Timing Matters: The Impact of Early Referral on Transplant Outcomes

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Objectives

- **Recognize the clinical importance of early referral** for transplant evaluation in patients with advanced organ disease.
- **Identify appropriate indications and timing** for transplant referral.
- **Describe the role of the referring provider** in facilitating timely referral and optimizing patients for transplant evaluation.

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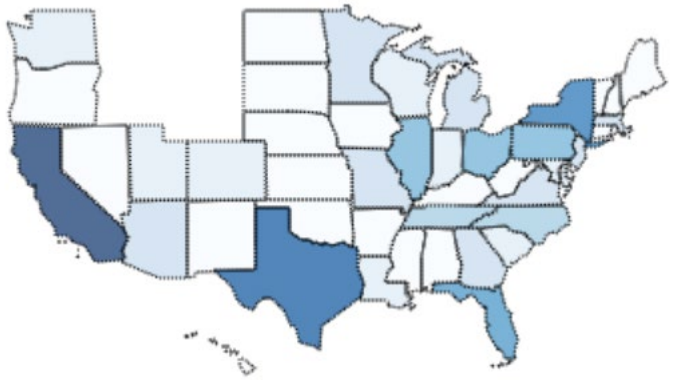
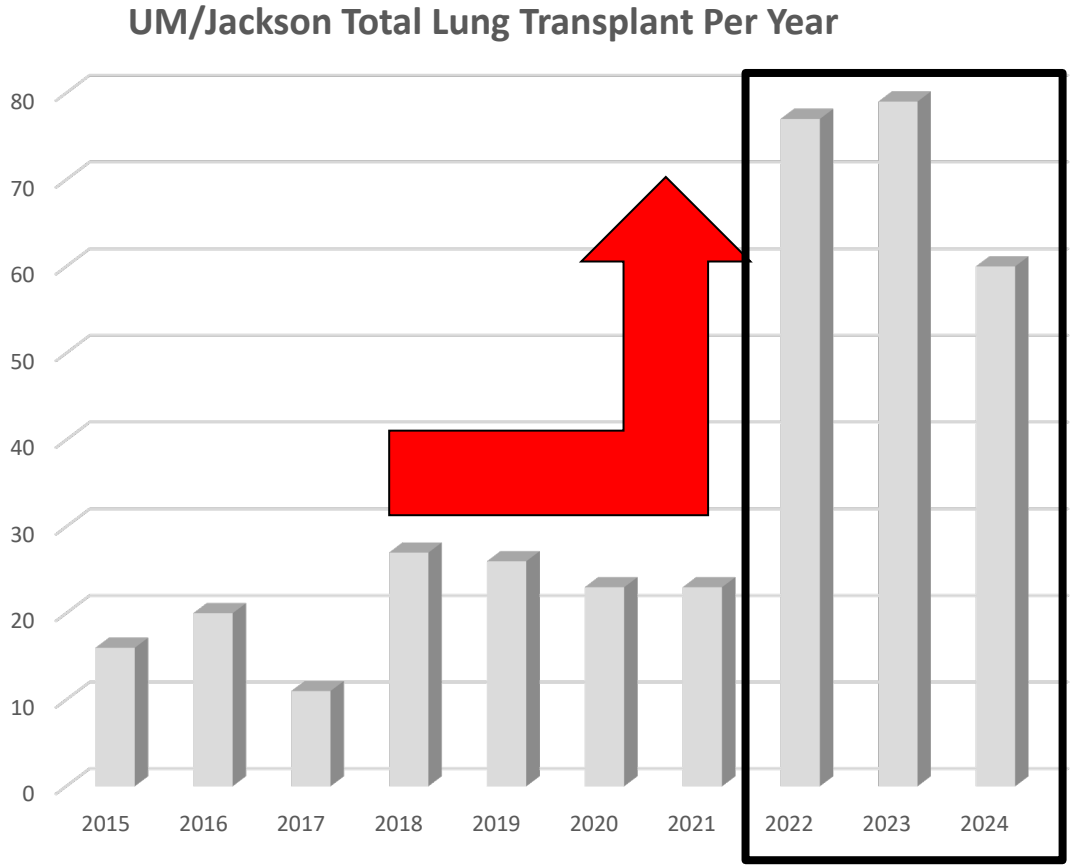
National Metrics in Organ Transplantation

- According to Organ Procurement and Transplantation Network (OPTN), a total of 46,609 transplants were performed in the United States in the year of 2025.



