

A Guide for People on Dialysis

Centers for Medicare & Medicaid Services

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Preparation and Background

Emergency preparedness for the dialysis community is essential for ensuring the continuity of patient care. Each of the various topics covered within this booklet has been thoroughly discussed and vetted, keeping in mind the essential needs of the kidney community during an emergency or disaster.

In addition, the content and material within this booklet have been created through a highly organized and collaborative approach that focuses on emergency preparedness. Subject matter expertise was essential to the development of this critical document and was provided by representatives from the End Stage Renal Disease (ESRD) Networks, dialysis organizations, national renal-related organizations, clinicians with renal-specific focus, renal dietitians, and the Kidney Community Emergency Response (KCER) Program.

The time, effort, and dedication from all who assisted in the development of this booklet are reflective of the strong commitment to both emergency preparedness and people on dialysis within the ESRD community.

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Introduction

It is important for people on dialysis to plan ahead for emergencies and disasters in order to stay safe.

Emergencies and disasters often happen without warning, so it is important to prepare before they happen. When you are on dialysis, disasters can make it hard for you to get your treatment because of changes to water, power, sanitation, or transportation.

This booklet provides information that will help you prepare for an emergency, including:

- Helpful tips to make sure that you are prepared
- What to include in your Emergency Go-Kit
- What grocery items to have ready for your **3-Day Emergency Diet**
- What to do when you cannot leave your home
- What to do when you must leave your home
- What to do when your dialysis facility is closed

What to Do to Get Ready for an Emergency or Disaster

- \Box I have made my **<u>Emergency Go-Kit</u>** (page 8).
- □ I have read and understand my dialysis facility's disaster plan.
- □ My dialysis team has taught me how to unhook from the machine in an emergency.
- □ I have made alternative arrangements for my treatment before an emergency happens (page 6).
- □ I have filled out and added important contact information to my <u>Personal</u> <u>Information Form (page 10)</u>.
- □ I have completed my <u>Medical Supplies Checklist</u> (page 9).
- □ I have added my **Personal Information Form** and **Medical Supplies Checklist** to my **Emergency Go-Kit**.
- □ I keep my **Personal Information Form** and **Medical Supplies Checklist** current and update it if necessary whenever something changes.
- □ I have made sure that I have enough food in the house for a <u>3-Day Emergency</u> <u>Diet</u> (page 16).
- □ I will listen to my local news to learn about the emergency or disaster. I make sure cell phones are always charged and ready to use.
- □ I have two options for places to stay, near and far, if I must leave my home. I have added this information to my **Personal Information Form**.
- I make and share my emergency plan with household members and my dialysis facility.
- \Box I have plans in place for my pets (if applicable).
- □ I have arranged back-up transportation to the dialysis facility and added it to my **Personal Information Form**.
- □ I have contacted my local or city Emergency Management Office to find out about services to help prepare for and manage an emergency.
- \Box I have made sure that my car has enough gas in it (if applicable).

Make Alternative Arrangements for Your Treatment Before an Emergency

If you get hemodialysis at a dialysis facility:

- Make sure your dialysis facility has your current street address and phone number(s) in case they need to contact you.
- □ Make arrangements for back-up transportation to your dialysis facility.
- □ Ask your dialysis facility about other dialysis facilities near you that can treat you if your dialysis facility closes.

If you perform home hemodialysis:

- Contact your water and power companies to register for special priority to restore your lost services. Keep their phone numbers up-to-date on your Personal Information Form.
- □ Keep a flashlight and batteries near your dialysis machine.
- □ Contact your local dialysis facility about back-up treatment locations both near to and far from your home.

If you use Continuous Ambulatory Peritoneal Dialysis (CAPD):

- □ Keep the battery charged at all times if you use an ultraviolet device. (Note: The charge should last for three days.)
- □ As directed by your dialysis team, keep a five-to seven-day supply of peritoneal dialysis supplies at home. Check expiration dates and replace as needed, or every six months.

If you use Continuous Cycling Peritoneal Dialysis (CCPD):

- □ Learn and practice manual CAPD, so if you lose power, you can switch from CCPD to manual CAPD.
- □ As directed by your dialysis team, keep a five-to seven-day supply of CCPD (and CAPD if you have learned to do manual CAPD) supplies available.
- $\hfill\square$ Check the expiration dates and replace as needed.
- Contact your water and power companies ahead of time to register for special priority to restore lost services. Keep their phone numbers up-to-date on your Personal Information Form.

