

ESRD Network #12 Patient Newsletter

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

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Evaluating



Alternatives

Technology continues to advance, and with it options for dialysis patients. This newsletter will provide information regarding Dialysis Facility Compare; a website hosted by Medicare that provides information on dialysis units in the United States, treatment options currently available, and things to consider for emergency preparedness.

When evaluating the treatment options currently available, consider discussing the choices with your renal treatment team. The team at your dialysis unit is the most familiar with your care and needs, and as such best able to discuss the pros and cons of any change you may want to consider regarding your current treatment.

Dialysis Facility Compare

Interested in traveling, vacationing, or simply want to know how your unit is performing compared to other dialysis units? Centers for Medicare & Medicaid Services (CMS) hosts the website Dialysis Facility Compare or DFC. The website allows anyone to review characteristics and quality measures. The web address is www.medicare.gov/dialysis/home.asp Some of the information available on the DFC website is listed below and on the following page.



Dialysis Facility Characteristics

Includes the:

- ☞ Address and telephone number of the facility,
- ☞ Facility's initial date of Medicare certification,
- ☞ Shifts starting at 5 p.m. 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 - displayed on Compare Quality Tab

Includes information about:

- ☞ The percent of patients at a facility with a urea reduction ratio (URR) of 65 or greater, known as adequacy of dialysis,
- ☞ The percentage of patients treated with Epogen® with a hematocrit of 33 or greater, and
- ☞ Patient survival information.

Resources - includes information on kidney disease and dialysis treatments

Links to other websites with information on/for:

- ☞ Family members, patients on peritoneal dialysis, and patients on hemodialysis,
- ☞ Chronic kidney disease, pediatric dialysis, transplantation.



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DFC

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By Name - I want to find a dialysis facility by entering all/some of its name then click on: **Dialysis Facility Name**

By Proximity - I want to find all dialysis facilities within a certain distance of “x,y,z” then click on: **City** or **Zip Code**

By Geography - I want to find all dialysis facilities within a certain area then click on: **State** or **County**

Choosing any of these options allows patients, families and the public to review specific information about the dialysis facility and the quality of service provided. Several additions have been made to the site over the last year making the site more patient friendly and easier to navigate. This website is especially beneficial for patients and families desiring to make travel arrangements.

Another addition to Dialysis Facility Compare is the **Patient Tools Section**. This area provides information on questions to consider asking your doctor, dialysis staff, dietitian and social worker. It additionally provides checklists for things to think about when changing dialysis facilities, infection control measures in the dialysis unit, and facility policies and procedures. Lastly, this section contains patient rights and responsibilities.

Dialysis Options & Opportunities...

There are several methods of dialysis available today. Please discuss the options available to you with members of your renal healthcare team.



Home Hemodialysis

Peritoneal Dialysis

Nocturnal Dialysis

Incenter
Hemodialysis

Nocturnal Home Hemodialysis

Nocturnal hemodialysis is usually easier tolerated than in-center conventional hemodialysis. This type of dialysis takes place in your home while you sleep for about 6 - 8 hours a night, 5 - 6 nights a week. The blood flow is much slower than on in-center dialysis and this allows for more gradual fluid and toxin removal. The longer dialysis times and mild fluid removal more closely mimic natural kidney function and therefore do not put as much strain on the heart, decreases cramping and episodes of low blood pressure.

Toxins, wastes and fluids are removed more gently with nocturnal and because of the additional time and days of treatment, patients generally feel better, are able to decrease the amount of medications they take, have an increase in libido and feel better overall. Because dialysis is taking place during the night, your day is not restricted by the need to go to the center, which allows more time for work, leisure or recreation. The treatments take place in the comfort and privacy of your home relieving you of the need to travel to a center for treatment.

Nocturnal hemodialysis allows people with kidney failure the opportunity to continue with their usual daily lives and maintain their independence, while feeling better and healthier than with conventional in-center dialysis.

Nocturnal hemodialysis is usually a cost expense for the facility and Medicare does not fully cover the cost of treatment. Patients interested in nocturnal hemodialysis must be fully committed and willing to work with the renal treatment team for this option to be successful for both facility and patient.