Our Lung Center Growth



SRTR SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS

Lung Transplant 1-Year Graft Survival

	FLJM	U.S.
	52	5,769
January **2023** Release	70.80%	87.71%
	95	6,041
January **2024** Release	90.71%	92.68%
	139	6,427
January **2025** Release	95.47%	93.48%

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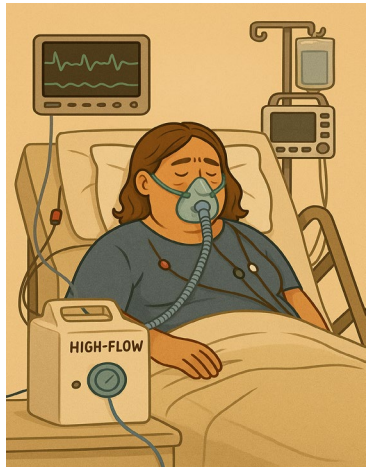
Real life Case Study

58 yrs old F

Early referral can help patients reach the finish line- TRANSPLANT

Mid 2023	11/2023	06/03/2024	06/06/2024	08/05/2024	08/13/2024	09/2024
ILD diagnosis, CTD + ANA and Ds DNA and high inf markers	Hospitalized due to Covid 19 pneumonia, discharged on O2	Referred for transplant	First visit, on 2-3 liters of O2, decondition, using wheelchair Eval on hold, high BMI (33) and fragility	No rehab progress Still on wheelchair, BMI 31	Increase of O2 requirements, now on 8 L. Pt still didn't meet criteria Deconditioned and BMI 33. Admitted to ICU x optimization	**Patient Expired** **Multi-organ failure**



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Benefits of Early Referral for Transplant Evaluation

- **Improves quality of life**
- **Maximizes graft survival and long-term outcomes**
- **Reduces morbidity and mortality**
- **Prevents irreversible organ damage and complications**
- **Preserves transplant candidacy and expands treatment options**
- **Allows optimization of modifiable risk factors**
  - Obesity and nutritional status
  - Frailty and functional capacity
  - Psychosocial readiness and social support

Barrier to Transplant Access

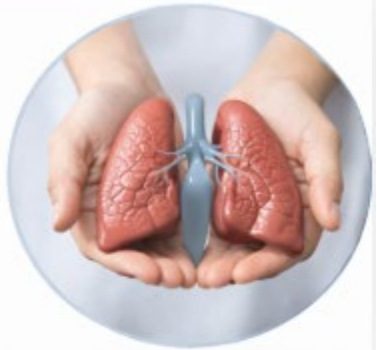
- Late referral for transplant evaluation
- Limited education about transplant as a treatment option
  - ❖ Contributing factors include:
    - ❑ Difficulty identifying transplant candidates, especially by providers not managing advanced ILD regularly.
    - ❑ Lack of awareness of referral guidelines
    - ❑ Possible unawareness of local transplant centers or how to initiate referrals.
- Progression of comorbidities
- Psychosocial barriers
- Limited access to specialty care
- System level barriers

Ideal Candidate?

Is the Patient with:

- Chronic Organ Disease
- Good Rehabilitation Potential
- Supported by Family

Early recognition and timely referral for comprehensive transplant evaluation are **essential** to **optimize candidacy** and overall transplant readiness in patients with **advanced organ disease.**



