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SPECIAL EDITION

Family Focus

The Renal Community's Newspaper

VOLUME 8, NUMBER 4

VOLUME 9, NUMBER 1

What Does NKF-DOQI
Mean to You?



A Word About This Special Issue...



NKF-DOQI Seal

Perhaps many of you have already heard about the National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF-DOQI). We would like to give you a little history on it, and tell you why it is so important for you, as patients and concerned family and friends, to learn how it will impact the care you receive and how well you do on dialysis.

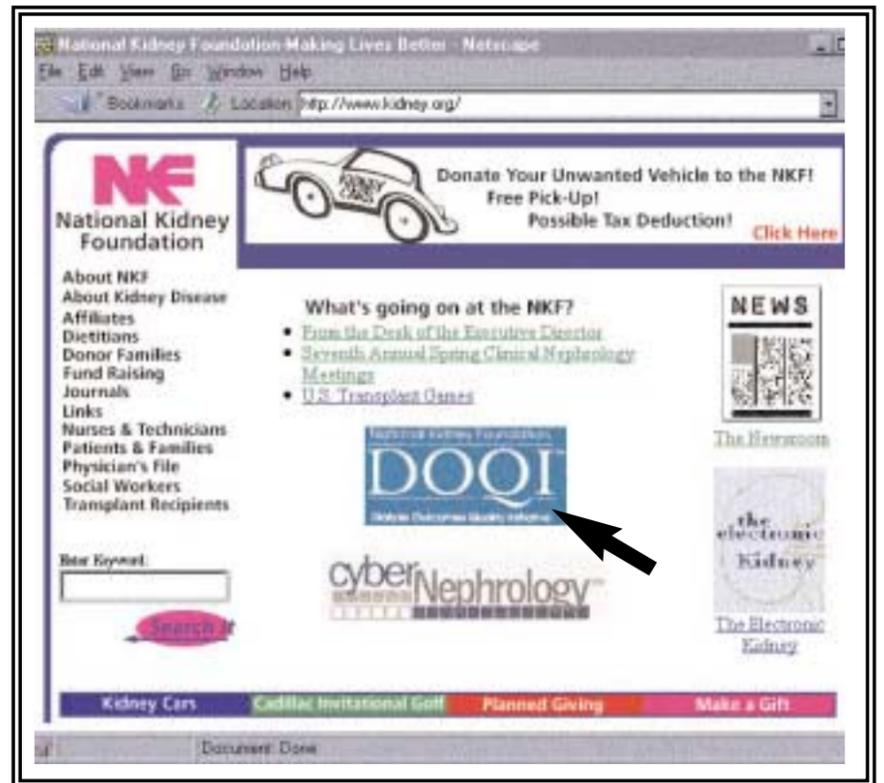
The National Kidney Foundation began its Dialysis Outcomes Quality Initiative in March 1995 with the generous financial support of Amgen Inc. The goal of NKF-DOQI is to improve outcomes and quality of life for people with end-stage renal disease who are on dialysis. To meet this goal, NKF-DOQI set up a process to develop clinical practice guidelines in the areas of hemodialysis adequacy, peritoneal dialysis adequacy, vascular access, and anemia associated with chronic kidney failure. Clinical practice guidelines are recommendations for health care workers to follow in order to meet a certain standard of care. Development of the guidelines involved a large effort and the commitment and cooperation of many people—kidney patients, physicians, nurses, technicians, social workers and dietitians.

The *NKF-DOQI Clinical Practice Guidelines* were completed in the fall of 1997, and published as supplements to September and October issues of the *American Journal of Kidney Diseases*, and as a set of separate books. In addition, the guidelines can be found

on NKF's World Wide Web site (www.kidney.org). A boxed set of the *NKF-DOQI Clinical Practice Guidelines* was hand-delivered by Amgen to every dialysis unit in the country so that all dialysis professionals have access to them.

NKF-DOQI does not end with publishing the guidelines, however. NKF-DOQI is concerned about dialysis patient outcomes and quality of life, which will improve only if these guidelines are used by dialysis health care professionals. It is also essential that you, as renal care consumers, learn key points about these guidelines. You can work to improve your health and quality of life by asking questions and making any changes in your treatment plan recommended by your health care team. The NKF is developing educational materials for patients and families to help them learn more about NKF-DOQI. An example of some of these educational materials is this special edition of *Family Focus*, devoted completely to NKF-DOQI. Brochures such as "Getting the Most from Your Treatment" are also available. These brochures discuss hemodialysis, peritoneal dialysis, anemia and vascular access. You can call your local NKF affiliate or (800) 622-9010 for more information.

The NKF has designed a special NKF-DOQI seal to be put on all educational programs that correctly communicate



Visit the NKF Home Page at www.kidney.org and click on NKF-DOQI to access the guidelines.

the *NKF-DOQI Clinical Practice Guidelines*. Look for the NKF-DOQI seal of approval on these educational materials. It will be your insurance that you are getting the most-up-to-date dialysis information!

If you have any questions about the NKF-DOQI guidelines, call the National Kidney Foundation at (800) 622-9010.

Garabed Eknoyan, MD

Nathan Levin, MD
NKF-DOQI Co-Chairmen



This publication is a Family Focus Program of the National Kidney Foundation, Inc. This special issue on NKF-DOQI was made possible through an unrestricted educational grant from Amgen Inc., Founding and Principle Sponsor of NKF-DOQI.

Additional unrestricted support was received from Schein Pharmaceutical, a primary sponsor for NKF-DOQI Implementation; Gambro Healthcare and American Regent Laboratories, Inc., contributing sponsors.

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Making Lives Better



FROM THE EDITOR

This issue of *Family Focus* is a highly important one for each of you in terms of your overall health and well being. It is a special issue,



Karren King

highlighting the National Kidney Foundation-Dialysis Outcomes Quality Initiative (NKF-DOQI). Although dialysis technology has made considerable advances over the years, the renal community believed that patient outcomes and care could be further enhanced if guidelines for practice were established. The NKF, joined by other renal organizations, led this effort, the result of which is NKF-DOQI. It is my belief that NKF-DOQI will have a profound positive impact on nephrology practice both within the United States and around the world. I also want to acknowledge the support and assistance of the United States Renal Data System in making the direct mailing of this particular issue possible, and to assure you that patient confidentiality was not breached in doing the mailing.

The NKF has always believed that those who are the recipients of care are the most important members of their renal team. Yet to function as active participants, you must possess the information that is necessary to guide you in this endeavor. Read this issue closely and thoroughly. Then, utilize the information you gather to assist in examining your own care and communicating about it with the other members of your health care team.

While reviewing this issue, it is also important to assess those aspects of your care over which you have direct control and to understand why they are important to you. These would

include such areas as attending each scheduled hemodialysis session and dialyzing the entire length of your prescribed treatment, or performing each of your peritoneal dialysis exchanges, adhering to your diet and medication plans, and developing an exercise routine. There are both rights and responsibilities that accompany life on dialysis. This issue should assist you in understanding these. Remember that if you both exercise your rights and meet your responsibilities, your reward should be enhanced health and quality of life. It's well worth the effort. 

Karren King
For the Editorial Board

Are we missing you?

We'd like to make sure that *NKF Family Focus* is making its way to every dialysis unit and transplant center in the country. If we're missing anyone, or if you would like to receive a copy at your home, please let us know by dropping us a note or by giving us a call at

(800) 622-9010.



NKF Family Focus is published quarterly by the National Kidney Foundation, Inc.

Opinions expressed in this newspaper do not necessarily represent the position of the National Kidney Foundation, Inc.

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In Memoriam

Irv Wolper

I would like to dedicate this issue of *Family Focus* to a very special person. Although I realize that doing this is somewhat unique, I was the person, the late Irv Wolper, to whom I am dedicating this issue. Irv had been on hemodialysis for many years, yet he exemplified the concept of rehabilitation and did not allow his treatments to interfere with his goals. Luckily for the National Kidney Foundation, Irv's goals encompassed the NKF's vision statement, "Making Lives Better." He set out to do this for those on dialysis in many ways. He began by dedicating countless hours to the NKF of Florida's Patient Services programs, coming to their office daily as a volunteer. He was also a member of their Executive Committee and Board of Directors. I became familiar with Irv when he began attending the National Kidney Foundation's national quarterly meetings, where he served on the Patient Services Committee and the Patient/Family Council Executive Committee. Irv's dedication to the NKF and what it stands for was exceptional. Although the NKF has lost a true friend, our lives have been enriched by having had the opportunity to know and work with him. He will be greatly missed.

Going From Surviving To Thriving

by Wayne Nix

I was an angry man in 1991 when I walked through the front door of the National Kidney Foundation office in Ann Arbor, Michigan. I should have been happy. After being on dialysis for 17 years, I had just been successfully transplanted. But my recent brush with the renal treatment complex had also made me painfully aware of the problems facing end-stage renal disease (ESRD) patients in the United States. What was worse was that no one seemed to care. I went to the NKF to find some answers. For U.S. renal patients, the mortality rate was more than 25 percent—nearly double that of other countries in Europe or in Japan. It was unacceptable to me that in this country one in four ESRD patients dies on dialysis. But rising costs and patient loads had combined with declining funds to create what seemed to be an atmosphere of apathy and unfettered cost-cutting. It appeared that patients were often not being dialyzed enough, and frequently there was no effective monitoring of both hemo- and peritoneal dialysis treatments. Even the most basic level of counseling about renal patients' mental and physical health seemed out of reach.

