

ESRD Network # 12 Patient Newsletter

Providing kidney patients and their families information on diet, health, and kidney disease.

Volume 4.

Spring 2004

Issue 1.

Nephron News & You is written and distributed under Centers for Medicare & Medicaid Services Contract #500-00-NW12. For more information, please contact the newsletter editor: Kimberly F. Thompson, R.N., C.N.N. at 1-800-444-9965 Monday – Friday from 8 a.m. – 4:30 p.m. Central standard time.

Choosing the Path



of KNOWLEDGE

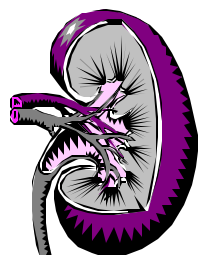
About every 12 minutes, more than 100 times a day, someone in the United States is told he has Chronic Kidney Disease (CKD). Many of these new patients feel this will mean the end stage of their lives. A few may even allow the illness to destroy their hopes and dreams.

How much will it, or has it changed your life? A lot depends on you.

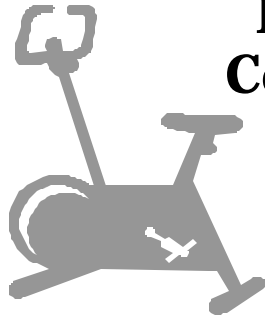
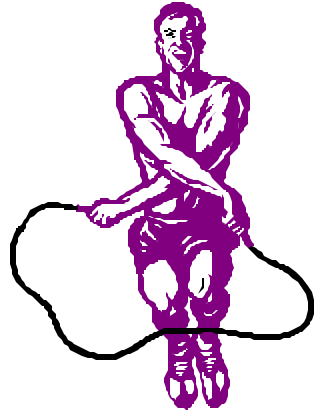
It is up to you how much you want to keep your life the way it has been or make changes to improve your situation.

It is normal to be afraid at first, and worried about how your life may change. You are not alone. There are many people who can help, provide good sources of advice and help you with rehabilitation.

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Rehabilitation means restoring you to stable health, a positive outlook, and activities you enjoy. Changes in medicine and treatment have made dialysis treatment for chronic kidney disease more effective. This means that now more than ever before, kidney patients have the potential to return to an active and productive life. Rehabilitation for kidney patients means a coordinated program of:



Medical Treatment
Education
Diet
Exercise
Counseling

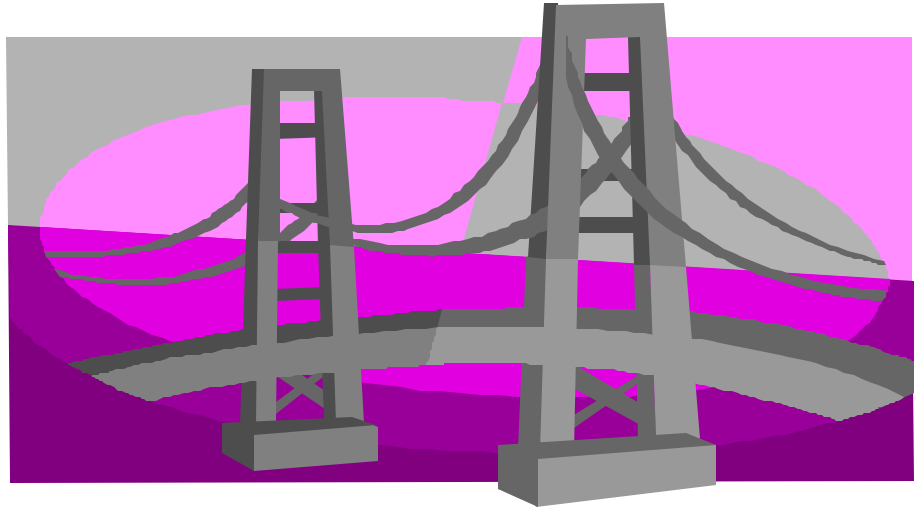
These pieces of rehabilitation all work together and can improve your fitness and energy, increase your ability to work, and help you have a better life. Setting goals for yourself is important and can include:

- A good understanding of your treatment and taking part in planning
- Better fitness, getting back to activities you enjoy
- Education and
- Employment

Myths and Obstacles

The myths range from “dialysis patients are too sick and unstable to work and will die soon”, to “people with CKD who are working or who have had a transplant don’t need and aren’t eligible for vocational rehabilitation services”. The fact is that people on dialysis, or who have had successful transplants, are still living more than 30 years. The clear message is that people with CKD are fully able to participate in the workforce. If you are new to dialysis you may not know what to expect. If you have been on dialysis for a while, you may wish that you had known some things a lot earlier. Learning about them early and knowing what to do can overcome many obstacles to rehabilitation like poor attitude, not enough information, and lack of exercise.

