

# Take Charge of Your Health: Reduce Unnecessary Hospitalizations

*Your ESRD • Your Care • Your Priority*



*ESRD Networks 7, 13, 15, 17, 18*

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This booklet was developed by HSAG: ESRD Networks 7, 13, 15, 17, and 18 to assist end stage renal disease (ESRD) patients, their families, and their caregivers to help avoid unnecessary hospitalizations and to take charge of the flow of information before, during and after a hospitalization, including follow-up visits.

## Steps You Can Take to Avoid Unnecessary Hospitalizations

Not every hospitalization can or should be avoided. There are times when a hospitalization is necessary. Listen to your care team and know when to go. However, who wants to go to the hospital if it can be avoided—no one, of course! Following are steps *you* can take to protect yourself against the need for an unnecessary hospitalization.

Action		How
<b>1</b>	<b>Prevent Blood Infections</b>	<ul style="list-style-type: none"> <li>• Wash your hands before touching your fistula or graft               <ul style="list-style-type: none"> <li>○ Wash the skin over your fistula or graft with warm, soapy water just prior to your dialysis treatment</li> </ul> </li> <li>• Learn the infection prevention practices in your facility</li> <li>• Know the signs and symptoms of infection:               <ul style="list-style-type: none"> <li>○ Fever, fatigue, diarrhea, and/or redness and swelling around a catheter or fistula site</li> </ul> </li> </ul>
<b>2</b>	<b>Protect Your Access</b>	<ul style="list-style-type: none"> <li>• Listen to your access for a whooshing sound</li> <li>• Feel your access for a buzzing feeling (thrill)</li> <li>• Talk to facility staff about your access at each treatment</li> <li>• Let staff assess the need for treatment by the surgeon or access center</li> <li>• Get treatment as soon as an issue is identified</li> </ul>
<b>3</b>	<b>Reduce Your Risk of Fluid-Related Issues</b>	<ul style="list-style-type: none"> <li>• Attend all of your dialysis treatments</li> <li>• Follow salt and fluid intake rules</li> <li>• Let staff know if your thirst increases between treatments               <ul style="list-style-type: none"> <li>○ Drinking too much fluid between treatments makes the fluid harder to remove</li> <li>○ Too much fluid may cause shortness of breath and/or heart problems</li> </ul> </li> </ul>
<b>4</b>	<b>Protect Your Heart</b>	<ul style="list-style-type: none"> <li>• Keep your phosphorous in the range of 3.5–5.0 mg/dl</li> <li>• Keep a healthy body weight</li> <li>• Get help to quit any smoking habit</li> <li>• Take your blood pressure medicine as ordered</li> <li>• Follow salt and fluid intake rules</li> <li>• See your heart doctor on a regular basis</li> </ul>
<b>5</b>	<b>Address Digestive Problems Before They Become Serious</b>	<ul style="list-style-type: none"> <li>• Talk with facility staff about dietary concerns</li> <li>• Let facility staff know about symptoms you may be having so they can be addressed before they require a hospitalization.</li> <li>• See your gastroenterologist (stomach doctor) on a regular basis</li> </ul>

Action		How
6	Prevent Blood Pressure Problems	<ul style="list-style-type: none"> <li>• Take your blood pressure medicine as prescribed</li> <li>• Know your current dry weight</li> <li>• Tell the care team of any changes that could affect your dry weight <ul style="list-style-type: none"> <li>○ Extreme thirst, loss of appetite, or increased appetite with body weight gain</li> </ul> </li> <li>• Discuss how you feel with facility staff after each adjustment of your dry weight <ul style="list-style-type: none"> <li>○ Removing too little fluid can increase blood pressure</li> <li>○ Removing too much fluid can cause your blood pressure to drop</li> </ul> </li> </ul>
7	Ensure Your Medicines and Doses Are Correct	<ul style="list-style-type: none"> <li>• Bring in a list of ALL of your current medications (use the <i>Medication List</i> on <b>Page 16</b> of this booklet) or your medicine bottles to discuss with facility staff <ul style="list-style-type: none"> <li>○ Tell them if there is anything new or different about your list</li> </ul> </li> <li>• Tell your nurse or social worker if you cannot get your medicines <ul style="list-style-type: none"> <li>○ Do this right away!</li> </ul> </li> </ul>
8	Track Your Hemoglobin (Hgb) Levels	<ul style="list-style-type: none"> <li>• Know your Hgb lab test results</li> <li>• Ask facility staff if your Hgb is out of target range (10–13) <ul style="list-style-type: none"> <li>• Low hemoglobin can leave you feeling weak and tired, and short of breath.</li> <li>• High hemoglobin can pose serious health risks even though you may not feel differently.</li> </ul> </li> <li>• Report any signs of trouble, including: <ul style="list-style-type: none"> <li>○ Infection, open sores or wounds, or change in the color of your stool</li> </ul> </li> </ul>
9	Avoid Falls at Home	<ul style="list-style-type: none"> <li>• Tell your care team if you are feeling weak or overly tired <ul style="list-style-type: none"> <li>○ They may be able to help you find services or options to assist you</li> </ul> </li> <li>• If you have a fall at home, tell your care team right away!</li> </ul>
10	Prevent Pneumonia	<ul style="list-style-type: none"> <li>• Get the flu vaccination every year</li> <li>• Get a pneumonia vaccination if you have not had one in the last five years <ul style="list-style-type: none"> <li>○ Ask your care team for more information</li> </ul> </li> <li>• As about other vaccinations or immunizations that might help you stay out of the hospital</li> </ul>

