

“BEE” INFORMED ABOUT YOUR RIGHTS AND RESPONSIBILITIES

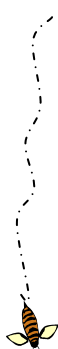


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Mission Statement

The mission of the Network of New England is to facilitate the improvement of health care and quality of life for individuals who have chronic renal insufficiency and those treated with dialysis or transplantation.

Overview



No one knows what living with End Stage Renal Disease is like unless it has happened to you. Family members, doctors, nurses, social workers, and the Network all want to help you attain the best treatment possible. Being self informed and educated gives you the insight to advocate for yourself and your own health. Maintaining independence over your life could increase your quality of life, and your quality of care. This pamphlet will give you guidance about your rights and responsibilities, what to expect from your dialysis facility, and the process for reporting complaints or grievances. If you feel confused or shy about asking for more information, you should have a family member or friend come with you when you meet with the facility staff. Having someone with you can help to clarify information for you and be a fresh set of eyes and ears. Sometimes all the information you receive can be told to you all at once and it is easy to forget some things. Request from the staff written information that you can take home about your illness and the types of treatment options. Make a list of questions as you read through the material and then ask for time to discuss them. Be a part of the team that makes the decisions about your care.

Most of the time discussions about your care can take place within your facility. Other times, however, you may want to talk with others outside the facility. The Network of New England, which is funded by the Centers for Medicare and Medicaid Services (CMS), adheres to the rules and regulations under Medicare. The role of the Network is to be available in those times when communication between a patient and the facility becomes difficult.

You have the Right to be treated with dignity and respect. You have the Responsibility to treat other staff and patients with the same respect as you would like to be treated.

In the Dialysis Unit

- You have the Right to quality care in a comfortable atmosphere.
- You have the Right to meet with your whole health care team (i.e. Doctors, Nurses, Social Workers, and Dieticians) to plan and maintain your treatment (i.e. Social worker for counseling, Dietician for food planning).
- You have the Right to be told about your health in a way you understand.
- You have a Right to information about your diagnosis, treatment options, advantages and disadvantages of each treatment, including side-effects, changes in lifestyle, dietary limits, etc.
- You have a Right to choose your treatment choices and accept or refuse any procedure, treatment or medicine your doctor orders for you. You can expect clear answers to your questions. No treatment shall be given without your informed consent. (*Note: If you are under 18, you may have limited rights to certain decisions about your care.)
- You have the Right to be told about any expenses that you have to pay for that aren't covered by insurance or Medicare.
- You have the Right to be told about any financial help available to you.
- You have the Right to be told about all rules at your treatment facility. Such rules include eating, rules for visitors, personal conduct etc. This right should include a supportive atmosphere for listening to your concerns.

- You have the Right to make decisions about your health care based on information given to you by your doctor (nephrologist).
- You have the Right to equal consideration of treatment without regard to age, sex, race, religion, or ethnic origin.
- You have the Right to be informed of what to do in an emergency (i.e. hurricane, fire).
- You have the Responsibility to tell your healthcare team if you refuse any treatment or medicine that your doctor has ordered for you.
- You have the Responsibility to tell your health care team if you don't understand your medical condition or treatment plan.
- You have the Responsibility to be on time for your treatments or when you see your doctor.
- You have the Responsibility to tell the staff at the center if you know that you're going to be late or miss a treatment or visit with your doctor.
- You have the Responsibility to tell your health care team if you have medical problems, are going to the dentist, are being treated by another doctor, or have recently been to the hospital.
- You have the Responsibility to follow the rules.
- You have the Responsibility to pay your bills on time. If this is difficult you can inquire about a payment plan.
- You have the Responsibility to get to and from the center for your treatments. You can talk with your social worker if you need help doing this. Medicare does not pay for routine transportation.
- You have the Responsibility to learn what an emergency is and what actions must be taken in emergency situations.
- You have the Responsibility to be respectful, courteous and considerate.



Transplantation

- You have the Right to receive a full explanation of the kidney transplant process.
- You have the Right to select a transplant center at which you desire to receive a transplant after consultation with the nephrologists.
- You have the Responsibility to take the necessary steps prior to receiving a transplant to aide your body in accepting the transplant.
- You have the Responsibility to inform your doctor, transplant coordinator, transplant social worker etc. about your medical history.



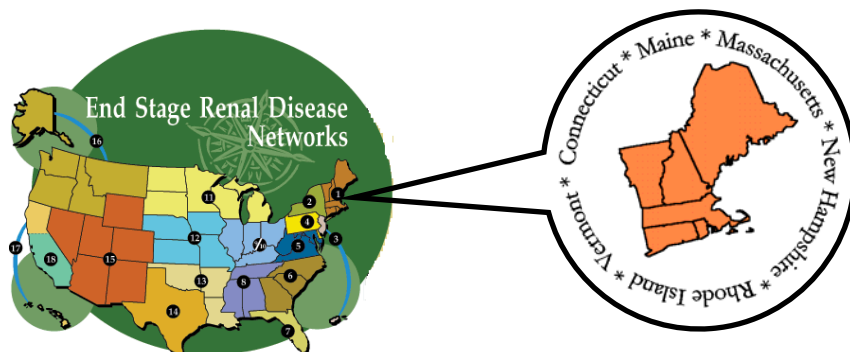
Advance Directives and Research

- You have the Right to choose if you want to be a part of any research study
- You have the Right to an advance directive stating your wishes.
- You have the Responsibility to indicate your refusal of an advance directive in writing.

What is the Network?

The Network of New England, funded by the Centers for Medicare and Medicaid Services (CMS), is one of 18 networks throughout the U.S. Its function is to assist CMS with the quality of care provided by dialysis and transplant facilities to patients with End Stage Renal Disease (ESRD). This Network is responsible for Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont. In addition, the Network assists and/or conducts projects to improve patient care. The Network office distributes ESRD information to patients, nurses, dietitians, social workers, physicians, administrators, and other healthcare personnel. Members of the Network Board of Directors and Medical Review Board include patients and healthcare personnel.

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Network Grievance Policy and Procedures

You are encouraged to contact your Nurse Manager or any member of your health treatment team if you have a concern regarding your care or facility conditions. Working with the people in your facility is the best way to handle an issue that arises.

You may contact the Network with a grievance if you believe that your problem was not handled well at the facility. The Network can help solve problems by working with you and the facility staff. When filing a grievance, you will be asked whether you would like to remain anonymous. Your identity will be kept confidential and will not be revealed unless you give your permission. If the Network cannot process the grievance without using your name, you will be informed.

All materials related to the problem will be kept confidential and access to the information will be restricted. Once the grievance is received, the Network will give quick and unbiased attention to the problem. A Network staff member will call you to talk about a reasonable course of action. Some situations may require the Network to work together with another agency such as the State Health Department.

The Network staff will contact the facility to collect, verify and clarify information about the nature of the problem. When necessary the Network will submit the problem to the Network Grievance Committee. The committee will meet to decide what actions, if any, should take place.

The Network staff will make sure that any necessary actions take place in a reasonable amount of time. Although the Network cannot handle matters dealing with money, payment of bills, or State or Federal licensure issues, a staff person may be able to direct you to someone who can help you.

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