The “Five E’s” – Bridges to Rehabilitation



The “Five E’s” – Bridges to Rehabilitation First and foremost, you are the key member of the treatment team. It is up to you to be active, motivated, and verbal. Your treatment team includes you, your nephrologist, nurses, social worker, dietitian, and your family. The staff on your team are good resources for you. It is good to know what options are available.

To assist patients in living better lives, the Life Options Rehabilitation Advisory Council identified five “bridges” or Five “E’s”:

Encouragement – working hard for something and taking control of your life gives you a sense of purpose.

Education – the more you learn about your illness and its treatment, the better you will 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 self esteem, identity, independence, a sense of accomplishment, a social outlet, and a higher standard of living.

Evaluation – research is being done across the country on ways to support rehabilitation, you too can evaluate what barriers to rehabilitation are.

Special thanks are extended to the Transpacific Renal Network for the previous information; funded in accordance with the Department of Health and Human Services, contract #500-00-NW17.

Vocational Rehabilitation

Every state has a rehabilitation council. Network #12 serves the ESRD Community in Iowa, Kansas, Missouri and Nebraska. For more information on vocational rehabilitation or if you are interested in returning to work, the social worker at your facility is an excellent resource for assisting you with this goal.

IOWA'S MISSION STATEMENT

Our mission is to work for and with individuals with disabilities to achieve their employment, independence, and economic goals. Economic independence and more and better jobs are what we are about for Iowans with disabilities. To contact the Division of Vocational Rehabilitation in Iowa you may write to 510 E. 12th Street, Des Moines, IA 50319-0240 or call 515-281-4211. They can also be located on the web at: <http://www.dvrs.state.ia.us/>

KANSAS' MISSION AND VISION STATEMENT

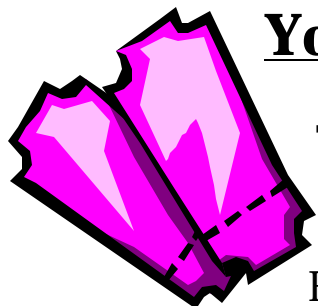
Our Mission: To protect children and promote adult self-sufficiency.
Our Vision: Partnering to connect Kansans with supports and services to improve lives. To contact the Kansas Department of Social and Rehabilitation Services you may write to 915 SW Harrison Street, Topeka, KS 66612 or call 785-296-3959. They can also be located on the web at: <http://www.srskansas.org/>

MISSOURI'S MISSION AND VISION STATEMENT

Making a positive difference through education and service. We provide leadership and promote excellence and promise to greatly exceed our customers' expectations.
Vocational Rehabilitation 3024 W. Truman Blvd. Jefferson City, MO 65109-0525
573/751-3251 (voice) 573/751-0881 (TDD)

NEBRASKA'S MISSION AND GOAL STATEMENT

Vocational Rehabilitation is an employment program for people with disabilities. We help people with disabilities make career plans, learn job skills, get and keep a job. Our goal is to prepare people for jobs where they can make a living wage and have access to medical insurance. To contact the Nebraska Department of Education-Vocational Rehabilitation you may call toll free 1-877-637-3422 (1-877-NE REHAB) or they can also be located on the web at <http://www.vocrehab.state.ne.us/>



Your Ticket to Work

The Ticket to Work and Self-Sufficiency Program is the centerpiece of the Ticket to Work and Work Incentives Improvement Act of 1999 and has been incorporated as part of President Bush's New Freedom Initiative. It is a comprehensive national program designed to provide SSA beneficiaries with disabilities more choices for receiving the employment, vocational rehabilitation (VR), and other support services they need to obtain and maintain employment, as well as increase provider incentives to serve these individuals.

Day-to-day administration of the Ticket Program is the responsibility of the Program Manager (PM). SSA has contracted with MAXIMUS, a private company, to perform this role.

How Many People Are Eligible for the Ticket Program?

Most Social Security beneficiaries with disabilities, ages 18-64, receive a Ticket (Ticket-holders). More than 10 million Ticket-holders are eligible to participate in this Program nationwide and many are already working.