There I was, though, alive and active. What was so different about my situation, when so many like me were unable to live—let alone enjoy—life after being diagnosed with ESRD? I realized there were two basic reasons why I had survived and thrived. The first was that the tremendous support of my wife and children allowed me to get the best possible dialysis treatment—at home. Runs were never cut short and my artificial kidneys did not see multiple use. The second was that I always viewed my illness as a major inconvenience, not the focal point of my existence. I continued to teach and do the things I love.

That is not the case for many of the more than 220,000 Americans on dialysis today. But, while six years ago I was unhappy with the efforts being made to improve care, I am now very excited about a project I believe will not only improve dialysis treatment in this country, but one that will certainly improve overall quality of life for ESRD patients—the National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF-DOQI).



Wayne Nix

NKF-DOQI was launched in 1995, and represents two years of intense work, coordination and commitment on the part of the entire renal care community. I had been wrong. People did care, and they were doing something about it.

The resulting guidelines, announced in October 1997, boldly set new standards in renal health care, focusing on adequate goals for hemodialysis and peritoneal dialysis, the most effective vascular access techniques and anemia prevention. NKF-DOQI is not just some abstract, medical lingo. With these clinical guidelines, we can finally move beyond dialysis for survival to a health care approach that helps patients live their lives to the fullest.

Specifically, NKF-DOQI addresses the essential core of what it takes for dialysis patients to feel as healthy as possible. Obviously, getting enough dialysis is at that core, and in the last couple of years, we have seen an increase in the percentage of the treatment population receiving adequate dialysis, from less than 50 percent to well over 60 percent. (HCFA Core Indicators Report 1997). NKF-DOQI now raises the bar on other core indicators as well, including Kt/V, hematocrit and serum albumin levels. In effect, it calls all treatment to a higher level. Carefully watching those levels has been an important part of my long-term success, and NKF-DOQI's guidelines in these areas will no doubt have a major impact on the survival rates of other patients.

As we see in many other countries, renal care in the United States will be working toward optimal dialysis, moving the paradigm from dialysis just to stay alive, to dialysis for true

rehabilitation. Patients will feel better and perhaps we will soon see an increase in the area of vocational rehabilitation. Dialysis consumers will hopefully lead more productive lives, build their self-esteem and feel empowered.

An important thing to keep in mind, however, is that while NKF-DOQI is about helping renal care providers to keep their end of the deal, much of the responsibility for good care still lies with the patient. Patients need to be involved and assertive in their treatment plans. Sticking to an optimal dialysis schedule, watching diet and fluid intake, taking medication and exercising are all vital elements in feeling good. And, I always tell consumers: If you think you're not getting good treatment, find out what it is and make sure you get it. It's that simple.

“Patients need to be involved and assertive in their treatment plans.”

For too many years, we operated under the assumption in the renal community that life was over once ESRD was the diagnosis. From the very start of their illness, many patients were told, by doctors and social workers, not to worry—that they could go on disability and their treatment would be taken care of for them. They were *told* to drop out. Meanwhile, costs for this government medical experiment were rising, while funding was drying up. Standards fell and mortality and morbidity rates rose while heads were turned. Those days, however, are gone.

NKF-DOQI will help reverse these trends and hopefully change the way we think about end-stage renal disease. As in my case, patients won't be devastated by their illness. They will learn how to take control, manage their disease and become long-term survivors.

It will not be about “the end” anymore. NKF-DOQI is about a new beginning. 

NKF-DOQI: What It Means To You

THE HISTORY—The How and Why—of NKF-DOQI

by Garabed Eknoyan, MD

For the centuries that came before the beginning of dialysis treatment, progressive kidney disease was just another disease from which people died. Since the 1960s, when the “artificial kidney” was shown to be helpful for patients whose kidneys had failed, and the 1970s, when dialysis became widely available for patients with end-stage renal disease (ESRD), dialysis has provided life-saving treatment to thousands of people with kidney disease. Since the 1970s, advances in dialysis science, the understanding of complications that can develop during chronic dialysis, and the availability of substances to replace those that the failed kidney can no longer make (epoetin or EPO and Vitamin D), have led to considerable improvement in the length and quality of life achieved by dialysis patients.

These otherwise major achievements were overshadowed in the 1990s by concern about the frequent occurrence of medical problems and complications in chronic dialysis patients and the high death rates of patients receiving dialysis. It became clear that some dialysis units and some countries had very high complication and death rates, while others had much lower rates.

It was obvious to many health professionals that although there was reason for satisfaction for what had been accomplished so far, there was much room for improvement. It is this realization that focused the attention of the entire renal community on the quality of

care in dialysis. Of the several organizations that addressed the issue, the Renal Physicians Association (RPA) was the first to realize the need for guidelines for use by kidney doctors and other health care workers who care for patients with ESRD. The

conference on “Controversies in the Quality of Dialysis Care” in March of 1994. The participants in this conference had the wisdom to realize that the care of dialysis patients involves more than just whether each patient receives



Dr. Eknoyan, NKF immediate past president, announces the final NKF-DOQI Clinical Practice Guidelines at a press conference held in October 1997. More than two years of research and development went into this initiative to improve patient outcomes.

“Clinical Practice Guidelines of Adequacy of Hemodialysis” issued by the RPA in December of 1993 have been very helpful in the gradual improvement over the past few years in the dialysis dose (amount of dialysis) delivered to patients.

Along with representatives of other organizations, the National Kidney Foundation (NKF) held a consensus

conference on “Controversies in the Quality of Dialysis Care” in March of 1994. The participants in this conference had the wisdom to realize that the care of dialysis patients involves more than just whether each patient receives enough dialysis. They recommended that the best way to improve the quality of care and the quality of life for dialysis patients was to develop a series of rigorous evidence-based guidelines for some of the many problems that affect kidney patients. These recommendations were the final recommendations of the “Evolving Plan for the Continued Improvement of the Quality of Dialysis Care”

adopted by the NKF in November of 1994. Evidence-based means that the guidelines are supported by well-designed scientific studies that not only show that certain ways of doing things achieve better results, but that these results can occur in many different dialysis units and with many different kinds of patients. In other words, the effect of these practices can be reliably reproduced. Opinion-based means that most people think that the practice is correct, but there have not yet been enough studies that show this.

The first four sets of guidelines produced through the National Kidney Foundation-Dialysis Outcomes Quality Initiative (NKF-DOQI) cover:

1. Adequacy of Hemodialysis
2. Adequacy of Peritoneal Dialysis
3. Vascular Access
4. Anemia Management of Chronic Renal Failure

Two more sets of guidelines are under development:

1. Nutrition
2. Bone Disease

These topics were selected because they are very important and because there is enough scientific information available to develop good guidelines.

Guidelines mean different things to different people, and are used for many purposes. It is quite easy for any group of concerned people to get together and issue guidelines. The group’s purpose in developing the guidelines will affect the type of

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THE HISTORY—The How and Why—of NKF-DOQI

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guidelines issued. For that reason, it is important that the group developing the guidelines be independent and representative of those affected by the guidelines, and that the process be public and open to review by the community. One purpose of the guidelines is to improve quality of care and quality of life; another is to decrease costs. Guidelines can decrease the cost of health care by providing a "road map" to the most cost-effective and efficient way of doing things. The NKF believes that the most important purpose of its guidelines is to improve quality of care and quality of life.

Another important factor is the scientific validity of the guidelines. Are the guidelines based on evidence or opinion? One easy way of writing guidelines is to have selected authorities in a field write a set of guidelines on which they agree. A

number of guidelines now available are weak because they are based primarily on opinion. To arrive at sound conclusions, it is important that all of the available evidence be subjected to thorough and rigorous analysis, not only to form evidence-based guidelines, but also to provide a basis

"It became clear that some dialysis units and some countries had very high complication and death rates, while others had much lower rates."

for the opinion-based guidelines that are unavoidable in the absence of definite evidence. The methods used to accomplish this analysis is time-consuming and expensive. Many factors, such as scientific rigor, interdisciplinary approach, independence

of the work groups and an open review process, have been the guiding principles of the guidelines developed by NKF-DOQI.

The guidelines issued are no more than guidelines based on the best information available at the time. They are not standards of care. Rather, they are meant to assist in the decision-making process that must be individualized for each patient within the setting where the care is delivered.

Much like providers of care, patients must be informed and participate in decisions about their health care. Patients took part in the work groups that developed the guidelines and were an essential part of the review process before the final guidelines were released. Patients will also be part of the implementation (and evaluation) plan that is now in place. The guidelines are meant for patients as much as anyone else on the health care team. It is essential that you, the patient, know about the guidelines and participate in making them work. 



MAIL BOX

Dear Editor:

I am writing this letter to you because of my interest and concern for kidney patients, having been one of them for at least two years now. Since I have been on dialysis, I have been very interested in reading all materials distributed at the renal center where I get my dialysis treatment. My center is at the Long Island College Hospital in Brooklyn, New York. It is a marvelous center indeed.

Not long ago, a few copies of *Family Focus* newspaper were dropped at our center for patients to read. We usually get copies of other brochures or literature related to renal matters but *Family Focus* is very good and better than any we have been reading in terms of news coverage and policy about renal patients. The contents cover very special areas of interest and problems of greater interest for the renal patients and their families and friends.

Your effort to make this paper available to everybody is commendable. Thus, patients who share common interests, likes and dislikes as well, are able to know and form any kind of relationships they may choose at no cost of money to any of them. As people having common problems they can form friendships and other related

nuclear groups that appeal to them as adults. They do not make sizable incomes to be able to pay heavy dues or initial membership fees to become members. Those who are able to choose people who share their interests and characteristics can form any relationships any length of time without having to pay anything to find such friends or acquaintances.

