

ENCOURAGEMENT

Renal Rehabilitation Bridging The Barriers: For Patients and their Families



Developed by
The Life Options Rehabilitation Advisory Council

Supported by
Amgen Renal Advances

Administered by
Medical Education Institute, Inc.

Bridging the Barriers: For Patients and their Families was written for patients and their families to help them learn about dialysis and how it will affect their lives. This booklet is not intended as a substitute for medical counseling or legal or other professional advice, and should not be considered as such.

Readers must recognize that some suggested activities, exercise in particular, involve certain risks, including the risk of severe injury, disability, or death. These risks cannot be completely eliminated even when done under expert supervision. Use of these materials indicates acknowledgment that Amgen Inc., Medical Education Institute, Inc., and the Life Options Rehabilitation Advisory Council will not be responsible for any loss or injury sustained in connection with, or as a result of, the use of this booklet.

In addition, readers must understand that this material may not address all issues of concern to you in light of your particular circumstances. Also, future legislation and court decisions may significantly change the current law or interpretation of current law. None of, Amgen Inc., Medical Education Institute, Inc., or the Life Options Rehabilitation Advisory Council is under any obligation to update the materials contained within which are based on information available as of the date of publication.

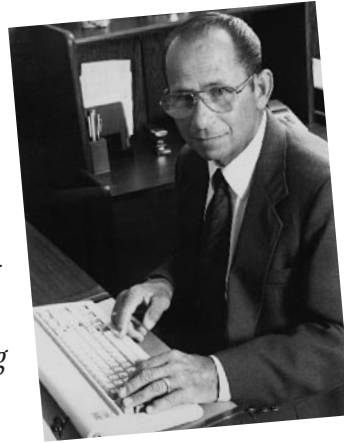
If medical, legal or other professional advice is required, please seek the personalized service of a competent professional.

July, 1994

Dear Fellow Patients:

I'm writing to you because I share your interest in renal rehabilitation. I've been on dialysis since 1970. And I'm a survivor of three failed transplants.

Despite these challenges, though, I returned to school after starting dialysis and got an associate degree in mechanical technology. Eventually, I became manager of my company's tool engineering department. More recently, I've been spending my time setting up an employment program for other kidney patients.



I'm also an emeritus member of the Life Options Rehabilitation Advisory Council. This Council includes patients, care providers, government representatives, and researchers. While we have different experiences and training, all of us have one common purpose: working to identify and address renal rehabilitation issues.

Recently, the Council developed a renal rehabilitation resource report called **Bridging the Barriers**. The following pages of this booklet present a specially prepared summary of that report for patients and family members living with renal disease.

As you can see, the Council has identified five "bridges" to rehabilitation. The Council refers to these bridges as the "5 E's": encouragement, education, exercise, employment, and evaluation.

This booklet details how you can approach life with these "5 E's" so you can get the most out of life on dialysis.

As an individual living and working with renal disease, I've learned that you can, with some effort, take control of your life and do better than you think.

Remember, you're not alone.

Sincerely,

Bruce Lublin

Dialysis Patient
Emeritus Member of the Life Options Rehabilitation Advisory Council



Bridging the Barriers: For Patients and their Families

A Project of
The Life Options Rehabilitation Advisory Council

Funded by
An Educational Grant from Amgen Inc.

Developed by
Medical Education Institute, Inc.

ADVISORY COUNCIL: MEMBERS AT LARGE

Christopher Blagg, MD
*Northwest Kidney Centers
Seattle, Washington*

Ann Compton, RN, MSN
*Northwest Kidney Centers
Seattle, Washington*

Nancy Kutner, PhD
*Emory University
Department of Rehabilitation Medicine
Atlanta, Georgia*

Bruce Lublin
Hartland, Wisconsin

Anthony Messina, BSC
*Dialysis Clinic, Inc.
Nashville, Tennessee*

Spero Moutsatsos, MS
*ESRD Network of Florida, Inc.
Tampa, Florida*

John Newmann, PhD, MPH
*Health Policy Research & Analysis, Inc.
Reston, Virginia*

Patricia Painter, PhD
*UCSF Transplant Service
San Francisco, California*

George Porter, MD
*Oregon Health Sciences University
Portland, Oregon*

Richard Rettig, PhD
*Institute of Medicine
Washington, D.C.*

John Sadler, MD
*University of Maryland
Baltimore, Maryland*

Theodore Steinman, MD
*Beth Israel Hospital
Boston, Massachusetts*

Beth Witten, ACSW, LSCSW
*Johnson County Dialysis
Lenexa, Kansas*

ADVISORY COUNCIL: AMGEN REPRESENTATIVES

Kenneth Chen, MS

Donna Mapes, DNSc, RN

Michael Savin, PhD

EDITORIAL TEAM

EDITOR:

Edith Oberley, MA

WRITERS:

Steve Essex

Anne Morgan Giroux

Paulette Sacksteder

Elizabeth Schumacher

Dorian Schatell, MS

TABLE OF CONTENTS

1. Rehabilitation and You	5
2. Encouragement Is Essential	9
3. Education Is a Tool Everyone Can Use	11
4. Exercise Keeps You Active	13
5. Employment Can Be a Goal for You	15
6. Evaluation Is the Basis for Knowledge	19
7. Common Questions about Kidney Disease	20
8. Working with Your Treatment Team	23
9. Tips for Traveling	28
10. For Family Members: Your Role in Rehabilitation	29
11. Table of Contents of the <i>Bridging the Barriers</i> Report	33
12. Renal Rehabilitation Resources	34

Medical Education Institute, Inc.
414 D'Onofrio Drive, Suite 200
Madison, WI 53719-2803
(608) 833-8033

© Medical Education Institute, Inc. 1994

REHABILITATION AND YOU

Every 12 minutes, more than 100 times a day, someone in the U.S. is told they have “end-stage renal disease.”

Many of these new patients will fear that end-stage renal disease (ESRD) will mean the end stage of their lives. A few may even allow the illness to destroy their hopes and dreams. Other patients, though, will keep doing the things that are most important to them – like working, traveling, exercising, doing hobbies, and remaining active in family and community life.

How much will your life change? That depends a lot on you. There are countless patients who look at dialysis as a quiet time to read or relax, and then go back to doing all the things they did before. It’s up to you how much you want to keep your life the way it has been.

It is very normal to be afraid at first, and worried about how your life will change. *You’re not alone.* There are many, many people who can help you. Your dialysis team (doctor, nurse, dietitian, social worker and technician) is a good source of advice and help about rehabilitation.

What is rehabilitation?

Rehabilitation means restoring you to stable health, a positive outlook, and activities you enjoy. Why do you need rehab? To help you feel better both physically and mentally, and live your life to the fullest.

Recent breakthroughs in medicine and technology have made treatment for kidney failure more effective. Some of these advances include new medicines and more efficient equipment. This means that now more than ever before, kidney patients have the potential to return to an active and productive life.

The Life Options Advisory Council – a group of doctors, nurses, administrators, social workers, patients, researchers, and others – has been working on renal rehabilitation. They wrote a report called *Bridging the Barriers*, to help focus national attention on rehabilitation issues.

This booklet brings you key points from that report. It was written with patients and their families in mind.

Rehabilitation for kidney patients means a coordinated program of:

- **Medical treatment**
- **Education**
- **Exercise**
- **Counseling**
- **Diet**

These pieces of the rehabilitation puzzle all work together. Rehabilitation can improve your fitness and energy, increase your ability to work, and help you have a better life.

What Goals Should You Set For Yourself?

Some key rehabilitation goals for patients with kidney failure include:

- A good understanding of how to live well with dialysis
- Taking part in your own treatment as much as possible
- Better fitness
- Getting back to the activities you enjoyed before kidney disease
- Employment, if you are able to work

Ask yourself, “What is my dream?” It may help to write down your major goals. Break them down into action steps. And put the list where you can see it every day.

Do Renal Patients Work?

Kidney failure affects people of every age, race, and walk of life. Yet, as a group, the nearly 200,000 renal patients are somewhat different from the whole U.S. population. Here are some interesting facts:

- In 1992, 42 percent of the ESRD population was over the age of 60, up from 32 percent in 1978.
- About half of kidney patients are within working age. Many have at least a high school diploma and the physical ability to work.
- Only about 25 percent of dialysis patients are working now. But many more say they are able to work! The number of working renal patients could probably be doubled, according to recent studies.
- Many kidney patients want to work and have important contributions to make. Our nation can't afford to waste their unique talents!

You need to know that if you leave school or your job, it may be hard to return. As a dialysis patient, it's important that your treatment team (doctor, nurse, social worker, etc.) continuously look at how you can work together to improve your ability to work. This will help ensure the right rehabilitation efforts for you.

Does Rehabilitation Mean More Than Working?

Yes. When possible, work is an important goal to help rehabilitate patients with kidney failure. But there's more to rehabilitation than working. Also important are motivation, education, and improving the quality of your life.

Some patients can be encouraged to do recreational activities such as classes, hobbies, or travel. Some need physical and occupational therapy to increase strength and endurance. Others would be helped by counseling in peer groups or by professionals to help them adjust to renal disease.

All patients and their families need ongoing education. When it's possible, you can even start learning what to expect *before* you begin dialysis. It's a real plus to know the facts about your disease, types of treatment, diet, and what to expect in your personal and family life. Education and better physical fitness are rehabilitation goals for all patients with kidney failure.

Obstacles You Can Overcome

If you're a new kidney patient, you probably don't know what to expect from life on dialysis. If you've been on dialysis for a while, you may wish that you had known some things a lot earlier. Many obstacles to rehabilitation, like poor attitudes, not enough information, and lack of exercise can be overcome if you learn about them early and know what to do.

Attitudes can help – or harm

Attitudes are *very* important. At some point, you may meet people who have negative attitudes about kidney disease.

They may not support your desire to remain an active person. These feelings can be contagious and harmful. Feeling depressed or less than whole makes it very hard to look for a job, exercise, or even enjoy a favorite activity.

BRIDGES TO REHAB: THE "FIVE E'S"



The obstacles we talked about are challenges for many patients. To help patients overcome these barriers and live better lives, the Council has named five "bridges," or five "E's:"

- **Encouragement.** A positive attitude is one key to a good life – with or without kidney failure. Working hard for something and taking control of your life gives you a sense of purpose.
- **Education.** The more you can learn about your illness and its treatment, the better you will be able to manage it.
- **Exercise.** Regular exercise can improve your fitness, give you more energy, and make your general health and outlook better.
- **Employment.** If possible, don't quit your job! A job gives you self-esteem, identity, independence, a sense of accomplishment, a social outlet, and a higher standard of living. If you can't keep your job, you and your social worker need to look at programs that can help you retrain or find a different job.
- **Evaluation.** Research is being done all across the country on ways to support rehabilitation, and to help you live a fuller life.