Want to know where you could find a unit that offers nocturnal home hemodialysis?

Visit www.medicare.gov/dialysis/home.asp

Home Hemodialysis & Home Daily 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 better for patients who perform their own dialysis at home. Control of their own treatments allows home hemodialysis patients to understand their condition and symptoms more clearly. This also allows them to tailor their dialysis experience which helps promote their individual needs. Home hemodialysis allows patients with kidney failure to become involved in the basic and necessary aspects of their health and ultimately assists shaping their day-to-day quality of life.

Home hemodialysis offers independence and flexibility, which is usually lacking in routine in-center hemodialysis. Patients are able to dialyze according to their own schedule and time frame and are not hindered by delays in treatment as sometimes seen in the dialysis units. Home hemodialysis provides the added benefit of dialyzing in the comfort of the patient's own home.

Home hemodialysis relieves patients from the burden of getting to dialysis. Whether that be waiting for transportation for an hour before or after treatment, or weather delays due to snow or ice. Home hemodialysis increases the time the patient has to spend with family, friends, employment and community service.

Daily home hemodialysis varies slightly from home hemodialysis. The main difference between home hemo and daily home hemodialysis treatments is that daily treatments are performed 5 - 7 days a week, usually for 3 hours each session. The increased frequency of dialysis treatments allows for less diet and fluid restrictions than conventional in-center hemodialysis.

Want to know more about home hemodialysis therapies?

Ask the social worker, staff nurse, or call 1-800-444-9965 and ask for Kim.



Peritoneal Dialysis

The last options for dialysis include peritoneal (pear-eh-ta-kneel) dialysis. The peritoneum (pear-eh-ta-knee-um) is the thin membrane that lines your abdomen, (belly, stomach area) and pelvis, (hip area) while the space inside your abdomen and pelvis is referred to as the peritoneal cavity. The peritoneum acts very similar to an artificial kidney to remove wastes, fluid, and toxins. Peritoneal dialysis is not for everyone, patients **MUST** follow **STRICT** hand-washing and infection prevention techniques to prevent an infection in the peritoneal cavity. Infections can cause scar tissue, hospitalizations, and decrease the ability for the peritoneum to remove wastes and toxins.

A soft plastic tube called a catheter, (cath-it-er) is placed in your abdomen by surgery. Sterile fluid is put into your peritoneal cavity using this tube. When the filtering process is complete, the fluid leaves your body through the catheter. There are two types of peritoneal dialysis available; continuous ambulatory peritoneal dialysis, (CAPD), and continuous cycling peritoneal dialysis, (CCPD). The basics for the treatment are the same, however the number of treatments and the way the treatment is done are the key differences in this type of dialysis. Planning by the renal team with you will determine which treatment may be best for you.

CAPD

This type of dialysis is continuous, machine-free, and done while you go about your normal activities such as work or school. You do the treatment by placing several quarts of cleansing sterile fluid into your abdomen and later draining it. This is done by hooking up a plastic bag of cleansing fluid to the tube in your abdomen, raising the bag to about shoulder level, which causes gravity to pull the fluid into your abdomen. Some patients have stated that they feel “pressure” or like they have a “full stomach”, but this sensation becomes less noticed over time. When the bag is empty, it 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 is done 3, 4, or even 5 times in a 24-hour period while you are awake. Each exchange takes about 40 minutes. Mealtimes and bedtimes are typically exchange times as well.

CCPD

This type of dialysis is different because the exchanges are done by a machine or “cyclor”. The cyclor delivers and drains the fluid for a patient. This treatment is usually done at night while you sleep.



Emergency Preparedness - What You Should Know

Tornados, floods, ice storms and flash floods are yearly occurrences in the midwest. Unpredictable and devastating, they can strike quickly and without warning. Patients should have a back-up plan and be prepared for emergencies in the event a natural disaster strikes.

Dialysis patients are dependent on electricity and water for treatment. Out-of-service utilities, road closings due to hazardous traveling conditions, bridges and overpasses closed due to water making them impassable all have the ability of preventing patients from receiving treatment. This information provides a general reference to assist you with preplanning in the event you are not able to receive dialysis for several days.