Please drop a copy of this prestigious newspaper to me at my home address and keep them coming to the Long Island College Hospital center. We like it — all of the very interesting information and educative material included in *Family Focus*. Thank you.

*The Most Rev. Agu Theomus Obiakor
Bishop of the Universal Church Messiah
Brooklyn, New York*

Thanks for your letter. In addition to Family Focus, the National Kidney Foundation has a membership council for patients and family members. Membership is free and includes a subscription to Family Focus, quarterly membership updates and more. For more information or to become a member of the Patient and Family Council, call the NKF at (800) 622-9010. 

NKF-DOQI: What It Means To You

Patients Improving Patient Outcomes: NKF-DOQI Recommendations For You To Know and Understand

Recommendations for Hemodialysis Adequacy

- Research has shown that getting enough dialysis is very important to how well you feel and how long you live on hemodialysis. **Your dialysis care team will do a blood test each month to measure the amount of dialysis you receive (your delivered dose).** The numbers used to measure your delivered dose of dialysis are called your Kt/V and your URR. Ask your dialysis care team which of these measures they use. Your results on these tests should be as follows:

- **Your Kt/V should be at least 1.2.**
- **Your URR should be at least 65 percent.**

- To measure your delivered dose of dialysis, your dialysis care team takes samples of your blood before and after your dialysis treatment. **It is important that they take these two blood samples on the same day and that the samples are drawn correctly using the NKF-DOQI procedure.**
- Many dialysis centers use the same dialyzer (artificial kidney) more than once on the same patient. This is called "reuse," and it is generally considered safe if it is done properly. Your dialysis care team cleans and sterilizes your dialyzer before each treatment. **They should test your dialyzer before every treatment to make sure it is still working well.** If it is not, you may not be getting enough dialysis. Ask your care team if they have tested your dialyzer and what the results showed.
- Your dialysis care team should do its best to make sure you are as comfortable as possible during your dialysis treatment. **If you are having headaches,**

dizziness, cramps or other uncomfortable symptoms during dialysis, your care team may be able to make some changes in your treatment to help you. You can also help yourself by following your fluid allowances between treatments. Having to remove too much fluid during your treatment is one of the things that can cause discomfort. **Keep all your dialysis appointments. Arrive on time, stay for the full time prescribed for you and try not to interrupt your treatments. Missing just a few minutes each time adds up and will harm you over the long term.**

Recommendations for Peritoneal Dialysis Adequacy

- Many patients who have not begun treatment want to put off dialysis as long as possible. However, it is important to listen to your kidney doctor's advice about when you should begin treatment. **The decision about when to start dialysis is based on tests to determine your remaining kidney function and your nutritional status.** Starting early enough will increase the chances of doing well on treatment and decrease the chances that you will have symptoms of uremia, such as nausea, vomiting and extreme fatigue.
- Getting enough dialysis is as important to peritoneal dialysis patients as it is to hemodialysis patients. Studies have shown that patients feel better and live longer when they get enough treatment. In peritoneal dialysis, your delivered dose of dialysis is measured on a weekly basis. **Your weekly Kt/V should be at least 2.0.** Your remaining kidney function is also important to tell how well you do on peritoneal dialysis. **Your dialysis care team should do blood tests to measure your delivered dose of**

dialysis (Kt/V) and your remaining kidney function two or three times during the first six months of treatment and every four months after this initial period.

Recommendations for Anemia

- **People with chronic kidney failure should be evaluated for anemia** when their hematocrit (red blood cell count) is:
 - less than 33 percent (women before menopause and children before puberty)
 - less than 37 percent (adult men and women after menopause)
- The most common cause of anemia in chronic kidney failure is a low level of the hormone erythropoietin (EPO). **If a low level of EPO is found to be the cause of your anemia, treatment with a man-made form of EPO should be started. The most effective way of receiving EPO is by injection under the skin (subcutaneous).** Many patients learn to give themselves their EPO injections.
- **The target hematocrit for EPO treatment is 33 to 36 percent.** You should reach this target in about two to four months after starting treatment for anemia. You will probably start to notice a difference in how you feel when your hematocrit has gone up about five points or more.
- To achieve and maintain the target hematocrit, **most patients also need to take iron supplements.** EPO is not effective without enough iron. Iron works with EPO to make red blood cells. **In order to get enough iron, most patients need to have their iron injected directly into a vein (intravenous) or into the blood lines during hemodialysis treatments.**

Continued on page 7

Improving Patients Outcomes...

Continued from page 6

- The benefits of correcting anemia are:
 - It helps you live longer on dialysis.
 - It decreases your chance of having a heart problem.
 - It improves your quality of life.
 - It increases your ability to exercise.

Recommendations for Vascular Access

- A patient's own artery and vein should be used to create an access (called an arteriovenous fistula) rather than using an artificial implant. Fewer complications will result.
- The guidelines recommend ways to choose the best type and location of your vascular access. (See story on page 12.)
- The guidelines list ways your access can be monitored so that complications are prevented and your access can be maintained. (See story on page 12.) 

Thank You

The officers, volunteers and staff of the National Kidney Foundation gratefully acknowledge the leadership and vision provided by the NKF-DOQI co-chairs, **Garabed Eknoyan, MD**, and **Nathan Levin, MD**; the NKF-DOQI Work Group chairs, **William Owen, MD**, **Thomas Golper, MD**, **Steve Schwab, MD**, **Joseph Eschbach, MD**; and members of the Work Groups, Advisory Council and Steering Committee for their innumerable hours of dedication and commitment. The enthusiasm, leadership and tireless efforts of the entire renal community to achieve a quality product made the *NKF-DOQI Clinical Practice Guidelines* what they are today—a beacon to provide guidance, direction and vision on a set of diverse issues with a single focused goal: improving patient outcomes.

Special thanks to **AMGEN INC.**, founding and principal sponsor of NKF-DOQI.

Additional thanks go to Schein Pharmaceutical, (Primary Sponsor), Gambro Healthcare and American Regent Laboratories (Contributing Sponsors), partners in NKF-DOQI implementation.



P O E T R Y

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Just Look Around

by Joann Mallet



If it seems your life is only darkness and
No light can be found,
Just take a minute and look around.
When it seems that troubles would get you down
Just look at all the beauty that can be found.
When it seems there is no peace abound
Just look around at the quietness of an early morn.
The beauty of a rose without a thorn.
A baby just born.
Just look around and all that you can see
God gave to you and me. 



Joann Mallet lives in Fresno, CA, with her husband, who has both been on dialysis and received a transplant. Writing about her feelings has helped Joann cope with her husband's illness.

What Does NKF-DOQI Mean TO YOU?

by Nathan W. Levin, MD

What do the NKF-DOQI guidelines mean to you? How can you use them to find out how closely your current treatment follows the guidelines? How can you take an active interest in having them apply to you in the future if they do not at present? Before attempting to answer these questions, a short summary of the basic ideas expressed in the guidelines is in order.

- ① In each of the four major areas — hemodialysis adequacy, peritoneal dialysis adequacy, vascular access and anemia — the work group selected the most important topics for consideration.
- ② For each important topic, everything concerning that subject that was described in medical journals was discussed and the usefulness of the articles evaluated. Where there was nothing convincing in the journals in the way of reliable evidence, the opinions of all groups involved in dialysis were requested. These groups included patients, doctors, nurses, technicians, dietitians, social workers, administrators, representatives of the federal government, dialysis chains, manufacturers and managed care organizations. Consequently, the final guidelines contained the best opinions available to supplement those based on definite evidence.
- ③ Guidelines are intended to be actually used (implemented) for the benefit of dialysis patients, and to the extent possible, the effects of implementation widely using and following the guidelines will be measured.

Now to answer frankly the questions raised initially about how the NKF-DOQI guidelines relate to you. In those situations in which you feel that the details of the treatment you are receiving are not what they should be, these guidelines give you the facts to support your point of view. For example, if you are not receiving an adequate dose of hemodialysis (Kt/V equal to or more than 1.2 or URR equal to or more than 65 percent), you



Dr. Levin (right) and Dr. Eknoyan explain the significance of the NKF-DOQI guidelines.

can use the impressive information in the guidelines to ask why. Asking “why” or “why not” is particularly important when your access is not working well or if you have an external venous catheter, so that the time on dialysis needs to be prolonged. (This will also give a push toward improving your access if this is possible.)

The following are a few of the important issues that should be addressed to your satisfaction:

- **Proper drawing of your blood at the end of the treatment.** This is important to give a true picture of how well the treatment is working.
- **Make sure your reused dialyzer retains its original efficiency.** Ask for the facts.
- **Get an AV fistula if this is possible.** This may not apply to you if you already have a well-functioning graft, but sometimes a poorly functioning graft can be properly transformed into a fistula that might work better.
- Check whether the dialysis unit has a program of **tests to detect failure of an access device** before it clots so that you are spared extra procedures and surgery later.
- **Make sure that your hematocrit (measure of red cells in the blood) is at the correct level** and that you are receiving **appropriate**

amounts of epoetin (to stimulate the bone marrow), and **intravenous iron** to maintain your hematocrit.

If you are on peritoneal dialysis, make sure you receive the correct dose of dialysis. This varies slightly, depending upon whether you are on CAPD (weekly Kt/V equal to or greater than 2.0) or automated dialysis (weekly Kt/V equal to or greater than 2.2). You should understand that this target includes the function remaining in your own kidneys.

