UPNIC LIFE CHANGING MEDICINE

I was referred for Liver Transplant: Now What?!

Proactive Planning Before Transplant

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Choosing a Center

Considerations:

- Insurance coverage
- Distance from center
- Survival statistics
- Costs
- Transplant MELD Scores by UNOS Region



UNOS Region

UPMC Liver Transplant Program

- Established 1981
- Over 5,000 liver transplants performed
- Part of UNOS region 2



The Transplant Process

- Referral
- Fiscal Clearance
- Evaluation
- Presentation at Selection Committee
- Listing
- Call for transplant surgery





Meet the Transplant Team

- Nurse Coordinator
- Hepatologist
- Surgeon
- Pharmacist
- Social Worker
- Transplant Psychiatry/Behavioral Health
- Nutritionist
- Financial Analyst
- Ancillary services determined by specific testing





What to Expect

- <u>Testing, testing and more testing</u>
- Education
- Medical History
- Psycho/Social History
- Insurance/Rx Coverage
- Long days

* Don't be afraid to be honest with your clinicians



Listing Process

- Presented at Selection Committee
- Criteria for transplant
 - Medical
 - Psychosocial
- Blood type, size, MELD





MELD score-<u>Model for End-Stage Liver Disease</u>

- MELD Score evaluates liver and kidney function by measuring 3 blood tests
 - **Bilirubin** causes jaundice/yellow eyes
 - INR measure blood clotting
 - Creatinine measures kidney function
- PELD score for children <12
 - Total bili, INR, albumin, height, weight
- MELD score exceptions



Waitlist Waiting...

• Take Care of Yourself

- Fatigue is common
- Anxiety is common
 - Inactivity increases fatigue
 - Move a little
 - Sleep
 - Keep a positive attitude
 - Keep your mind busy





Taking Care of Yourself

- Nutrition
 - Option to follow with Transplant Nutritionist
 - Eat Healthy
 - Nutritional supplements
 - Low sodium
 - Small amounts of protein
 - Small, frequent meals

*Do not take any supplements or make changes to your diet with out consulting your Physician.



Taking Care of Yourself

- Physical Therapy
- Work v. Disability
- Caregivers
 - Friends
 - Family
 - Church/Community members



*Accept offers for help



Communication in Medical Care

- Communication with the Transplant Team is important
- Authorization to share medical information
- Call your Nurse Coordinator with **any changes** in medical conditions, changes in your insurance, any other questions, concerns.



Preparing for "The Call"

- More than 4 hours from the Center?
 - Will you drive, fly?
- Help
 - Who will watch your kids, your pets? Who will help with home chores (like mail) while you're away?
- Pack:
 - Comfortable Clothes
 - Portable Hobbies
 - Insurance cards and financial information
 - MPOA, Living Will
- False Alarms





Financial: Before and after transplant

- Insurance: Know your coverage!
- Medication coverage
- Fundraising
- Travel/lodging to and from Pittsburgh
- Time off work



Considerations



Psychosocial:

- Family support/caregivers
 - Caregiver burnout
- Transportation
- Substance abuse rehabilitation
- Mental Health treatment
- Motivation for transplant
- Goals post transplant
- Medication regime and costs
 - Pillbox, list in purse/wallet, know name, dose and frequency
- Advanced Directives



Considerations

Medical:

- Multiple Listing
- Living Donor vs. Deceased Donor
 - CDC High risk donors
 - Costs to Living Donor
 - Travel, lodging, lost wages
- Disease Recurrence



Always remember...

- The process is overwhelming for everyone
- Your Transplant Team is here to support YOU.



The only dumb question, is the question not asked!



Thank You





Additional Resources

- UNOS: <u>www.unos.org</u>
- www.transplantliving.org
- Fundraising: <u>www.helphopelive.org</u>
- American Liver Foundation
- Angel Flight: <u>www.angelflight.org</u>
- Transplant Recipients International Org <u>www.trioweb.org</u>