DIALYSIS PATIENTS SHOULD NEVER ASSUME THAT THEY WILL RECEIVE TIMELY TREATMENTS FROM AN EMERGENCY ROOM, OR THEIR DIALYSIS UNIT DURING A NATURAL DISASTER!

Frequently Asked Questions...

I dialyze at home. What about my utilities...

Most companies have a system in place for restoring services. Notify them that you are a dialysis patient receiving treatment at home so you can be added to their priority list.

I don't drive. How do I get to another clinic?

Preplan emergency transportation with your family, friends, church members or neighbors. Utilize the diets provided in this newsletter or from your dietitian to stay within your eating guidelines if dialysis is not possible for several days.

How long can someone live without dialysis?

Survival without dialysis is based on each patient and takes into account any remaining kidney function, dietary and fluid restrictions, and additional medical problems, such as diabetes or heart disease. Typically, a patient can live 10 - 14 days or longer without treatment, however this varies by individual and missing treatment is NEVER advisable.

Where can I find a list of other dialysis facilities?

Ask the facility social worker or go to www.medicare.gov/dialysis/home.asp

Dietary Information

If you are unable to receive dialysis for several days, it is important to have discussed with your dietitian an emergency eating plan. The following several pages offer example diets for diabetics and non-diabetics, as well as a grocery list on the last page. Consider purchasing a sealable tote to store your supplies and prevent water damage. This diet will lessen the chances of sodium and potassium overload. Sodium causes swelling and high blood pressure, while potassium causes heart problems including heart attacks. This information was adapted from Network 14's Emergency Preparedness Guide for Dialysis & Transplant Patients. For the entire manual, please visit their website at www.esrdnetwork.org



Fluids, Sodium, Storage and Safety!

The importance of restricting your fluid intake cannot be stressed enough! Gum can help quench thirst. Limit = 2 cups of fluid per day. Avoid, Avoid, Avoid table salt and all salt substitutes during this time period! Use herbs, juices and seasoning powders if extra flavor is needed. Purchase reduced sodium canned meats such as tuna if the power is lost. Ice or snow can be used to keep food cold without power, but if food cannot be kept cold enough, it should be thrown out after 4 hours. Powdered drinks can be used but require bottled water. **DO NOT** use bottled sports drinks - they contain added potassium and sodium and are definitely harmful to dialysis patients.


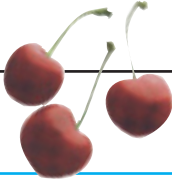


Speak with your dietitian and social worker for additional emergency preparedness options. Your dietitian may have meal supplements to consider instead of the diets outlined in the next several pages. As usual, before using any information offered in this newsletter, please check with the renal treatment team, they know your needs best and can help you make the correct decisions for your health!

Adult Diabetic 3-Day Meal Plan for Emergencies

The sample meal plan as listed allows approximately 43 grams protein, 1200 mgs. sodium, 1300 mgs. potassium, 675mgs phosphorus, 190 gms carbohydrates, and 1700 calories.

*** Spoilage is possible after opening, discard any unused contents or use single serving containers.**




Breakfast	Lunch	Dinner
1/2 cup non-dairy creamer	2 slices white bread	2 slices white bread
3/4 cup dry cereal	2 ounces unsalted tuna fish*	2 ounces unsalted chicken*
1/2 cup drained pineapple (canned in juice)	1 1/2 Tablespoons oil, margarine or mayonnaise*	1 1/2 Tablespoons margarine, oil or mayonnaise*
	1/2 cup low sodium green beans	1/2 cup drained peaches (canned in juice)
	1/2 cup carb reduced cranberry juice or sugar-free powdered drink mix.	1/4 cup carb reduced cranberry juice or powered drink mix.
	Afternoon Snack	Evening Snack
	1/2 cup no sugar added applesauce	1/4 cup carb reduced cranberry juice
		5 vanilla wafers or 3 graham crackers or 6 unsalted crackers
		1 teaspoon marjarine or 1 Tablespoon jelly