As time passes, some of the specifics in the guidelines are likely to change, but most of the information will continue to be relevant for some years. The more you know about the contents of the guidelines, the better it is for you, since you will be in a position to ask the right questions. At present, NKF-DOQI is working on guidelines on nutrition and bone disease. These will help you understand the importance of adequate nutrition and how bone disease and its treatment affects you, so that you may make improvements in your care.

Family Focus welcomes accounts of your experiences with using the NKF-DOQI guidelines to improve the care you are given. 

Parent Connection

What NKF-DOQI Means for Children and Young Adults

by Bradley Warady, MD

The guidelines for patient care that have been developed by the National Kidney Foundation-Dialysis Outcomes Quality Initiative (NKF-DOQI) may have a greater impact on the care of the more than 5,000 children in the United States who receive chronic dialysis than on any other portion of the end-stage renal disease (ESRD) community.

This statement may seem somewhat paradoxical to those of you who recognize that although the guidelines were developed for children and adults following an exhaustive review of medical journal articles pertaining to the provision of dialysis and the treatment of anemia, the majority of the articles were based on the results of research studies conducted with adult dialysis patients only.

Indeed, pediatric dialysis patients are a special population with many unique concerns, such as growth and development, that differentiates them from adult patients. However, the relatively small number of pediatric patients that receives dialysis when compared to the adult population have limited the ability of the pediatric medical community to adequately study many of the patient-care issues addressed by NKF-DOQI. Thankfully, the similarities that exist between the pediatric and adult populations in terms of dialysis needs and the utilization of recombinant human erythropoietin (EPO) make it possible for both the pediatric and adult caregivers to use the same

NKF-DOQI guidelines. For the very first time, these guidelines provide treatment strategies and goals that are designed to achieve the best dialysis care possible for all children. Whereas differences in these goals may have even existed from one pediatric dialysis program to another in the past, the availability of the guidelines now diminishes any differences and provides a uniform approach that should benefit all children who receive dialysis.

In what ways will the NKF-DOQI guidelines directly influence the care of children? As an example, let's look at some of the recommendations pertaining to peritoneal dialysis (PD). This will result in the need for children to collect their dialysis fluid and urine several times per year so that the creatinine clearance and Kt/V, tests that evaluate the removal of body waste products or so-called clearance, can be determined and used to judge how effective dialysis is. When the effectiveness needs to be increased because of the failure to achieve target clearance values, changes in the child's dialysis prescription (e.g., exchange volume, number of exchanges, use of daytime exchanges) may be recommended.

Likewise, the guidelines for children on hemodialysis (HD) also require the evaluation of dialysis effectiveness using Kt/V, in this case conducting the evaluation on a monthly basis during a routine hemodialysis session. Here, too, a determination that suggests the need to

increase the effectiveness of dialysis will result in a change of the child's dialysis prescription.

The vascular access guidelines provide treatment recommendations designed to maintain the function and minimize the complications associated with grafts, fistulas and central lines used for HD.

Finally, greater attention will be paid to the prevention of iron deficiency through repeated monitoring of the iron status of children. Treatment with oral and/or intravenous iron in order to maximize the effect of EPO as recommended in the anemia management guidelines can now be more effective for pediatric patients as well.

The challenge that now lies before the pediatric community is to evaluate the benefit of the guidelines by closely monitoring the outcomes of children on dialysis following the implementation of the NKF-DOQI process. Do the recommendations regarding the amount of hemodialysis or peritoneal dialysis that a child is to receive result in better growth or improved

school performance? Do the recommendations regarding EPO and iron usage result in higher hematocrit levels for children on PD and HD? Are the recommendations regarding vascular access for HD particularly applicable to children, the majority of whom use a central line in contrast to a graft or fistula? The outcomes evaluation is ever so important to the pediatric patient because it is only in this way that the guidelines can be evaluated and, if necessary, modified to benefit children.

Finally, the process of establishing the NKF-DOQI guidelines has clearly pointed out that there are a number of topics related to the care of the dialysis patient about which there is little or no information specific to the pediatric population. Accordingly, these are areas for further research that must be investigated by pediatric health care providers nationwide. In this way, the NKF-DOQI guidelines can serve as the all-important springboard for efforts designed to optimize the care of the pediatric dialysis patient. 

NEPHKIDS:

Online Chat and Support for Parents and Kids

A discussion group, NEPHKIDS, was established through NKF's cyberNephrology initiative. NEPHKIDS is free and designed for families with children who have kidney disease. The chat group provides educational information and support for participants and allows them to share common experiences. Families, adolescent patients, physicians, nurses and other renal health care professionals are welcome to participate. To subscribe, send an e-mail to majordomo@UAlberta.CA with the words "subscribe NEPHKIDS" in the body of the message.

How To Read and Understand Your Lab Values

by Wayne Nix

NKF-DOQI addresses the core of what it takes for dialysis patients to feel as healthy as possible. Obviously, getting enough dialysis is at that core. To be able to determine if you are getting adequate dialysis you need to be able to read and interpret your monthly blood laboratory values.

There are many values reported on your monthly laboratory tests but three are very important to reduce the likelihood of death and medical problems, and improve your quality of life. The Health Care Financing Administration (HCFA), the arm of Medicare that pays for 80 percent of dialysis charges, refers to these as the core indicators. They cover adequacy, anemia and nutrition.

The National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF-DOQI) has reviewed adequacy and anemia, and is in the process of reviewing nutrition. Here are the recommendations and what you need to look for on your monthly blood laboratory reports.

1 Adequacy... Hemodialysis patients should have a Kt/V of 1.2 or higher. Under 1.2 means inadequate dialysis and could result in medical problems or even premature death.

Peritoneal dialysis patients should have a Kt/V of 2.0 or higher. Under 2.0 means inadequate dialysis and could result in medical problems or even premature death.

2 Anemia... To keep anemia at bay, your hematocrit (which appears as the letters HCT) should be between 33 percent and 36 percent. A low hematocrit can cause fatigue but also can have an impact on heart function.

3 Nutrition... A stable or rising serum albumin that is greater than or equal to the lower limit of normal (LLN) for each laboratory should be the goal. The HCFA core indicator study recommends a number at or above the lower limit of normal (LLN) for the laboratory at your hospital or dialysis facility if you are on hemodialysis. Poor nutrition (serum albumin) has been identified as a very important indicator of premature death.

With the new NKF-DOQI clinical guidelines, we can finally move beyond dialysis for survival to a health care approach that helps patients live their lives to the fullest. Our job as responsible consumers is to be involved in the decisions that are being made about our care. Knowing how to read your monthly laboratory results is an important step. 

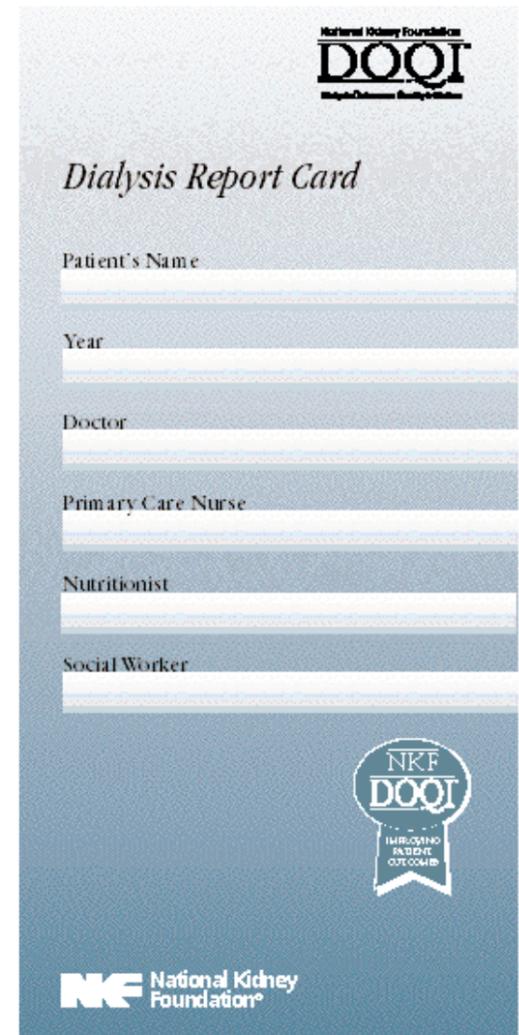
Understanding Your Lab Values

Kt/V and URR	To help reach your target Kt/V (at least 1.2) or URR (at least 65 percent), do not miss any treatments and stay on the dialysis machine for the full time prescribed for you. Follow your diet and fluid allowances so your dialysis treatments are comfortable.
nPNA	Your nPNA (normalized protein equivalent of total nitrogen appearance) is another way to tell if you're getting the right amount of protein from your diet.
Albumin	Albumin is a type of body protein made from the protein and calories found in the foods you eat each day. A low albumin level can signal a loss of muscle tissue. This kind of muscle loss can reduce your body's ability to fight off infections. Ask your dietitian how to eat the right amount of protein and calories to keep you healthy.
Hematocrit	Your hematocrit is a measure of the red blood cells your body is making. A low hematocrit can mean you have anemia. To help correct your anemia, you will probably need to take a hormone called EPO and extra iron. You will feel less tired and have more energy when your hematocrit reaches about 33 to 36 percent.
Hemoglobin	Hemoglobin is the part of red blood cells that carries oxygen to all the cells in your body. Your hemoglobin level is another way to tell if you have anemia. Your hemoglobin level should be at least 11 to 12.
TSAT and Serum Ferritin	Your TSAT (transferrin saturation) and serum ferritin are measures of iron in your body. Your TSAT should be at least 20 percent and your serum ferritin should be at least 100 to make sure you have enough iron to reach your target range hematocrit. You may need extra iron to reach these goal numbers.
Parathyroid Hormone (PTH)	A poor balance of calcium and phosphorus in your body can lead to high levels of parathyroid hormone (PTH). This can cause bone disease. Your PTH levels will be checked about every three months. Ask your doctor and dietitian how your calcium and phosphorus levels can be kept in balance so your PTH level does not get too high.

