



Transplant
Recipients'
Bill of Rights
and
Responsibilities

This publication is based on the consensus of the transAction Council Executive Committees and representatives of the broader transplant community who were invited to be participants of the Work Group.

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Dear Fellow Transplant Recipients:

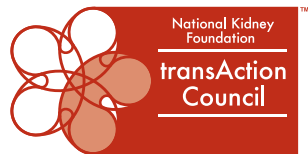
We are of every age, and of many different cultures and religions. Though every one of us is unique, we all share the need to take special care of our health. This Transplant Recipients' Bill of Rights and Responsibilities was created to empower recipients to be proactive in obtaining the specialized health care we need.

For more than three years, the transAction Council executive committee worked to create this document. We held focus groups with recipients and then collaborated for more than a year and a half with representatives of a number of transplant organizations. Finally, we solicited feedback from our transAction members. We thank all those who helped with this effort by sharing their time and expertise.

As you travel on your transplant journey we hope the Transplant Recipients' Bill of Rights and Responsibilities reminds you that you are not alone and gives you access to health care professionals, transplant recipients and others who will support and encourage you through your times of need and times of joy.

Sincerely yours,

The transAction Council
Executive Committee
National Kidney Foundation



In 1973, the American Hospital Association adopted a Patients' Bill of Rights to ensure that health care facilities and health care workers respect and honor the rights of individuals under their care. While acknowledging that transplant recipients share those same basic rights, this document also incorporates several specific rights and issues that are unique to recipient aftercare.

Although solid organ transplantation is a successful intervention that prolongs and improves the quality of life for recipients, transplantation is a treatment, not a cure. Recipients face a new set of challenges and responsibilities, such as the potentially serious side effects of immunosuppressant medications, and have a continuing need for specialized aftercare, both medical and psychosocial. While there are some common needs that all recipients share, the exact nature and type of these aftercare services will vary according to individual needs.

Because transplant programs vary in size and scope of available support services, this document is intended to empower all recipients. It represents a nondiscriminatory, culturally-sensitive framework for identifying and addressing the continuing needs of recipients.

Just as each patient is unique, each transplant program has a different or unique capacity or procedure for providing follow-up medical and psychosocial services to its patients. It is critical that all recipients receive quality long-term medical and psychosocial care by qualified health care professionals to ensure each patient's well being and to enhance the survival of the transplanted organ. If the transplant facility does not provide those services to any or all of its patients, it has the responsibility to assist those patients in securing such services.

The American health care environment has changed in the past fifteen years and patients may be more mobile. Whether it is due to the requirements of managed care providers or the patient's moving, the facility that provided the transplant services may no longer provide long-term care. It is imperative that the transplant provider assure continuity of care and provide the patient's new medical and psychosocial provider(s) with accurate medical

record documentation, including a long-term care plan. The transplant provider must be available for consultations as required in the patient's best interest for the life of the organ.

The health care providers for the transplant recipient should strive to empower each recipient to assume responsibility for his or her own care and to be provided with such rehabilitation services as may be required to permit the return to a normal, age-appropriate life.

In addition, because recipients must partner with their health care team to receive optimum care, this document also includes a set of basic responsibilities that recipients must fulfill in order to maintain that partnership.

✦ RIGHTS ✦

Transplant Recipients Have the Right to:

◆ *Quality Care*

- ✓ impartial access to quality follow-up medical and psychosocial care regardless of ethnic background, national origin, religion or age.
- ✓ have access to transplant physicians, nurses, social workers and dietitians.

Continued access to appropriate staff is necessary because while recipient health care needs change following transplantation, they are no less important than similar needs prior to transplantation.

- ✓ expect continuity of care and coordination of effort between their transplant health care team and primary care provider.

The provision of ongoing care may pose difficulties for recipients' primary care physicians, who may be unfamiliar with the care of transplant recipients. Care providers and

support systems in transplantation need to work cooperatively at both the transplant center and any site involved in the care of recipients.

◆ *Respect and Personal Dignity*

- ✓ be treated with respect, dignity, courtesy, compassion, and cultural sensitivity.
- ✓ have privacy and confidential handling of all medical records and communication.

◆ *A Voice in Decision Making*

- ✓ be consulted for their view of “quality of life.”

Each recipient with the capacity to make medical decisions should have his or her unique views on what constitutes “quality of life” considered when setting aftercare goals and making informed choices. When a legally designated surrogate is the decision maker, the surrogate should be consulted as to the values and goals and views on quality of life.

- ✓ participate as full partners with their health care team, and to have their opinions heard and valued in the decision-making process and in the development of a comprehensive plan of care.

In making medical decisions, the health care team must respect the principle of patient autonomy. Recipient preferences, values and short- and long-term goals need to be incorporated into the decision-making process as long as the recipient has the capacity to make medical decisions.

- ✓ have treatments, treatment options, possible complications and self-care requirements explained in an understandable manner, with sufficient time to ask questions and have them answered.
- ✓ appeal decisions made by a physician, hospital staff, managed care plan or other health care provider.

✓ obtain a second opinion, and/or accept or refuse medical treatment.

✓ change physicians.

◆ *Information*

✓ have family members or significant others they designate be kept informed of their medical condition during hospitalizations.