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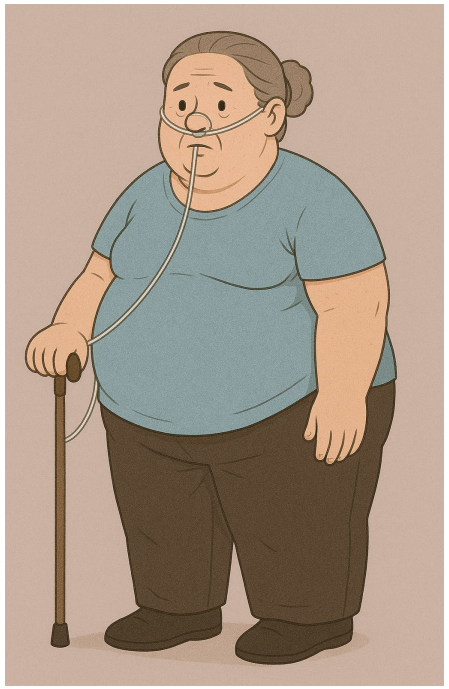
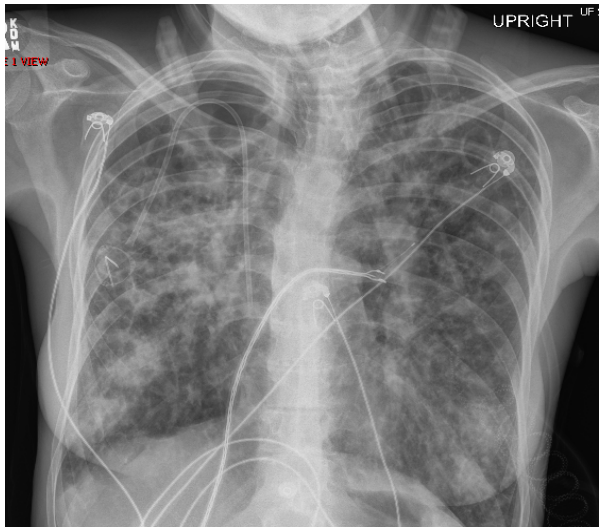
Case Presentation:
When to Refer for Lung Transplant Evaluation

- 58 year old female
- **PMH:** COPD
- **Current status:**
  - Progressive dyspnea limiting daily activities despite optimal medication regimen and pulmonary rehabilitation
  - Declining pulmonary function tests (FEV1 worsening over 12 months)
  - Now need Oxygen for activities
  - Multiple hospitalizations for acute exacerbations
- **Clinical concern:** Progressive disease with declining functional status and poor prognosis
- **Next: Refer for lung transplant evaluation**



Advanced Lung Diseases That May Progress to Require Lung Transplant



Common Conditions:

- Pulmonary Fibrosis
- ILD
- Cystic Fibrosis
- Pulmonary Hypertension
- COPD
- Sarcoidosis

Challenges:

- Unpredictable progression (DOE, O2)
- Frequent exacerbations, requiring frequent hospitalizations
- Decline of pulmonary lung function
- Limited treatment options
- Growing comorbidities: PAH, RHF
- High morbidity & mortality
- Substantial healthcare burden

Timing for Lung Transplant Evaluation Referral

ILD/PF

- **At the time of ILD/PF diagnosis**
- Histopathological or radiographic changes, irrespective of stable lung function
- Any dyspnea or functional limitation attributed to advance lung disease
- Any oxygen requirement (at rest or exertion)
- Any exacerbation or evidence of Pulmonary Hypertension

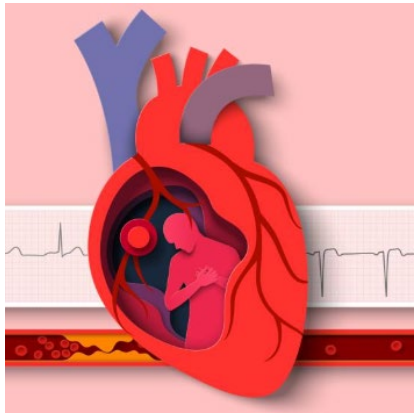
COPD

- Any dyspnea or functional limitation attributed to lung disease
- Any oxygen requirement (at rest or exertion)
- Any history of exacerbation or hospital admission
- Decreased quality of life due to lung disease
- Chronic hypercapnia or evidence of pulmonary hypertension

Role of Referring Providers (Primary Care/ Pulmonologist)

- **Early referral at diagnosis when indicated** (e.g., ILD/IPF, CF), **despite initiation of therapy**, due to unpredictable disease course
- **Ongoing surveillance for progression**: declining PFTs, escalating oxygen needs, recurrent exacerbations/hospitalizations
- **Optimize disease-specific medical therapy**
- **Refer to pulmonary rehabilitation** to improve functional status
- **Optimize nutritional status** (underweight or overweight)
- **Provide patient education and counseling**
- **Ensure appropriate vaccination**, including completion of multi-dose series

