisions for themselves the right to make decisions today about health care treatment they would want to receive in the future if they could not communicate their wishes.

An advance directive is a legal document that directs physicians and health care providers how to carry out medical decisions made for future crisis care, even if the person cannot communicate these decisions themselves.

There are two basic types of advance directives (please review state specific laws at the link at the bottom of this page to determine which document is legally viable in your area):

- **Living Will:** Directs a physician or health care provider in writing what type of medical care an individual wants or does not want if he/she should become unable to make these decisions.
- **Durable Power of Attorney for Health Care Decisions or Health Care Proxy:** Allows the individual to name someone, such as a husband, wife, daughter, son or close friend, to act on his/her behalf if unable to make medical decisions. It is important that the individual asks their designee in advance if he/she is willing to represent them in this role and discusses their wishes regarding acceptable and unacceptable treatments, and short-and long-term goals and values.

Individuals are encouraged to discuss the following issues with a family member or a close friend.

1. What is the minimum quality of life acceptable?
2. Attitudes towards death and dying.
3. Importance of being independent and making own decisions.
4. Current health problems.
5. Religious beliefs that may affect the initiation of life-sustaining treatments.
6. If terminally ill with no hope of recovery, which life-sustaining treatments would you want to continue?
7. If severely and permanently brain damaged, would you want any life-sustaining treatments. If so, which ones?
8. If in a coma with no expectation of recovery, would you want any life-sustaining treatments? If so, which ones?
9. Will family and friends support your decisions?
10. Your views on Organ Donation.
11. Verify that the person you would like to speak for you if you were unable to do so is agreeable to doing so.

Additional tools and resources may be found at Kidney End-of-Life Coalition, www.kidneyeol.org; Partnership for Caring, www.partnershipforcaring.org; and American Bar Association, Commission on Legal Problems of the Elderly, www.abanet.org/elderly. State specific advance directive forms are available at the National Hospice and Palliative Care Organization web site, www.caringinfo.org.

HELPING PATIENTS UNDERSTAND HOME OPTIONS IN CHOOSING THE TREATMENT THAT'S RIGHT FOR THEM

By: Mary Dooley, MSW
Chronic Kidney Disease Educator
Northwest Kidney Centers

“How long will I live?” “How well will I live?” According to a survey by Life Options, these are the two foremost questions in our patients’ minds when they face dialysis. These questions are seldom directly addressed when we help patients make choices about treatment modality. There is now considerable evidence that home hemodialysis and peritoneal dialysis can provide patients with positive answers to these questions, with better quality of life and improved medical outcomes. Yet these options continue to be underutilized.

Of course, not every patient is a good home candidate. Patients need to be medically stable, be able to responsibly follow a treatment plan, have appropriate support at home if needed, adequate housing, and the physical ability to manage self-care (or a support person who can help).

In every center, on every shift, there are patients who meet these criteria, yet they never consider home dialysis. Why, and what can we do better?

Timely education. Patients who have predialysis education are more likely to choose a home modality. They have time to prepare and plan instead of responding to a crisis as so often happens.

Accurate and complete education. Many modality education materials focus on how a treatment works, not on long-term health benefits. Information such as improved survival with more frequent treatments on home hemodialysis or how peritoneal dialysis can save vessels for vascular access and preserve residual renal function is not always made available to patients.

Patient-centered education. Good modality education should not just be about making a

choice, but rather about life planning. What’s most important in the patient’s life? What does he or she want to be able to continue to do? How much does the patient value independence? When patients start thinking about how to keep working, how they can still enjoy travel and hobbies, how they can still be there for their families, they are more open to considering home modalities.

Acknowledge the challenge of increased responsibility. The nature of in-center hemodialysis makes a certain degree of dependence unavoidable. From a chair in the center, home dialysis can look pretty scary. The initial reaction is very often “no way”, and the conversation stops there. A prime example is self-cannulation for home hemodialysis, which many patients identify as the most significant barrier to choosing this option. Patients should be encouraged to put in their own needles at home if possible. If they have a dialysis helper, this makes that job less stressful, and more patients are now dialyzing with minimal assistance with new machines designed for self-care. Acknowledging that the patient’s fear of sticking a sharp object into oneself is normal and healthy, and while difficult it is not impossible to overcome, is a start. Other examples include fear of having a peritoneal catheter and body image concerns. Normalizing initial anxieties about self-care and offering support can be effective, as well as having them speak with other home patients for peer support.

