

COMMON

News and information

ESRD Network



Concerns

for kidney patients and their families

From the Network 11 Consumer Committee Chair

It is Saturday morning and I am sitting at my table surrounded by gardening magazines, quilting magazines, and past issues of Common Concerns. This is the morning I have set aside to plan my projects for the next six months.

This is really something! Eight years ago, when my kidneys failed and I began dialysis, I didn't plan beyond the next day. Sometimes I didn't plan beyond the next minute. I was sick. I was scared. And my life had just changed drastically. Then I received my first issue of Common Concerns and, slowly, things began to turn around. It started to sink in that there were others out there somewhere who had gone through the same things I was going through. There were actually groups of people out there whose sole job it was to try to make things easier for me and teach me how to live this new life. There was a Network out there that really cared enough about how I was doing to send me information and offer me any help they could.

Network 11 has now become a very big part of my life. It has introduced me to people who have done remarkable things with their lives even though they are on dialysis. And it has introduced me to people who are leading just plain ole' ordinary lives even though they are on dialysis. Eight years ago I would not have thought my life would ever be ordinary again. But now it is.

The Consumer Committee is made up of a group of 13 renal patients in varying stages of life who volunteer to work closely with the staff of Network 11. We

represent the needs of other renal patients in the five states that we serve: North Dakota, South Dakota, Minnesota, Wisconsin and Michigan. Quality of Life is a big focus for us. It is our fervent desire to see all renal patients in our five states enjoying and experiencing life to its utmost. And we feel that this is most achievable through varying levels of rehabilitation. The resources are out there, and we have taken on the job of showing you where they are and how to use them. This is, in fact, our top priority.

We have just adopted a two-year plan to address Vocational Rehabilitation and quality of life issues for the Network 11 consumers and providers. We are looking forward to addressing such issues as volunteering, exercising, family life, and depression management. We intend to show you the how's and why's of Vocational Rehabilitation and, in doing so, we hope to see an improvement in the number of referrals to Vocational Rehabilitation services, and possibly the number of patients attending school or working.

Do you want to join us on this mission? There are several ways of doing so, but I would like to take this opportunity to showcase one of them. Our election process is soon to begin and most positions on the Consumer Committee are up for re-election. Some existing members are choosing to run again, and some are stepping down. I urge each and every one of you to look at your life and see if there is something missing. If so, look further inside and see if serving your

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fellow renal patients by seeking a position on the Consumer Committee might be an answer for you. We are looking for people in all walks of life with varied experiences to represent the needs of others in your area. The mission is important. The challenges are very real. And the rewards are incredible. If you are interested, if you can give us some of your time and energy, and if you are ready to experience the satisfaction of helping others achieve their highest potential, please read the accompanying article on the election process. We would love to hear your voice during our up-coming elections.

Maggie Carey
Renal Network 11 Consumer Committee Chair

Quality of Life and You

As an ESRD patient, whether your modality treatment method is hemodialysis, peritoneal dialysis, or transplant, you have probably heard the terms clinical indicators or clinical outcomes. These terms generally refer to laboratory tests such as hemoglobin, albumin, URR, Kt/V, phosphorous, or other treatment markers your dialysis center measures to gauge your clinical status. Most likely you hear about these outcomes on a monthly basis from a dietician, physician, or nurse in your clinic. Without question it is important for you as a patient to understand these lab tests and how they impact your physical health. But there is another term, which is also indicative of your overall well being that might not receive as much attention in your treatment as do the laboratory tests. This term, Quality of Life, is an important indicator for you to consider and is receiving increased attention in the renal community.

What is quality of life? There are many answers to this question, depending on who is responding to the question. Quality of life may be measured by the amount of time you are able to travel, be with family and friends, or exercise. For others, their quality of life is best measured by the amount of time they are

able to spend working, attending school, or volunteering in the community. Yet others gauge quality of life on how they are feeling, both physically and emotionally. Most frequently, quality of life includes many of the above factors. As an ESRD patient it is an important aspect of your treatment to consider.

Why is quality of life important? Generally, most of us seek out activities that improve our quality of life. As an ESRD patient, you have made a decision to seek a treatment (dialysis or transplant) that is intended to extend your life in spite of kidney disease, and at the same time improve your quality of life. As you navigate your way through your journey with ESRD, there is a good chance your quality of life has been impacted in some manner. As an ESRD patient, understanding what is important to you and how you define quality of life are vitally important as you face choices related to your treatment. For example, you might be faced with a decision to attend your regularly scheduled dialysis treatment or attend the graduation ceremony of a family member. Missing either your treatment or the graduation ceremony might have a negative impact on your quality of life. However, if you are aware of what is important to you in respect to your quality of life, this decision might be easier for you to make.