10 Million People, 50 States, 1 Program

Contact us to find out more.

Toll Free: 1-866-968-7842

How Does the Program Work?

The Ticket Program is flexible and voluntary – SSA beneficiaries are not mandated to participate and in most cases, ENs can choose which services they want to provide, where, and to whom. Beneficiaries receiving Tickets can contact one or more ENs to discuss services and once an agreement between the beneficiary and EN is reached, the two work together to develop a work plan to assist the beneficiary in reaching his or her employment goal. Every month a Ticket-holder is employed at a certain wage level, ENs receive revenue.

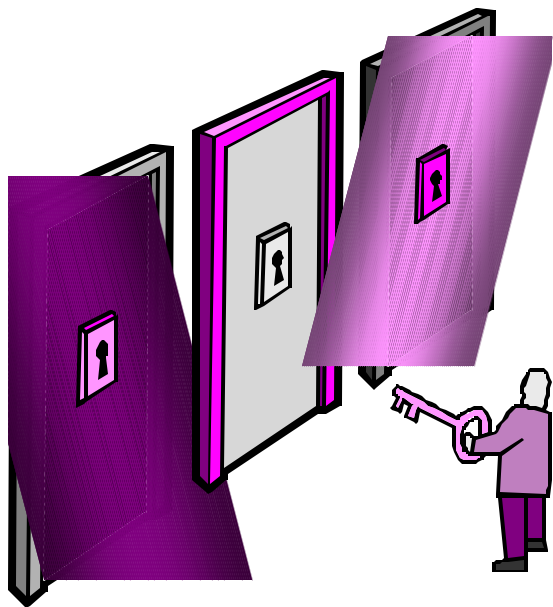
Benefits and Work Incentives

For Social Security Benefits (SSD and SSI) see: <http://www.ssa.gov/work>

For SSD beneficiaries there is a 9-month trial work period with no earning limitations. Following the trial work period, if you earn less than \$800 per month (beginning January 2003) you will continue to receive your full SSD benefits. If you earn more than that amount, you will not receive a benefits check but will continue your Medicare coverage. If you stop working you can get Expedited Reinstatement, enabling you to resume your SSD benefits without a waiting period.

For SSI recipients there are different work incentives. Depending on income your SSI checks may be reduced, but your Medicaid coverage will continue. See: www.ssa.gov/work/resourcestoolkit/redbook/html

Ticket to Work increases opportunities for SSA recipients to pursue vocational goals. See: <http://www.yourtickettowork.com>



Laws to Protect Disabled Workers

Family Medical Leave Act (FMLA) entitles eligible employees to take up to 12 weeks of unpaid, job protected leave each year for special medical reasons. If you have worked for at least 12 months for a public or private sector employer with 50 or more employees you should be covered. The 12 weeks may be taken in one block or intermittently in increments of as little as 15 minutes at a time.

FMLA will help you maintain your health insurance and seniority. See: <http://www.dol.gov/dol/esa/public/regs/compliance>

Americans with Disability Act (ADA) prohibits discrimination against people with disabilities and applies to employers with 15 or more employees. If you can perform the essential functions of your job, with or without reasonable accommodations you can request ADA protection. You must disclose your disability to your employer by going to the person in the company who has the power to make the necessary change. See: <http://www.Usdoj.gov/crt/ada>