## Keep Your Dialysis Facility Staff Informed

In order for the staff at your dialysis facility to provide you with the best care possible and so they can help you avoid unnecessary hospitalizations, you need to keep them informed about changes in your life that might affect your health. Even if you don't think something is kidney-related, it could be. Let your care team know if you have:

- Been in the hospital.
- Been to the emergency room.
- Been to an Urgent Care center.
- Been to see a specialty doctor, such as your cardiologist or gastroenterologist (stomach doctor).
- Started a new medication, for any reason.
- Stopped taking a medication, for any reason.
- Experienced any bleeding for longer than 10 minutes from anywhere, including a cut, nosebleed, and/or your gums.
- Been experiencing any new pain, changes, or problems of any kind with your access.
- Had a fall at home.



## Maintenance Measures

Some things, which may not seem critical as a one-time situation, can be very important on an ongoing basis. It is important to always:

- Have transportation to and from your doctors' appointments and dialysis treatments.
- Follow-up with your specialists on a regular basis.
- Know where the closest Urgent Care centers are near you.
- Know/manage your dry weight.
- Care for and protect your vascular access.

Because you may not always have advance notice of a hospitalization, there are some things you must be sure to have in place, documented, and current, including:

- Your Advance Directives (a written statement of your wishes regarding medical care, also sometimes called a "living will")
- Information on all of your medications, including medicine names and dosages
- Who you would use for home health services, if covered and required
- Who you could look to for support at home

If you need any help with anything on the lists above, call your dialysis clinic.

## A Discharge Planning Checklist

- Sometimes, even when you've done everything right, you cannot avoid a hospitalization. When that happens, the goal is for you to get in and get out as quickly as possible. Remember, from the moment you are admitted, the point of a hospital stay is to get you well enough to leave so that you may return to normal activity. Therefore, it makes sense to plan for your discharge right from the start. Use this **Discharge Planning Checklist** to prepare for your discharge. If you need help in completing the checklist for any reason, ask a friend, family member, or even a facility or hospital staff member to assist you. Use this checklist early and often during your stay. As you complete your checklist be sure to: Talk to your doctor and the staff (like a discharge planner, social worker, or nurse) about the items on this checklist.
- Check the box next to each item when you and your caregiver complete it.
- Use the notes column to write down important information, like names and phone numbers.
- Skip any items that don't apply to you.

<input checked="" type="checkbox"/>	Action	Notes
<b>Your Health</b>		
<input type="checkbox"/>	Ask the staff about your health condition and what you can do to help yourself get better.	<hr/> <hr/>
<input type="checkbox"/>	Ask about problems to watch for. <ul style="list-style-type: none"> <li>• Ask what to do about them.</li> <li>• Ask for/write down the name and phone number of a person to call if you have problems.</li> </ul>	<hr/> <hr/> <hr/>
<b>What's Ahead?</b>		
<input type="checkbox"/>	Ask where you'll get care after you leave the hospital. <ul style="list-style-type: none"> <li>• Do you have options, like home health care?</li> <li>• Be sure to let staff know what you prefer.</li> </ul>	<hr/> <hr/> <hr/>
<input type="checkbox"/>	Make sure you have a caregiver in place that can help you after discharge. <ul style="list-style-type: none"> <li>• Write down their name and phone number.</li> <li>• Ask hospital staff to note your caregiver's name/phone number in your medical record.</li> </ul>	<hr/> <hr/> <hr/>

<input checked="" type="checkbox"/>	Action	Notes
<b>Recovery and Support</b>		
<input type="checkbox"/>	<p>Ask if you'll need any medical equipment.</p> <ul style="list-style-type: none"> <li>• Make note of who will arrange for the medical equipment.</li> <li>• Write down the name and phone number of a person to call if you have any questions about medical equipment.</li> </ul>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Ask if you're ready to do the following activities on your own or if you will need assistance:</p> <ul style="list-style-type: none"> <li>• Bathing/dressing</li> <li>• Using the bathroom</li> <li>• Climbing stairs</li> <li>• Cooking</li> <li>• Food shopping</li> <li>• House cleaning</li> <li>• Paying bills</li> <li>• Getting to doctors' appointments</li> <li>• Picking up prescriptions</li> </ul> <p>Circle the ones you think you'll need help with and let staff know—<b>before you leave the hospital.</b></p>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Ask staff to show you and your caregiver, as appropriate, any tasks that will require special skills, like changing a bandage or giving a shot.</p> <ul style="list-style-type: none"> <li>• Have staff observe you or your caretaker perform these specialized tasks to ensure you are doing them correctly.</li> </ul>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Ask to speak to a social worker if you are concerned about:</p> <ul style="list-style-type: none"> <li>• How you and your family are coping with your illness.</li> <li>• What your insurance will cover and how much you will have to pay. <ul style="list-style-type: none"> <li>○ Ask about possible ways to get help with costs.</li> <li>○ Write down information about support groups and other resources.</li> </ul> </li> </ul>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