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Breakfast	Lunch	Dinner
1/2 cup non-dairy creamer	2 slices white bread	2 slices white bread
3/4 cup dry cereal	2 ounces unsalted chicken*	2 ounces unsalted tuna fish*
1/2 cup drained cherries (canned in juice)	1 1/2 Tablespoons oil, margarine or mayonnaise*	1 1/2 Tablespoons margarine, oil or mayonnaise*
	1/2 cup low sodium carrots	1/2 cup drained peaches (canned in juice)
	1/2 cup carb reduced cranberry juice or sugar- free powdered drink mix.	1/4 cup carb reduced cranberry juice or powered drink mix.
	Afternoon Snack	Evening Snack
	1/2 cup no sugar added applesauce	1/4 cup carb reduced cranberry juice
		5 vanilla wafers or 3 graham crackers or 6 unsalted crackers
		1 teaspoon marjarine or 1 Tablespoon jelly



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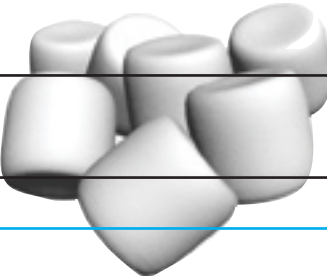
Breakfast	Lunch	Dinner
1/2 cup non-dairy creamer	2 slices white bread	2 slices white bread
3/4 cup dry cereal	2 ounces unsalted tuna fish*	2 ounces unsalted chicken*
1/2 cup drained pineapple (canned in juice)	1 1/2 Tablespoons oil, margarine or mayonnaise*	1 1/2 Tablespoons margarine, oil or mayonnaise*
	1/2 cup low sodium green beans	1/2 cup drained peaches (canned in juice)
	1/2 cup carb reduced cranberry juice or sugar-free powdered drink mix.	1/4 cup carb reduced cranberry juice or powered drink mix.
	Afternoon Snack	Evening Snack
	1/2 cup no sugar added applesauce	1/4 cup carb reduced cranberry juice
		5 vanilla wafers or 3 graham crackers or 6 unsalted crackers
		1 teaspoon marjarine or 1 Tablespoon jelly



Adult Non-Diabetic 3-Day Meal Plan for Emergencies

The sample meal plan as listed allows approximately 42 grams protein, 1200 mgs. sodium, 1200 mgs. potassium, 630 mgs phosphorus, and 1925 calories.

*** Spoilage is possible after opening, discard any unused contents or use single serving containers.**

Breakfast	Lunch	Dinner
1/2 cup non-dairy creamer	2 slices white bread	2 slices white bread
3/4 cup dry cereal	2 ounces unsalted tuna fish*	2 ounces unsalted turkey*
1 Tablespoon sugar	1 Tablespoon oil, margarine or mayonnaise*	2 Tablespoons margarine, oil or mayonnaise*
1/2 cup drained pears	1/2 cup low sodium carrots	1/2 cup drained cherries
	1/2 cup cranberry juice or powdered drink mix.	1/2 cup cranberry juice or powdered drink mix.
Morning Snack	Afternoon Snack	Evening Snack
10 marshmallows	10 candies - see grocery list	5 vanilla wafers or 5 sugar wafers or 3 graham cracker squares or 6 unsalted crackers.
1/2 cup applesauce		2 Tablespoons honey or jelly
10 candies - see grocery list		10 candies - see grocery list



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Breakfast	Lunch	Dinner
1/2 cup non-dairy creamer	2 slices white bread	2 slices white bread
3/4 cup dry cereal	2 ounces unsalted turkey*	2 ounces unsalted chicken*
1 Tablespoon sugar	1 Tablespoon oil, margarine or mayonnaise*	2 Tablespoons margarine, oil or mayonnaise*
1/2 cup drained peaches	1/2 cup low sodium asparagus	1/2 cup drained pineapple
	1/2 cup cranberry juice or powdered drink mix.	1/2 cup cranberry juice or powdered drink mix.
Morning Snack	Afternoon Snack	Evening Snack
10 candies - see grocery list	10 marshmallows	5 vanilla wafers or 5 sugar wafers or 3 graham cracker squares or 6 unsalted crackers.
1/2 cup applesauce	10 candies - see grocery list	2 Tablespoons honey or jelly
		10 candies - see grocery list



Adult Non-Diabetic 3-Day Meal Plan for Emergencies

The sample meal plan as listed allows approximately 42 grams protein, 1200 mgs. sodium, 1200 mgs. potassium, 630 mgs phosphorus, and 1925 calories.