It is normal to be scared and depressed at first. It is normal to feel that your body let you down, and even to think, “Why me?” Learning all you can and talking to people will help you overcome those feelings. Kidney failure is only one fact about you. The rest of you is still the same.

Many people with renal disease who receive proper treatment can enjoy many of the same activities they enjoyed prior to their renal failure. The single most important thing you can do is decide that you will keep doing what you love – whatever that is.

Adequate dialysis is a must

Besides having a positive frame of mind, getting enough dialysis is also important to your well-being. Dialysis must do the work of your kidneys which normally worked 24 hours a day. Every minute of dialysis is important, and more is better. If you don't get adequate dialysis, you won't have the energy to do the things you enjoy. Ask your treatment team about your dialysis prescription.

Be informed

Be an informed patient and healthcare consumer. Learn all you can and ask questions. Knowing about your disease and working together with your doctor allows you to take some control over your life with kidney disease.

Keep fit – and you'll have more energy

Have you ever heard of “use it or lose it?” Patients with kidney failure don't know what activities they can safely do so they do nothing and their muscles get weak. Then they feel tired, and they don't want to do anything physical. It's a cycle that you can prevent. Ask your doctor what activities you can do safely. You will probably be surprised to find out all that you can do. Exercise actually gives you energy. To keep your muscles strong and your energy up, stay active. If you were never active before, now is the best time to start.

The following pages explain how you can use the rehab “E’s” to make the most of life on dialysis.

ENCOURAGEMENT IS ESSENTIAL

Is important for new patients to know that you *can* keep doing things that are important to you. Talking to someone who knows how much kidney patients can do can be very helpful. This is what we mean by encouragement. We hope you will have the chance to talk to someone who can encourage you to learn as much as you can and to work hard to keep your life the way you want it. You must believe in this, too.

Kidney disease can turn your life upside down. It can be very easy to give up and let other people take care of you. If you rely on everyone else, it can be hard to take control of your life again. That's why it's critical for you take responsibility for your own health right from the start.

A key part of that responsibility is for you to exercise, learn about kidney failure and its treatment, and follow your treatment plan of good dialysis, diet, and exercise. Nobody can "rehabilitate" you if you aren't interested. You have to want it yourself.

Adjusting to kidney failure and finally accepting it can take time. It is quite a blow to learn that you'll need lifelong treatment because your kidneys no longer work. Even if you knew it would happen, it can be difficult to cope. Many patients go through several stages of getting used to the idea.

Denial is usually the first phase. Patients may refuse to accept that they are ill. It is very important to follow the diet and fluid plan, and take the medications your doctor prescribes for you. If you deny that you have kidney failure and don't follow your treatment plan, dialysis will be even more of a shock to your system.

A later phase of adjustment is discouragement, or depression. Patients may feel hopeless, or that life isn't worth living because it isn't the same. Others may be angry at their bodies for letting them down, at themselves for not following the doctor's orders earlier, or even at God for letting this bad thing happen to them. It just doesn't seem fair.

Patients adjusting to kidney failure also have to face their fears of the treatment itself, and their fear of dying. It's a lot to deal with. At a time like this, a helpful way for people to lessen their fears and learn to cope is to talk about what is happening.

*"I thought I would never smile again,
that I would never stop thinking about
my misery and my unfair fate.
I have gained spiritual strength.
Though physically I am more frail,
I am actually stronger than before.
Working through all my physical and
emotional problems with dialysis and
having been so close to death,
now I know what's really important in life.
Now I am really living."*

Anonymous patient quote

Your nurse, social worker, dietitian, technician, or nephrologist can answer many of your questions. They can talk to you and your family together. They can help teach you what to expect and how you can keep your health as good as it can be. They can encourage you to do things for yourself and learn as much as possible.

You can also talk to your family, your friends, your religious advisor, or a counselor about the change in your life. Other transplant and dialysis patients may be helpful too. If you can voice some of your feelings and face your fears, you'll begin to feel better.

It is normal to grieve for what you've lost. But you may find one day that you are living life with new appreciation and awareness.

Lilly



Who does nurse Ann Compton have patients talk with if they have any fears or concerns about living on dialysis? She has them meet 86-year-old hemodialysis patient Lilly Robinson who lives alone. "I tell them that if I can do it, you can, too," says Lilly. "All you have to do is try. If I had given up I would have been in a nursing home."

Lilly dialyzes three hours, three times a week at a dialysis center in Richmond, Virginia. She has been on dialysis since 1991.

Besides encouraging patients in her dialysis center to keep trying, Lilly also gets a lot of exercise. She walks 4 or 5 blocks, twice a week in downtown Richmond. Before starting dialysis Lilly felt very weak.

"I tell other patients to do for themselves, don't depend on somebody else to do everything." Long before Lilly developed kidney disease, she had to be independent. Her husband (who died in 1989) had a stroke in 1971. "It was up to me to go out and do. And look at me now. I didn't give up."

EDUCATION IS A TOOL *EVERYONE* CAN USE

One of the hardest things to do when you know you have a medical problem may be to learn more about it. But even though you may have many frightening questions, you may find comfort in knowing the answers.

Learning about your disease and its treatment puts *you* in charge. Education helps you understand the “*why*” behind your treatment. After all, even though your nephrologist (kidney specialist) knows more about kidney disease than you do, you are the expert about *you*.

Patients with kidney failure who learn as much as they can, make sure that they get enough dialysis, and take the right medications at the right time, can avoid health problems later.

Patients often do best if they learn about their treatment and take an active part in the dialysis itself. In many facilities, patients learn to weigh themselves, take their own blood pressure and temperature, and assist with other aspects of the dialysis.

It can be easy to sit back and let the dialysis staff take care of you. But education helps patients like you take control of their treatments *and* their lives. Taking part in rehabilitation activities that are offered is another important part of learning how to live well with kidney failure.

There is a lot for you to learn about ESRD and dialysis. It may seem overwhelming, but you don't have to learn everything in one day or even one month.

Through education you can find answers to questions like:

- How do I talk about kidney failure with my family?
- How do I talk about kidney failure with my boss?
- What's the best treatment for *me*?
- How can I eat better?
- How do I start a safe exercise program?
- How do other patients cope with kidney disease?
- How can I share what I've learned with other patients?

Have you been on dialysis a long time? You may be surprised to know that there are things you need to learn too – like the newest technology, medicine, and rehabilitation efforts.

Your facility may have pamphlets, videos, and booklets to help both new and ongoing patients. A handy list of resources can be found on page 34.

Charlie



Charlie Rodriguez of Tampa, Florida uses his experience as a nineteen-year kidney patient to educate other patients about finding new jobs. Charlie, 40, is the coordinator of the Renal Employment Program, a new program sponsored by the Florida Renal Coalition and the State of Florida.

The program will help patients learn about finding jobs, “connecting patients with employers that the patient is suited to.” According to Charlie, the employer is made aware of all the patient’s needs so that dialysis and health are integrated into the job schedule.

Charlie’s need to educate kidney patients about employment stems from not only his own personal experience, but also his extensive volunteer work experience as a patient advocate, patient services chairman, and public education speaker with the NKF and AAKP. Charlie is living proof of what he promotes and educates other ESRD patients about.

His schedule begins with 5:30 am dialysis followed by working 10:00-5:00 on Mondays, Wednesdays, and Fridays. On Tuesdays and Thursdays, Charlie works full time. Charlie says the key to his success is “managing dialysis, diet, and exercise well,” as well as support from his wife, son, and doctors.

According to Charlie, “Physical and mental well being changed my outlook from a negative to positive. It took three years for me to face kidney failure. You have to work with this machine-it’s going to be part of your life.”

EXERCISE KEEPS YOU ACTIVE

Surprisingly, many patients – and even many health professionals – don't yet know that exercise is important for patients with kidney disease. There is plenty of evidence now that shows that people on dialysis can benefit from regular exercise.

Wastes that build up between dialysis treatments and lack of exercise may lead to loss of muscle mass and tone. Mild exercise is one of the first rehabilitation tasks a patient can begin that will help both the body *and* the mind.

Regular exercise can also help you sleep better, reduce depression and anxiety, fight anemia (low red blood cell count), and strengthen your bones and muscles. It also helps control your blood pressure and reduce your risk of heart disease.

Keeping up with the activities you want to do takes energy, flexibility, strength, and endurance. Whether it's dancing to music around the house, playing catch with a child, walking through the mall, planting flowers in the garden, cleaning the house, or walking to a friend's house ... the fact is, you *need* exercise.

Exercise doesn't just happen. It requires active participation on your part. There are many levels of activity to fit different levels of ability – from a vigorous workout to walking around the block to stretching exercises.

Exercise physiologist Patricia Painter, PhD, has some suggestions for putting together an exercise program. Your program should include:

- **Flexibility Exercise** – such as gentle stretching of your arms, legs, neck, and back
- **Endurance Exercise** – such as walking, bicycling, swimming, etc.
- **Strengthening Exercise** – lifting small weights at first (like one-pound cans of food) and building up to more repetitions or slightly heavier weights.

The key is to start slowly, move gently, and if anything hurts, stop. Stretching before you exercise helps warm up your muscles and prevent injury. Exercise should be done regularly – at least 3 times a week. Get together with other patients at your facility, your family or friends and start a walking club. It can also be an enjoyable social outlet and give you a sense of accomplishment.

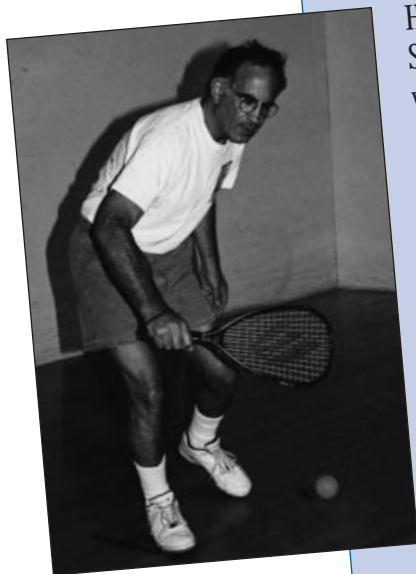
"I've always felt the best on dialysis when I was exercising.

I can't stress the importance of keeping active.

Not only does it help you physically but it really helps your sense of confidence, your self worth."

Steve Coons, on dialysis since 1978

Herb



Herb Davis is a 57-year-old physicist and dialysis patient from the San Francisco Bay area. A technical writer with a biotech firm, Herb writes computer software manuals for researchers studying DNA.

