

Adjusting to life after kidney transplant

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Thanks to our speaker!



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Topics

1. The physical challenges patients face after kidney transplant
2. The role of immunosuppressive medications
3. The emotional and psychological aspects of kidney transplant
4. The financial responsibilities kidney patients and their families face after transplant
5. What the 'new normal' looks like for kidney transplant recipients

Physical Challenges

Physical Challenges

- Physical health and functioning before transplant is a strong predictor of physical well-being after transplant
 - Pre-transplant Karnofsky Score

Karnofsky Performance Score

Able to carry on normal activity and to work; no special care needed.	100	Normal; no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

Physical Challenges

- Pain after surgery
 - Tapered to oral medication within 24-48 hours
 - Early mobility key to pain control

Physical Challenges

- Changes in weight
 - Initial weight gain in the hospital from fluids given *during* surgery and *after* surgery
 - Average weight gain post-transplant is 30 lbs
 - Exercise is essential to managing weight gain and associated complications



Role of Immunosuppressive Agents

Post-Transplant Medications

- The role of immunosuppressive agents in life post-transplant
 - What is an immunosuppressive drug and how does it work?
 - Why is it important to adhere to treatment as prescribed?

Post-Transplant Medications

- Main purpose of these drugs is to prevent rejection of the new kidney
 - Our bodies are built to recognize “non-self” entities and attack invaders
 - Usually consists of IV medication at the time of surgery and 2-3 oral medications for the life of the kidney
 - Designed to stop the immune system from attacking the new kidney

Post-Transplant Medications

- Strict adherence to medication schedule is crucial for maintaining the health of the transplanted kidney
 - Rejections are most often “silent”
- This can be challenging for most patients initially
 - Dosing of medications twice daily at strict 12 hour intervals
 - Frequent adjustment of dosage
 - Need for lab draws after medications are adjusted

Post-Transplant Medications

- Possible medication side effects
 - Immunosuppression medications
 - Tremor
 - Hair loss/growth
 - Suppression of cells that help fight infection
 - Metabolic abnormalities
 - Elevated triglycerides/cholesterol
 - Elevated blood sugars
 - Elevated blood pressure
 - Talk to your doctor about any issues you feel or to make adjustments to your treatment



Emotional Aspects

Emotional Aspects

- Underlying mental health disorders (i.e. – anxiety, depression, bipolar disorder)
 - Established care with mental health care professionals is very important
 - Worsening of underlying mood disorders due to transplant medications
 - Close follow-up essential to maintaining stable mental health

Emotional Aspects

- Guilt
 - Associated with both living donor and deceased donor transplants
 - Living donors – guilt associated with asking/accepting organ from family member or friend
 - Deceased donors – dealing with emotional burden of receiving a deceased organ

Emotional Aspects

- Burden of Responsibility
 - Caring for a transplanted organ requires effort
 - Complicated medication regimens
 - Frequent blood draws and follow up visits
 - Complications often happen
 - Kidneys can be slow to wake up and may require short continuation of dialysis after transplant
 - Multiple office visits or hospitalizations
 - Worsening of associated medical conditions
 - Can lead to frustration/depression/anxiety

Emotional Aspects

- Improving emotional health
 - Involve family and friends early in the process
 - Manage expectations
 - Stay in contact with your transplant team (physicians, nurses, coordinators)



Financial Responsibilities

Financial Responsibilities

- ESRD Medicare – 36 month limit (3 years)
 - Medicare will end three years after a successful transplant for recipients under the age of 65
 - Cost of medications is high
 - Careful planning prior to transplant will help in endeavors to return to work or for financial stability if unable to return to work

Financial Responsibilities

- ESRD Social Security Disability
 - Disability status will more than likely be reviewed within a year after a successful transplant
 - May lose eligibility for disability based insurances like Medicaid

Financial Responsibilities

- Lack of transportation
 - Typically due to lack of insurance
 - Loss of coverage for transportation to and from appointments after disability ends
 - Many transplant centers are located a significant distance away from a patient's home
 - Can result in missed lab/clinic follow ups
 - Compromises the health of the patient and survival of the transplanted kidney