Special Web Sites for People with Disabilities

<http://www.abletowork.org>

Business Consortium led by Microsoft

<http://www.jobaccess.org>

Job Service

<http://www.choiceemployment.com>

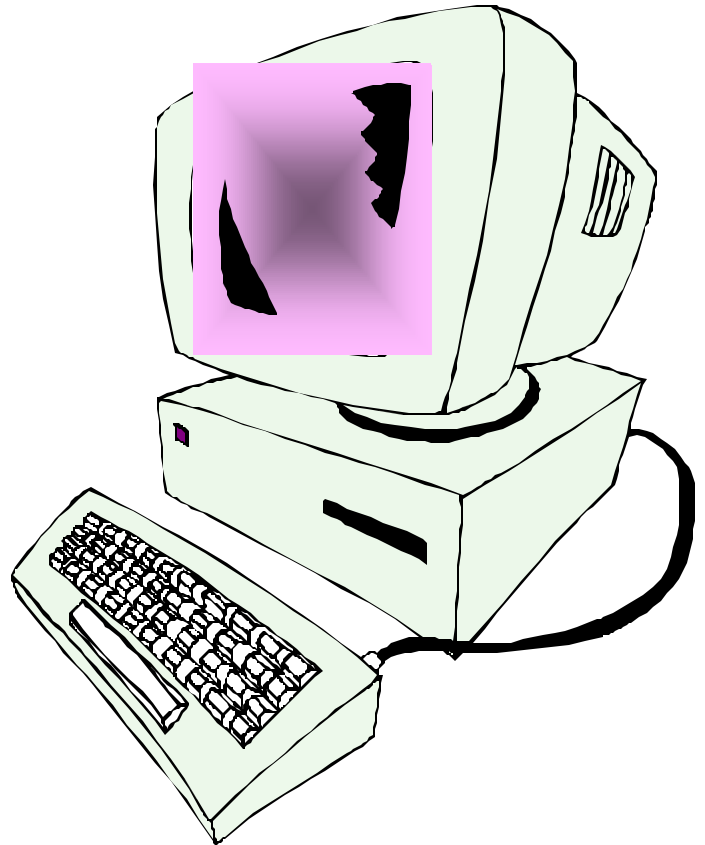
Employment Agency

<http://www.wemedia.com>

Life style and job-hunting tips

<http://www.pcepd.gov>

President's Committee on
employment of people with
disabilities



Dialysis Facility Compare

Interested in traveling, vacationing or simply want to know how your unit is performing compared to other dialysis units in your area? Centers for Medicare & Medicaid host the website Dialysis Facility Compare – www.medicare.gov/Dialysis/Home.asp. Dialysis Facility Compare has information about:

Dialysis Facility Characteristics and includes the:

- address and telephone number of the facility,
- facility's initial date of Medicare certification,
- shifts starting at 5 PM or later (if you need your treatments in the evening),
- number of treatment stations,
- types of dialysis offered (in-center hemodialysis, peritoneal dialysis, and home hemodialysis training),
- facility ownership type (profit or non-profit), and
- chain name (if applicable).

Quality Measures and includes information about:

- the percent of patients at a facility with a Urea Reduction Ratio (URR) of 65 or greater known as adequacy of hemodialysis,
- the percent of patients treated with Epogen® with a hematocrit of 33 or greater, and
- the patient survival information.

Dialysis Facility Compare is as easy to use as 1, 2, 3, 4... just look below:

(Step 1 of 4) Select a Geographic Area – at this step, you simply choose which state or territory you would like to search.

(Step 2 of 4) Narrow Your Search – at this step, you may choose to narrow your search in a variety of ways; by the entire state, county, city, or by zip code.

(Step 3 of 4) Select a Dialysis Facility – at this step, you may select a specific dialysis unit, or all units listed.

(Step 4 of 4) Select a Topic You – at this step, you may choose to view information on Dialysis Facility Characteristics or Quality Measures.

Choices & Decisions

There are several different methods of dialysis available today. It is important to discuss the options with the members of your renal healthcare team.



Home Hemodialysis

Home hemodialysis is a technique whereby patients and their designated partners are trained to perform all their dialysis treatments independently at home. Home hemodialysis offers several advantages over conventional in-center dialysis. Quality of life is superior for patients who undergo dialysis in their own home. Control of their own treatments allows home hemodialysis patients to understand their own condition and symptoms more clearly. This also allows them to tailor their dialysis experience to one, which is most accommodating to their individual needs. Home hemodialysis allows patients with kidney failure to become integrally involved in the most essential aspect of their health care and to shape the day-to-day quality of their life. Home hemodialysis offers the independence, which is otherwise lacking in conventional in-center hemodialysis. Patients no longer need to tolerate delays in treatment start times. They will have the freedom to schedule their treatments at times, which are more convenient and will undergo their dialysis treatments in the comfort of their own homes.

Home hemodialysis eliminates the patient's need to commute to the dialysis facility thereby increasing the time available to spend with family, friends, employment and community service.

Nocturnal Hemodialysis

Nocturnal hemodialysis is usually easier tolerated than in-center dialysis. This form of dialysis takes place in your home while you sleep, for approximately eight hours, using slow blood flows and gradual removal of water and toxins. The longer dialysis times and mild fluid removal more closely mimic regular kidney function. Elimination of toxins and waste products by nocturnal dialysis is more efficient than conventional dialysis, and electrolytes are better maintained. Since dialysis is taking place at night during sleeping hours, the day is not restricted by the need to dialyze, and more time can be spent at work, leisure or recreation. The dialysis treatments take place in the comfort and privacy of your home, relieving you of the need to travel to a dialysis center for treatment.