Calcium	Calcium is important for strong bones. To help keep your calcium level from getting too low, take your vitamin D3 (calcitriol) and calcium supplements as prescribed by your doctor. Be sure the phosphorus in your blood is within normal levels.
Phosphorus	A high phosphorus level can lead to weak bones. Make sure to follow your diet and take your phosphate binders with all meals and snacks.
Potassium	Too high a level of potassium in your blood can lead to heart problems and even a heart attack. Follow your diet allowances of potassium. Make sure you learn what foods are high and low in potassium.
Target Weight	Ask your doctor what your target weight should be. You will be weighed after each treatment to see how close you are to your goal. Record your target weight each month.
Average Weight Gain	Too much fluid weight gain between treatments can cause swelling, weakened heart muscle, shortness of breath, high blood pressure, and may make your dialysis treatment uncomfortable. Make sure to follow your fluid and salt allowances so you do not gain too much weight between your dialysis treatments. Record your average fluid weight gain each month.
Blood Pressure	Ask your doctor what your blood pressure should be. List your average pre- and post-dialysis blood pressures each month. Remember to take your blood pressure medications as prescribed. Follow your fluid and salt allowances.

Your Dialysis Report Card

In addition to measuring your Kt/V and URR, your dialysis care team will also do other blood and urine tests each month to help them plan treatment. They will also weigh you before and after treatment. Additionally, blood pressure should be monitored during your treatment. You should keep track of all your important test results. A copy of this report card is enclosed with this issue of *Family Focus*, so you can keep track of your test results. You may obtain another copy by calling the National Kidney Foundation at (800) 622-9010.



Sample Dialysis Report Card

Name Mary C.

Year _____

Name of Test	Goal	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Kt/V	≥ 1.2	1.3	1.2	1.2	1.3	1.4	1.2	1.2	1.3	1.2	1.4	1.2	1.2
URR	≥ 65%	67	65	65	67	70	65	65	67	65	70	65	65
nPNA	≥ 0.8	1.0	1.2	1.1	0.9	1.0	0.9	0.8	1.0	1.0	1.2	1.0	1.0
Albumin (BCG Test)	≥ 4	4.0	3.9	3.8	4.2	4.1	4.0	3.9	3.9	3.9	4.0	4.0	3.9
Hematocrit	33-36%	36.3	33.0	34.2	36.3	36.0	36.3	37.8	36.0	33.0	34.8	35.4	36.6
Hemoglobin	11-12	12.1	11.0	11.4	12.1	12.0	12.1	12.6	12.0	11.0	11.6	11.8	12.2
TSAT	20-50%	20			20			22			22		
Serum Ferritin	100-800	120			150			200			200		
Parathyroid Hormone	150-250	200			254			327			403		
Calcium	9-11	8.5	8.2	8.0	7.9	7.9	7.8	9.0	9.5	9.2	9.4	9.3	9.1
Phosphorus	3.5-6.0	7.0	7.5	8.0	6.9	9.2	8.3	7.1	8.1	7.4	7.2	7.1	6.0
Potassium	3.5-6.0	4.0	4.2	4.1	4.4	4.3	4.6	4.5	4.8	4.7	5.0	4.9	4.0
Target Weight	132 lbs.	134	134	133	132	132	132	132	132	132	132	132	134
Average Daily Weight Gain	1-2 lbs.	2.5	2.5	2.0	2.0	2.0	1.5	2.5	2.0	2.0	2.0	1.5	2.5
Pre-Dialysis Blood Pressure	< 140/90	140/91	140/91	133/97	142/85	139/88	140/95	133/85	147/95	150/91	150/98	146/97	145/99
Post-dialysis Blood Pressure	< 140/90	110/71	122/74	116/82	123/90	114/77	120/88	122/76	118/86	123/88	128/72	132/81	121/85

*This is how a sample dialysis report card might look when filled out. Ask your dialysis care team for your own copy so you can track your progress during the year. Your dialysis care team will fill in your goal numbers in the shaded column. Then you can list your

results each month. Ask your dialysis care team to highlight any results that need to be improved to achieve your goal. (See above sample).

Vascular Access

by Deborah Brouwer, RN

The purpose of the NKF-DOQI vascular access guidelines is to improve outcomes for all patients with a hemodialysis vascular access. What do these guidelines mean to an ESRD patient? The first and most important message is that an AV (native) fistula is the best access. A fistula connecting your own artery and vein should be the first choice for a new access or for a replacement if a previously placed access fails and a new one is required.

The fistula can be created in the lower arm near the wrist or in the upper arm near the elbow. The fistula should be placed well in advance of the start of hemodialysis in order to allow it to mature. The size of the vein needs to increase to allow for needle insertion. It should mature for at least one month but may need up to four months.

A fistula requires special

care when needles are placed for the first few uses. The first "sticks" may be difficult because the needle may infiltrate or come out of the vein and bleed into the tissue, causing swelling and bruising. Patience is needed to get through the early uses until the fistula is developed. Very few access failures occur in a developed fistula, and a well-developed fistula can last a lifetime.

If a fistula is not possible or has failed, the next choice is a PTFE graft. This graft can be placed in the forearm, upper arm, leg, chest, or even across the abdomen. These grafts tend to clot due to stenosis (narrowing) in the vein above the graft. If clotting occurs, the graft should be de-clotted as soon as possible to avoid the need for placement of a temporary dialysis catheter. The de-clotting can be done

in the operating room or

special X-ray room as an outpatient procedure.

For all patients with a PTFE graft, the direction of blood flow within the graft must be determined (Hemodialysis Adequacy Guideline 14, Table 1-5 NKF-DOQI hemodialysis adequacy guidelines). Most, or 80 percent of patients, have the arterial, or red, side of the graft on the inside of the arm. To assist in understanding this concept, imagine that your little finger is the red side, and the side where your thumb is, is the blue side (blue thumb). The other 20 percent of patients have reversed blood flow, with the red side where the thumb is (red thumb) and the blue side at the little finger. If the blood flow through the graft is reversed (red thumb) and the dialysis needles are placed as if the flow was "blue thumb," the

hemodialysis adequacy,

measured by the URR or Kt/V, will be decreased. (Vascular Access Guideline 21). Ask your dialysis staff to assess this and tell you the direction of the blood flow within your graft. It is important to be certain that the red/arterial and blue/venous blood tubes are connected correctly.

The last choice for a hemodialysis access should be the catheter. Hemodialysis catheters should be placed in the neck, or jugular vein, and not in the chest (subclavian vein). The tunneled, cuffed catheter is often tunneled into the chest, but the catheter should enter the vein near the neck. Frequent hemodialysis catheter complications are infections, poor blood flow and clotting. To decrease the chance of infection in a catheter, you and your

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The NKF-DOQI guidelines suggest the following "Patient Education Basics":

All patients should be taught how to:

1. Compress a bleeding access.
2. Seal the site of a central venous catheter, or any hemodialysis catheter, with ointment to keep an air embolus from entering should the catheter be dislodged.
3. Wash the skin over the access with soap and water daily before dialysis (for fistula or graft patients only).
4. Recognize signs and symptoms of infection.
5. Select proper methods for exercising the AV fistula arm.
6. Palpate for a thrill/pulse daily, and after any episodes of hypotension, dizziness or lightheadedness.
7. Listen for a bruit if the thrill cannot be felt for any reason.

All patients should:

1. Avoid carrying heavy objects over the access arm or wearing obstructive clothing.
2. Avoid sleeping on the access arm.
3. Insist that staff use different places to insert the dialysis needles and not use the same holes as the last treatment.
4. Ensure that staff use proper techniques in preparing the skin prior to sticking. The AV fistula or AV graft site should be washed with soap and water. Also, Betadine or povidone iodine must dry before the needle is inserted, and alcohol must be wet when the needle is inserted.
5. Report any signs and symptoms of infection and if you have an AV fistula or AV graft, let the dialysis staff know immediately if the bruit/thrill is absent.

Vascular Access

Continued from page 12

dialysis staff should wear a mask when the catheter is opened to be connected or disconnected to the dialysis machine and for dressing changes. As most infections are caused by a *Staphylococcus Aureus* germ that is commonly found inside the nose, the mask helps keep the germs away from the catheter and bloodstream.

It is important to protect your “vascular real estate,” or your veins, and the dialysis unit needs to use a screening protocol to evaluate patients’ vascular accesses. The screening techniques include monitoring intra-access flow or venous pressure. Other ways to monitor your vascular access are recirculation studies, decreased hemodialysis adequacy (URR or Kt/V), physical symptoms such as limb swelling, clotting of the graft, prolonged bleeding from the needle sites greater than 30 minutes, or changes in the bruit, or thrill, of the graft, elevated pre-pump arterial pressures and doppler ultrasound. You should ask your dialysis team which protocol your

unit uses to monitor your access for stenosis (narrowing).