It is unethical to provide medical information to any person or organization without the written consent of the patient (or the patient's surrogate if the patient lacks the capacity to make medical decisions), yet important to give information when a person is so designated. However, care providers are obligated to maintain appropriate communications with each patient's designated surrogate.

✓ know the identity and profession of any individual providing a service to them.

✓ prompt communication regarding lab work, medical tests and advice of their medical team, and to have access to all medical records.

✓ receive a complete explanation of the total bill for services rendered.

◆ *Emotional Support*

✓ have feelings respected and, when appropriate, addressed by their health care team.

✓ receive a comprehensive psychosocial plan developed and updated by an appropriately trained mental health provider.

✓ have correspondence forwarded to the family of a deceased donor, provided the donor family has expressed a willingness to receive communication from the recipient.

◆ *Freedom from Discrimination*

✓ have access to employment, insurance and essential medicines.

Although recipients may feel better than they have in years, the fear of losing disability benefits and employment opportunities, as well as the high cost of life-sustaining medications, can create significant burdens for many recipients and their families. Recipients and transplant facilities should unite to act as effective advocates for solutions to these concerns.

✓ rehabilitate to meaningful activity.

By providing referrals to appropriate government or private vocational and education programs, the health care team should support and encourage recipients' efforts to obtain employment and/or pursue other meaningful activities.

✿ RESPONSIBILITIES ✿

Transplant Recipients Have the Responsibility to:

◆ *Maintain Long-term Health*

✓ schedule appointments and tests at appropriate intervals with the health care team.

It may be necessary to periodically return to the transplant center even if a local physician is following the recipient.

✓ be prompt in attending such appointments and if it is necessary to cancel, to give notice as early as possible of the need to reschedule.

✓ adhere to transplant medical regimes and inform the health care team when unable to do so.

✓ learn the names, dosages, indications and adverse reactions of all prescribed medications, and to report all adverse reactions to the appropriate health care team members.

✓ learn to identify and report any signs or symptoms of rejection and infection and know when to report any such signs or symptoms. (Rejection and infection make symptoms less detectable only by examination, blood test or other test.)

✓ maintain their primary care health needs (dental, gynecological, dermatological, etc.) and to know when to report any abnormalities.

✓ ask questions and obtain clarifications to ensure understanding of all communication from the health care team.

✓ commit to healthy living by making necessary lifestyle changes, such as incorporating exercise into daily routines and changing pre-transplant diet as recommended by the health care team.

◆ *Provide Information*

✓ inform the health care team if name, address or phone number changes.

✓ inform the transplant team about any changes in health condition including: any desire to take new medications (including herbal, vitamins, mineral, alternative or over-the-counter); any change in daily activities (starting or stopping an exercise regimen or nutritional program, new employment, etc.); or any other situation that may have an effect on emotional or physical well-being.

✓ provide information from other treating physicians to the transplant center by giving written permission for records to be sent to the transplant center.

✓ provide the health care team with the names and contact information of designated family members or significant others who should receive appropriate updates on the recipient's medical and psychosocial condition.

- ✓ request results of medical and lab tests if these are not provided to them in a timely fashion.
- ✓ ask for, and obtain, the name of the specific health care team member to contact for questions or concerns.
- ✓ provide appropriate team members with a copy of an advanced directive, and/or medical power of attorney.

Advance Directives or Medical Powers of Attorney (Health Care Proxies) are not mandated by all transplant programs. However, we encourage recipients to take this initiative to assure that end-of-life issues are known and followed.

◆ *Display Mutual Respect*

- ✓ treat all health care professionals with respect and courtesy.
- ✓ cooperate and follow facility rules regarding patient conduct.

◆ *Meet Financial Obligations*

- ✓ make prompt payment of all financial obligations to the health care team.

The recipient should maintain all existing public and/or private medical insurance for as long as the recipient is eligible for such insurance. If such insurance coverage is lost for any reason, to secure other insurance coverage, if such coverage is available.

- ✓ provide information to the health care team regarding the recipient's public and/or private health care insurance coverage and to apply for public and/or private financial assistance if and when the recipient is eligible for such assistance.

Recipients should take the initiative to obtain advice and help from their health care team when in need of financial assistance.

✓ inform the health care team if they cannot meet their financial obligations.

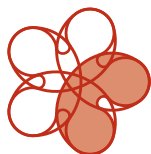
◆ *Recognize Financial Contingencies*

In recognition of the financial contingencies of the current health care system, which may limit access to specific providers and services, recipients and health care professionals must continually work together to maximize access to quality transplantation aftercare services.

Developed by the transAction Council of the National Kidney Foundation in collaboration with the following organizations:

- American Society of Multicultural Health and Transplant Professionals
- American Society of Transplantation
- Council of Nephrology Social Workers
- Council of Nephrology Nurses and Technicians
- Division of Transplantation, Health Resources Services Administration
- International Transplant Nurses Society
- Latino Organization for Liver Awareness
- Minority Organ Tissue Transplant Education Program
- National Donor Family Council of the National Kidney Foundation
- North American Transplant Coordinators Organization
- Society for Transplant Social Workers
- Transplant Recipients International Organization
- United Network for Organ Sharing

Established in 1996, the transAction Council is committed to actively meeting the unique needs and concerns of individuals with all types of organ transplants. The Council is a constituent council of the National Kidney Foundation. Its mission is to ensure a better quality life for transplant recipients and increase the availability of all organs for transplantation.



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