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Breakfast	Lunch	Dinner
1/2 cup non-dairy creamer	2 slices white bread	2 slices white bread
3/4 cup dry cereal	2 ounces unsalted tuna fish*	2 ounces unsalted chicken*
1 Tablespoon sugar	1 Tablespoon oil, margarine or mayonnaise*	2 Tablespoons margarine, oil or mayonnaise*
1/2 cup drained pineapple	1/2 cup low sodium green beans	1/2 cup drained pears
	1/2 cup cranberry juice or powdered drink mix.	1/2 cup cranberry juice or powdered drink mix.
Morning Snack	Afternoon Snack	Evening Snack
10 candies - see grocery list	10 marshmallows	5 vanilla wafers or 5 sugar wafers or 3 graham cracker squares or 6 unsalted crackers.
	1/2 cup applesauce	2 Tablespoons honey or jelly
	10 candies - see grocery list	10 candies - see grocery list



Emergency Grocery List - Diabetic Meal Plans

Bread/Cereal (Choose 5 servings per day)

White bread	Dry cereal (sweetened preferred)
Graham crackers	Puffed wheat
Unsalted crackers (plain)	Puffed rice
Vanilla wafers or sugar wafers	Crisped rice

Fruits (Choose 3 servings per day - used the canned in juice variety)

Applesauce	Pears
Peaches	Pineapple
Cherries	

Fish/Meat (4 ounces per day)

Tuna*	Chicken*	Turkey*
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Vegetables - choose low sodium varieties (1/2 cup per day)

Carrots	Green Beans	Asparagus
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Juices/Beverages (Limit to 1/2 cup per day in addition to meal plan)

Spring water	Diet Lemon-lime soda
Diet Gingerale	Sugar-free powdered drink mixes

Fats (Choose 6 or more servings per day)

Margarine*	Oil	Mayonnaise*
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High Calorie Foods (Choose 3 servings per day)

(1 additional serving may be added to raise blood sugar)

Honey - 1 Tablespoon	Sugar - 4 teaspoons
Jelly - 1 Tablespoon	Reduced carb cranberry juice - 1/2 cup

Other

Frozen or shelf stable non-dairy creamer	
Herbal seasonings	Garlic powder
Breath spray	Sugar-free gum
Lemon juice	

* Spoilage is possible after opening, discard any unused contents or use single serving containers

Emergency Grocery List - Non-Diabetic Meal Plans

Bread/Cereal (Choose 5-6 servings per day)

White bread	Dry cereal (sweetened preferred)
Graham crackers	Puffed wheat
Unsalted crackers (plain)	Puffed rice
Vanilla wafers or sugar wafers	Crisped rice

Fruits (Choose 2-4 servings per day)

Applesauce	Pears
Peaches	Pineapple
Cherries	

Fish/Meat (4 ounces per day)

Tuna*	Chicken*	Turkey*
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Vegetables - choose low sodium varieties (1/2 cup per day)

Carrots	Green Beans	Asparagus
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Juices/Beverages (Limit to 1/2 cup per day in addition to meal plan)

Spring water	Lemon-lime soda
Gingerale	Cranberry juice
Powdered drink mixes	

Fats (Choose 6 or more servings per day)

Margarine*	Oil	Mayonnaise*
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Sweets

Marshmallows	Honey	Sugar
Jelly	Candies - jelly beans, sourballs, mints, hard candies	

Other

Frozen or shelf stable non-dairy creamer	
Herbal seasonings	Garlic powder
Breath spray	Gum
Lemon juice	

* Spoilage is possible after opening, discard any unused contents or use single serving containers