"Get-Ready" Emergency Go-Kit Checklist

- Get your **Go-Kit** ready before an emergency or disaster happens.
- You may put these items in more than one bag or container.
- Make sure you know where your **Go-Kit** is stored.
- Check items every six months to ensure your medications have not expired, that your food is still fresh, and that batteries are working.

3-Day Emergency Diet Plan and Shopping List items

- □ Bottled or distilled water
- □ Small radio with batteries or a hand crank
- □ Flashlights and batteries
- □ First-aid kit
- □ Hand sanitizer
- □ Plain, unscented household chlorine bleach (<u>How to Disinfect Water</u>, page 27)
- $\hfill\square$ Cell phone and charger
- □ Measuring cups, teaspoons, and tablespoons
- \square Manual can opener
- \Box Cash
- $\hfill\square$ Walking shoes and a change of clothes
- \square Food and water for your pets (if you have pets)
- □ Personal Information Form and Medical Supplies Checklist

"Get-Ready" Medical Supplies Checklist

- Add these items to your **Emergency Go-Kit**.
- Check your medications to ensure they have not expired.
- □ Five-to seven-day supply of all prescription medicines. Check the expiration dates of all of your medications each month. Use and replace the ones that are due to expire.
- □ Five-day supply of antibiotics if you are on peritoneal dialysis and it is recommended by your doctor.
- □ Add these to your medical supplies if you have diabetes: Glucose meter, one spare battery and testing fluid.
- □ Five-to seven-day supply of blood sugar test strips and lancets.
- □ Five-to seven-day supply of syringes and insulin if you use insulin. (Keep insulin cool but do not freeze it. It is best kept in the refrigerator, but it can be kept at room temperature for up to a month.)
- □ Glucose (glucose tablets, Glucagon, oral glucose gel) in case your sugar level drops.

Personal Information Form

To be ready for an emergency, complete the **Personal Information Form** with a list of people and organizations you will need to reach. Family, household members, caregivers, and friends will want to know where you are. They may even be able to help you safely leave your home, if you need to. Include on your list your nephrologist (kidney doctor) and your dialysis facility. You will need to let them know if you can't get your treatments. You can get this form from your dialysis facility or ESRD Network.

You can also get a **Wallet Card** from your dialysis facility or ESRD Network (page 38) to record your important medical information. You may carry this card in your wallet.

Personal Information Form directions:

Please fill out the form, beginning on the next page, with your personal information. Write in pencil to make it easy to change. Put your **Personal Information Form** in your **Emergency Go-Kit**.

Have copies of your identification and medical information available:

- Driver's license, ID card, and/or US permanent resident card
- Social Security card
- Passport
- Healthcare insurance card
- Treatment orders
- Legal documents (e.g., advance directive, do not resuscitate [DNR] order, or medical power of attorney information)

Personal Information Form

In all emergencies, call 9-1-1.
Non-emergency phone #:
My Dialysis Facility:
Phone Number:
Emergency Hotline:
Back-Up Facility Near Home:
Phone Number:
Back-Up Facility Far from Home:
Phone Number:
Kidney Doctor (Nephrologist):
Phone Number:
Primary Care Doctor:
Phone Number:
My Pharmacy:
Phone Number:
Transportation Company:
Phone Number:
Transportation (family/friend):
Phone Number:
My ESRD Network:
Phone Number:

Family Members, Caregivers, and/or Friends

Name/Relation:	

Medical Information Form

Health Insurance Provider:

Policy Number:

Phone Number:

Medication and Dosages:

Allergies:

Treatment Type:

- \Box Hemodialysis
- □ Home Hemodialysis
- □ CAPD
- \Box CCPD

Local Emergency Information

Local Hospital:
Phone Number:
Local Fire Department:
Phone Number:
Local Police:
Phone Number:
Electric Company:
Phone Number:
Utility Company:
Phone Number:
Water Company:
Phone Number:

Medical ID Jewelry

If you are injured or unable to communicate, medical staff will need to know quickly that you are on dialysis and other important facts about your health. One way to alert people to your health needs is to wear a medical ID on a bracelet or necklace. These medical IDs show an internationally recognized symbol to alert responders of medical conditions. They can be specified to list any medical information that may need to be relayed in the event of an emergency. It also provides a phone number that medical staff can call to get more detailed medical information about you. The ID also comes with a medical information card, which has important information about your health. It is important to carry this medical information card with you at all times.

