

# Kidney *Chronicles*

IPRO END-STAGE RENAL DISEASE NETWORK OF NEW ENGLAND

MARCH 2016

HELPFUL TIPS  
TO EMPOWER  
ESRD PATIENTS  
AS CONSUMERS



Improving Healthcare  
for the Common Good®

## Ten Tips to Help You Become Active in Your Care

### 1. Know your Annual Care Plan.

Your Annual Care Plan is your road map to better health. Your doctor, dialysis facility staff members, and you should meet every year to create a plan that sets specific goals for you, your health and your quality of life. If you have not yet discussed your care plan with your healthcare team, speak to your social worker or nephrologist and request a copy of your most recent care plan; file it with your medical records at home, and share it with other healthcare providers with whom you may be working.



### 2. Ask questions.

Your healthcare team is your best resource to support you in living the best life that you can with ESRD. If you have a question or don't understand something...ASK. And if you can't seem to find an answer, call your ESRD Network and ask if they have any resources to assist you in finding answers.

### 3. Know your dialysis options.

Did you know there are different ways to dialyze that include: in-center dialysis, in-center nocturnal dialysis, peritoneal dialysis, and home hemodialysis. One option may suit your needs/lifestyle better than others; some will free up time for you to work, go to school, or travel. Ask your healthcare team for information to help you understand the advantages of each type of dialysis.

### How the Network Serves You

- Advocates on your behalf;
- Answers your questions about treatment, modality choices or other issues;
- Develops and provides educational materials, i.e., newsletters, for you and your family;
- Works with renal professionals to improve the care provided to you;
- Helps keep you informed and updated to support your involvement in your care and treatment options; and
- Evaluates and resolves grievances.

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### 4. Know yourself.

You know your body better than anyone else. If you don't feel well and things seem to be "not normal" for you, tell your doctor and healthcare team how you feel. You may need to change medications, see a specialist or change something in your care plan. Your healthcare team needs your feedback to make your treatments and care plan work for you.

### 5. Notice trends.

Has your blood pressure been high lately? Are you cramping more? Are you having trouble sleeping at night? These things could indicate that your treatments/care plan should be adjusted. Talk to your healthcare team about any changes you notice.

### 6. Educate yourself.

Don't be shy or afraid to ask your healthcare team to explain medical terms in words you can understand. Ask where you can get more information about medical issues that might affect you. They are important! Consider volunteering as a Network Patient Advisory Committee (PAC) representative so you can share with others what you have learned! To learn more about the PAC, speak with your social worker or visit our website <http://esrd.ipro.org/initiatives/patient-engagement/patient-advisory-committee-pac/>

### 7. Speak up.

You are the star of your healthcare team. Make sure that your voice is heard. The more you take part in your healthcare, the more you will benefit.

### 8. Keep Appointments. They're important.

Your medical appointments are focused entirely on your health and how to improve it. Your healthcare team is committed to working with you and helping you, so if you are unable to keep an appointment, let them know in advance and reschedule as soon as possible. Some appointments can be done over the telephone. Ask your doctor or social worker if there is a way that you can have a meeting over the phone. (You can also ask that a family member or care partner join in on the call!)

### 9. Decide together.

Make sure you understand what each part of your care plan means and how it will affect your health. You will be asked to approve the decisions made by the doctor and staff, so you need to understand each part of your care plan and how it will affect you.

### 10. You don't have to go alone.

It's okay to bring someone to your medical appointments to help you ask questions and understand the answers. Under special circumstances, you can have someone go in your place, but of course it's best for you to be there and actively participate.

The content included in this newsletter was adapted from the ESRD NCC document "10 Tips to Help You Become Active in Your Care!" available at [http://esrdncc.org/wp-content/uploads/2015/12/ESRD\\_NCC\\_Care\\_Plan\\_Tips.pdf](http://esrdncc.org/wp-content/uploads/2015/12/ESRD_NCC_Care_Plan_Tips.pdf)

### To file a grievance, please contact:

**IPRO End-Stage Renal Disease Network of New England**  
1952 Whitney Avenue, 2nd Floor, Hamden, CT 06517

**Main: (203) 387-9332 • Patient Toll-Free: (866) 286-3773**

**Fax: (203) 389-9902 • E-mail: [info@nw1.esrd.net](mailto:info@nw1.esrd.net) • Web: [esrd.ipro.org](http://esrd.ipro.org)**

