

# Renal ROUNDUP

## SELF-CARE: TAKING CONTROL AGAIN

**N**ot surprisingly, with the onset of renal disease patients often experience a sense of lost control over their lives. They may feel powerless to face their disease and helpless to perform even simple tasks that they accomplished before ESRD.

Engaging in self-care can restore dialysis patients' lives by increasing feelings of control, empowerment, and independence. Some researchers and clinicians interested in renal rehabilitation have even begun to view dialysis self-care as "a therapy in itself."

### Choosing a Level

In basic terms, self-care simply means taking an active role in the treatment process and taking responsibility for one's own health. Self-care for the dialysis patient can encompass many forms.

For some patients, self-care may be learning as much as possible about the dialysis process and understanding treatment, diet, and medication. For others, it may consist of basic tasks such as weighing oneself before a treatment. Still other patients may choose the most advanced level of self-care: conducting hemodialysis at home.

One level of self-care often progresses to another level at which the patient feels comfortable and in control. For example, patients who begin monitoring their own weight or blood pressure may become more attuned to fluctuations,

learning about the causes and what can keep fluctuations under control.

Whatever the level of involvement, dialysis patients find that taking a positive and active part in some aspect of their care contributes to the quality of life and sense of well-being they experience.

*... taking a positive and active part in some aspect of their care contributes to the quality of life and sense of well-being ...*

### Patient Compliance

In his article "Measuring Quality: Patients as Consumers and Suppliers," Dr. Paul Kurtin points out that, "Chronic dialysis requires a great deal of patient compliance; however, little attention has been paid to the patient as a 'supplier' of care within the dialysis unit." When patients are seen as suppliers, says Dr. Kurtin, an interesting change in perspective occurs as "dialysis is no longer something done to a patient, but a process in which the patient actively participates."

### Advantages of Self-Care

Such a relationship, in which the patient plays a vital role in his or her own care, can benefit not only the patient, but also the dialysis team.

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# What is the ImESRD Network?



**T**he Intermountain End-Stage Renal Disease Network (Network #15) is a federally mandated nonprofit Colorado corporation that contracts with the federal government Centers for Medicare and Medicaid Services (CMS). Network #15 is involved in the assurance of quality care to individuals with ESRD, and also in the collection and validation of information about, and treatment of, persons with ESRD.

Federal ESRD Program Objectives include:

- Developing standards and criteria
- Encouraging self-dialysis or transplantation
- Encouraging patient and staff participation in vocational rehabilitation programs
- Providing a patient grievance mechanism
- Collecting, validating, and analyzing data
- Providing accurate, timely data to federal government agencies and to the public

CMS contracts with 18 Network organizations covering all 50 states and U.S. territories to implement the ESRD Network program as mandated by federal legislation. ESRD is the only disease that entitles an individual to Medicare benefits (with some minimum requirements).

***ESRD is the only disease that entitles an individual to Medicare benefits . . .***

The territory of Network #15 includes six states: Arizona, Colorado, Nevada, New Mexico, Utah, and Wyoming. It includes a consortium of about 200 renal facilities and serves a population of approximately 12,000 dialysis patients and over 600 transplant patients each year.

Most of the Network's programs are accomplished through volunteers, health care professionals who deal with kidney disease (physicians, nurses, dieticians, social workers, technicians, administrators), as well as patients. These volunteers work through the Medical Review Board, the Board of Directors, and the Patient Advisory Committee.

## Of Note . . .

**I**f you are a home hemodialysis patient please remember to contact your water department and ask to be notified if there are any water composition changes. If changes are made, be sure to take this information to your dialysis facility for review.

**S**everal studies have shown that regular exercise can provide benefits to people on dialysis. These include: increased energy, less anxiety, better circulation, stronger bones, and help in sleeping. Talk to your doctor about what type of exercise program is best for you.

**T**he American Kidney Fund (AKF) maintains a national, toll-free Help Line that provides information about kidney disease, its prevention and treatment, and organ donation. Experienced Patient Services staff and renal Social Workers will provide answers to questions from kidney patients, their families, and the general public.

**AKF Help Line: 1-800-638-8299**



# Get the Skinny Here

## How does dialysis affect my skin?

People on dialysis often experience skin changes—flaking, itching, and bruising—that can be physically uncomfortable or embarrassing. The good news is, many skin problems *can* be helped.

## Why do I bruise more easily?

You may bruise easily if your dose of blood thinner (heparin) is too high. Bruising also occurs when you have too few platelets (the cells that help your blood clot), a condition that can lead to bleeding gums or prolonged bleeding when you cut yourself. In addition, drugs like prednisone or coumadin can increase bruising.