<input checked="" type="checkbox"/>	Action	Notes
<b>Recovery and Support (cont.)</b>		
<input type="checkbox"/>	<p>Ask for written discharge instructions and a summary of your current health status.</p> <ul style="list-style-type: none"> <li>• Make sure you can read and completely understand the instructions.</li> </ul> <p>Bring this information to any of your follow-up doctor's appointments.</p>	<hr/> <hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Use the <i>Appointment Tracker</i> on <b>Page 14</b> of this booklet to write down any appointments and tests you will need in the few weeks following your discharge.</p>	<hr/> <hr/> <hr/>
<b>Dialysis-Related</b>		
<input type="checkbox"/>	<p>Ask if your hospital records have been shared with your facility.</p>	<hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Ask staff what your dry weight was from your last dialysis treatment.</p>	<hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Ask if you need to follow a special fluid management regimen.</p>	<hr/> <hr/> <hr/>
<input type="checkbox"/>	<p>Ask if your dialysis treatment orders have changed or if you require anything new at dialysis.</p>	<hr/> <hr/> <hr/>



## Important Notices

### **If you think you're being asked to leave a hospital or other health care setting (discharged) too soon:**

You may have the right to ask for a review of the discharge decision by the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO) before you leave the hospital. A BFCC-QIO is a type of quality improvement organization (a group of doctors and other healthcare experts under contract with Medicare) that reviews complaints and quality of care for people with Medicare. To get the phone number for your BFCC-QIO, call **1.800.MEDICARE** (1.800.633.4227). You can also ask the staff for this information. If you're in a hospital, the staff should give you a notice called "Important Message from Medicare," which contains information on your BFCC-QIO. If you don't get this notice, ask for it. For more information on your right to appeal, visit [www.medicare.gov/appeals](http://www.medicare.gov/appeals).

### **If you need help choosing a home health agency or nursing home:**

- Talk to the staff.
- Visit [www.medicare.gov](http://www.medicare.gov) to compare the quality of home health agencies, nursing homes, dialysis facilities, and hospitals in your area.
- Call **1. 800.MEDICARE** (1.800.633.4227). **TTY users** can call 1.877.486.2048.

## You're Out the Hospital. Now What?

Once you have been discharged from the hospital, it is very important that you **follow all of your discharge instructions**. Remember, these should have been made with your input and preferences in mind. Exactly what your discharge plan will look like depends on your individual needs. Next, take your discharge instructions *and* your new medication list to your dialysis facility to share with staff. This will help them to review the information with you and to update your records.

If you are confused about anything in your discharge plan or are unsure about any part of your follow-up care, **call your dialysis facility**. Your care team will help you.

# **TOOLS TO HELP YOU BEFORE, DURING, AND AFTER A HOSPITALIZATION**

## Appointment Tracker

One of the most important things you can do **before you leave the hospital** is to make sure your follow-up doctors' appointments have been scheduled. Know who you need to see, when, where, and why. Then, be sure to keep your appointments!

Appointment Date	Appointment Time	Doctor's Name Office Location* and Phone	Reason for Visit
Example June 5	Example 10 a.m.	Example Dr. Jane Doe 1234 Street, Suite 200 XYZ Town and Zip Code 123.456.7891	Example Medication review

\* While you may know how to get to your doctor's office or the local lab for tests, someone helping you may not. It can be helpful to have the correct office or lab address written down, including ZIP code for GPS directions!

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\* While you may know how to get to your doctor's office or the local lab for tests, someone helping you may not. It can be helpful to have the correct office or lab address written down, including ZIP code for GPS directions!





## Important Contact Information

Type of Doctor	Doctor/Facility Name	Contact Details
Dialysis Center		<b>Phone:</b> <b>Email:</b> <b>Address:</b> <b>Fax:</b>
Nephrologist		<b>Phone:</b> <b>Email:</b> <b>Address:</b> <b>Fax:</b>
Primary Care		<b>Phone:</b> <b>Email:</b> <b>Address:</b> <b>Fax:</b>
Cardiologist		<b>Phone:</b> <b>Email:</b> <b>Address:</b> <b>Fax:</b>
		<b>Phone:</b> <b>Email:</b> <b>Address:</b> <b>Fax:</b>
		<b>Phone:</b> <b>Email:</b> <b>Address:</b> <b>Fax:</b>
Network		<b>Phone:</b> <b>Address:</b> <b>Fax:</b>





*ESRD Networks 7, 13, 15, 17, 18*

**To learn more about the ESRD networks please  
visit <https://www.hsag.com/en/esrd-networks/>.**

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