Case Presentation:
When to Refer for Heart Transplant Evaluation

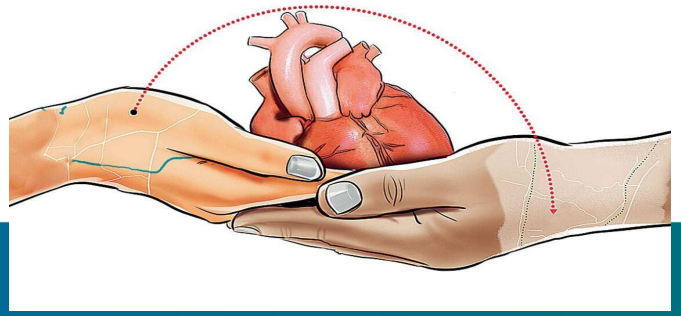


- 60 year old female
- **PMH:** Advanced Cardiomyopathy
- **Current status:**
  - Worsening heart failure symptoms despite treatment
  - Low Ejection fraction < 35 %
  - Two hospitalizations for decompensated heart failure in the past 6 months
  - Worsening renal function and hypotension limiting medication optimization
- **Clinical concern:** Progressing heart failure with poor prognosis and declining end-organ function
- **Next: Refer for heart transplant evaluation**

Advanced Heart Diseases That May Progress to Require Transplant

Common Conditions:

- Advanced cardiomyopathies
- Advanced HFrEF
- Inotrope-dependent heart failure (IV)
- Refractory ventricular arrhythmias (ICD)
- Adult congenital heart disease
- Progressive/ Irreversible right heart failure



Challenges:

- Persistent symptoms leading to poor quality of life: dyspnea and fatigue
- Recurrent hospitalizations (frequent exacerbation)
- Hypotension and end organ hypo-perfusion due to low cardiac output
- Progressive kidney and liver dysfunction
- Life threating arrhythmias
- Fragility and Malnutrition

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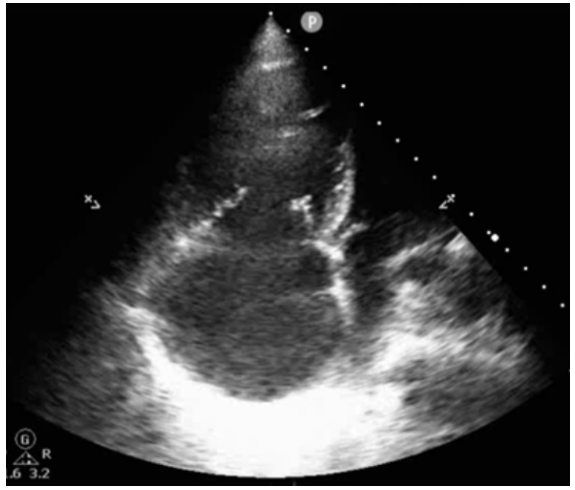
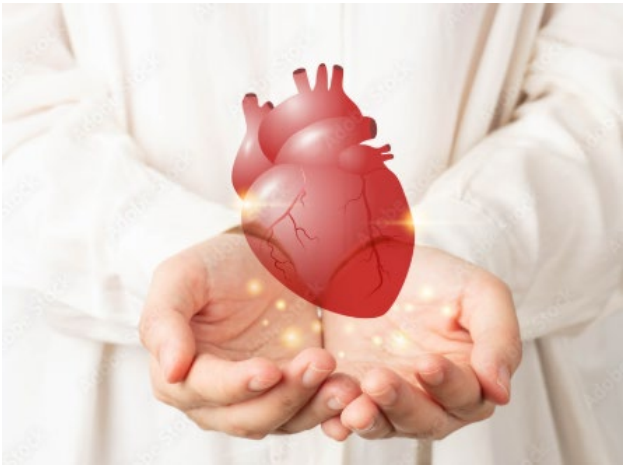
Timing for Heart Transplant Evaluation Referral

- **Advanced heart failure** despite optimal medical and device therapy
- **Persistent severe symptoms** with poor functional capacity
- **Recurrent heart failure hospitalizations** (≥2 in 12 months)
- **Inotrope dependence or low cardiac output** with hypotension or hypo-perfusion
- **Progressive end-organ dysfunction** (renal or hepatic) due to heart failure
- **Life-threatening ventricular arrhythmias** despite ICD or ablation
- **Advanced cardiomyopathy or congenital heart disease** with no further surgical options



Role of Referring Providers (Primary Care/ Cardiologist)

- **Recognize progression** of the disease and refer before irreversible kidney, liver or fragility decline
- **Optimize and reassess** guidelines to slow progression and deterioration
- **Monitor for red flags** (recurrent admissions, increase need of diuretics, cachexia, worsening kidney or liver function)
- **Prevent and manage comorbidity related barriers** (poor glycemic control, obesity, anemia)
- **Manage arrhythmias and cardiac devices** proactively to reduce sudden death risk factors.
- **Educate patients and coordinate with transplant centers** to avoid delays and improve reediness.