Wearing a medical ID at all times helps ensure that you get the care you need, and that you don't get care that could be harmful to someone with your medical condition.

Note: A necklace might be missed if it gets tangled in your clothes. A bracelet is easy to see, but don't wear one on the same side as your dialysis access. It could block blood flow if it is pulled up the arm.

To get a Medical ID: Ask your nurse or social worker for information about medical IDs.

Sources of medical IDs include:

National Kidney Foundation

- 1-855-NKF-CARES (1-855-653-2273)
- <u>www.kidney.org</u>

MedicAlert Foundation

- 1-800-ID-ALERT (1-800-432-5378)
- <u>www.medicalert.org</u>

American Medical ID

- 1-800-363-5985
- <u>www.americanmedical-id.com</u>

Medical Tags

- 1-888-679-4292
- <u>https://medicaltags.com/</u>

Your Local Pharmacy

3-Day Emergency Diet Plan

Hemodialysis takes some of the water and wastes out of your blood. Wastes and water build up between treatments. When you get three or more treatments a week, this build-up should not cause a problem. When you can't get a treatment, the extra water and wastes in your body can cause problems. When you can't get your treatments, you will need to follow a special, strict diet to limit buildup of water, protein wastes, and potassium.

The **3-Day Emergency Diet Plan** will help you follow an emergency diet. This diet does not take the place of dialysis, but you can reduce the waste that builds up in your blood if you follow the plan and change what you eat. **This may save your life**. Review the plan with your facility dietitian to see if you need to make changes based on your own personal needs. Ask questions before an emergency. If you are on peritoneal dialysis and can't do your treatments, this diet may apply to you, too.

In an emergency or disaster situation, you should do everything you can to get your regular dialysis treatments. If you miss one or more treatments, follow the **3-Day Emergency Diet Plan** until you can get treatment. You should always try to get dialysis within three days of your last treatment.

The best way to get ready for an emergency is to plan before one happens. Collect the foods on the **3-Day Emergency Diet Shopping List**. Keep them someplace close in your home so you can get your emergency food easily. The list allows for six days of food and water so the 3-Day Emergency Diet can be repeated a second time if needed.

In an emergency situation, eat fresh foods first, while you have them. If you have diabetes, avoid the sweets in this plan. But do have some high sugar foods like hard candies on hand in case your sugar is low.

Pediatric Dialysis Diet Plan

Talk to your doctor and dietitian about what to feed infants, children, and teens who are on dialysis. Children's food will need to be adjusted for their age and weight.

3-Day Emergency Diet Shopping List

This shopping list is for six days of food and water for the kidney patient, so the **3-Day Emergency Diet** can be repeated a second time if needed.

Review this list with your dietitian to tailor it for your needs and local availability.

Drinks

What to Buy	How Much to Buy
Distilled or bottled water	1 to 2 gallons
Dry milk or evaporated milk	3 packages of dry milk or 4 cans of evaporated milk (8 oz. each)
Cranberry, apple, or grape juice	6 cans or boxes (4 oz. each)

Food

What to Buy	How Much to Buy
Cold cereal No bran, granola, or cereal with dried fruit or nuts.	6 single-serving boxes, or 1 box
Fruit or "fruit cups" with pears, peaches, mandarin oranges, mixed fruit, applesauce, or pineapple packed in water or juice. No heavy syrup, raisins, or dried fruit.	12 cans or individual cups (4 oz. each)*Be sure to drain liquid from fruit or count toward daily fluids.
Low sodium vegetables, such as asparagus, carrots, green beans, peas, corn, yellow squash, or wax beans.	6 cans (8 oz. each) *Be sure to drain liquid from vegetables or count toward daily fluids.
No dried beans such as pinto, navy, black, ranch style, or kidney beans. No potatoes or tomatoes.	
Low sodium or no-salt-added tuna, crab, chicken, salmon, or turkey	6 cans (3 or 4 oz. each)
Unsalted peanut butter or almond butter	1 jar

Mayonnaise	3 small jars (or 8 to 12 single-serve foil-wrapped packs and discard once opened)
Jelly (sugar-free if you have diabetes)	1 small jar
Vanilla wafers, graham crackers, or plain unsalted crackers	1 box
Sugar-free candy, such as sourballs, hard candy, jelly beans, or mints	1 package
Sugar-free chewing gum	1 jumbo pack

Foods That Will Spoil

What to Buy	How Much to Buy
Dry milk	3 packages
White bread *Keep frozen, so always available when needed.	1 loaf

Note: Use before expiration date and replace with fresh items. Discard after expiration date.