At a recent conference, I asked a roomful of dialysis nurses, dietitians, and social workers if they would choose home dialysis, or dialysis in a center, if they needed treatment. Not a single person chose the center. Granted this was a different group than our typical patients, but *that* different? Apparently, we know something about how to live long and how to live well that our patients don’t know. Our challenge is to communicate it to them.

GUIDELINES FOR ASSESSMENT AND REFERRAL TO VOCATIONAL REHABILITATION



ESRD patients can and are encouraged to work. Dialysis patients are a unique population because of their constant changing health status. A patient might initially present

as healthy, but due to the disease process their health status can change quickly. This sometimes makes relationship building with Vocational Rehabilitation Services a challenge because patients might be hard to reach if they are in and out of the hospital. It is important to remember that this does not mean they do not or cannot work.

Sometimes finding a job, or staying in a job is difficult because of conflicting schedules due to dialysis. Patients can often benefit from vocational rehabilitation because they might need to explore new career venues.

Social work efforts to promote vocational rehabilitation are important interventions in trying to improve the social functioning of patients. These include providing patients with job retention strategies, or making referrals to job training, re-training, and employment counseling and placement services.

Vocational Rehabilitation Checklist

The following best practices checklist may be of assistance when discussing rehabilitation options with patients:

1. Upon admission meet with the patient and:
 - Encourage work retention
 - Educate about the benefits of employment
 - Engage in a discussion of personal rehabilitation goals, including but not limited to:
 - Vocational Rehabilitation programs
 - Activities that enhance independence and a higher quality of life
2. Provide patients with these tips about Vocational Rehabilitation (VR) services.
 - Offer to help with identified areas of need
 - Refer to resources as appropriate
 - Provide materials to aid in making important work, insurance and other lifestyle decisions
3. Patients who are already receiving SSDI or SSI may be referred to:
 - End Stage Renal Disease (ESRD) patients are eligible for VR counseling
 - VR can assist with training
 - VR offers help to individuals with keeping their current job
 - Be persistent with VR counselors
 - Inform the renal social worker if you need help
4. Prior to each Care Plan meeting, ask patients:
 - Social Security Administration (SSA) *Working While Disabled* information
 - www.ssa.gov/work/ticket/ticket-info.html/
 - www.ssa.gov/redbook/
 - Local vocational rehabilitation office
 - If they are satisfied with their current level of activity
 - If there have been any changes in their employment status
 - If they are interested in pursuing new education interests
 - If they need assistance with their rehabilitation goals

Continued on page 5

GUIDELINES TO ASSESSMENT AND REFERRAL TO VOCATIONAL REHABILITATION

Continued from page 4

5. Annually, per Network 16 Criteria & Standards:

- Evaluate each patient age 18 through 54 for VR referral and make available to patients the VR resources obtainable in the area
- Document VR status in the patient's medical record

RESOURCES

Alaska: 800-478-2815 (in-state use only) or 907-465-2814
www.labor.state.ak.us/dvr/disable.htm

Idaho: 208-334-3990
www.vr.idaho.gov

Montana: 877-296-1197 or 406-444-2590
www.dphhs.mt.gov/dsd/index.shtml

Oregon: 877-277-0513 or 503-945-5880
www.oregon.gov/DHS/vr/index.shtml

Washington: 800-637-5627 (V/TTY) or 360-725-3636.
www1.dshs.wa.gov/dvr.

Life Options Rehabilitation Program: Fact sheets about rehabilitation and other resources. www.lifeoptions.org.