## Why does my skin itch all the time?

Itching can be symptomatic of high levels of phosphorus in the blood. Extra phosphorus accumulates in your body from foods you eat, binding with calcium to form sharp, “itchy” crystals. Taking phosphate “binders” with food can help. In addition, people with kidney disease may have poorly functioning sweat and oil glands, causing the skin to become very dry. Avoid long, hot baths and *alcohol-based* lotions or creams that strip the skin of oils. Be aware that inadequate dialysis can also cause itching. You may need a dialyzer that clears more wastes or longer run times to address this potentially serious problem.

## Why do I itch only at dialysis?

If you only itch while *on* dialysis, an allergy may be the cause. Heparin, which keeps your blood from clotting in the dialyzer, could be the culprit. There are different types of heparin; one might make you itch while another does not. Not allergic to the heparin? You might have a reaction to the components of the dialysis set up, or the gas or chemical used to sterilize the components. If you have sensitive skin, bleach (used to clean the chair) could be an irritant. Alert the dialysis staff to this possibility, and try resting against a towel or blanket during your treatment.

## Fragile skin?

Skin that bleeds at the slightest bump and has purple or brown itchy blisters can be a sign of a rare skin disease called “porphyria” (por-feer’-ee-a). This problem needs the attention of a skin specialist.

## TIPS . . .

### How can I prevent bruising?

- Verify with your doctor that your heparin dose is not too high
- Ask your doctor about your platelet count and check clotting times if you are taking coumadin

### How can I prevent itching?

- Try to figure out what is causing the itching. What helps or makes it worse?
- Try over-the-counter lotions that are oil-based or “super fatted” (possibly Coconut Oil)
- Ask your doctor about prescription lotions, and see if he/she has any samples that you may test out
- Ask your doctor if antihistamine or UV light would help

### What if I get cracked and blistered skin?

- Get a referral for a skin doctor

**Tell your doctor ASAP if your skin problem affects how you feel about yourself**

# Have Problems?

## Who to call for help

**P**atients and family members have a right to address problems they identify in a facility, without fear of discrimination or punishment. To address a problem you should:

- Carefully review ESRD Network #15 Statement of Patient Rights and Responsibilities, available at your facility or from the Network, in English and Spanish as well as on audiotape in English;
- Make every attempt to resolve issues informally with your facility staff;
- Follow the grievance procedure at your own facility; and, if still not resolved,
- Contact ESRD Network #15 to use the Network's Grievance Protocol.



you can withdraw a grievance at any time.

### You may contact Network #15 at:

1301 Pennsylvania St  
#750  
Denver, CO 80203  
303-831-8818  
1-800-783-8818  
E-mail:

[info@nw15.esrd.net](mailto:info@nw15.esrd.net)

In addition, the following ESRD State Survey Agencies can be contacted for quality of care issues in dialysis facilities:

Arizona Dept of Health Services,  
Division of Assurance and Licensure  
Services  
ESRD Surveyor  
1647 East Morten, Suite 110  
Phoenix, AZ 85020  
602-674-9750

Colorado Dept of Public Health  
4300 Cherry Creek Dr South  
HFD - A2  
Denver, CO 80222-1530  
1-800-886-7689 (toll free in-state)  
303-692-2800

Nevada Division of Health,  
Bureau of Licensure and  
Certification/EMS  
1550 College Pkwy #158  
Carson City, NV 89706-7921  
775-687-4475

New Mexico Dept of Health, Health  
Facility Licensing and Certification  
ESRD Surveyor  
2040 S Pacheco St #413  
Santa Fe, NM 87505  
1-800-752-8649 (toll free in-state)  
505-476-9025

Utah Dept of Health, Medicare/  
Medicaid Program, Certification/  
Resident Assessment  
ESRD Surveyor  
P.O. Box 144103  
Salt Lake City, UT 84114-4103 . . .

## The Network's Role

In quality-of-care issues, the Network can assist in the resolution of a grievance by acting as a third party between a patient and a facility or professional provider. If you need help, or information, you can write or call the Network office. Here are some rules you will have to follow:

- You will need to confirm the grievance in writing if you make the initial contact by phone.
- You may designate another person as your representative, but you must put this in writing if you want that person to act in your behalf.
- Though you are not required to use the facility grievance procedure before contacting the Network, it is recommended; if you fear reprisal by your facility, you may contact the Network first.