Herb, a 3-year dialysis patient who exercises each week, by treadmill walking, weight lifting, yoga, and playing racquetball regularly. Renal exercise physiologist Patricia Painter, PhD, tested Herb's fitness level. "He's in the best physical shape of anyone on dialysis I've ever seen," she says. Herb believes Dr. Painter helped raise his expectations. "She is very inspirational – I think she's helped me push myself."

Herb's expectations remain very high, and he charges other patients to: "Keep active. Do as much as you can. Ask a lot of questions and expect to get straight answers."

Medication Helps Anemia, Fitness

Years ago, dialysis patients needed blood transfusions to help treat anemia (a shortage of red blood cells) which made them tired and weak. The anemia was caused by a lack of a hormone called erythropoietin that tells the bone marrow to make new red blood cells. These days, anemia is treated with a synthetic form of erythropoietin (often called EPO).

Studies of patients receiving EPO have shown that they feel much better. They have more energy to do exercise, leading to better aerobic fitness and muscle strength. In fact, the studies show that patients on EPO feel they have a better overall quality of life.

Two good sources of information for starting your exercise program are available. A brochure, *Fitness after Kidney Failure*, is available from the National Kidney Foundation by writing to NKF, 30 East 33rd Street, New York, NY 10016. A new fitness book for older adults, *Pep Up Your Life*, is available by writing to the American Association of Retired Persons and President's Council on Fitness, at 601 E Street NW, Washington, DC 20049.

EMPLOYMENT CAN BE A GOAL FOR YOU

Finding, changing, or keeping a job may be one of the first challenges faced by kidney patients who are of working age. If you're working, it's *very* important to keep your job if you can, especially if it comes with health insurance.

Don't jump into a decision about your job until your body has had a chance to get used to dialysis. At first you may feel tired and out of sorts. After a few weeks or so, you'll begin to adjust to the treatments, and then you can decide what to do.

Instead of quitting your job right away, talk to your dialysis team. Tell your doctor how you feel now, and ask him or her how soon you'll feel more normal again. If you want to keep your job, ask your social worker how you can talk to your boss about this issue. Taking sick time, vacation time, or a temporary leave of absence can buy you some time to think about your plans. You may even be able to work part time for a while or switch to a different shift or job.

What About Job Discrimination?

If your job calls for a lot of heavy lifting or standing, you may need to change job assignments. Maybe you could keep track of inventory or do something else less physical. A law called the Americans with Disabilities Act (ADA) makes it illegal for employers to discriminate against people with disabilities who can do the required work. The ADA requires employers to make minor changes called "reasonable accommodations" so people with special health care needs can work. This law also forbids discrimination against people with disabilities in transportation, and public accommodations like schools, stores, libraries, and recreational facilities.

You may not have thought of yourself as having a "disability," and that's good. You should know that this law was passed to help people who have a disability or *who are thought of* as having one. Even though you don't think of kidney failure as a disability, other people (like your boss) might.

The kinds of accommodations most ESRD patients need are reasonable. More frequent breaks, a chair to sit in, a place to do CAPD exchanges, and flexible scheduling to work around dialysis are some ideas. The ADA protects you if your employer has more than 25 employees. Your social worker can call your state department of vocational rehabilitation to help you get more education or retraining if you need to change jobs.

"It's very important to have some activity that's meaningful to you outside the home.

Employment is one area where people can get a lot of satisfaction because it gives a social outlet, self-satisfaction, sense of identity, and increases their standard of living."

Bruce Lublin, on dialysis since 1970

John



Kidney patients need to be health care consumers and integrate dialysis into their normal work and life schedule, according to John Smith.

John, 39, is an 11-year hemodialysis patient who is a full time city bus driver for the Greater Richmond Transit in Richmond, Virginia.

John begins his schedule with 7:00-11:30 am dialysis at a dialysis center that is "close to home and work." John works as a bus driver from 4:00 pm-12:30 am. John says that his 5-year employer is supportive of his needs. "I made a promise to the Personnel Manager – I'd give 100 percent effort if the company would give me 100 percent support." John says he rarely misses work, "except for a few health problems" not related to work.

John emphasizes personal involvement with health care. "Patients have different needs, priorities, and psychological needs." John promotes "individualized" health care, and a co-working relationship between patient and physician. John says he has "defied the odds across the board," because he is so actively involved with his health. He has always worked while on dialysis, has an 8-year old son, and actively recruits and attends NKF patient and doctor workshops. "The better prepared you are, the better off you are. If you go into a chronic disease with a negative attitude, you won't beat it. If you want to beat it, you will."

If you feel you are being discriminated against for a job or promotion because of your kidney failure or other disability, the Equal Employment Opportunities Commission (EEOC) will look into your claim and protect you against retaliation for filing a charge. To report a violation of the ADA or to get more information, you can call the EEOC, toll-free at 1-800-USA-EEOC. Your state may also have laws to forbid job discrimination. Look in your phone book's Government section for a Human Rights or Civil Rights agency to call.

Scheduling Dialysis Around Your Work

If you are working and want to keep working, there are two things you can do about your dialysis schedule. You can ask for a dialysis schedule that will make it easier to keep working or you can try to change your work schedule.

Some dialysis facilities have early morning or evening shifts that are good choices for working patients. Don't be afraid to ask for what you need. Talk to your social worker and your doctor. If they know how important working is to you, they may be able to change your schedule.

Sometimes, schedules in facilities are very tight because staff members are trying to accommodate the needs of many new patients. Your staff may be working very hard to take care of many patients on each shift.

Other ideas you may wish to consider include choosing a different treatment that allows you more scheduling control, like CAPD, CCPD or home hemodialysis. Talk to your doctor about what you can do.

When you try to solve this problem, take notes. Write down the names of people you talk to, their phone numbers and dates, so you can call them back if you have questions later. Together with your team you can make your rehabilitation better.

We hope scheduling will be easy for you. But if it isn't, working to solve a problem like this can give you a sense of what you can do if you put your mind to it. You'll see how useful that positive attitude can be.

*"Not only do you need to be educated
when you start dialysis,
but your employer needs
to be educated too."*

Steve Coons, airport planner and
dialysis patient for 15 years

Looking For A New Job

In a slow economy, it can be hard for *anyone* to find a new job. If you are having a hard time finding one, it may not be your kidney failure that is the problem. You may need to try new ways to look.

“You have to look at your job search as your full-time job. It takes determination, networking and a lot of resumes. I sent out about 250 resumes in 8 months. You have to be willing to work at your job search week after week after week.”

Tom Howard,
senior buyer at manufacturing firm
and transplant patient

Newspaper ads are not the only way to find out about new jobs. Tell everyone you know what kind of work you hope to find. Someone may know of an opening that you would be suited for. Learn as much as you can about the companies who do the type of work you’re interested in, and write to them. If you’re in a trade or profession that has a newsletter or journal, you can watch for jobs there, or even put in an ad yourself.

Civil service jobs through cities, states, counties, and the federal government usually offer good benefits and have antidiscrimination policies that may make it easier for you to get hired. Usually you will need to fill out an application, and then take a test for the job. You can often have civil service job listings mailed to your home for a small fee. Look in the phone book government listings to find out how to get the listings. (The public library has study books for many of the civil service tests to help you prepare).

You may be thinking about switching to a new line of work. Talk to your social worker or vocational counselor about it. Every state has a Division of Vocational Rehabilitation (DVR) to help people learn new job skills. They may be able to help you take classes at a

technical school, start an apprenticeship, or even go back to school for that college or graduate degree you wanted. Scholarships, loans, or veteran’s benefits for education may also be available. Most schools have a financial aids office that explain loans or scholarships for which you may qualify.

EVALUATION IS THE BASIS FOR NEW KNOWLEDGE

You can be hopeful – because research is being done all across the country to evaluate ways to support rehabilitation, and to help you live a fuller life! Many test programs and projects are helping scientists and the government figure out what works and what doesn't in rehabilitation.

Evaluation, however, does not belong solely to doctors or researchers.

You too can evaluate what your barriers to rehabilitation are. And you can work with your family and treatment team to set specific goals for overcoming those barriers.

The more you evaluate what you *can do* and *want to do*, the more you'll be able to focus your energy for rehabilitation. Evaluation means getting a better understanding of the limits you set for yourself, and the ones that really exist.

If you are asked to be part of a research study, think about it. Often these studies are set up to learn how to help kidney patients live better lives.

COMMON QUESTIONS ABOUT KIDNEY DISEASE

Here are some questions that many patients and family members ask about kidney disease. If you have other questions or would like more detailed answers to these questions, you can contact some of the resources listed at the back of this booklet and talk to your treatment team.

What Is Kidney Disease?

End-stage renal disease is the complete loss of kidney function. This loss is permanent.

As you may know, kidneys have several vital jobs. They rid the body of extra fluid and wastes through the urine. They control the body's acid/base balance (pH), and fluid balance.

Your kidneys produce several hormones that act on other parts of the body. Calcitriol, or active vitamin D, controls the levels of calcium and phosphorus in the body for healthy bones. Erythropoietin signals the bone marrow to make red blood cells. Both of these hormones can now be given to kidney patients as medicines prescribed by a nephrologist. Other kidney hormones control blood pressure.

When kidneys fail, the abilities to regulate blood pressure, acid/base balance, fluid levels, bone formation, and red cell production go haywire. Hemodialysis, peritoneal dialysis, or a kidney transplant are needed to replace some of the kidney's functions and keep you alive.

Kidney disease would be fatal without treatment, but fortunately treatment can keep patients alive, active, and productive.

What Causes Kidney Disease?

Many things can cause kidney failure. Diabetes is the number one cause. More than a third of new patients with kidney disease have diabetes. Hypertension is the second leading cause of kidney failure. Other causes are glomerulonephritis, polycystic kidney disease, interstitial nephritis, and other diseases. Less common causes are a bad reaction to toxins in drugs, birth defects, lupus, AIDS, drug abuse, sickle cell disease – even some types of food poisoning.

Complications of kidney disease may include insomnia, fatigue, weight gain and swelling in your body, loss of appetite, headaches, itching, restlessness, shortness of breath, and muscle cramps.

What Are The Treatment Options?

Your treatment needs may change as your condition changes. In the early stages of chronic kidney failure, medicine and a special diet may help. Following a special diet *very* carefully may even put off the time when you'll need dialysis or a kidney transplant. Talk to your doctor or dietitian about this. You may need to ask for a referral to a nephrologist, a doctor who specializes in kidney diseases, if you are not yet seeing a specialist.