Options to Season Your Food

What to Buy	How Much to Buy
Olive oil or vegetable oil	1 small bottle
Balsamic or flavored vinegar	1 small bottle
Salt-free seasonings, spices, and dried herbs such as cinnamon, dill, oregano, rosemary, garlic powder, and onion powder	

Sweets

What to Buy	How Much to Buy
Sourball candy, hard candy, jelly beans, or mints	1 package
Honey	1 small jar
White sugar	1 small box granulated or packets
Marshmallows (optional)	

Note: If you have diabetes, avoid the sweets in this plan; but keep some high-sugar foods (hard candy) on hand in case your sugar is low. Speak to your dietitian.

Do not include these foods in your 3-day emergency diet:

- Sports drinks and drinks with phosphates
- Powdered drink mixes other than powdered milk
- Foods high in potassium such as:
 - Dried beans (e.g., pinto, navy, black, ranch style, or kidney beans)
 - Potatoes
 - Tomatoes
 - Sports drinks (e.g., Gatorade)

3-Day Emergency Diet

If there is an emergency and you think you may have to miss your dialysis treatment, start the **3-Day Emergency Diet** right away. It won't harm you to start it sooner than you need to.

Tips

- Use fresh foods first, if you have them.
- Once you open a can or a frozen item, throw out the opened item if you can't keep it cold or **use it within four hours**.
- After losing power, it is safe to use food in the freezer as long as there are ice crystals in the food.
- You can freeze bread for three months in a sealed bag.
- Speak to your dietitian if you are on a gluten-free diet.
- You may want to have a mix of sugar candy and unsweetened candy.
- If you have diabetes, avoid the sweets in this diet plan. Check your blood sugar to see if you need a snack. Have some high-sugar content foods like hard candies in case you go "low" with too little sugar in your body.
- If you have diabetes, speak to your dietitian for snack ideas.
- Water is the best choice to drink.
- No sports drinks or beverages that contain phosphate.

Restrict fluid intake

A fluid plan will help you avoid trouble with breathing and swelling. Speak to your healthcare team about how much fluid you can have. Try taking medications with applesauce to reduce fluid intake.

• Remember that all fruits and vegetables contain water.

Tips to help reduce your thirst

- Suck on hard candy
- Chew gum
- Limit salt intake
- Have a mix of sugared candy and unsweetened candy
- Rinse your mouth out with mouthwash

Day One (example)

Drink no more than 4 oz. of water each time you take your medicine, and remember to count this toward your daily fluid allowance.

Breakfast

Cereal and fruit:

- ¹/₂ cup milk or mix ¹/₄ cup evaporated milk with ¹/₄ cup distilled water, from sealed containers
- 1 serving of cereal (No bran. No granola. No cereal with dried fruits and nuts.)
- 1 tbsp. sugar (optional)
- ¹/₄ cup (2 oz.) fruit from a can or jar, drained

Morning Snack (optional)

- 5 vanilla wafers or 1¹/₂ squares graham crackers
- 2 tbsp. peanut butter
- 10 hard candies or sourballs (People with diabetes should have sugar-free candies.)