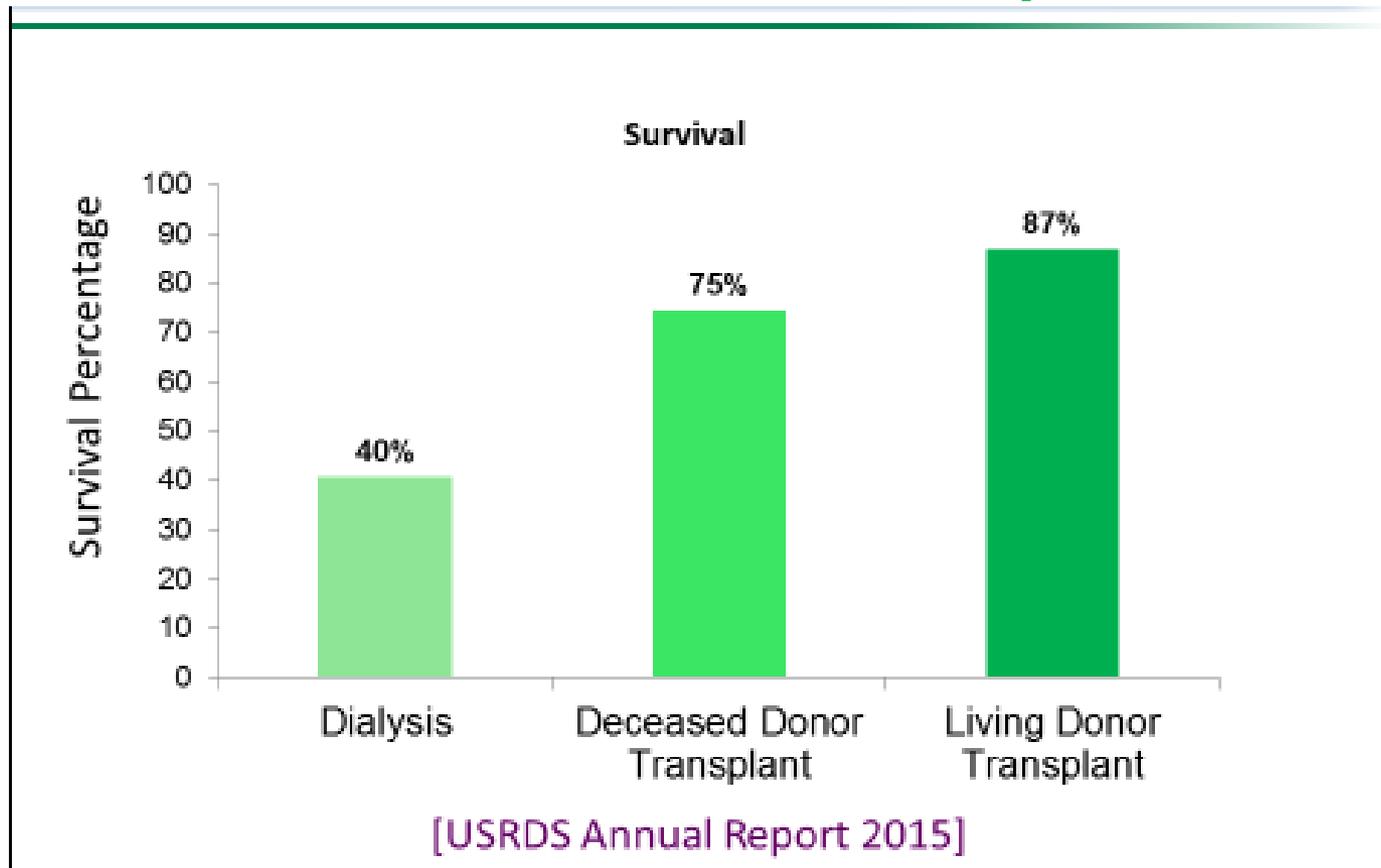
Why Should I Get a Kidney Transplant?

Benefits of Kidney Transplant

- Kidney transplant is the BEST treatment for end stage kidney disease
- 5 year mortality rates for patients on dialysis is 40-60%
- Coming off dialysis improves quality of life significantly for patients and their families

Benefits of Kidney Transplant

Survival Benefits of Renal Transplantation



Benefits of Kidney Transplant

- Improvement in related illnesses and complications that result from end stage kidney disease
 - High blood pressure
 - Anemia
 - Bone disease (no more phosphorus binders!)
 - Diet restrictions

Life After Transplantation: “The New Normal”

The New Normal

- Increased energy levels
- More time with family and friends
 - Travel becomes easier and more feasible
- Ability to return to work
 - May improve feelings of despair, depression associated with chronic dialysis
- Renewed sense of purpose

The New Normal

- Instead of dialysis treatments, focus will be on keeping your new kidney healthy
 - Following medication instructions and attending follow-up visits
- Most complications happen soon after transplant
 - First 6 months > Year 1 > Year 2 > Life of the kidney
 - Complications early on tend to be either infection/rejections
 - Most are reversible if caught early
 - Compliance plays a key role in frequency of complications

The New Normal

- Tips for the best post-transplant outcomes:
 - Use your resources (coordinators, social workers, etc.)
 - Involve family and friends early in the transplant process
 - Manage your expectations
 - Plan ahead
 - Decide who will help organize your medicines
 - Set alarms to remember to take medicines
 - Use pillboxes



Summary

- Kidney transplant is the best treatment for end stage renal disease
- The more educated patients and their families are before transplant, the better survival for both patients and their new kidneys



Summary

- Incorporating healthy diet and exercise into your life prior to transplant will help with both surgical recovery and weight gain after transplant
- The emotional burden of receiving a kidney transplant can be overwhelming but it is still a lifesaving endeavor

Summary

- It is important for patients to identify family members/friends who can help with emotional support after surgery
- Complications will happen! Don't take it personally or feel you have done something wrong

Additional Resources

- Additional information can be found at the following websites:
 - <https://www.pparx.org/>
 - <https://www.pharma.us.novartis.com/our-products/patient-assistance/patient-assistance-foundation-enrollment>
 - <http://www.needymeds.org/>
 - <http://www.rxassist.org/>

Questions?

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