Open discussion with your caregivers about how your dialysis unit is going to use the NKF-DOQI

vascular access guidelines to improve your care is a must for all ESRD patients. You have a right and a responsibility to know and understand issues related to keeping you and your lifeline healthy! **F**

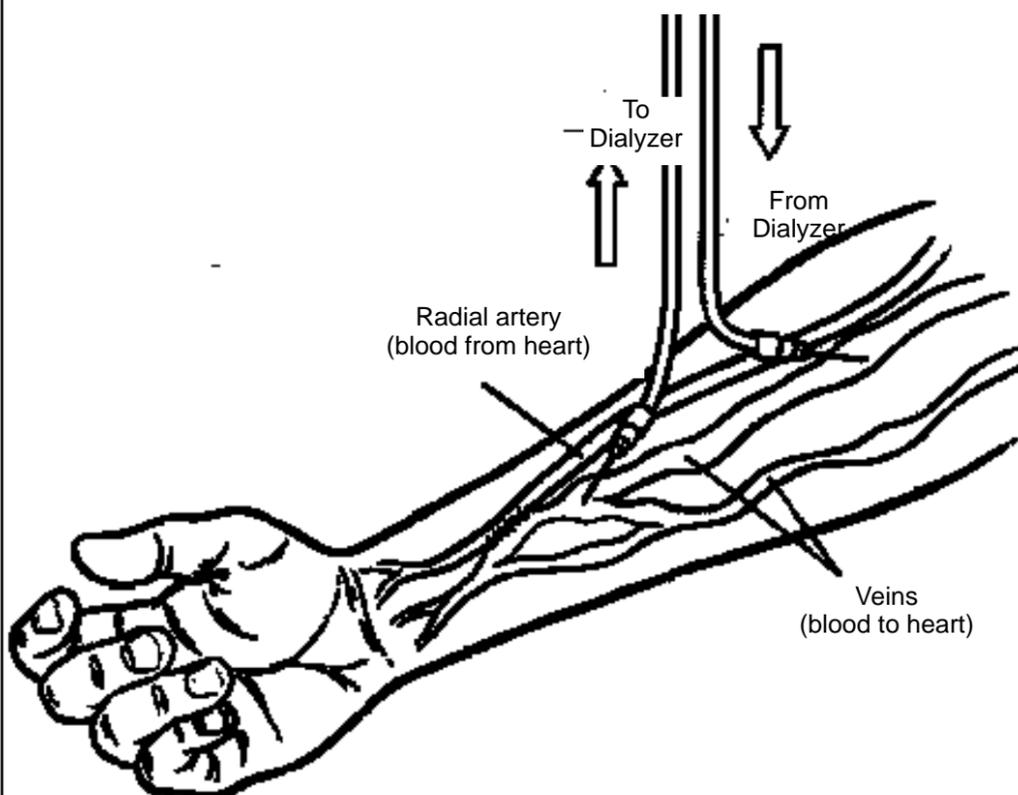


Figure 1. This diagram shows an AV fistula, created in the lower arm. According to NKF-DOQI guidelines, an AV native fistula is the best hemodialysis access.

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by Robert Vasquez, dialysis patient.



Good Nutrition

NKF-DOQI, Nutrition and You

by Linda McCann, RD

The National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF-DOQI) guidelines deal with a number of nutrition issues that may impact the care you receive. Each of the published guidelines (anemia, adequacy of hemodialysis, adequacy of peritoneal dialysis, and vascular access) involves the renal dietitian in a number of ways. The nutrition guidelines promise to clarify consistency of nutrition care.

The **anemia** guidelines provide specific iron monitoring goals. They define both the iron parameters that should be monitored and the levels that indicate adequate iron stores.

This will help ensure that all patients are treated equally and that their iron stores will be kept at adequate levels. The guidelines also make specific recommendations on the type and dose of iron supplements as well as the conditions that will allow iron to be optimally used. We know that adequate iron stores are critical for the treatment of anemia, especially when EPO is being administered. The NKF-DOQI guidelines can help your dialysis care team provide the right amount and type of iron to keep your hematocrit at the best level for you to feel your best.

The **vascular access** guidelines recognize the importance of good nutritional health to preserve your graft or fistula. Good nutrition helps you resist and/or fight infection. Graft problems

and infections are two of the most common causes for hospitalization. Staying well-nourished may help you stay out of the hospital. Good fluid balance is also important for graft function. Your renal dietitian should review your fluid balance with you on a regular basis. It is important for you to get enough fluid, but not too much. Learn what is best for you.



Adequacy of dialysis is critical to the success of both hemodialysis and peritoneal dialysis. The **hemodialysis (HD) adequacy guidelines** recognize the value of formal urea kinetic modeling over other measures of adequacy. With formal urea kinetic modeling, it is possible to “prescribe” dialysis that is right for your individual needs. “Modeling” can be done to determine how much time, what blood flow rate, and what dialyzer are needed to meet your dialysis prescription. Many renal dietitians perform the urea kinetic modeling for the health care team. They evaluate the data and run the computer program that calculates a number (Kt/V)

indicating the level of dialysis you are receiving. The level of dialysis that the guidelines recommend is a Kt/V of at least 1.2. If your dialysis provider uses urea reduction ratio (URR), the target is 65 percent. Keep in mind that the URR does not provide a way to identify treatment errors or to model an individual prescription, nor does it count any of the remaining urine output you may have. You should know

how adequacy is being measured for you and know your numbers.

The dietitian also works with the dialysis care team to identify problems in the treatment and to solve any inadequacies of treatment through the use of formal urea kinetic modeling. The hemodialysis adequacy guidelines give extensive information to help in the analysis of urea modeling results. Formal urea kinetic modeling also adds a nutrition checkpoint by estimating how much protein you are actually eating. It is quite accurate if your weight is stable (losing weight and muscle or gaining weight and muscle makes the estimate less

accurate). By comparing how much protein you are eating to the level of protein that has been prescribed for you, your renal dietitian can help you modify what you are eating to meet your protein goal.

The **peritoneal dialysis adequacy (PD)** guidelines provide many of the same areas of information as the HD guidelines. The guidelines give target values for adequate peritoneal dialysis therapy based on the type of therapy. It is also possible to “model” your specific situation and determine the best dialysis regimen for you. The adequacy parameters for PD, Kt/V and creatinine clearance are as follows:

- **Continuous Ambulatory Peritoneal Dialysis:**
Kt/V at least ≥ 2.0 /week and
Creatinine clearance 60 L/week
- **Continuous Cyclic Peritoneal Dialysis:**
Kt/V at least ≥ 2.1 and
Creatinine clearance 63 L (normalized to BSA)
- **Nightly Intermittent Peritoneal Dialysis**
Kt/V at least ≥ 2.2 /week and
Creatinine clearance of 66 L/week (normalized to BSA)

The PD guidelines also incorporate several nutrition-related aspects. First, they give suggestions on when to initiate dialysis. It is important to initiate dialysis before the negative side effects of kidney failure begin. For example, if you

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More Good Nutrition

Nutrition

Continued from page 14

become very uremic, you may develop malnutrition because of an inability to eat and/or nausea, vomiting, and taste changes. If you become malnourished prior to starting dialysis, your dialysis course may be more difficult. The PD guidelines also stress the importance of nutrition monitoring on a regular basis. The dietitian and/or nurse need to take your medical history and give you a minimal physical exam every four months to assess your nutritional status and classify you as well nourished, mild to moderately malnourished, or severely malnourished. This provides an ongoing picture of your nutrition status, which is very important to the success of your treatment and your well-being.

Adequate dialysis can help you maintain your appetite, illness and hospitalization,

and help you feel your best. You can only receive adequate hemodialysis treatment if you dialyze your full time at the blood flow rate that is prescribed and do not miss any treatments. If you are on peritoneal dialysis, you must perform all of your exchanges and use the prescribed volumes

team by dialyzing your full amount, follow your meal and fluid patterns, and take medications as prescribed. You should also know your adequacy numbers and discuss them with your doctor, nurse and/or dietitian. If you are not meeting the NKF-DOQI targets, you need to know

translate your nutrition needs into an understandable meal pattern, monitor and report your progress, maintain up-to-date knowledge of renal nutrition, incorporate new nutrition strategies into practice, and develop, revise and improve care plans to provide the best possible nutrition care for you.

“If you are not meeting NKF-DOQI targets, you need to know why and how to correct any problems.”

of dialysate. Your roles in your treatment are to participate in decisions about your care, become educated about your medical condition and treatments, follow the direction of the health care

why and how to correct any problems.

The roles of your renal dietitian are to listen to your concerns, educate you about your nutrition needs,

Each of the NKF-DOQI recommendations guide the health care team (that includes you) toward the best clinical practice. The guidelines can provide consistency of care from center to center and improve the overall quality of care. They provide ways for the health care team to monitor the effects of treatment and continually improve treatments. They set minimum goals for you to require from your provider of dialysis services. Use the guidelines to help improve your overall well-being. 

YUMBERRY CASSEROLE

We received some phone calls regarding the potassium content of this recipe, which appeared in a previous issue. In reviewing it, we have modified the recipe as below, so it is appropriate for peritoneal dialysis patients who have low serum potassium levels. For hemodialysis patients, one serving may be substituted for two high potassium vegetables. It is always advisable to check with your dietitian before using any recipe. Another suggestion may be to substitute apples or pears for the yams to lower the potassium content.

Canned yams, because they have been cooked in water, are lower in potassium than fresh yams or sweet potatoes, but they are still a high-potassium food and must be eaten sparingly. (A two-pound can of yams drained is equal to about 20 ounces of yams). In this recipe, the cranberry sauce adds color and a nice tartness but very little potassium. The oatmeal mix provides a healthy crunch to the topping.