When your kidneys no longer function alone, there are three major treatment options you can select, with the help of your doctor and health care team: hemodialysis, peritoneal dialysis, or a kidney transplant. Learn as much as possible about your options.

Hemodialysis cleans the blood by passing it through tubing to a special filter called a "dialyzer." Wastes and extra water pass into a fluid called "dialysate," and are washed away. A dialysis machine pushes the blood through the dialyzer at the right speed for your body. Alarms and monitors on the machine help assure safe and effective treatments.

Patients who choose hemodialysis need an "access," a special blood vessel created surgically. At each dialysis treatment, two needles are put into the access and hooked up to the dialysis tubing. Some facilities use a local anesthetic (pain killer) to make the needle insertion almost painless.

Hemodialysis can be done at a dialysis center or at home. Training programs teach a patient and helper to do the treatments at home. Scheduling can be at the family's convenience. Backup help is always available by phone. Home hemodialysis has an excellent record for helping patients lead full, active lives.

Even in a dialysis center, it is important for patients to do as much as they can for themselves. As we've said earlier in this booklet, learning to take temperature, blood pressure, and predialysis weight, cleaning off the access, and even putting in the needles helps patients keep control of their lives.

Peritoneal dialysis uses the same principles as hemodialysis, but without the dialyzer. Instead, the lining of the patient's abdomen is used to filter the blood. To do this, a tube called a *catheter* is surgically placed in the belly. Dialysate fluid is placed into the abdomen through the catheter. Wastes and extra fluid move into the dialysate. After several hours the used dialysate is drained off into a bag, and a fresh bag of dialysate is put in. The process is called an *exchange*.

Because the catheter leads directly into the body, it is vital to use sterile procedure for every exchange. Otherwise bacteria can enter the abdomen and cause painful infection (peritonitis). Patients who choose peritoneal dialysis are taught how to do the exchanges properly.

Most patients who do peritoneal dialysis do four exchanges a day, or *Continuous Ambulatory Peritoneal Dialysis (CAPD)*. “Ambulatory” means walking around. CAPD exchanges can often be worked around school or work schedules, which makes it a good choice for many working people, if it suits their medical needs.

Some patients use a cycling machine to move dialysate in and out of the abdomen, usually just at night while they sleep. This is called *Continuous Cycling Peritoneal Dialysis (CCPD)*.

A kidney transplant is an operation to put a healthy donor kidney into the body of a patient with end-stage renal disease. The healthy kidney can either come from a living person, usually a relative, or from someone who is brain dead but whose body and kidneys have not died (cadaver transplant). To have the best chance of success, the new kidney must be a close match to the patient’s blood and tissue type, and the patient must be in good health except for their kidney disease.

Because the patient’s immune system may try to attack the new kidney, transplant patients must take medications for the rest of their lives to prevent the immune system from causing the body to reject the kidney. With a successful kidney transplant, patients do not need daily treatment to remove toxic wastes from the body.

WORKING WITH YOUR TREATMENT TEAM

First and foremost, you are the key member of your treatment team. It's up to you to be an active, motivated and verbal member! Your treatment team typically includes you, your nephrologist (kidney specialist), nurse, social worker, dietitian, and dialysis technician. Of course, your family is also a critical part of your care team. Here are some tips for working effectively with your treatment team.

How Can I Work With My Doctor Or Nurse?

Your doctor's role is to assess your needs, prescribe treatments and medicine, and check your progress. The nephrologist directs the rest of your medical treatment team.

Your nurse keeps track of your treatments and concerns. Your nurse also looks at what you need and encourages you to be independent. When you see your nurse or doctor, it's a good idea to:

- **Write down your list of questions.** It's easy to forget what was on your mind when you're talking to a doctor or nurse, especially if he or she is asking you questions. A written list will help you remember. When the doctor or nurse sees that you have a list, he or she will know that you've been thinking about your treatment and that you want to learn more. Share your concerns and fears, too, so your nurse and doctor can help you learn what you need to know to cope with kidney failure.
- **Ask for answers in language you can understand.** Doctors, nurses, and other medical people are so used to medical words that sometimes they forget other people don't understand them. If you have lots of medicines to take, for example, you might ask the doctor or nurse to draw you a chart for the week, and show you what to take when.
- **Take notes.** Bring a notepad along, and write down what the doctor or the nurse tells you. This way, you'll have something to look back at later when the details start to fade, and it may help you think of other questions. You might even want to keep your questions and the answers you get in a special notebook or binder.
- **Know what options are available.** We discussed the different treatments on page 21. Learn as much as you can and talk to your doctor about the right choice for you.
- **Understand and follow your treatment plan.** The best way to be sure that you're healthy enough to keep doing the things you love is to take good

care of yourself. This means taking your medications when you're supposed to, following your diet, getting exercise and enough dialysis. Understand how your therapy works and what will happen if you don't follow it.

How Can I Work With My Social Worker?

Most facilities have a renal social worker. Your social worker is there to help you and your family adjust to kidney disease. Support may be in the form of individual and/or group counseling, or helping you find financial, transportation, or job services. When you see your social worker, it's a good idea to:

- **Write down your goals.** What do you want to accomplish? What activities do you want to continue? Now that you have kidney failure, you need to look at your life and make some decisions about what you want to do. Make a list of the things that are most important to you, and ask your social worker how you can keep doing them. Traveling? Working? Taking care of a family? Your list of goals will help you and your social worker decide what needs to be done first.
- **Talk about your feelings.** Your social worker has helped many patients learn to adjust to kidney failure. It can help you to talk about your feelings to someone who understands. Talk about your problems and keep an open mind for solutions. Your social worker can help you find other patients to talk with, and help your family learn how to help you.
- **Ask for help.** When you have a question like how to get from work to dialysis, or how to plan a family vacation, or how to find an exercise class, or go to college so you can get a better job, ask your social worker for ideas. Even if you're not sure if they'll know the answer, social workers spend a lot of time learning about what is available in the community, and may be able to help you find the answers.

How Can I Work With My Dietitian?

Your dietitian's role is to help you plan healthy, enjoyable meals that follow your doctor's orders. Healthy kidneys have the job of taking chemical wastes out of the body that build up from food you eat or medicines you take. Dialysis takes over some of the work of the kidneys, but it can't remove all the wastes your kidneys used to take out.

Since it's much harder to take wastes out, it is now very important to avoid certain foods that make a lot of waste in the body. Your dietitian will help explain this to you.

It's not a lot of fun to pay attention to every sip of fluid and every bite you eat. Like any other "diet," it's easy to feel deprived, especially when other people

around you seem to eat and drink whatever they want. Here are some important things to remember:

- **Your dietitian is on your side.** Most people these days do pay some attention to the amount of fiber, fat and cholesterol in their diets to stay healthy. But most people don't get to meet regularly with a dietitian to help plan meals that will meet their health needs – you have that opportunity. Ask how to make good choices when you're eating out at a restaurant or party. Ask for ideas on how to make special foods healthier. Be honest with yourself and your dietitian.
- **Ask for the help you need.** It isn't easy to learn to cook and eat in a new way. There are many cookbooks that can help you, and your dietitian can help you find them. Ask for ideas on spices to replace salt, since you'll probably be on a low salt diet. If you have a question about how much potassium is in a potato – your dietitian is the one to ask.

How Can I Work With My Dialysis Technician?

If you do hemodialysis at a center, you may actually have more than one dialysis technician for your treatments. Some technicians take care of patients and perform the treatments. Others reprocess dialyzers, or work with the equipment. Dialysis technicians are not counselors, but they often talk to many patients, and have good ideas about how these patients have solved some problems. An idea:

- **Ask the technician to explain your treatments.** One of the best ways to learn about dialysis is to watch it, step by step. Ask your technician to explain how the machine works, what each monitor does, and what the alarms mean. Even if you only learn one small fact at each treatment, over time you'll understand more and more.

How Can I Work With My Fellow Dialysis Patients?

You can learn a lot from other patients. And they can learn a lot from you.

A few ideas:

- Ask questions about how they are dealing with working, sticking to the diet, learning about dialysis, and other things you're wondering about
- Organize a support, exercise or social group
- Keep your sense of humor

Your fellow dialysis patients are not just in your own facility. They're all across the country in every city. By reading about and talking to patients outside your facility, you'll get a sense for how other people handle kidney disease, and

how other places may do things differently. Some of these ideas may be just what you've been looking for. How can you find them? Through organizations formed to help patients connect with each other all over the country, and share ideas and solutions. Here are just a few national groups. There may be more in your area.

American Association for Kidney Patients

The American Association for Kidney Patients (AAKP) has been helping kidney patients for many years. For just \$15 a year, patients and their families who join the AAKP will get the AAKP *Bulletin*, the official AAKP newsletter. The *Bulletin* has stories about patients, information about vacations, updates on national health issues, and more.

AAKP members will also get *Renalife* magazine twice a year. *Renalife* has articles about issues important to kidney patients, such as how to keep your independence, exercises you can do safely, living with diabetes, and keeping healthy after a transplant.

Each year the AAKP holds a convention for members, where you can meet patients and staff from around the country, and learn how to take better care of yourself. The conventions include entertainment, a banquet and awards dinner, and lots of useful information for patients and their families.

The AAKP has produced other publications, such as a helpful guide to the Americans with Disabilities Act. They also monitor national health insurance to be sure that kidney patients' needs are included. There may be a local AAKP chapter in your area. To reach the AAKP and learn more, call 1-800-749-2257, or write to: The American Association of Kidney Patients; 111 South Parker Street, Suite 405; Tampa, FL; 33606.

National Kidney Foundation, Inc. (NKF)

The National Kidney Foundation is a large organization that helps kidney patients and their families to learn more and live better. The NKF is also a leader in teaching professionals – like doctors, nurses, dietitians, and social workers – how to take better care of patients.

The NKF has 52 affiliates, or local groups, across the country. Many of these affiliates are doing exciting work in rehabilitation. In one state, scholarships are offered to patients who want to get an education. Other states have predialysis education programs, or programs to help patients find jobs. A good way to find out what your local affiliate is doing is to call them up and go to their next meeting. You can find your affiliate by looking in the phone book under "National Kidney Foundation."

Besides the affiliate activities, the NKF has many booklets, brochures, videos and other information about many different aspects of kidney diseases and kidney failure. If you have a question about a certain disease, a type of treatment, drug abuse, fitness, sexuality, or many other topics, your NKF affiliate may have the answers.

The NKF has also launched *Family Focus* magazine, to provide information and encouragement to patients to help them take control of their lives. *Family Focus* magazine is sent to every dialysis unit in the nation – so every dialysis patient in the country should have access to it. Ask about it!