Lunch

- Peanut or almond butter and jelly sandwich: 2 slices of white bread
- 2 tbsp. unsalted peanut butter or almond butter 2 tbsp. jelly or sugar-free jelly
- ¹/₂ cup canned or jarred fruit, drained
- ¹/₂ cup (4 oz.) water (or beverage from shopping list)

Afternoon Snack (optional)

For people who do not have diabetes:

- 5 vanilla wafers or 1¹/₂ squares graham crackers
- 2 tbsp. peanut butter
- ¹/₂ cup applesauce

For people who have diabetes:

• ¹/₂ cup applesauce

Dinner

Chicken sandwich:

- 2 slices of white bread
- $\frac{1}{2}$ can (2 oz.) chicken with 2 tbsp. mayonnaise
- ¹/₂ cup canned vegetables, drained
- ¹/₂ cup cranberry juice

Evening Snack (optional)

For people who do not have diabetes:

- 10 jelly beans
- 5 vanilla wafers or 1¹/₂ squares graham crackers

For people who have diabetes:

- 1 slice of bread
- 1 oz. (2 tbsp.) of protein (peanut butter, almond butter, chicken, or tuna)

Note: Once you open a can or a frozen item, throw out the opened item if you can't keep it cold or use it within four hours.

Day Two (example)

Drink no more than 4 oz. of water each time you take your medicine, and remember to count this toward your daily fluid allowance.

Breakfast

Cereal and fruit:

- ¹/₂ cup milk or mix ¹/₄ cup evaporated milk with ¹/₄ cup distilled water, from sealed containers
- 1 serving of cereal (No bran. No granola. No cereal with dried fruits and nuts.)
- 1 tbsp. sugar (optional)
- ¹/₄ cup (2 oz.) fruit from a can or jar, drained

Morning Snack (optional)

- ¹/₂ cup applesauce
- 10 jelly beans (People with diabetes should have sugar-free jelly beans.)

Lunch

Chicken sandwich:

- 2 slices of white bread
- $\frac{1}{4}$ can (1 oz.) chicken with 1 tbsp. mayonnaise
- ¹/₂ cup canned or jarred fruit, drained
- ¹/₂ cup (4 oz.) water

Afternoon Snack (optional)

- 10 mints (People with diabetes should have sugar-free mints.)
- ¹/₂ cup applesauce

Dinner

Tuna sandwich:

- 2 slices of white bread
- $\frac{1}{2}$ can (2 oz.) tuna with 1 to 2 tbsp. mayonnaise/oil
- ¹/₂ cup canned vegetables, drained
- ¹/₂ cup cranberry juice

Evening Snack (optional)

For people who do not have diabetes:

- 5 vanilla wafers or 1¹/₂ squares graham crackers
- 10 hard candies

For people who have diabetes:

- 1 slice of bread
- 1 oz. (2 tbsp.) of protein (peanut butter, almond butter, chicken, or tuna)

Note: Once you open a can or a frozen item, throw out the opened item if you can't keep it cold or use it within four hours.

Day Three (example)

Drink no more than 4 oz. of water each time you take your medicine, and remember to count this toward your daily fluid allowance.

Breakfast

Cereal and fruit:

- ¹/₂ cup milk or mix ¹/₄ cup evaporated milk with ¹/₄ cup distilled water, from sealed containers
- 1 serving of cereal (No bran. No granola. No cereal with dried fruits and nuts.)
- 1 tbsp. sugar, optional
- ¹/₄ cup (2 oz.) canned or jarred fruit, drained

Morning Snack (optional)

- 5 vanilla wafers or 1¹/₂ squares graham crackers
- 10 hard candies (People with diabetes should have sugar-free candies.)

Lunch

- Peanut or almond butter and jelly sandwich: 2 slices of white bread
- 2 tbsp. unsalted peanut or almond butter 2 tbsp. jelly or sugar-free jelly
- ¹/₂ cup canned or jarred fruit, drained
- ¹/₂ cup (4 oz.) juice

Afternoon Snack (optional)

- ¹/₂ cup applesauce
- 10 jelly beans (People with diabetes should have sugar-free jelly beans.)

Dinner

Salmon sandwich:

- 2 slices of white bread
- $\frac{1}{2}$ can (2 oz.) salmon with 1 to 2 tbsp. mayonnaise/oil
- ¹/₂ cup canned vegetables, drained
- $\frac{1}{2}$ cup water

Evening Snack (optional)

For people who do not have diabetes:

• 5 vanilla wafers or $1\frac{1}{2}$ squares graham crackers

For people who have diabetes:

- 1 slice of bread
- 1 oz. (2 tbsp.) of protein (peanut butter, almond butter, chicken, or tuna)

Note: Once you open a can or a frozen item, throw out the opened item if you can't keep it cold or use it within four hours.