What impacts quality of life? Many factors can play a role in diminishing your quality of life. From a medical standpoint, being anemic, being underdialyzed, suffering from depression, or having poor nutrition can negatively impact your quality of life. Many practical factors such as finances, insurance concerns, transportation problems, scheduling challenges, and employment issues can have a negative impact on your quality of life.

What can you do to improve your quality of life? In an effort to improve your quality of life, you need to think about what is important to you and understand how you define quality of life. As you begin to understand what you are trying to achieve while coping with dialysis or transplant, you will be able to focus

your energy in that direction. Educating yourself about your treatment options is also important. As you begin to understand the recommendations of your medical team, you will be more able to make decisions about which aspects of your treatment are vital to your physical well being and which aspects you might be able to negotiate with your health care team. Engage the support of your health care team; you have access to professionals who are well educated in the physical, emotional, and practical aspects of your quality of life. Remain as active as possible. Research has shown that ESRD patients who remain engaged in of the activities they participated in prior to beginning treatment (working, exercising, traveling, etc.) tend to score higher on Quality of Life measures. Finally, recognize that your quality of life and how you define your quality life is an ever-changing process. As you cope with the burdensome aspects of kidney failure you might have days when you define a good quality of life as simply making it to treatment that day. Hopefully though you will have more days than not when your quality of life is high in your mind because you are actively participating in your treatment plan and engaging in the activities that you have defined as important to you.

ESRD and Vocational Rehabilitation

Josephine Mahi



Adjusting to life after a diagnosis of end-stage renal disease (ESRD) is a challenge that brings forth special courage and resolve from thousands of patients. Making a smooth transition for successful results requires the involvement of a multi-disciplinary team made up of nephrologists, dietitians, nurses, social workers, and dialysis technicians. An additional member of the team who could be an important part of your success, is a vocational rehabilitation counselor. Individually and as part of a larger team, these professionals can help you to overcome

the physical/functional, psychological and emotional issues, which often accompany renal failure.

Like butterflies emerging from a cocoon, ESRD patients are better rehabilitated to participate in and enjoy life again when they have greater personal control over chronic anemia, muscle weakness, reduced capacity for exercise, and sense of loss and sadness.

“To fully participate with the medical team in your care, it is very important for you as an ESRD patient to have a full understanding of your disease.”

To fully participate with the medical team in your care, it is very important for you as an ESRD patient to have a full understanding of your disease. ESRD patients are asked to adhere to a challenging dialysis schedule, a strict renal diet, and frequently a complicated medication regimen. In addition, it is important for you to be involved in a suitable exercise program. Once you have the above in your control, like a solid foundation in any good structure, it is much easier to regain the sense of control that activates the natural drive to return to school, work, or skill enrichment training.¹

The state vocational rehabilitation (VR) office is the designated service provider for the renal patient. State and federal funding provide a public service to develop, improve or reinstate the ability of the disabled, ESRD patients included, to become employed, or as self-sufficient as possible. Among the services offered are vocational counseling, skill enhancement training, finding a job, supported employment, and assistive technology such as computers.

Upon gaining access to the vocational rehabilitation office in your state, you will be set up for an initial intake appointment. This appointment may occur over the telephone or in-person. The initial intake is a process of meeting with potential recipients to assess the level of disability, employment history, unique strengths, interests and abilities. The

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assessment is usually followed by an in-depth interview to identify and agree upon an employment goal. Each vocational rehabilitation department in Network 11 (Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin) offers services that vary a bit from state to state; generally, however, they share the same procedure of developing a detailed plan of services aimed at achieving goals, oftentimes called an Individualized Written Rehabilitation Program.

As mentioned, the vocational rehabilitation department is not intended solely to assist you to gain employment. Individuals may receive vocational skills, when the required skills are lacking. You might also be eligible for on-the-job training through supported training at a vocational technical school, or at a college or university. Personal support services are also available for individuals who have unique employment and training needs such as sign language interpreters, readers, job coaches, personal attendants or note-takers.

For some people special equipment or altering the way a job is done may be necessary to meet work requirements in the job place. This may involve purchasing special equipment such as electronic systems or appliances, or redesigning a work area for an employer by adding wheelchair access, for example. Where necessary medical services such as artificial limbs, hearing aids, wheelchairs, or corrective surgery may be needed before an individual can obtain work.