The NKF has an information line to answer questions you may have about kidney disease and treatment. You can contact them at 1-800-622-9010, or write to: The National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016.

American Kidney Fund (AKF)

The American Kidney Fund (AKF) was started in 1971 to give funds to needy kidney patients. Individual grants are given to eligible patients who need help paying for medications, transportation, a special diet, home dialysis supplies, or other needs. Patients are usually referred by their doctor or social worker.

The AKF Emergency Fund helps patients who are having a medical crisis. The Disaster Relief Fund gives cash grants for clothing, rent, and other needs after a flood, hurricane, fire, or other disaster.

Patients who need extra money to take a vacation may be eligible for the Sherer Travel-Related Dialysis Program. The program helps pay for dialysis that is not covered by Medicare or insurance when a patient is away from home.

Other AKF patient programs include a program to help children with kidney disease go to camp, a program to pay for iron pills, and educational pamphlets. The AKF also has a kidney donor awareness program, and many educational programs for professionals and the public.

To learn more about the AKF, call the toll-free Help Line at 1 800-638-8299, or write to: American Kidney Fund, 6110 Executive Boulevard, Suite 1010, Rockville, Maryland 20852.

TIPS FOR TRAVELING

Part of the fun of taking a vacation is planning out where you'll go and what you'll see. Kidney patients can travel nearly anywhere that dialysis is available (and some places it isn't, if you bring your own equipment). You just need to plan ahead.

Consider the case of dialysis patient Patty Stewart. She and her husband, Kent, loaded a camper with dialysis equipment and traveled across the country for *two years*. If they could manage a trip like that, surely you can go fishing at a lake, make it home for the holidays, attend the AAKP annual meeting – or nearly anywhere else.

If you're planning on traveling out of town on business or pleasure, talk to your social worker to help you set up dialysis while you're out of town. There are even cruises and vacation centers especially for kidney patients, which you can contact. You'll want to ask about how out of town dialysis is paid for. If you are part of a Health Maintenance Organization (HMO), you may have to pay for the part of your out-of-town care that the federal government doesn't cover. Some facilities may require you to pay your copayment amount for treatment including drugs. Here are some ideas for selecting a dialysis center:

- Before you leave, call several dialysis units and talk with the head nurse or social worker. Ask them about their equipment, shifts, even their philosophy about dialysis, and then make your arrangements.
- If possible, talk to other people who have been patients there.
- Make sure the unit can accommodate your schedule.
- Give the nurse or social worker some of your history and what is specifically important to you in your treatment.
- Tell them what you expect and learn what they expect. You may have to compromise but at least you shouldn't have any big surprises.
- If you are on CAPD or CCPD, it may be possible to have supplies shipped to where you'll be staying in your vacation area.

FOR FAMILY MEMBERS: *YOUR ROLE IN REHABILITATION* ≡

This section is devoted to family members. You have a very important role in your loved one's rehabilitation. People with kidney failure are not helpless. If they learn as much as they can, exercise, follow their treatment plan, and keep a positive attitude, they can do many activities they did before renal failure.

Anyone with experience with kidney failure knows how much the disease can affect the family. The patient's limits are, to some extent, the family's limits. Like the patient, the family needs time to adjust and learn how to live with kidney failure.

It's perfectly normal for you to feel frustration, resentment, anger, detachment, guilt, fear, or helplessness toward the situation or the patient. Recognizing and coming to terms with such feelings helps you grow beyond them.

Figuring out how to provide the right amount of support for your loved one is a big job. Often, you can find yourself torn. You want to make sure the patient follows the treatment plan. But you also want to see the person be independent. Families often teeter between denying the person is sick – like forgetting about the special diet or fluid limits – and smothering him with too much care. It isn't easy to find a balance.

The best way to help your family member with kidney failure is to talk about it with him or her. Take your cues from the patient. This won't always be easy. As the patient gets used to the idea of kidney failure, he or she may change his or her mind from day to day regarding the amount of help needed. Do your best to show you care. Over time, the right balance will happen.

In the long run, it's best to encourage the patient to be more independent. Don't let kidney failure be an excuse for doing nothing all the time. After the first few weeks or months when the patient's body begins to adjust to the treatments, it's OK to push a little. Remind the patient of things he or she liked to do before that can still be done. Kidney patients can work, take vacations, go fishing, garden, sew or knit, read, cook, do the dishes, take out the garbage ... and much more. If you're not sure, ask the doctor or nurse.

If you find you are arguing a lot about the same things – or not talking about the really important things – it may be time to talk to a renal social worker, religious advisor, or other counselor. Having a person with a chronic disease in the family is a major life change, and talking to a professional can help you sort it all out.

As a family member, your attitudes about what a patient with kidney disease can do are vital. It's hard for a patient to keep a positive attitude if the

people around them don't do so. Today we know more about how to help patients live normal lives than ever before. The technology and medicines available are better, too. Many patients with kidney failure keep leading active, busy, enjoyable lives, and your family member can, too. You can help your family member or friend return to the activities enjoyed before kidney failure.

Use the "E's" described earlier to help improve the quality of your loved one's life. (These "E's" can help improve your quality of life, also!)

Encouragement

There are a number of ways you can use *encouragement*. Give emotional support during the hard times. Tell him or her that dialysis or transplantation need not dominate every part of family life. Keep a positive attitude yourself, and learn as much as you can about how other patients and families cope.

Talk to other patients and family members who have experienced the disease about how they coped with it. Talking to families who have adjusted to kidney failure and kept doing the things they enjoy can really help. Ask if there is a support group in your area. If your family is experienced with kidney failure, you can reach out and provide encouragement, too. Helping others may make you feel good yourself.

Education

Educate yourself about kidney disease. It's vital to learn what's happening to the body.

Many symptoms and problems can be avoided by understanding the patient's condition. The more you learn about kidney disease, the more you help your loved one and your whole family to learn. (The National Kidney Foundation has a number of excellent patient education materials, as do other organizations.)

You need to learn about emotional adjustments to the disease. It's important to know that adjustment to chronic illness for patients and family members is a *gradual, ongoing* process of acceptance. It takes time. Along the way, problems arise which need solving. You and your loved ones need to draw on educational resources for solving these problems. To help you find what you need, a list of resources are on page 34.

Exercise

Talk with the doctor about the best *exercise* level for your loved one. You can help by suggesting outings or family activities to include exercise appropriate for the patient. Maybe you could take a family walk a few evenings a week after dinner, or play an easy game of softball in the park. Swimming, golf, bicycling ... the list goes on and on.

Don't neglect your own exercise. *Your* physical and mental well-being are important, too!

Employment

Employment provides many benefits, including self-esteem, independence, a social outlet, and income.

Not everyone with kidney failure is a candidate to be employed. Some people are retired. Others have disabling health conditions. If the patient in your family was working before kidney failure, it's very important *to encourage him or her to keep the job*, if possible. It's best to wait to make a final decision until after the patient's body gets used to the dialysis treatments.

Summing It All Up

Your role in rehabilitation is key. You are there for emotional and physical support. But keep *your* perspective in balance. It's important for you to lead your own life, have your own friends, and pursue your own interests, too.

To restrict your own life by focusing totally on the patient's condition is not healthy for either of you. You'll all need to find ways to build treatment for kidney failure into your lives, while still doing the things you value the most.

A GRANDCHILD'S DEFINITION OF RENAL REHABILITATION

Grandma Tipler



“My Grandma Tipler is seventy-five years old, but acts like twenty. She has a short, curly wig because of her frail hair, but wants to look nice. On her wrinkled right arm she has some bumps from shots at dialysis. She is slight and slender. My grandma walks slowly and carefully so she doesn't fall down.

Even though she has been on dialysis 14 years, grandma never lets her disabilities get in her way. She helps my sister and me cook. She also helps me with my projects like the science fair project and projects for the fair. My grandma joins clubs and travels a lot. She also saves a lot of things. Grandma has been retired for at least ten years and still has her teaching materials.

My grandma is very energetic. She cans foods and works in her garden constantly. In the summer she has had boys from high school come over and help her hoe, and she has tired them out.

My grandma is very encouraging. She always wants our cousins and me to try something new. When I was in kindergarten, I would go over to the babysitter's house. Every Tuesday, my grandma said she would let me stay at her house if I played the piano. That is how I got started with the piano. Grandma also doesn't want us to give up. Whenever I am frustrated, she always has me work until I understand it.

My grandma is comforting. Whenever I get mad or sad, she comforts me. Whenever my sister and I get mad at each other, she works things out so we aren't mad.

My grandma is friendly and caring. She puts others first. She never leaves anyone out of something. Whenever my sister and I are playing games, she makes sure no one is left out who wants to play.

I feel my grandma is important to me because she has helped me start the things that I am good at now. She also has helped me learn to try new things and not give up. Grandma is very important in my life.”

By Laura Tipler, Age 12
Oshkosh, Wisconsin

TABLE OF CONTENTS FOR BRIDGING THE BARRIERS REPORT

The following is the table of contents of the full *Bridging the Barriers* report. It is meant to show you more detailed information that is available to you. If you would like a copy of the full report, please fill in the reply card in this booklet.

I. Summary

II. Renal Rehabilitation: Definitions and Goals

Introduction

Expectations vs. Reality: Changing Demographics

Goals and Purposes of Renal Rehabilitation

The Broad Spectrum of Renal Rehabilitation

Targeting Vocational Rehabilitation Resources to the Appropriate Recipients

Objectives of the Life Options Rehabilitation Program

Advisory Council Role

III. Participants in the Rehabilitation Process

The Patient

The Dialysis Facility

The Business Community

The Public Service and Professional Organizations

The Government

IV. Barriers to Renal Rehabilitation

Barriers in Patient and Professional Attitudes

Barriers at the Facility Level

Barriers in the Business Community

Barriers in Government Programs

V. Bridges to Renal Rehabilitation: The Five E's

Encouragement (Patient and Staff Commitment)

Education of Patients and Staff

Exercise

Employment

Evaluation

VI. Case Reports

VII. Appendix

Addendum A: ESRD Treatment Modalities

Addendum B: Costs of Rehabilitation

Addendum C: Demonstration Projects and Model Programs

Program 1: Florida Network 7

Program 2: Development of a Comprehensive Job Retention/Return Service Delivery System for People with Kidney Failure, New York, New York

Program 3: Renal Rehabilitation Assessment Center Pilot Project, Madison, Wisconsin

Program 4: Rehabilitation Project, Cleveland, Ohio

Program 5: Forward Bound, Jackson, Mississippi

Program 6: Vocational Rehabilitation for ESRD Patients, Austin, Texas

Program 7: Promise for Living, Hartford, Connecticut

Addendum D: Recommendations for Renal Rehabilitation Made in the Past 15 Years

Addendum E: Why Aren't More Dialysis Patients Working? Employment Study Results

Addendum F: Recommendations from 1993 NKUDAB Workshop

Addendum G: Health Outcomes Assessment: Relevance for Renal Rehabilitation Research

Addendum H: Philosophy of U.S. Programs for the Disabled

Addendum I: Legislative History of ESRD Program

Addendum J: Patient Education Resources

Addendum K: State Kidney Disease Programs and State Vocational Rehabilitation Agencies

Addendum L: Glossary of Renal Organizations

Addendum M: Glossary

VIII. References

RENAL REHABILITATION RESOURCES

A major portion of this listing is courtesy of the National Kidney and Urologic Diseases Information Clearinghouse, an information and referral service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Audiovisual Materials

Abbott Laboratories. (1993). *Your Kidneys, Your Bones, and You.*

(Available from Renal Care/Abbott Laboratories, North Chicago, IL 60064) 1-800-457-9472

American Association of Kidney Patients. *Dialysis: The Patient Perspective.* (Available from AAKP, Inc., New York Chapter, Box 6044, New York, NY 10150. 212-288-5385. Price: \$150. 20 min.)

