

# Patient Rights and Responsibilities

*Produced by the Intermountain ESRD Network #15*

*Adopted by the American Association of Kidney Patients Patient Advisory Committee*

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The Southeastern Kidney Council presents this document of patient rights and responsibilities, an important part of a patient's care, with the expectation that observance of them will contribute to more effective care and greater satisfaction for both patients and facility staff. Each patient has the right to competent, high-quality medical care by trained personnel without regard to sex, race, economic status, religion, sexual orientation, or to the source of payment for his/her care.

## **RESPECT, PRIVACY, AND CONFIDENTIALITY**

**Rights:** It is your right to be treated with respect, dignity, and consideration of your rights as an individual by everyone involved in your care: and, to have as much privacy in treatment as possible. Case discussion, consultation, examination, and treatment are confidential and should be conducted in a manner which protects these rights for you.

It is your right to expect all communications and records of your care to be treated as confidential. You may approve or refuse to release your records to any individual outside of the facility, except if you transfer to another healthcare institution, or as required by federal, state, or local laws.

**Responsibilities:** It is your responsibility to treat the staff with the same respect and individual consideration as you expect for yourself. This includes the responsibility to be honest and direct about everything that relates to you as a patient, to respect the rights and private property of other patients, and see that your visitors are considerate as well.

## **INFORMATION, EDUCATION, AND COUNSELING**

**Rights:** It is your right to be told, in terms which you can understand, all about your disease and its treatment. This includes diagnosis, medical procedures, tests to be done, equipment to be used, your progress, your future prospects, the risks involved, and the treatment choices and locations where treatment is available. You also have the right to know the person responsible for the procedures and/or treatment. It is your right to seek your own nephrologist and treatment facility and to participate in the planning of your medical care.

You have the right to education on the various treatment choices including hemodialysis, peritoneal dialysis, and transplantation. However, be advised that not everyone is a suitable candidate for every treatment method; but those who are not, have the right to be told by their physician why they are not.

You have the right to assistance which deals with specific problems or special needs that include (but are not limited to) blindness, hearing loss, language barrier, limited mental capacity, and financial restrictions that may limit your ability to comprehend your condition or carry out your treatment plan.

It is your right to have access to qualified social work and dietary counseling.

**Responsibilities:** It is your responsibility to understand the nature and treatment of your kidney disease to the best of your ability. An important part of the success of the treatment plan is your understanding of your health problems. You should help plan and carry out the treatment program as much as you can. You are encouraged to ask questions of staff members to obtain further instruction if you do not understand or are unable to follow your treatment plan. Following your treatment plan closely can directly affect how you feel.

It is your responsibility to contact the staff about any medical, psychological, social, dietary, or financial problem with which you want assistance.

## **INFORMED CONSENT, TRANSFER, AND REFUSAL OF TREATMENT**

**Rights:** It is your right to receive information necessary for you to give **A**n informed consent **@**prior to any new procedure or treatment, meaning that you agree to things only after you understand them.

It is your right to be transferred or discharged only for medical reasons, for your own welfare, for the welfare of other patients, or for willful nonpayment of services provided to you (except as prohibited by the Social Security Act). You must be given reasonable advance notice of any transfer or discharge except in the case of an emergency as determined by the professional staff.

It is your right to refuse to allow a staff member undergoing training to provide treatment unless a competent and fully-trained staff member is present and directly supervising the trainee.

It is your right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of your action. In other words, most patients can refuse treatments, but they need to know that doing so can bring about great harm and even death in some circumstances.

Documents called **A**dvanced directives **@**can protect your right to refuse or limit future medical treatment if you ever become unable to communicate your wishes. This is done by writing them down ahead of time using documents such as Living Wills and Medical Durable Power of Attorney. Ask your treatment facility staff about information on

advance directives for more information.

**Responsibilities:** It is your responsibility to decide whether or not the information you get from your caregivers is enough for you to feel comfortable in agreeing to undergo new procedures.

If you transfer to another facility, it is your responsibility to secure the services of a nephrologist to provide your medical management at that facility.

It is your responsibility to notify the medical staff if you do not intend to follow your prescribed treatment plan.

It is your responsibility to understand what will happen if you do not follow your treatment plan and to explain your reasons for refusal to the medical staff. Also, you must sign any forms required by the facility to document your actions.

If you have chosen to use advance directives, it is your responsibility to furnish your facility with complete, current documents.

## **KNOWLEDGE OF FACILITY SERVICES**

**Rights:** It is your right to be dialyzed at the hours most convenient and desirable to you, as the facility schedule permits. Furthermore, it is your right to expect the facility to provide treatment at your regularly scheduled times, except in unusual circumstances.

It is your right to receive, upon request, information about facilities available to visiting patients and to receive assistance in arranging for dialysis when you plan to travel away from home.

It is your right to know all costs of your care, including costs for any consultants, if used, and to have access to individuals who know about Medicare and other potential sources of financial assistance, and to be told charges for services not covered by Medicare or other insurance.

**Responsibilities:** It is your responsibility to make every effort to keep all scheduled appointments and dialysis treatments and to be on time. If an appointment needs to be cancelled or delayed, a call to the unit should be made in advance. You should recognize the possibility of having to reschedule if you are late.

It is your responsibility, when dialyzing away from your usual facility, to plan your travel far enough in advance that arrangements can be made. You will need to confirm financial arrangements. Medical information should be available to the visited facility and medical reports should be sent back to your regular facility. When dialyzing away, you have a particular responsibility for being knowledgeable about your care and treatment to

ensure you receive appropriate care.

It is your responsibility to know the costs of treatment and provide accurate and complete information about your Medicare eligibility and other necessary financial matters. You are responsible for payment of all services provided to you and you should be aware of those services covered by insurance and those which you must pay yourself. If you have any change in insurance coverage, it is your responsibility to immediately notify your facility.

## **EMERGENCY CARE**

**Rights:** It is your right to expect emergency medical care to be available at all times and to be given to you without unnecessary delay. It is your right to be told exactly what to do and/or whom to call by your physician or other caregiver in case of medical emergencies such as access bleeding, clotting, or other situations which may happen for which there may be some advance action plan (fire, power outage, low water pressure, natural disasters, etc.).

**Responsibilities:** It is your responsibility to recognize what constitutes an emergency and what actions you or someone acting on your behalf need to take to appropriately deal with the emergency situation.

## **GRIEVANCE MECHANISM**

**Rights:** If you feel that there is a problem with the care that you receive, then it is your right to try to correct the situation by talking to the staff to voice a complaint or to suggest changes in policies or services. It is your right to do this, or have someone else do it on your behalf without fear of punishment or negative actions toward you. If, after talking to the appropriate facility personnel, the problem still continues, you may file a formal complaint called a grievance with the facility. Every facility is required by law to have a grievance procedure to help resolve the matter. If that process is not satisfactory to you and the problem pertains to a quality of medical care issue, you can contact your Southeastern Kidney Council for further information and/or assistance which might include filing a formal grievance with the Network. Upon request, your name can be held confidential.

**Responsibilities:** It is your responsibility to know and to follow your facility's posted rules and regulations. If a problem arises, it is your responsibility to know and follow the grievance procedure in your treatment center. If the grievance remains unresolved and pertains to a quality of medical care issue, you are encouraged to contact the Southeastern Kidney Council at 1-800-524-7139.