Nocturnal hemodialysis allows people with kidney failure to continue their usual daily activities and maintain their independence, while feeling better and healthier than with conventional dialysis.

In-Center Hemodialysis

In hemodialysis, an artificial kidney (hemodialyzer) is used to remove waste and extra chemicals and fluid from your blood. In-center dialysis requires the patient to travel to a clinic at least 3 times a week for treatment. During the in-center treatment, staff programs the machine, places the needles, monitors the treatments, draws any labs needed and removes the needles. Some units may allow patients to participate in any of the previous. Hemodialysis is a treatment that cleanses your blood of the wastes and excess fluid that have built up. During hemodialysis, your blood travels through soft tubes to a dialysis machine where it goes through a special filter called a dialyzer, or an artificial kidney. As your blood is cleansed, it is returned to your bloodstream. Only a small amount of blood is out of your body at any time. Your dialysis care team will monitor your treatment with monthly lab tests to ensure you are getting the right amount of dialysis. The dialysis unit may also serve as a backup unit for patients dialyzing at home.

Peritoneal Dialysis

A soft plastic tube (catheter) is placed in your belly by surgery. A sterile cleansing fluid is put into your belly through this catheter. After the filtering process is finished, the fluid leaves your body through the catheter. There are two kinds of peritoneal dialysis: Continuous Ambulatory Peritoneal Dialysis (**CAPD**) and Continuous Cycling Peritoneal Dialysis (**CCPD**). The basic treatment is the same for each. However, the number of treatments and the way the treatments are done make each method different.

CAPD is "continuous," machine-free and done while you go about your normal activities such as work or school. You do the treatment by placing about two quarts of cleansing fluid into your belly and later draining it. This is done by hooking up a plastic bag of cleansing fluid to the tube in your belly. Raising the plastic bag to shoulder level causes gravity to pull the fluid into your belly. When empty, the plastic bag is removed and thrown away.

When an exchange (putting in and taking out the fluid) is finished, the fluid (which now has wastes removed from your blood) is drained from your belly and thrown away. This process usually is done three, four or five times in a 24-hour period while you are awake during normal activities. Each exchange takes about 30 to 40 minutes. Some patients like to do their exchanges at mealtimes and at bedtime.

CCPD differs from CAPD in that a machine (cycler) delivers and then drains the cleansing fluid for you. The treatment usually is done at night while you sleep.

Concerns About Your Care

The following information is intended to assist patients and their families in mediating difficulties at the dialysis unit, and filing a grievance or concern with the Network.

“Patients are encouraged and assisted to understand and exercise their rights... without fear of discrimination or reprisal.”

Conditions for Coverage of Suppliers of End-Stage Renal Disease (ESRD) Services, Subpart U 405.2138(e)

ESRD Network #12 has Registered Dialysis Nurses on staff to listen to your complaint and assist you in mediation with the unit? Just call 1-800-444-9965 Monday through Friday and ask to speak with the Grievance Mediator.



Patients may remain completely anonymous through the concern/grievance process.



What exactly is a “complaint”, or “grievance”?

A complaint, or grievance is any concern that you have about the care that you receive from your healthcare facility. It may range from something that you believe affects your safety or the safety of other patients, to communication difficulties in the dialysis unit.

Who can file a complaint?

ANYONE! Patients, family members, dialysis staff, or anyone else who has concerns about a dialysis unit can report problems. If you have a complaint, it doesn't matter if you are on hemodialysis, peritoneal dialysis, home dialysis, or if you have had a transplant. It is ALWAYS important to let someone know if you have concerns about your medical care.

How can ESRD Network #12 assist?

Some of the things the Network is able to do to assist you are:

- ☞ Investigate a complaint or grievance
- ☞ Contact a dialysis unit to discuss your complaint
- ☞ Educate the staff at the dialysis unit and you about issues related to your complaint.
- ☞ Refer your complaint to another agency (State Survey Agency)
- ☞ Visit your dialysis unit to provide mediation (see below)
- ☞ Provide advocacy for your patient rights.

Why should I tell anyone?