Your identity will be kept confidential throughout the process, unless you specifically authorize a release, and

**Network #15 cannot handle issues dealing with money, payment of bills, or state or federal licensure or certification issues. These are handled by the following Regional Offices for the Centers for Medicare and Medicaid Services (CMS):**

### New Mexico:

(Region VI)  
1301 Young St  
#833  
Dallas, TX 75202  
(214) 767-6423

### Colorado, Utah, Wyoming

(Region VIII):  
1600 Broadway St  
#700  
Denver, CO,  
(303) 844-4024

### Arizona, Nevada

(Region IX): Division  
of State Operations, 4th Floor  
75 Hawthorne St  
San Francisco, CA,  
(415) 744-3679

1-800-662-4157 (toll  
free in-state)  
801-538-6158

Wyoming Dept of Health  
Office of Health Quality  
ESRD Surveyor  
2020 Carey Ave, 8th Flr  
Cheyenne, WY 82002  
307-777-7123

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The patient feels a greater sense of influence over his/her health, rather than leaving it "to chance or the actions of powerful others."

Dialysis professionals also report benefits. The time involved in teaching and encouraging patients to participate in self-care is rewarded with improved relationships, patients who have a more positive outlook, and patients who are generally in better health.

### Into the Looking Glass



The next step in the idea of self-care is to make patients self-managers of their renal disease. According to research, self-management would entail several types of activities. First, patients would learn to monitor their own symptoms and seek medical attention when appropriate. To do this, patients would have to become educated about the nuances of their disease and its treatment.

Secondly, patients and their care providers would have to establish a collaborative relationship. Patients would then become full partners in their care, rather than being dependent on or subservient to the medical team.

Finally, patients would need to engage in appropriate "coping skills and behaviors," such as maintaining a regular schedule of activity and exercise, attending to medications and nutritional needs, and applying their illness-related knowledge to better manage daily living activities.

Initially, such a full self-management program might seem unusual. However, dialysis patients can enjoy a better quality of life and come closer to the goal of "restoration through rehabilitation" if they become truly engaged in self-care.



*Adapted with permission from the Life Options  
"Renal Rehabilitation Report"*

## TIPS...

### Monitor Symptoms

- Pay attention to your body's warning signals
- Learn what is important to report
- Report serious problems immediately

### Become part of the dialysis care team

- Educate yourself about the dialysis process
- Perform dialysis tasks yourself when possible
- Treat health care staff the way you would like to be treated

### Maintain good health practices

- Follow dietary guidelines
- Follow exercise or activity guidelines
- Manage fluid levels



## We're Wired!

*Have questions? We've got the answers! (Maybe.)*

Find out by visiting our new website at [www.esrdnet15.org](http://www.esrdnet15.org). The site is geared for renal professionals as well as patients. We will continue to add material, but a sample of the information currently available for patients includes: treatment choices; a dialysis facility locator; and links to other helpful websites.

**Visit us at [www.esrdnet15.org](http://www.esrdnet15.org)**



## Add Your IQ to the QI Team!

All of us in the dialysis industry are trying to achieve excellence in the way we provide care. In the areas of patient satisfaction, hospitalization rates, staff training, or the undertaking of daily tasks, there is always room for improvement. Administrators, medical staff, **and patients** are looking for “better” ways of doing things, to positively impact patient outcomes. Continuous Quality Improvement (CQI) methods help us reach this goal.

CQI is a systematic, evidence-based method of identifying areas that can be improved, the cause(s) of problems/unwieldy processes, and formulating action plans in response. A plan is then implemented on a small scale, and re-measurement is done periodically to see if a “positive” impact has been made.



CQI allows the nephrology team—nephrologists, administrators, nurses, technicians, social workers, dietitians, **and individual patients**—to make huge advances in the way dialysis care is delivered.

### Did you know ...

Network #15 is currently involved in a National Quality Improvement Project aimed at improving the adequacy of dialysis in hemodialysis patients?

### Why?

Because getting adequate dialysis decreases patient complication rates and improves patient longevity!

### What has been done so far?

One hundred percent of the facilities in Network #15 participated in gathering information related to dialysis adequacy and accesses. This assessment confirms that most patients are reaching targets set for adequate dialysis. However, patients who use long-term central venous catheters for an access are less likely to achieve these targets, compared to fistulas or grafts.

### What we are doing now . . .

Dialysis unit staff members and physicians, along with Network staff, are striving to improve adequacy and long-term catheter rates for dialysis patients in Network #15.