When the available services at the state vocational rehabilitation center are effectively combined, it should enable an ESRD patient to develop a resume and placement plan to find employment or re-join the work force. At the University of Michigan Medical Center, a unique program offers peer counseling. Peer counselors who listen and share their own experiences visit each new dialysis patient. Michigan also offers new renal patients a VR workshop, thus improving the chances that patients will complete the assessment process without becoming discouraged. In some states VR counselors take a more proactive approach

by making regular visits to dialysis facilities to provide forms and vocational rehabilitation counseling. New York, in a pilot program, has a VR specialist who is certified to work with ESRD patients.

Finally, there is no doubt that a person needs help to return to a full, productive life after kidney failure. One simply has to ask for help in taking the first step on a new journey. The most significant person in the rehabilitation plan is the person with the kidney disease. With hard work and determination you can take charge like the growing numbers of disabled people who daily demonstrate that the results can be worth the effort to regain self-worth.

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If you are interested in learning more about the services your vocational rehabilitation department offers, you should speak with the social worker in your clinic.

¹“Renal Rehab,” by Elizabeth Baker, M.D., www.rehabmed.net/documents/renal.html

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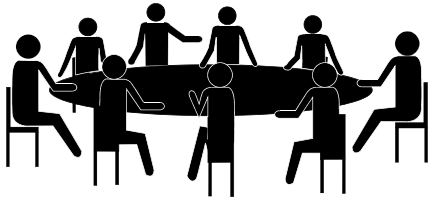
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Consumer Committee Special Project 2003-2004



The Consumer Committee of Network 11 is an instrumental group in developing, coordinating, and disseminating special projects related to patient education materials. In the past the Consumer Committee has developed tools, such as key-chains and magnets to make consumers aware of how to get in contact with Network 11; the Committee also developed Patient Grievance posters and helped to produce an educational video entitled "Living Well on Hemodialysis." Recently the Consumer Committee of Network 11 has looked at the outcome data from the annual Network 11 Vocational Rehabilitation Data Collection effort. Based on the outcomes of this data collection, the Consumer Committee has identified an opportunity for improvement in the area of vocational rehabilitation, as well as other quality of life related issues.

Special Project Proposal

The Consumer Committee proposes a two-year plan to address Vocational Rehabilitation and Quality of Life issues for the Network 11 consumers and providers. The following timeline has been laid out.

2003

1. Begin to gather resources currently available regarding Vocational Rehabilitation and Quality of Life (i.e., volunteering, exercising, family life, depression management).
2. Compile resources into a central source (e.g., bibliography, toolbox) and develop a consumer and provider friendly resource.
3. Distribute information to Network 11 consumers and providers.

2004

1. Identify and locate key new personnel associated with the Vocational Rehabilitation programs within Network 11.
2. Develop working relationships with Network 11 Vocational Rehabilitation contacts.
3. Identify methods to link providers and consumers with their state Vocational Rehabilitation programs.

ARE YOU A DIALYSIS OR TRANSPLANT PATIENT WHO LIVES IN NORTH DAKOTA, MINNESOTA, WISCONSIN, OR MICHIGAN?

If you answered, "yes" to this question, you should consider serving on the Renal Network 11 Consumer Committee. The Consumer Committee is made up of 13 ESRD consumers from the states of Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin. The members of this committee help to support Network 11 in its mission to assess and improve the quality of care provided to individuals with End Stage Renal Disease (ESRD). Specifically the Consumer Committee works to assist in the development of educational materials, such as this issue of Common Concerns. The Consumer Committee meets via conference calls and in-person meetings. The Consumer Committee will be holding an election this fall for a four-year term starting in 2004. If you would like more details about serving on this important committee, please call Mark Meier at 1-800-973-3773.

National Kidney Foundation Calendar of Events

Contact the **NKF of Michigan** at **800-482-1455** for a listing of upcoming events.

Contact the **NKF of Wisconsin** at **800-543-6393** for a listing of upcoming events.

Contact the **NKF of Minnesota** at **952-544-7300** for a listing of upcoming events.

The **NKF of South Dakota** will hold the NKF Gift of Life Run Poker Run on September 13, 2003. They will also be sponsoring KEEP Screening in Yankton on September 16, 2003 and a Patient Picnic on September 21, 2003. On November 2, 2003, they will be hosting a Feast of the Great Chefs and an auction. For more information on these events and to RSVP for the patient picnic, call the South Dakota NKF at **605-338-0518**.

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