American Association of Kidney Patients. *Kidney Failure: Your Options.* (Available from AAKP, Inc., New York Chapter, Box 6044, New York, NY 10150. 212-288-5385. Price: \$150. 30 min.)

American Association of Kidney Patients. *Life Without Kidneys: A Second Chance at Living.* (Available from AAKP, Inc., New York Chapter, Box 6044, New York, NY 10150. 212-288-5385. Price: \$175. 15 min. b/w)

Baxter Healthcare, Dialysis Therapy Division. *Feeling Good.* (Available from Baxter Healthcare Corporation. Dialysis Division, 1425 Cook Rd., Deerfield, IL 60015)

Medcom/Trainex. *Dialysis: An Overview.* (Available from Medcom/Trainex. P.O. Box 3225, Garden Grove, CA 92642. 800-877-1443. Order No. 687. 15 min.)

Medcom/Trainex. *Your Hemodialysis Therapy* (Available from Medcom/Trainex. P.O. Box 3225, Garden Grove, CA 92642. 800-877-1443. Order No. 691TP. 9 min.)

Medcom/Trainex. *Your Peritoneal Dialysis Therapy* (Available from Medcom/Trainex. P.O. Box 3225, Garden Grove, CA 92642. 800-877-1443. Order No. 692TP. 9 min.)

National Kidney Foundation, Inc. (1987). *Diet: An Essential Part of Treatment.* (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Price: \$85.00 [videocassette, includes 50 accompanying booklets - KUBR00049]. Additional booklets: \$20.00 per 50 copies. Costs include shipping. Payment must accompany order.)

National Kidney Foundation, Inc. *Equation for Living, Part I: Emotional Impact.* (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Price: \$100.00)

National Kidney Foundation, Inc. *Equation for Living, Part 2: Diet, Medication and Fluid Compliance.* (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Price \$100.00.)

National Kidney Foundation, Inc. (1987). *Hemodialysis.* (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Price: \$85.00 [videocassette, includes 50 accompanying booklets - KUBR00051]. Additional booklets: \$20.00 per 50 copies. costs include shipping. Payment must accompany order.)

National Kidney Foundation, Inc. (1987). *Meeting the Challenge of Kidney Disease and Treatment.* (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Price: \$425.00, includes six video programs and 50 accompanying booklets for each program. Also sold individually. Payments must accompany order.)

National Kidney Foundation, Inc. *People Like Us*. (Video and accompanying booklets available for viewing through your dialysis unit. A dialysis professional can obtain copies of this material by contacting the National Kidney Foundation, Inc. at 1-800-622-9010.)

National Kidney Foundation, Inc. (1987). *Peritoneal Dialysis*. (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010.

Price: \$85.00 [videocassette, includes 50 accompanying booklets - KUBR00049]. Additional booklets: \$20.00 per 50 copies. Costs include shipping. Payment must accompany order.)

National Medical Care. *Living With Dialysis*. 1989. (Available from National Medical Care, Inc. 1601 Trapelo Road, Waltham, MA 02154. 617-466-9850. 18 min.)

Regional Kidney Disease Program. *Continuous Ambulatory Peritoneal Dialysis*. (Available from DIALYRN. Regional Kidney Program, 107 Park Ave. South, Minneapolis, MN 55415. 612-347-5986. Price: \$500 (Videotape set); \$30.00 (manual only); preview available.)

Regional Kidney Disease Program. *Home Hemodialysis Training*. (Available from DIALYRN. Regional Kidney Program, 107 Park Ave. South, Minneapolis, MN 55415. 612-347-5986. Price: \$625.00 (Videotape Set); \$25.00 (manual only), \$20.00 each manual for ten or more manuals; Preview available.)

Regional Kidney Disease Program. *Patient's Guide to Understanding Hemodialysis*. (Available from DIALYRN. Regional Kidney Program, 107 Park Ave. South, Minneapolis, MN 55415. 612-347-5986. Price: \$415.00 (videotape set), \$15.00 (manual only). Preview available.

Regional Kidney Disease Program. *Vascular Access Surgery for Hemodialysis*. (Available from DIALYRN. Regional Kidney Program, 107 Park Ave. South, Minneapolis, MN 55415. 612-347-5986. Price: \$225.00 for videotape and 15 booklets; \$3.00 (1 booklet only); \$25.00 (10 booklets only)

South-Eastern Organ Procurement Foundation. *Road Ahead: A Guide to the Treatment of End States Renal Disease*. (Available from South-Easter Organ Procurement Foundation, Suite 301, 7200 Glen Forest Drive, Richmond, VA 23226. 804-289-2050. Price to purchase, contact the Foundation.)

Diabetes

American Diabetes Association. (1989, April). *Kidney Complications (Nephropathy)*. (Available from American Diabetes Association, Diabetes Information Center. 1660 Duke Street, Alexandria, VA 22314. 800-232-3472 or 703-549-1500. Also available from local chapters. Price: Bulk price, single copies are free.)

Diabetes Services Division, National Medical Care, Inc. (1989). *Living with Diabetes*. (Available from Patient Videotape, Diabetes Services Division, National Medical Care, Inc. Reservoir Place, 1601 Trapelo Road, Waltham, MA 02154. 617-466-9850. Price: \$19.95 includes postage and handling.)

Eli Lilly and Company. (1989). *Managing Your Diabetes: Kidneys*. (Available from Eli Lilly and Company. Lilly Corporate Center, Indianapolis, IN 46285. 317-276-2000. Price: Free.)

National Kidney Foundation, Inc. *Diabetes and Kidney Disease*. 1992. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Price: single copy free. Order No. 02-09-PP)

Northwest Kidney Foundation. *How Diabetes Can Affect Your Kidneys*. (Available from Northwest Kidney Foundation. P.O. Box 3000, Seattle, WA 98114. 206-543-6397.)

Schmidt, L.M. (1991). *Independent, Home Self-Care Dialysis Possible for Blind Persons with Kidney Failure*. *Voice of the Diabetic*. 6(1): 4.

Employment, Insurance, Rehabilitation

American Association of Kidney Patients. *Americans With Disabilities Act of 1990: Your Rights in the Workplace*. (Available from American Association of Kidney Patients, 111 South Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

National Kidney Foundation, Inc. *Working with Kidney Disease: Rehabilitation and Employment*. (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010.)

Oberley, Sacksteder, & Schatell. *Employment, Insurance, & Finance: Facts and Resources for the Dialysis Patient*. (Available by asking your dialysis professional to contact their local Amgen representative.)

U.S. Department of Health and Human Services. (1990, August). *A Guide to SSI for Groups and Organizations*. (SSA Publication No. 05-10015). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Justice, Civil Rights Division. (1990). *The Americans with Disabilities Act*. (Available from U.S. Department of Justice, Coordination and Review Section, Civil Rights Division, U.S. Department of Justice, P.O. Box 66118, Washington, DC 20035-6118. 212-514-0301 or 202-514-0381.)

U.S. Department of Health and Human Services Social Security Administration. (1991, January). *The Appeals Process. Factsheet/No. 16*. (SSA Publication No. 05-10041). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services. (1990, February). *Benefits for Disabled People Who Return To Work*. (SSA Publication No. 05-10095). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1990, January). *Benefits for People With Disabilities Who Work*. (SSA Publication No. 05-11002). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services. (1991, January). *Disability*. (SSA Publication No. 05-10029). (Available from Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1988, January). *Disability Reviews. Factsheet/No. 9*. (SSA Publication No. 05-10068). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1991, May). *Medicare*. (SSA Publication No. 05-10043). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Health Care Financing Administration. (1991). *Medicare Coverage of Kidney Dialysis and Kidney Transplant Services: A Supplement to Your Medicare Handbook*. (Publication Number HCFA-10128). (Available from U.S. Department of Health and Human Services, Health Care Financing Administration, 6325 Security Blvd., Baltimore, MD 21207.)

U.S. General Accounting Office, Human Resources Division. *Medicare Payments for Home Dialysis*. (GAO/HRD-90-37). (B-230526). (Available from U.S. General Accounting Office, Human Resources Division, Washington, DC 20548.)

U.S. Department of Health and Human Services, Social Security Administration, Office of Programs, Office of Disability. (1991, June). *RED BOOK ON WORK INCENTIVES – A Summary Guide to Social Security and Supplemental Security Income Work Incentives for People With Disabilities*. (SSA Publication No. 64-030). (Available from Social Security Administration Regional Offices. Consult your local office for your region's address.)

U.S. Department of Health and Human Services, Social Security Administration. (1991, January). *Retirement*. (SSA Publication No. 05-10035). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1990, April). *Should You Buy A Supplement to Medicare? Factsheet/No. 15*. (SSA Publication No. 05-10039). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1989, January). *Social Security and Your Right to Representation. Factsheet/No. 10*. (SSA Publication No. 05-10075). (Available from U.S. Department of Health and Human Services

U.S. Department of Health and Human Services, Social Security Administration. (1991, March). *Social Security Disability Programs*. (SSA Publication No. 05-10057). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration, Office of Disability. (1986, April). *Social Security Regulations: Rules for Determining Disability and Blindness*. (SSA Publication No. 64-014). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1990, August). *SSI Eligibility Requirements*. (SSA Publication No. 05-11001). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services. (1991, January). *SSI, Supplemental Security Income*. (SSA Publication No. 05-11000). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1991, January). *Survivors*. (SSA Publication No. 05-10084). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services. (1991, January). *Understanding Social Security*. (SSA Publication No. 05-10024). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration, Office of Programs, Office of Supplemental Security Income. (1990, September). *Understanding SSI*. (SSA Publication No. 17-008). (Available from U.S. Department of Health and Human Services, Social Security Administration, Office of Programs, Office of Supplemental Security Income, Baltimore, MD 21235.)