- 1/4 cup of flour
- 1/4 cup of oatmeal
- 1/4 cup of light brown sugar
- 1/4 cup of soft butter or stick margarine
- 1 cup of whole cranberry sauce
- 1-2 pound can of yam pieces, drained



Mix the first four ingredients in a small bowl and set aside. In a large bowl, gently mix the yams and cranberry sauce. Don't stir so the yams get mashed, but keep breaking up the cranberry sauce so it evenly surrounds the yam pieces. Gently stir in one cup of oatmeal mixture until it's evenly distributed.

Butter a deep round casserole dish and place yumberry mix inside. Top with the remaining oatmeal mix. Bake 35 minutes at 350 degrees, or until it is hot throughout. Makes eight servings.

Analysis:

Each serving contains approximately

Calories	225 Kcal
Carbohydrate	42 gms
Protein	2 gms
Fat	6 gms
Sodium	83 mgs
Potassium	522 mgs
Phosphorus	55 mgs

BON APPETIT!

NKF-DOQI and Exercise

by Patricia Painter, PhD

First things first, as the saying goes. This holds true for dialysis also. NKF-DOQI outlines basic guidelines that are considered to be the foundation of dialysis treatment. If the foundation of care is not present, no other interventions will be as effective. With regard to physical functioning, it should be obvious that if not adequately treated for uremia, the individual will not feel well, and therefore will not be interested or able to participate in any program of regular physical activity.



■ ADEQUACY OF DIALYSIS

It is clear that the circulating toxins negatively affect the way many systems of the body work, including muscles. Thus, the ability to perform physical activity is very likely affected by the adequacy of dialysis received. When inadequate dialysis is delivered, the individual also does not feel well enough to get moving and maintain his or her strength. There have been no studies performed to determine how exercise capacity is affected by different levels of dialysis, however, it should be obvious that the better dialyzed someone is, the functioning of all cells in the body will be improved. There is some speculation that if someone exercises during dialysis treatment, it may help improve the clearances. Eighty percent of our bodies is muscle tissue, which has very little blood flow at rest. Thus,

there is about 80 percent of tissue to which blood is not exposed during dialysis. When the muscles are moving, the blood flow increases. Increasing the blood flow to the muscles may increase clearances just by exposing blood to more tissue.

Although this is only speculation, it is worth exploring. In any event, it is probable that the higher the Kt/V or URR, the better an individual will feel and the more he or she will be motivated to participate in regular exercise.

■ ANEMIA MANAGEMENT

Red blood cells carry oxygen in the blood. When someone is anemic, he or she has low levels of red blood cells, and therefore the individual is limited in the amount of oxygen that can be carried. In order to

percent, the ability to exercise is improved.

It must be stated, however, that once enough oxygen is transported, the muscles must be conditioned in order to effectively use the oxygen that is transported to them. If the muscles are wasted and weak from not being used for a long time (sound familiar?), then the oxygen transported to them will not be efficiently used and will make little difference in exercise capacity. So, we need to think about making the best of the effects of EPO and the increased hematocrits by building up muscles and making them work so they can effectively use the oxygen that is delivered to them. The only way to build up the muscles is to use them on a regular basis with a program of exercise, such as walking,

arm in which their vascular access has been placed. Most say they were told NOT to use that arm. This is an accurate and appropriate recommendation initially after surgical placement of the access. But, once the surgical incisions are healed, there is no reason not to use the fistula arm. In not using it, the muscles become weak, the range of motion in the shoulder is lost, and the person eventually ends up with a “frozen shoulder”—unable to lift his or her arm above his or her head. Gripping and lifting abilities are lost, all because no one followed up with the surgeon’s recommendation, when the incisions were healed, to start using the arm in a normal manner. Using the access arm will actually enhance blood flow through the access, build up or maintain muscles around it, which will stabilize it, and make it easier to place needles in it. BUT—avoid lifting very heavy objects, as that causes the muscles to cut off circulation to the access, and don’t place anything on the access that would cut off blood flow. Gripping and low-level strengthening exercises along with stretching and range of motion exercises will help the fistula arm to maintain full range and function.

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***“You can become fit and healthy
and enjoy your life the way
you want!”***

perform exercise of any kind, the muscles require oxygen. If inadequate oxygen is available, the muscles can only contract for a short period of time. Thus, anemia management with EPO is critical to an individual’s ability to exercise. Anemia also results in general fatigue, and with fatigue, people do not feel like doing much of any kind of physical activity. It appears that once hematocrit levels are stabilized and maintained at a minimum of 33-36

bicycling, swimming and strength exercises.

■ VASCULAR ACCESS

Placement of a vascular access is a surgical procedure, and a surgical procedure is not really affected by regular physical activity. However, regular exercise is definitely affected by the vascular access. For example, if the individual is admitted for a clotted fistula, he or she may not be able to continue a normal activity program. Many people on dialysis are not using the

■ NUTRITIONAL



NKF-DOQI and Exercise

Continued from page 16

MANAGEMENT

In order to function well, the muscles also require adequate energy. This energy comes from food. In individuals with renal failure, the buildup of substances such as potassium and imbalances in calcium/phosphorus can affect the contraction operations of the muscles. It is critical to follow a proper diet, which means eating enough calories and watching the levels of the various substances in your diet to assure that the muscles can contract properly.

The NKF-DOQI guidelines are the foundation. Once the foundation is

established, we cannot stop there. From adequate dialysis, anemia management and nutritional status, we can build in physical functioning through regular exercise. The foundation will allow people on dialysis to carry out such rehabilitation goals as education and employment. Efforts to establish recommendations to assist in attaining these goals should be part of the next quality initiative process. So, don't stop at the foundation — work with your physician and dialysis providers and launch your life from there. You can become fit and healthy, and enjoy your life the way you want! 



F U N & G a m e s

Find all the words that are printed in **BOLD** in the paragraph below.

S	Y	E	N	D	I	K	D	O	C	T	O	R
X	O	U	R	E	A	P	D	B	I	P	Z	V
S	I	Z	E	N	T	T	I	M	E	A	N	C
V	W	A	D	E	Q	U	A	C	Y	T	I	D
S	R	T	U	K	F	C	L	Q	U	I	R	O
O	T	E	C	H	L	M	Y	C	K	E	A	O
C	R	A	T	I	O	E	S	R	U	N	P	G
I	V	R	I	P	W	D	I	E	T	T	E	L
A	D	O	O	L	B	N	S	X	Y	U	H	E
L	I	J	N	U	M	B	E	R	P	O	F	E
W	O	R	K	E	R	B	R	E	U	S	E	F

What is **UREA REDUCTION RATIO**? It is the **NUMBER** (%) that tells you how much the waste product, urea, in your **BLOOD** has decreased in one **DIALYSIS** treatment. Your URR is affected by a number of things: treatment **TIME**, dialyzer **SIZE** and the blood **FLOW** rate, use of **HEPARIN**, and the unit's **REUSE** policy. URR is a measure of **ADEQUACY**, to adequately clean your blood as close to how your **KIDNEYS** would do. To do a good job, your URR should be at or more than 65 percent—meaning that 65 percent of the urea should be removed from your blood each treatment. The dialysis team, the **DOCTOR, NURSE, TECH**nician, **SOCIAL WORKER**, and **DIET**itian, along with you, the **PATIENT**, work together to improve your number and therefore, help you **FEEL GOOD!**

Getting the Most From Your Hemodialysis

Why is it important to get the right amount of dialysis?

Getting the right amount of dialysis treatment is important to:

- ▼ improve your overall health
- ▼ help you live longer on dialysis
- ▼ improve your quality of life on dialysis
- ▼ keep you out of the hospital.

Research has shown that patients feel better and live longer when they get enough hemodialysis. The best way to ensure that you are getting enough treatment is for your dialysis care team to measure your “**delivered dose**” of dialysis. This tells them how well your treatment is removing a waste called **urea** from your blood. The numbers used to measure your delivered dose of dialysis are **Kt/V** (pronounced kay tee over vee), and **URR**, or urea reduction ratio. Your dialysis care team will collect blood samples from you once a month to do these measurements. You may also be asked to collect a urine sample.

Your dialysis center may use either Kt/V or URR to measure your delivered dose. To be sure you are receiving enough dialysis, **your Kt/V should be at least 1.2, or your URR should be at least 65 percent**. The amount of time you need on dialysis is based in part on how long it takes to reach these important target levels. Hemodialysis is usually done three times a week. In general, each treatment lasts between three and four hours, but **you may sometimes need to be on the machine longer to get the most from your treatment**.

How is my delivered dose of dialysis measured?

The most accurate way to measure your delivered dose of dialysis is a method called **formal urea kinetic modeling, or UKM**. To do this, your dialysis care team will take samples of your blood with your dialysis treatments. You may also be asked to collect a urine sample. These samples will be used to measure how your dialysis reduced the level of urea in your blood. Other things that are taken

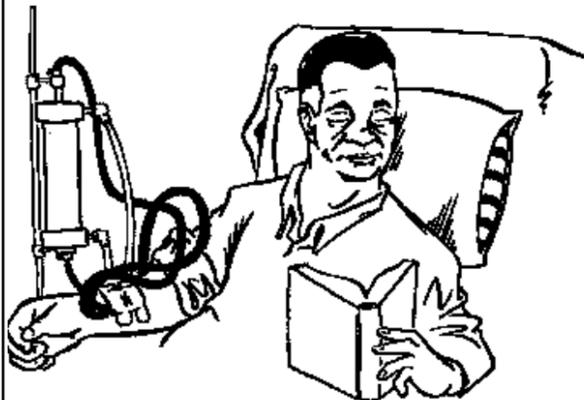
into account include your weight before and after your treatment and the amount of time on dialysis. All the information is fed into a computer to find **your Kt/V**. This method of measuring your delivered dose of dialysis helps your dialysis care team to:

- ▼ plan your treatment better
- ▼ check for errors that might prevent you from reaching your target delivered dose.