### Doctors and staff members are:

- Working to improve the adequacy of dialysis in patients who must use long-term central catheters for access. These patients often need longer treatment times; they might also require a different dialyzer or an alternate form of dialysis to maximize treatment and enjoy a higher quality of life.
- Monitoring fistulas—the preferred access for dialysis—and grafts in order to foresee potential problems inside an access. Early identification of problems (like narrowing inside the access) can help prevent clotting, which in turn might prevent the need for a temporary or permanent catheter. Prompt attention to problems helps preserve remaining blood vessels.
- Working with surgeons and radiologists to ensure the timely placement of accesses.



### How Can Patients Help?

Run the amount of dialysis time that is prescribed. If your doctor thinks you need longer times to get adequate treatment, act on this recommendation.

Be open to the type of access suggested by your kidney doctor. Recommendations are made with your best interest in mind!

Keep your appointments. Referral to a surgeon or radiologist might just save your access. (If you are having difficulty getting an appointment scheduled, ask your nurse for help.)

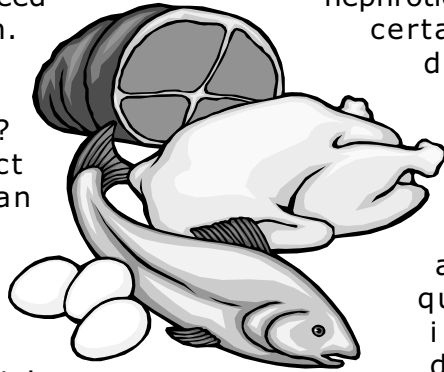


**Get involved.** Offer your perspective; help formulate a plan for improving your own outcomes and those of your unit; join the QI team!

# Albumin: Why is it Important?

Lauren Maister-Green, RD; Alisha Chasey, MS, RD; Beth Spanier, RD; Meredith Gilliatt-Wimberly, MS, RD

**I**n monthly lab reviews, dialysis patients may be told that their albumin level is low and they need to eat more protein. But what is albumin? Why is an albumin blood test important? What factors affect albumin? How can albumin levels be improved?



## What is albumin?

Albumin is a major protein found in the blood. Protein plays a big role in fighting off infections and building or repairing muscle tissue. When a person does not eat enough calories or protein, the liver doesn't have enough protein to make new albumin, which causes lower albumin levels in the blood. Research has shown that patients with low albumin levels over time have a higher death risk. Testing albumin levels helps assess a person's nutritional status and risk for malnutrition.

## What is a good level for albumin?

The normal range for albumin is 3.5-5.5 g/dL (optimal level 4.0 g/dl). This may vary slightly between laboratories and the method the lab uses to process the blood sample. Check with your unit's renal dietitian to see what your goal for albumin should be.

## What other factors can affect albumin levels?

Albumin is a valuable test but it is slow to change. It can also be affected by a number of other health conditions. It can be low in persons with a history of liver

disease, since albumin is made in the liver. It can also be low in persons with a history of nephrotic syndrome or certain kidney diseases that cause protein to be lost in the urine. Albumin levels can also drop quickly if an infection develops.

Because it is hard to tell exactly what has caused the decrease, a health care team will use the albumin test along with other tools to monitor continued health. The dietitian will often ask about appetite, monitor weight and muscle tone, and review other blood tests including those that measure adequate dialysis (KT/V and URR).

## How much protein should patients eat to stay healthy?

Most people on hemodialysis should try for a goal of 8-10 ounces of protein each day, or 10-12 ounces for those on peritoneal dialysis. Check with your dietitian for your specific protein goal. An easy way to estimate your protein intake is to compare your portion size to the following objects: A match box is equal to 1 oz. of protein, a deck of cards is equal to 3 oz. of protein, and a paperback book is equal to 8 oz of protein.

*Special thanks to Brenda Murphy, RD, for her help in reviewing this article.*

## TIPS . . .

- At each meal try to include one of these high quality protein foods: chicken, turkey, fish, beef, pork, or eggs.
- Notify your dietitian ASAP if you are experiencing nausea, vomiting, diarrhea, difficulty chewing and swallowing, or lack of appetite.
- Eat protein snacks, such as an egg salad sandwich or tuna on crackers.
- Check w/ your dietician about a protein drink, powder, or bar that would be right for you.
- Try to eat 5-6 small meals a day.
- Try new recipes that include protein. Ask your dietitian for suggestions.
- If you need help making meals, check with your social worker for options such as Meals on Wheels.
- Try a protein supplement. Speak with your dietitian to find the one that would be best for you.
- If diet changes or supplements don't help, speak with your physician. An appetite stimulant or zinc supplement may be helpful.