How to Disinfect Water

Keep distilled or bottled water on hand to drink. If you run out of stored water, you may disinfect water to drink, to brush your teeth, or for other uses. It is <u>not</u> safe to use this water for dialysis.

When using bleach to disinfect water, use <u>plain</u> household chlorine bleach that contains 8.25% of sodium hypochlorite. Do not use bleach that has other active ingredients. For example, do not use scented bleach. **Do not guess when measuring bleach**.

To disinfect water with unscented household liquid chlorine bleach:

- Filter the water through a clean cloth, paper towel, or coffee filter or allow it to settle.
- Put the clear water in a clean container.
- Use liquid chlorine bleach that has been stored at room temperature for less than a year. The label must say that it contains 8.25% of sodium hypochlorite. Use the table below as a guide to decide how much bleach to add to the water.
- Double the amount of bleach if the water is cloudy, colored, or very cold.

Disinfecting Water with Unscented Liquid Chlorine Bleach

Volume of Water	Amount of Household Bleach to Add
2 gallons	1/8 teaspoon
4 gallons	1/4 teaspoon
8 gallons	1/2 teaspoon

Stir water and bleach mixture and let stand for 30 minutes. The disinfected water should have a slight chlorine odor. If it doesn't, repeat the dosage and let stand for another 15 minutes before use.

Notes:

- If the chlorine taste is too strong, pour the water from one clean container to another and let it stand for a few hours before use.
- Make sure to keep this disinfected water in clean containers, sealed tightly.
- Listen for "Boil Water Advisories" from community officials.
- Do not drink water from a swimming pool or spa. Chemicals used to treat the water could harm you.
- Never mix bleach with ammonia or other cleaners.
- Open windows and doors to get fresh air when you use bleach.

When Your Dialysis Facility Is Closed

If an emergency or disaster happens near you, be ready with a back-up plan to get the care you need. Your dialysis facility may close because:

- There is no power or water.
- There is damage to the building.
- The facility is in an area that is under evacuation orders.
- The weather stops facility staff from getting there safely.

What to do when your dialysis facility closes:

- Call your dialysis care team or your facility's emergency phone number to learn where and when to get treatment.
- If you cannot call your dialysis care team or your facility's emergency phone number, call your back-up facility listed on your <u>Personal Information Form</u> (page 10).
- Tell your family and household members where you will be receiving treatment.
- Start your <u>3-Day Emergency Diet</u> (page 16).
- Start <u>limiting the fluids</u> you drink (page 20).
- If you drive to get treatment, have directions to get to your back-up facility and practice the route before an emergency. Check road safety too if possible, including if roads are impacted by flooding, downed power lines, etc.
- Make plans for a ride to your back-up dialysis facility. This could be a car service, bus, train, taxi, or a family member, household member, caregiver, or friend.
- Listen to your local news to learn about the emergency or disaster.

When You Cannot Leave Your Home

You may need to stay home to be safe in an emergency or disaster. Officials and/or local news reports will tell you when you should stay home. Staying at home in an emergency or disaster is known as "sheltering in place."

What to do when you cannot leave your home:

- Lock and seal windows and doors.
- Consider the specific emergency and select the safest room in your home. (ex: high winds—rooms with fewest windows)
- Keep your prescription medicines handy.
- Keep a cell phone and charger, home phone, battery-operated radio or computer with you.
- Call family, household members, caregivers, friends, and your dialysis facility to let them know where you are.
- Start your **<u>3-Day Emergency Diet</u>** (page 16).
- Start <u>limiting the fluids</u> you drink (page 20).
- Listen to your local news to learn about the emergency or disaster.
- Have your **<u>Emergency Go-Kit</u>** (page 8) ready in case public officials tell you to leave.

When You Must Leave Your Home

To stay safe in some emergencies, you may have to leave your home. You will be safest if you know your back-up treatment options before an emergency requires you to leave. You may need to leave your home if it becomes unsafe or if you receive a required evacuation order. An order will likely come from officials within your community to ensure your protection and safety.

It is very important that you follow any evacuation orders issued by emergency officials. If you chose not to follow evacuation orders, you may have difficulty accessing treatment for an extended period of time.