- ☞ To make sure you receive safe care. The most important purpose of complaints is to protect you and other patients at your dialysis unit. All dialysis units are required to follow basic guidelines for treatment under Medicare. When a unit is not following these guidelines, it is important that someone is aware of the situation so that it can be improved.
- ☞ To work through problems. Every patient and staff member has a different personality, so it is possible that in a dialysis unit there may be some communication difficulties from time to time. If a problem is left alone, it can potentially become worse. However, if you talk about your concern with someone, there is a better chance you will feel more comfortable about it.
- ☞ To help others. There may be other people in your dialysis unit who also have concerns but are not able to (or are afraid to) let someone know. In this case, telling someone about your concern might help other people as well.

Whose “side” is the Network on?

As a general rule, the Network is here as a neutral third party to help mediate disputes. Mediation means that we will listen to both sides and try to assist each in reaching the best possible outcome.

Any case where your safety may be at risk, our goal is to improve the situation and we will act on your complaint immediately. Sometimes this means that your complaint will be referred to the State Survey Agency for further investigation. This determination is made after receiving your complaint and identifying potential life-threatening risks to you or to other patients.

Who is the State Survey Agency and what is their responsibility?

The State Survey Agency's main responsibility is to inspect healthcare facilities, like dialysis units, in order to make sure that patients are receiving the safest care. Like the Network, they also receive and investigate complaints about dialysis.

The Survey Agencies are guided and funded by Medicare, which requires that all facilities that receive Medicare funds follow some basic guidelines of care, or MEDICARE REGULATIONS. The State Surveyors use these regulations during inspections and investigations. The inspections are conducted on a regular basis, but can also be conducted if they have received a complaint regarding the Medicare Regulations, or a call from the Network.

If you choose to contact the State Survey Agency, a trained professional will listen to your complaint and decide whether or not a surveyor needs to do an unannounced investigation at the clinic.

If the complaint could be resolved through mediation, the State Survey Agency may refer a complaint to the Network.

What do I do about my complaint?

The decision of what to do is always up to you - the patient. Here are a couple of things you can consider doing...

Try talking to someone at the facility where you receive dialysis. Each facility has its own "grievance procedure", which explains what to do with your complaint within the dialysis unit. Your unit may request that you try to solve the problem within the unit first, so it is helpful to find out whom to talk to. The dialysis facility has someone who will listen to your concerns and assist you in resolving them. Some people on your health care team that you could speak with are:

☞ **Head Nurses/Directors of Nursing**
☞ **Charge Nurses**
☞ **Administrators**

☞ **Social Workers**
☞ **Doctors**
☞ **Dietitians**
☞ **Regional Managers**

Emergency Preparedness

Emergency Preparedness

The following excerpt is from the Medicare and You publication; a collaborative effort with Network 17, "Preparing for Emergencies: A Guide for People on Dialysis". For more information or to obtain a complete booklet, please call 1-800-444-9965 ext. 18.

This information has broad tips on how to prepare for an emergency if you have end stage renal disease. These tips will **not** work for every patient or in every emergency situation. You may have special health problems or face unique conditions that make a different answer better for you. Please contact your doctor for medical advice or treatment. **Do NOT rely on this guide for treatment or medical advice.**

The 3-day Emergency Diet Plan

When dialysis is unavailable, your survival will depend on your ability to follow a limited diet. This information will help you prepare and manage an emergency diet plan. If you are able to communicate with your doctor at this time, he/she will be able to help you manage. If you are on CAPD and cannot get your supplies to do your exchanges, this plan will also apply to you.

The basis of this diet is 2 cups of fluid per 24 hours. The Northern California Council on Renal Nutrition developed the plan. It is stricter than the renal diet you normally follow to keep poisons from building up in your blood.

Bread/cereal.....	5-6 servings per day
Fruits/vegetables.....	2-4 servings per day
Meat/protein	3 ounces per day
Milk	½ cup per day
Fats.....	6 or more teaspoons per day
Sweets.....	as desired (except for diabetics)

Please speak with the Dietitian at your facility to determine the best emergency diet plan for you. Your healthcare team is the best resource for your individual needs and requirements as a patient.

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ANONYMOUS

BRIDGES

CAPD

CCPD

CONDITIONS

COUNSELING

DIALYSISFACILITYCOMPARE

DIET

EDUCATION

EMERGENCIES

EMPLOYMENT

ENCOURAGEMENT

EVALUATION

EXERCISE

HEALTHCARETEAM

LIFEOPTIONS

MEDIATE

MEDICALTREATMENT

NOCTURNAL

PLANNING

REHABILITATION

SUBPARTU

SUCCESSFUL

TICKETTOWORK

VOCATIONAL

Name _____ Facility Number _____

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