If your dialysis center uses URR to measure delivered dose, it is determined by comparing the amount of urea in your blood before and after your dialysis treatment. Your blood must be taken in a particular way in order to get accurate results. **Ask your dialysis care team about this if you have any questions.**

What if my numbers are too low?

If your numbers are too low, ask your dialysis care team what can be done to get them where they should be. If your Kt/V or your URR is below the target level, your dialysis care team should check to make sure:



- ▼ your access is working well
- ▼ your dialyzer is working well
- ▼ the blood flow and dialysate flow rates are not too slow
- ▼ your blood samples are taken correctly
- ▼ you are there for your full treatment time
- ▼ you did not miss any treatments.

Is reusing my dialyzer safe?

Many dialysis centers use the same dialyzer (artificial kidney) more than once on the same patient. This is called reuse. **Reuse is generally**

considered safe when done properly. Your dialyzer must be labeled carefully with your name and an identification number. You should ask to check this before each dialysis treatment to make sure you have your own dialyzer.

Dialyzers that are reused are **cleaned and disinfected** carefully before each treatment. In addition, your dialysis care team **tests your dialyzer before each use** to make sure it is still working well. If your dialyzer is not doing its job, you will not get enough dialysis. When your dialyzer no longer works well, it should be discarded, and you should be given a new one. **Before each treatment, ask your dialysis care team if they have tested your dialyzer and whether it still works well.**

If you do not wish to reuse your dialyzer, your dialysis center may be willing to supply you with a new one for each treatment. Check with your dialysis care team about the reuse policy at your center. For additional information, see the following brochure *Understanding Reuse: A Guide for Hemodialysis Patients*, soon to be available from the National Kidney Foundation.

How can I stay comfortable during my treatment?

Your dialysis care team will make sure you are as comfortable as possible during your treatment. You are more likely to stay on the machine for your full treatment if you do not have cramps, headaches, nausea or dizziness. These symptoms are not common, but if you do have any of them, **ask your dialysis care team if any of the following changes in your treatment could help you:**

- ▼ Slow down your fluid removal, which could increase your dialysis time
- ▼ Increase the amount of sodium in your dialysate
- ▼ Check your high blood pressure medications
- ▼ Adjust your dry weight, or target weight
- ▼ Cool the dialysate a little.

Continued on page 19

Treatment—Answers to Your Questions



How can I keep my access working?

Your dialysis care team will check your access often to make sure it is working well. An access that is *not* working well can decrease the amount of dialysis you receive. **If you have a fistula or graft, your dialysis care team will check the blood flow by feeling the access for a vibration called a pulse or thrill. They will also do some other tests, such as measuring the pressure inside your fistula or graft, to make sure your access is working well.** Your dialysis care team will teach you how to check your fistula or graft at home each day. Here are some tips you should follow to help keep a fistula or graft working longer:

- ▼ Check the blood flow several times each day by feeling for a vibration, also called a pulse or thrill. If you do not feel this, or if there is a change, call your doctor or your dialysis center
- ▼ Do not wear tight clothes or jewelry on your access arm
- ▼ Do not carry anything heavy or do anything that would put pressure on the access.
- ▼ Do not sleep with your head on the arm that has your access
- ▼ Do not let anyone use a blood pressure cuff on your access arm.
- ▼ Do not let anyone draw blood from your access arm
- ▼ Do not be afraid to ask your dialysis care team to rotate needle sites
- ▼ Apply only gentle pressure to the access site after the needle is removed. Too much pressure will stop the flow of blood through the access
- ▼ If you have breakthrough bleeding after you have dialysis, apply gentle pressure to the needle site with a clean towel or gauze pad. If the bleeding does not stop in 30 minutes, call your doctor or your dialysis center.

What are the benefits of treating my anemia?

Anemia can make you feel very tired. In most kidney patients, anemia happens because the kidneys no longer make enough of a **hormone**

called erythropoietin, or EPO. This hormone **tells your body to make red blood cells.** Red blood cells are important because they carry oxygen to all parts of your body.

Correcting your anemia has some important benefits for you:

- ▼ It decreases your chance of having heart problems
- ▼ It increases your energy level
- ▼ It improves your quality of life
- ▼ It improves your ability to exercise
- ▼ It helps you live longer on dialysis.



Many kidney patients need treatment for anemia even before they begin dialysis. Treating your anemia early improves your overall health and helps you do better when you need to start dialysis.

What can I do to get the most from my treatment?

Take an active role in your treatment. You can do a lot of things to help ensure that you are getting the most from your treatment, so you can feel better and live longer:

- ▼ Know the important numbers that tell how much dialysis you are getting. These include your Kt/V and URR. Keep a record of your numbers and talk to your dialysis care team if they are lower than the goal

- ▼ Keep all your dialysis appointments. Arrive on time, stay for the full time prescribed for you, and try not to interrupt your treatments. Missing just a few minutes each time adds up and will harm you over the long term
- ▼ Speak to your dialysis care team if you are having cramps or other uncomfortable feelings during dialysis. Ask what can be done to help
- ▼ Follow your special diet. If you are having a problem, ask your renal dietitian for recipe suggestions to make your meals taste better.
- ▼ Take all your medications just as they are prescribed for you
- ▼ Don't exceed your fluid allowances between treatments. Too much fluid weight gain increases the amount of fluid removal you need and may cause symptoms like cramps, dizziness, headaches or nausea during your treatment
- ▼ Avoid salty foods. Too much salt can make you thirsty, and you will want to drink more fluid
- ▼ Ask your doctor about an exercise program that is right for you. Exercising on a regular basis can make you feel stronger
- ▼ Take your EPO and iron as prescribed by your doctor. Correcting your anemia will help you feel more energetic so you can return to your normal activities
- ▼ Learn the steps to good access care. This can help to keep your access working well longer
- ▼ Learn all you can about your treatment. Speak to your dialysis care team if you have any questions at all. They are there to help you do well on your treatment.

This article is from the National Kidney Foundation brochure Getting the Most From Your Treatment: Hemodialysis Adequacy. © May 1998 and used with permission. 

Extraordinary People—Like You!

by Kay Smith, MSW

If you are the “average” dialysis patient, you are 60.5 years old and have been on dialysis about two years. You have survived the Great Depression, FDR’s New Deal, WWII, the Korean and Vietnam Wars, Frank Sinatra to Garth Brooks, and you know how to jitterbug and do the twist. Maybe you think you have seen enough change!

Working in the dialysis setting, it is common to witness how capable, “ordinary” people become extraordinary people while coping with the changes in their lives brought on by kidney disease. Anyone who has dealt successfully with renal disease has earned a PhD in adjusting to change! Now as you learn about the NKF-DOQI recommendations, you may find yourself facing additional changes, such as increasing your treatment time.

The American Heritage Dictionary defines change as “to cause to be different; alter; to give a completely different form or appearance; transform.” No wonder change is a threatening thing! If someone’s spouse came home and said, “I want to change things,” it would probably be received with anxiety or resistance. Yet we are all bombarded with the challenge of adjusting to change daily. How we cope is the essence of our satisfaction in life.

Some people begin dialysis after years of medical follow-up and the knowledge that their kidneys are failing. Some people have a sudden onset of illness and develop kidney failure with little or no warning. Yet everyone who has kidney failure is presented with the information that treatment is necessary to continue life. People who cope successfully with this challenge have embraced treatment as an opportunity to continue their lives. They feel the anger, the “why me,” but they also rejoice in the fact that treatment gives them life.

How you cope with the disease and its treatment requirements will make all the difference in the outcome of treatment and your “quality of life.” You are the main team member in your health care team. With your full participation your treatment is more likely to be successful and you will feel more “in charge.” While many of the other articles in this issue focus on the actual NKF-DOQI guidelines, let’s now take a look at some ways of coping with such things as treatment change and see where you may fit.

There are many styles of coping and there is no right or wrong way, yet there are things you can do to increase the possibility of a successful outcome. Four attributes that can increase your ability to cope are good self-esteem, a positive outlook, taking charge of your situation and being extroverted. Let’s examine these. It is important to remember that everyone has areas of strength and some aspects that could use more work.

Good self-esteem can be derived from knowing that you are valued for who you are. No matter what your health or ability to “do,” you are a unique individual unlike anyone else on earth. It will help to let friends and loved ones validate this fact. When you feel loved and valued just for being yourself, you will have improved your self-esteem.

A positive outlook refers to the ability to see the “half-full glass” rather than the “half-empty glass.” In terms of

renal disease, some patients say that they are grateful for the treatment options since other illnesses have none. The challenge of dealing with health problems takes a very strong individual, and a positive outlook will help supply the energy to meet that challenge.

Another way to cope successfully with renal disease is to **become the captain of your team**. You are the most important member of your health care team and by becoming involved in treatment decisions and treatment plans you will feel like you are taking charge of your life. Your doctor, nurse, dietitian, social worker and technician should welcome your active participation.

Some people are naturally more outgoing than others. Yet if you can **practice being more outgoing** with your health care team, you will again feel more in charge and a part of your treatment. Ask questions about renal disease and your treatment. Asking questions and learning about such things as adequacy of dialysis, dialysis accesses and anemia are important places to begin. Talk about your plans, expectations and goals. Get to know your health care team, and let them know who you are and what is important to you. Along the way you will meet many extraordinary people like yourself who are coping with the changes and challenges that chronic kidney disease brings. 