What to do when you must leave your home:

- Take your **Emergency Go-Kit** with you <u>**Emergency Go-Kit Checklist**</u> (page 8).
- Take your prescription medicines with you. The <u>Medical Supplies Checklist</u> (page 9) tells you how much medicine to bring.
- Take your <u>Personal Information Form</u> (page 10) with you.
- Tell family members, household members, caregivers, friends, and your dialysis facility where you plan to go.
- If your dialysis facility is closed, call your facility's emergency number to find out where you should go for treatment.
- If you cannot contact your dialysis facility, your back-up facility is listed on your **Personal Information Form.**
- Start your <u>3-Day Emergency Diet</u> (page 16).
- Start <u>limiting the fluids</u> you drink (page 20).
- If you must go to a shelter, tell the person in charge that you need dialysis.
- Listen to your local news to learn about the emergency or disaster.

How to Get Off of a Dialysis Machine in an Emergency

Your dialysis facility staff will show you what to do if you are on a dialysis machine during an emergency. You will practice this at least once a year at your facility. The instructions should include where your emergency pack is kept and how to disconnect yourself from the dialysis machine. An emergency pack usually contains tape, clamps, and other medical items and should be kept within your reach while you are on the dialysis machine, if possible.

If you are on a dialysis machine in an emergency, stay calm. Wait for the facility staff to tell you what to do.

These steps are **<u>only</u>** for emergencies in which you must leave the facility:

- Keep your access needles <u>in</u> until you get to a safe place.
- <u>Never</u> cut your access needle lines. <u>Never</u> cut the line between the clamp and your access—you will bleed to death.
- If you have a <u>catheter</u>, your staff should help you before you disconnect.
- Do not try to unhook yourself.

Care of Your Access in an Emergency

Once you are off of your machine, wait for someone in charge to tell you where to go. This could be a dialysis facility staff member or a paramedic, police officer, or fire fighter. Do not stop to pull out your needles until you have been checked by staff, or you are sure that you are out of danger.

Be careful! Do not let someone who does not know you touch or inject something into your access. Healthcare workers who are not familiar with dialysis may not know what a fistula, graft, or catheter is, and could harm you.

To Learn More

Medicare

- 1-800-MEDICARE (1-800-633-4227)
- TTY: 1-877-486-2048
- <u>Medicare Website: www.medicare.gov</u>

Dialysis facilities

- Find & Compare Providers: https://www.medicare.gov/care-compare/
- Call your <u>ESRD Network</u> (page 35) to learn about:
 - o Dialysis
 - Kidney transplants
 - Where to find dialysis facilities and transplant centers
 - How to get help from other agencies
 - What you can do when problems at your facility are not solved by talking to the staff at the facility

Your ESRD Network works to ensure that you are getting the best care, and communicates with facilities to keep staff aware of key issues about dialysis and transplants.

In addition, you can call your <u>State Survey Agency</u>. The State Survey Agency makes sure that dialysis facilities meet Medicare standards. Call 1-800-MEDICARE (1-800-633-4227) if you have problems with your facility that you cannot solve by talking to the facility staff.

Note: The phone numbers listed in this booklet were correct at the time of printing. Phone numbers can change. Utilize the resources below to get the most up-to-date phone numbers for dialysis facilities, ESRD Networks, and State Survey Agencies:

- 1-800-MEDICARE (1-800-633-4227; TTY: 1-877-486-2048)
- <u>Medicare Website: www.medicare.gov</u>
- <u>Map of ESRD Networks</u>

For More Information on Making an Emergency Plan

This booklet highlights the most important items specifically needed for a dialysis patient. You can make personal emergency plans that are specific for your situation and include more details.

The following websites for the Kidney Community Emergency Response (KCER) Program, Ready.gov, and the American Red Cross can help you plan in depth for an emergency.

Kidney Community Emergency Response (KCER) Program

Access resources for patients, providers, and other stakeholders that are geared toward preparing the dialysis community for emergencies and disasters.

- English:
- o <u>www.kcercoalition.com</u>
- Español:
- o <u>www.kcercoalition.com/en/en-espanol</u>

Ready.gov

It is a good idea to have an emergency plan in place before an emergency or disaster happens. This website is a good resource to help you make your plan.

- English:
- o <u>www.ready.gov</u>
- Español:
- o <u>www.ready.gov/es</u>

American Red Cross

This website can help you connect with family and household members in an emergency. Be sure they know where to look!