U.S. Department of Health and Human Services, Social Security Administration. (1988, September). *When Medicare Pays Second. Factsheet/No. 14.* (SSA Publication No. 05-10080). (Available from U.S. Department of Health and Human Services, Social Security Administration, Baltimore, MD 21235.)

Witt, M.A. (1992). *Job Strategies for People with Disabilities.* (Available from Peterson's Guides, Princeton, NJ.)

Living with Kidney Disease

Abbott Laboratories (1993). *Your Kidneys, Yours Bones, and You.* (Available from Renal Care/Abbott Laboratories, North Chicago, IL 60064, 1-800-457-9472)

American Association of Kidney Patients. *Blood Chemistry Values.* (Available from American Association of Kidney Patients. 111 South Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

American Association of Kidney Patients. *Bulletin.* (Subscription information for this quarterly newsletter can be obtained by contacting American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

American Association of Kidney Patients. *Kidney Patient* (medic alert card). (Available from American Association of Kidney Patients. 111 South Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

American Association of Kidney Patients (formerly known as NAPHT). (1987). *NAPHT's Statement on Reuse of Disposable Devices.* (Available from American Association of Kidney Patients. 111 South Parker Street, Suite 405, Tampa, FL 33606, 800-749-2257.)

American Association of Kidney Patients. *Renalife.* (Subscription information for this magazine can be obtained by contacting American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

Arizona Kidney Foundation. *Search for Answers: A Guide for Dialysis and Transplant Patients.* 1990. 217 pages, includes Q&A, cookbook, modalities. (Available from Arizona Kidney Foundation. 4019 North 44th Street, Suite 100, Phoenix, AZ, 85018. 602-840-1644. Price: Free to Arizona patients, others \$6.50 plus postage and handling).

Campbell, A. *Suggestions for Living More Comfortably with Kidney Disease.* (Available from National Kidney Foundation of Eastern Missouri and Metro East, Inc. 225 South Meramec Ave., Suite 200, St. Louis, MO 63105. 314-863-5858.)

Collins, J.L. *Emotional Problems of Dialysis and Transplant Patients.* (Available from Virgil Smirnow Associates, Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817. 301-469-7933. Price: \$1.95 each (1-99 copies); \$1.25 each (100 or more copies).

Fisher, M. (1989). *Key to Improving Your Care.* NKF Family Focus: 1 (2). (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010)

Gabriel, R. *Patient's Guide to Dialysis and Transplantation.* 4th ed. Hingham, MA: Kluwer Academic Publishers, 1990. \$24.50.

Jackson, S.J. (1988). *Social and Economic Aspects of Dialysis.* (GPO Stock number 817-004-00019-9). (Available from U.S. Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402. 202-783-3238. Price \$2.50.)

Lundin, M.F. (1989). *Living Well Long-Term: Twenty-Year Perspectives*. *Renalife*, 4(1): 10-11, 24. Winter. (Available from American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

Lundin, M.F. (1990). *You and Your Access*. *Renalife*, 5(2): 10, 24. Summer. (Available from American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

Medical Education Institute, Inc. (1993-) *Renal Rehabilitation Report*, bi-monthly newsletter supported by an educational grant from Amgen Inc. (Free subscription available by writing Medical Education Institute, University Research Park, 585 Science Drive, Suite B, Madison, WI 53711-1060 or by calling (608) 232-2336)

National Kidney Foundation, Inc. *Coping Effectively*. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Price: single copy free. Order No. 08-63)

National Kidney Foundation, Inc. *Coping Effectively: A Guide for Patients and Families*. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Price: single copy free. Order No. 08-71)

National Kidney Foundation, Inc. (1992). *Dialysis*. (Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 03-01-CP)

National Kidney Foundation, Inc. *Dining Out with Confidence: A Guide for Renal Patients*. 1992. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Order No. 04-05-MP)

National Kidney Foundation, Inc. *Family Focus*. (Free subscription available from the National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. A quarterly publication for kidney patients and their families.)

National Kidney Foundation, Inc. *Fitness After Kidney Failure: Building Strength Through Exercise*. 1990. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Order No. 08-58)

National Kidney Foundation, Inc. *Home Hemodialysis*. 1991. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Price: single copy free. Order No. KU-8)

National Kidney Foundation, Inc. (1990). *Nutrition and Changing Kidney Function*. (Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 08-55)

National Kidney Foundation, Inc. *Nutrition and Hemodialysis*. 1987. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Order No. 04-02-CP)

National Medical Care. 1990. *Patient Care Conferences: Taking an Active Role in Your Care*. *Dialysis Services News*, p. 1-2, Summer. (Available from National Medical Care, Inc., Dialysis Services Division. Reservoir Place, 1601 Trapelo Road, Waltham, MA 02154. 617-466-9850.

Oberley, E.T., Oberley, T.D. (1991). *Understanding Your New Life with Dialysis*. Fourth Edition. (Available from Charles C. Thomas Publisher, 2600 South First Street, Springfield, Illinois 62794-9265. 217-789-8980.)

Renal Network of Illinois. *Patients Rights and Responsibilities*. (Available from Renal Network of Illinois, 800 S. Wells, Suite 550, Chicago, IL 60607. 312-431-3690.)

Renal Network of Illinois. *What is a Grievance?* (Available from Renal Network of Illinois. 800 S. Wells, Suite 550, Chicago, IL 60607. 312-431-3690.)

Thomas, C. (1989). *Your Important Role on the Health Care Team*. NKF Family Focus, 1(2). (Available from National Kidney Foundation. 30 East 33rd Street, New York, NY 10016. 800-622-9010.)

University of Iowa Hospital and Clinics. (1989). *Controlling Your Fluid Intake*. (Available from University of Iowa Hospital and Clinics. Publications, Dietary Department, Iowa City, IA 52242. 319-356-2692. Price: 100 copies @ \$5.00 plus shipping/handling).

Medication

National Kidney Foundation, Inc. *Administering EPO: A Program For Kidney Patients*. (Available from National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010.)

National Kidney Foundation, Inc. *EPO: Treating Anemia in Chronic Renal Failure*. 1991. (Available from National Kidney Foundation. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 03-05-CP)

National Kidney Foundation of Nebraska, Inc. *Medication Handbook* (loose-leaf). 1989. (Available from NKF of Nebraska, Inc. 2212 North 91st Plaza, Omaha, NE 68134. 402-397-9234 or 800-642-1255 (in Nebraska). Price: \$29.95)

Quinn-Cefaro, R. (1989). *R-Hu EPO and the Patient*. *Renalife*, 4(2): 12, Spring. (Available from American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

Miscellaneous

Food and Drug Administration: Rockville, MD. (1990). *AIDS: Information for the Dialysis Patient*. (HHS Pub. No. FDA 90-4240). (Available from the Food and Drug Administration. Attn: Don Hamilton, Center for Devices and Radiological Health, 5600 Fisher's Lane, Rockville, MD 20857. 301-443-2436.)

Modality Choice

Gabriel, R. *Patient's Guide to Dialysis and Transplantation*. 4th ed. Hingham, MA: Kluwer Academic Publishers, 1990. \$24.50.

Mattern, W.D., ed. (1987). *Facts About Kidney Diseases and Their Treatment*. (Available from American Kidney Fund. 6110 Executive Boulevard, Rockville, MD 20852. 301-881-3052 or 800-638-8299.)

Medtronic, Inc. *Kidney Dialysis and You: A Patient's Manual* (1989). (Available from Medtronic, Inc., 7000 Central Ave. NE, Minneapolis, MN 55432. 612-574-4000 or 800-328-2518. Pub. No. UC8902223EN).

Myers, C.R. (1989). *If You Want the Best Care, Be Involved!* *Renalife*, p. 10-11, Fall. (Available from AAKP, 111 South Parker Street, Suite 405, Tampa, FL 33606, 800-749-2257.)

National Institutes of Health. (1991, September). *End-State Renal Disease: Choosing a Treatment That's Right For You*. (Available from The National Kidney and Urologic Diseases Information Clearinghouse, Box NKUDIC, 9000 Rockville Pike, Bethesda, MD 20892. 301-468-6345. Price: Free of charge in quantities up to 25.)

Oberley, E.T., Oberley, T.D. (1991). *Understanding Your New Life with Dialysis*. Fourth Edition. (Available from Charles C. Thomas Publisher, 2600 South First Street, Springfield, Illinois 62794-9265. 217-789-8980.)

Renal Network of Illinois. *Kinds of Treatment*. (Available from Renal Network of Illinois, 800 S. Wells, Suite 550, Chicago, IL 60607. 312-431-3690.)

Siemsen, A.W. *Self-Care Dialysis at Home or in a Facility*. (Available from Virgil Smirnow Associates, Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817. 301-469-7933. Price: \$1.95 each (1-99 copies); \$1.25 each (100 or more copies)

Pediatric Kidney Disease

Alexander, S.R.; Kennedy, J.E. (1987). *Children and Kidney Disease*. (Available from American Kidney Fund. 6110 Executive Blvd., Rockville, MD 20852. 301-881-3052 or 800-638-8299.)

Children's Hospital, Boston. (1989). *Chronic Renal Failure: An Introduction for Parents*. (Available from Children's Hospital. Attn: Evelyn Corsini, LCSW, Social Service Department, 300 Longwood Avenue, Boston, MA 02115. 617-735-6129. Price: \$0.75.)

National Kidney Foundation, Inc. *Countdown for Takeoff (Dialysis)*. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Distribution restricted to children about to initiate therapy. Health care providers must request kit in the name of the patient; include child's age. Price: free.)

Tina, L.U., et al. *Kidney Diseases in Children*. (Available from Virgil Smirnow Associates. Health and Public Affairs, 8501 Burdette Rd., Washington, DC 20034. Price: \$1.00.)

Peritoneal Dialysis

American Kidney Fund. (1988). *Diet Guide for the CAPD Patient*. (Available from American Kidney Fund. 6110 Executive Blvd., Suite 1010, Rockville, MD 20852. 301-881-3052, 800-638-8299 or 800-492-8361 [in Maryland].)