Home Dialysis Central: Information about home treatment modalities to suit individual schedule needs and enhance quality of life. www.homedialysis.org

DIALYSIS FACILITY COMPARE

Dialysis Facility Compare (DFC) is a page on the Centers for Medicare and Medicaid Services (CMS) website. DFC allows patients to search for Medicare-approved dialysis facilities based on a city, state, or specific zip code. DFC provides data about dialysis facilities* including facility characteristics such as address and phone number, types of dialysis offered, facility ownership, whether a facility offers dialysis shifts after 5 pm, and number of dialysis treatment stations.

DFC also has information about quality measures such as:

- percent of patients with adequacy of hemodialysis—Urea Reduction Ratio of 65 or greater
- percent of patients that have anemia under control (having a hematocrit of 33 or greater)
- patient survival information

There are also links to other websites, publications available by downloading, a glossary of terms, a list of useful contacts, and a kidney disease dictionary.

***Note:** DFC attempts to include all Medicare-certified dialysis facilities; however, it may take several months for newly-approved facilities to appear on this site. Also, there are a few dialysis facilities operating without Medicare certification, and these facilities are NOT listed.

KEEP AN  OUT FOR IMPORTANT E-BULLETINS FROM THE NETWORK WITH HELPFUL PATIENT INFORMATION, CLINICAL TOOLS, AND RESOURCES! Please contact us for details and to be added to our list.

BEYOND THE BODY (The Importance of Quality of Life Indicators)

Healthcare providers pay a great deal of attention to the impact of clinical indicators such as albumin and hemoglobin on the physical well being of patients. Unfortunately, less attention has historically been given to Quality of Life (QOL) indicators.

A number of clinical studies have illustrated a strong association with low QOL scores and higher risk of death and hospitalizations. Many quality of life measures have been used with renal patients including the Kidney Disease Quality of Life Instrument (KDQOL – SF). The KDQOL-SF attempts to specifically assess the quality of life in renal disease patients.

Regardless of the instrument, it is important that healthcare providers attempt to measure the QOL of their patients as it directly affects their physical health. Once measuring QOL, providers should be able to identify those patients at higher risk and provide focused interventions.

The Health and Human Services Agency for Healthcare Research and Quality (AHRQ) has made available their CAHPS (Consumer Assessment of Healthcare Providers and Systems) consumer satisfaction survey for in-center hemodialysis patients, in both English and Spanish. These tools are used to uncover opportunities for quality improvement and can be utilized to further assess quality of life indicators. The surveys can be downloaded, along with protocols, guidelines, sample materials for administering them, data analysis programs and reporting measures. See: www.cahps.ahrq.gov/cahpskit/ICH/ICHChooseQX.asp.

In addition, the Internet links below provide information about QOL indicators and instruments.

The KDQOL Working Group
<http://www.gim.med.ucla.edu/kdqol/index.htm>

Online Discussion Group Regarding the Use of SF Tools in Clinical Trials
<http://www.sf-36.org/cgi-bin/discuss/subject.cgi?sid=2>

Network 9/10 Summary on KDQOL
<http://www.therenalnetwork.org/QualityImprovement/kdqol.html>

American Thoracic Society
<http://www.atsqol.org/sections/instruments/ae/index.html>



TIMELY ASSESSMENT AND APPROPRIATE TRANSPLANT REFERRAL

The following guidelines may be of assistance in order to facilitate the referral and evaluation of patients for consideration as candidates for kidney transplantation.