- English:
- o <u>www.redcross.org/safeandwell</u>
- o <u>www.redcross.org</u>
- Español:
- <u>https://www.redcross.org/cruz-roja/obtener-ayuda/contactar-y-ubicar-a-los-seres-queridos.html</u>
- o <u>www.redcross.org/cruz-roja</u>

ESRD Network Contact Information

Network Number, Name, Coverage Area, and Contact Information
Network 1 (CT, ME, MA, NH, RI, VT)
IPRO: ESRD Network of New England
Toll-free Patient Line: (866) 286-ESRD (866-286-3773)
Phone: (203) 387-9332
Website: <u>www.esrd.ipro.org</u>
Network 2 (NY)
IPRO: ESRD Network of New York
Toll-free Patient Line: (866) 238-ESRD (866-238-3773)
Phone: (516) 209-5578
Website: <u>www.esrd.ipro.org</u>
Network 3 (NJ, PR, VI)
Quality Insights Renal Network 3
Toll-free Patient Line: (888) 877-8400
Phone: (609) 490-0310
Website: <u>www.qirn3.org</u>
Network 4 (DE, PA)
Quality Insights Renal Network 4
Toll-free Patient Line: (800) 548-9205
Phone: (610) 265-2418
Website: <u>www.qirn4.org</u>
Network 5 (DC, MD, VA, WV)
Quality Insights Renal Network 5
Toll-free Patient Line: (866) 651-6272
Phone: (804) 320-0004
Website: <u>www.qirn5.org</u>

Network 6 (GA, NC, SC) IPRO: ESRD Network of the South Atlantic Toll-free Patient Line: (800) 524-7139 Phone: (919) 463-4500 Website: www.esrd.ipro.org Network 7 (FL) HSAG: The Florida ESRD Network Toll-free Patient Line: (800) 826-ESRD (800-826-3773) Phone: (813) 383-1530 Website: www.hsag.com/esrdnetwork7 Network 8 (AL, MS, TN) Alliant Health Solutions Network 8 Toll-free Patient Line: (877) 936-9260 Phone: (601) 936-9260 Website: https://quality.allianthealth.org Network 9 (IN, KY, OH) IPRO: ESRD Network of the Ohio River Valley Toll-free Patient Line: (844) 819-3010 Phone: (216) 593-0001 Website: www.esrd.ipro.org Network 10 (IL) **Osource ESRD Network 10** Toll-free Patient Line: (800) 456-6919 Phone: (317) 257-8265 Website: https://esrd.qsource.org Network 11 (MI, MN, ND, SD, WI) Midwest Kidney Network Toll-free Patient Line: (800) 973-ESRD (800-973-3773) Phone: (651) 644-9877 Website: www.midwestkidneynetwork.org

Network 12 (IA, KS, MO, NE)
Qsource ESRD Network 12
Toll-free Patient Line: (800) 444-9965
Phone: (816) 880-9990
Website: <u>https://esrd.qsource.org</u>
Network 13 (AR, LA, OK)
HSAG: ESRD Network 13
Toll-free Patient Line: (800) 472-8664
Phone: (405) 942-6000
Website: <u>www.hsag.com/esrdnetwork13</u>
Network 14 (TX)
Alliant Health Solutions Network 14
Toll-free Patient Line: (877) 886-4435
Phone: (972) 503-3215
Website: <u>https://quality.allianthealth.org</u>
Network 15 (AZ, CO, NV, NM, UT, WY)
HSAG: ESRD Network 15
Toll-free Patient Line: (800) 783-8818
Phone: (303) 831-8818
Website: <u>www.hsag.com/esrdnetwork15</u>
Network 16 (AK, ID, MT, OR, WA)
Comagine Health ESRD Network 16
Toll-free Patient Line: (800) 262-1514
Phone: (206) 923-0714
Website: <u>www.nwrn.org</u>
Network 17 (AS, GU, HI, MP, N. CA)
HSAG: ESRD Network 17
Toll-free Patient Line: (800) 232-ESRD (800-232-3773)
Phone: (415) 897-2400
Website: <u>www.hsag.com/esrdnetwork17</u>

Network 18 (S. CA) HSAG: ESRD Network 18 Toll-free Patient Line: (800) 637-4767 Phone: (888) 268-1539 Website: <u>www.hsag.com/esrdnetwork18</u>