Baxter Healthcare Corporation. (1989). *Peritoneal Dialysis: Going Home with Confidence*. (Available from Baxter Healthcare Corporation. Renal Division, 1425 Lake Cook Rd., Deerfield, IL 60015.)

Baxter Healthcare Corporation. (1988). *Introduction to Continuous Ambulatory Peritoneal Dialysis: Patient Program*. (Available from Baxter Healthcare Corporation. Dialysis Division. 1425 Lake Cook Rd., Deerfield, IL 60015.)

Baxter Healthcare Corporation. (1987). *Taking Care of Yourself: An Introduction to Peritoneal Dialysis*. (Available from Baxter Healthcare Corporation. One Baxter Parkway, Deerfield, IL 60015. 312-948-2000.)

Campbell, S. (1989). *Psychosocial Perspective of Peritoneal Dialysis (CAPD/CCPD)*. *Kidney Chronicle*, 9(4), October.

Contemporary Dialysis and Nephrology. 3: 8-9,11,21 (1989). *Conversations. Sharing Dialysis Experiences*.

Epogen is a registered trademark of Amgen, Inc.

Gabriel, R. *Patient's Guide to Dialysis and Transplantation*. 4th ed. Hingham, MA: Kluwer Academic Publishers, 1990. Chapters: Continuous Ambulatory Peritoneal Dialysis (p. 88-97), Continuous Cycle Peritoneal Dialysis (p.105-107), and Intermittent Peritoneal Dialysis (p. 99-104.)

Kolff, W.J., Kablitz, C. *Peritoneal Dialysis – Including CAPD*.

(Available from Virgil Smirnow Associates. Health and Public Affairs, 8501 Burdette Rd., Washington, DC 20034. Price: \$1.95 (1-99 copies); \$1.25 (100 or more copies.)

Miller, L.A. (1990). *At-Home Help for the CAPD Patient*. RN, 53(8): 77-80.

National Kidney Foundation, Inc. (1990). *Nutrition and Peritoneal Dialysis*.

(Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 08-62)

National Kidney Foundation, Inc. (1992). *Peritoneal Dialysis: An Alternative to Hemodialysis*.

(Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 03-02-CP)

Twardowski, Z.J. (1989). *CAPD Catheters: Solving Problems Through Better Design*. Renalife, 4(1): 14-15. (Available from American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

Resource Guides

Amgen Reimbursement Hotline 1-800-2-PAY-EPO. This toll-free hotline can answer questions related to Medicare and Medicaid reimbursement for Epogen®. The hotline may also be able to provide referrals for other information on insurance and reimbursement.

Ford, J.F. *Sources of Help for Dialysis and Transplant Patients*. (Available from Virgil Smirnow Associates, Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817. 301-469-7933. Price: \$1.95 each (1-99 copies); \$1.25 each (100 or more copies).)

National Kidney and Urologic Diseases Information Clearinghouse. 1992. *Dialysis: Patient Materials*. (Available from Box NKUDIC, 9000 Rockville Pike, Bethesda, MD 20892. 301-468-6345).

National Kidney and Urologic Diseases Information Clearinghouse. (1988 to present, Aug. 1993). *Hemodialysis: Professional Materials* (Available from Box NKUDIC, 9000 Rockville Pike, Bethesda, MD 20892. 301-468-6345).

National Kidney and Urologic Diseases Information Clearinghouse. 1992. *Peritoneal Dialysis: Professional Materials*. (Available from Box NKUDIC, 9000 Rockville Pike, Bethesda, MD 20892. 301-468-6345).

National Kidney Foundation, Inc. (1993-1994). *Affiliate Catalogue of Development, Public Information and Education Materials*. (Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010.)

Smirnow, V., Gillaspay, J.A., Calcagno, P.L. (Eds.) 1991. *Nephrology Resource Directory, 4th Ed*. (Available from Virgil Smirnow Associates. 8501 Burdette Road, Bethesda, MD 20827. 301-469-7933. Price: \$22.95 plus \$2.00 shipping and handling).

Sexuality

Gabriel, R. *Patient's Guide to Dialysis and Transplantation*. 4th ed. Hingham, MA: Kluwer Academic Publishers, 1990. (p.116-121). \$24.50.

Levy, N.B. *Sex and Intimacy for Dialysis and Transplant Patients*. (Available from Virgil Smirnow Associates, Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817. 301-469-7933. Price: \$1.95 each (1-99 copies); \$1.25 each (100 or more copies).

McCann, L. 1991. *Nutrition and Sexual Function: Is There a Connection?* NKF Family Focus, 2(4): 12-13. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010).

National Kidney Foundation, Inc. *Sexuality and Chronic Kidney Failure*. 1991. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. Price: single copy free. Order No. 05-04-PP)

Painter, P. (1991). *Know Your Body, Know Your Partner's: Exercise and Your Love Life*. NKF Family Focus, 2(4):16. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010)

Pfeil, C.C. (1991). *Let's Talk About Sexuality*. NKF Family Focus, 2(4):1,4. (Available from National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010)

Materials In Spanish

Abbott Laboratories (1994). *Sus Rinones, Sus Huesos, Y Usted*. (Available from Renal Care/Abbott Laboratories, North Chicago, IL 60064, 1-800-457-9472.)

American Diabetes Association. (1989, April). *Complicaciones Renales (Nefropatia)*. [*Kidney Complications (Nephropathy)*]. (Available from American Diabetes Association, Diabetes Information Service Center. 1660 Duke St., Alexandria, VA 22314. 800-232-3472 or 703-549-1500. Also available from local chapters. Price: Bulk price, single copies are free.)

American Kidney Fund. (1988). *El Regimen Alimenticio del Paciente en Dialisis Peritoneal Ambulatoria Continua (D.P.A.C.)*. [*Diet Guide for the CAPD Patient*]. (Available from American Kidney Fund. 6110 Executive Blvd., Suite 1010, Rockville, MD 20852. 301-881-3052, 800-638-8299 or 800-492-8361 [in Maryland].)

American Kidney Fund. (1991). *Enfermedades Del Rinon: Guia Para el Paciente Y Su Familia*. [*Kidney Disease: A Guide for Patients and their Families*]. (Available from American Kidney Fund. 6110 Executive Blvd., Suite 1010, Rockville, MD 20852. 301-881-3052 or 800-638-8299 or 800-492-8361 [in Maryland]. Price: \$0.40.)

American Kidney Fund. (1988). *Regimen Alimenticio para los Pacientes de Hemodialisis*. [*Diet Guide for the Hemodialysis Patient*]. (Available from American Kidney Fund. 6110 Executive Blvd., Suite 1010, Rockville, MD 20852. 301-881-3052 or 800-638-8299 or 800-492-8361 [in Maryland]. Price: Free.)

Arizona Kidney Foundation. *Search for Answers: A Guide for Dialysis and Transplant Patients*. 1990. Available in Spanish. 217 pages, includes Q&A, cookbook, modalities. (Available from Arizona Kidney Foundation. 4019 North 44th Street, Suite 100, Phoenix, AZ, 85018. 602-840-1644. Price: Free to Arizona patients, others \$6.50 plus postage and handling).

Harum, P. (1988). *Manual De Alimentacion para personas con problemas de los rinones* [*Renal Diet Manual*]. (Available from Printing Plus. The Renal Diet Manual, 7928 SW 105th Place, Miami, FL 33173. Price: \$15.50, includes postage and handling.)

National Kidney Foundation, Inc. (1990). *Dialysis*. 1993. (Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 03-09-CM)

National Kidney Foundation of Texas, Inc. *Dieta Para Pacientes con Fallo Renal [Diet for Patients with Renal Failure]*. (order number: RD2). (Available from National Kidney Foundation of Texas, Inc. 3500 Midway Rd., Suite 101, Dallas, TX 75234. 214-934-8057. Price: \$2.50 plus postage and handling: 1-10 pages, \$0.75; 11-30 pages, \$1.50; 31-70 pages, \$2.75.)

National Kidney Foundation, Inc. *Sobre Los Rinones [About the Kidneys]*. 1992. (Available from National Kidney Foundation, Inc. 30 E. 33rd St., New York, NY 10016. 212-889-2210 or 800-622-9010. Order No. 12856)

Transplantation

Arizona Kidney Foundation. *Search for Answers: A Guide for Dialysis and Transplant Patients*. 1990. 217 pages, includes Q&A, cookbook, modalities.

(Available from Arizona Kidney Foundation. 4019 North 44th Street, Suite 100, Phoenix, AZ, 85018. 602-840-1644. Price: Free to Arizona patients, others \$6.50 plus postage and handling).

Ford, J.F. *Sources of Help for Dialysis and Transplant Patients*. (Available from Virgil Smirnow Associates, Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817. 301-469-7933. Price: \$1.95 each (1-99 copies); \$1.25 each (100 or more copies).

Hathaway, D.S. (1989). *Transplantation or Dialysis: Choosing One Over the Other*. NKF Family Focus 1 (2). (Available from National Kidney Foundation, Inc., 30 E. 33rd St., New York, NY 10016. 212-889-2210 or 800-622-9010.)

Levey, N. (1988). *Dialysis and Transplantation: A Source Book of Patient Perspectives*. (ISBN: 0398054339). (Available from Charles C. Thomas, Publisher. 2600 South First St., Springfield, IL 62794-9265. Price: \$19.75.)

Levy, N.B. *Sex and Intimacy for Dialysis and Transplant Patients*. (Available from Virgil Smirnow Associates, Health and Public Affairs, 8501 Burdette Road, P.O. Box 34425, Bethesda, MD 20817. 301-469-7933. Price: \$1.95 each (1-99 copies); \$1.25 each (100 or more copies).

National Kidney Foundation, Inc. *Facts About Transplantation and Kidney and Urologic Diseases*. (Available from National Kidney Foundation, Inc., 30 E. 33rd St., New York, NY 10016. 212-889-2210 or 800-622-9010.)

National Kidney Foundation, Inc. (1990). *Nutrition and Transplantation*. (Available from the National Kidney Foundation, Inc. 30 East 33rd Street, New York, NY 10016. 800-622-9010. Order No. 08-66)

Oberley, Edith T., MA; Glass, Neal R., MD, FACS. (1987). *Understanding Kidney Transplantation*. (Available from Charles C. Thomas, Publisher. 2600 South First St., Springfield, IL 62794-9265.)

Life Options Rehabilitation Program

c/o Medical Education Institute, Inc.

414 D'Onofrio Drive, Suite 200 • Madison, WI 53719

(608) 833-8033 • (800) 468-7777 • (608) 833-8366 (Fax) • lifoptions@MEIresearch.org • www.lifeoptions.org

Supported by Amgen Renal Advances

AMGEN RENAL ADVANCES