- Kidney transplantation requires teamwork and communication throughout the process, from initial referral to long term care of the transplanted kidney. The primary nephrologist, the patient, the dialysis social worker, the dietitian and the charge nurse all should work together to provide optimal quality of life for the patient.
- Individuals considered candidates for transplantation may be referred by their primary care nephrologist, dialysis unit, or by self-referral.
- Once the referral is made, follow-up of transplantation evaluation and waiting list status should occur as part of the short-term plan process.
- Dialysis facilities should respond promptly to all requests by the transplant organization for medical records or other referral information, if the patient has signed appropriate authorization for release of records.
- Each transplant center has guidelines for selection of appropriate candidates. Though each case is evaluated individually, transplant centers assess for the following: cancer, heart disease, acquired immune deficiency syndrome, hepatitis B, hepatitis C, other chronic diseases, the patient's weight, and level of compliance with medication or therapy.
- Patient evaluation from time-to-time will result in the discovery of a medical or surgical condition, which requires correction prior to the elective transplant procedure. The transplant center will consult with the patient and the primary care physician on how to intervene.
- Once the patient is accepted as a transplant candidate, histocompatibility tests will be performed by the transplant center. Family members and others available for living donor consideration will also have histocompatibility testing performed.
- Dialysis facilities can, as part of their treatment planning, assist kidney transplant candidates with factors that might affect their eligibility for transplant. These might include addressing severe obesity, reinforcing adherence to prescribed medication or therapy, and addressing social/emotional/financial factors related to ability to function after transplant.
- There is a national shortage of deceased donor organs. In spite of increased efforts for organ retrieval and expanding acceptance guidelines, the number of patients waiting for deceased donor kidneys continues to grow. Living related kidneys and living unrelated kidneys both have longer half-life than deceased donor kidneys, creating a significant benefit for the recipient without detriment to the donor. Therefore, transplant centers will make an effort to try and identify a suitable living donor for each recipient.

WHAT'S NEW AT THE NETWORK?

The Network received a new CMS contract July 1, 2006, with an updated Statement of Work defining CMS expectations of ESRD Networks for a three year period. The four primary task areas of the contract are Quality Improvement, Community Information and Resources, Administration and Information Management. Network staff includes the qualified key personnel that are required to conduct the activities in these areas. Over the past year, the Network has been developing new processes and projects to improve the effectiveness of our activities.

Quality Improvement (QI)– A new format for the Network's Quality Improvement Program was developed. A major component is the QI Work Plan, developed in conjunction with the Medical Review Board. It clearly defines goals for quality outcomes and QI projects with outcomes measures for issues identified by various analyses. This is a living document that allows for ongoing check-ins and updates of existing projects and development of new focus areas.

Community Information and Resources- The Network continues to focus on patient services, concerns and grievances, and the provision of education and technical assistance to patients and providers. Areas of development or expansion include the Patient Advisory Committee; the Renal Immunization Coalition partnering with providers, state organizations and Quality Improvement Organizations; and Emergency Preparedness for patients and providers. Several staff members participate on the national Kidney Community Emergency Response Coalition.

Administration– The new Internal Quality Improvement (IQI) program was developed to maximize the efficiencies of Network processes in delivering the contract requirements. IQI allows for rapid cycle analysis to evaluate effective processes that should be replicated and identify where efforts should be focused for improving effectiveness and efficiencies. The Network staffing structure was also reorganized to align with the new Statement of Work requirements.

Information Management– The data staff have continued to manage the substantial amount of data under the Network purview. New directions in this area include collaboration with CMS and their contractors in the development of the new CROWN WEB system that will eventually replace the manual forms processes used currently. Network staff are involved with input and testing.

ATTENTION SOCIAL WORKERS AND PATIENT CARE STAFF!

The Network is forming a Patient Advisory Committee (PAC). We are seeking 6 to 8 ESRD patients who would be willing to volunteer their time as liaisons to the Network. The PAC is designed to help the Network identify common patient concerns, problems and educational needs. We are looking for patients from all treatment modalities including transplant who are willing to commit two years as a member; are able to attend quarterly telephone calls and one annual in-person meeting; have access to a working telephone and email; and are outgoing and open communicators. For further information, please contact Christie Hurley at **(206) 923-0714 ext. 102** or churley@nw16.esrd.net.

*We are on the web! www.nwrenalnetwork.org
(206) 923-0714 and Fax (206) 923-0716*

The Consumer News is published by **Northwest Renal Network** under contract #HHSM-500-2006-NW016C with the Centers for Medicare & Medicaid Services. The contents of this document do not necessarily reflect CMS policy. Opinions expressed in articles appearing in this newsletter are those of the authors, and no endorsement is implied on the part of Northwest Renal Network or its Board of Directors.