Case Presentation:
When to Refer for Liver Transplant Evaluation

- 60 year old male
- **PMH:** Decompensated cirrhosis secondary to metabolic associated steatosis liver disease (MASLD)
- **Current status:**
  - Clinically declining despite optimal use of diuretics, lactulose, beta blockers, etc.
  - Recurrent ascites requiring frequent paracentesis
  - Episodes of hepatic encephalopathy affecting daily function
  - Prior hospitalization for variceal bleeding
  - Worsening kidney function
- **Clinical concern:** Ongoing decompensation with declining liver and renal function
- **Next: Refer for liver transplant evaluation**

Advanced Liver Diseases That May Progress to Require Transplant

Common Conditions

- Decompensated cirrhosis: Ascites, variceal bleeding, encephalopathy
- Metabolic steatosis liver disease: Progressive cirrhosis
- Acute Liver Failure
- Alcohol associated hepatitis not responsive to corticosteroids
- Chronic viral hepatitis (B or C)
- Autoimmune Hepatitis: Progression to cirrhosis/Liver failure

Challenges

- Frequent hospitalization associated with disease complications
- Intractable Ascites – frequent paracentesis, infections, and high risk for bleeding
- Encephalopathies and Cardiopulmonary complications
- Progressive Jaundice and Coagulopathies
- Developments of Hepato-renal syndrome
- Malnutrition and Sarcopenia

Timing for Liver Transplant Evaluation Referral

- Patients with cirrhosis should be referred for transplantation when they develop evidence of worsening hepatic dysfunction despite medical interventions or when they experience their first major complication (ascites, variceal bleeding, or hepatic encephalopathy)
- Decompensated cirrhosis of any etiology
- Hepato-renal syndrome: Rapid renal deterioration → urgent referral
- Progressive decline despite maximal medical therapy

Role of Referring Providers (Primary Care/ GI/ Hepatologist)

- **Identify and stage liver disease early** to guide prognosis and timely specialty referral.
- **Slow disease progression** through optimized, disease specific medical therapy and monitoring.
- **Prevent and manage decompensation** including ascites, variceal bleeding, encephalopathy, and infections.
- **Monitor for transplant referral triggers** such as first decompensation, rising scores, or renal decline.
- **Maintain transplant eligibility** by optimizing nutrition, managing comorbidities, and addressing frailty.
- **Support adherence and psychosocial stability** through patient education, abstinence support, and caregiver engagement.
- **Coordinate multidisciplinary care** to ensure timely referral and transplant evaluation when needed.

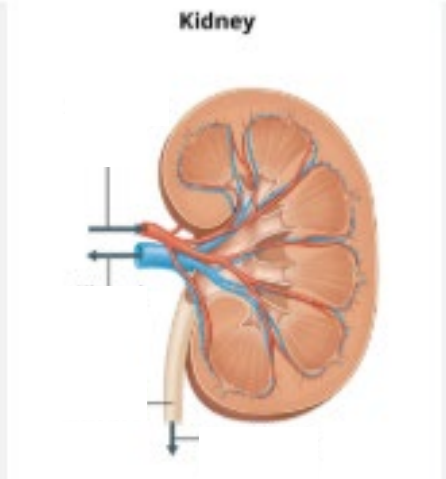
Case Presentation:
When to Refer for Kidney Transplant Evaluation

- 61 year old female
- **PMH:** Chronic kidney disease due to long-standing diabetes and hypertension
- **Current status:**
  - F/u by nephrologist for blood pressure and diabetes management
  - Estimated GFR 18 mL/min (CKD stage 4–5)
  - Progressive fatigue, nausea, and volume overload
  - Worsening anemia and electrolyte abnormalities
  - Preparing for dialysis but not yet initiated
- **Clinical concern:** Progressive end stage kidney disease with declining renal function
- **Next: Refer for kidney transplant evaluation**

Advanced Kidney Diseases That May Progress to Require Transplant

Common Conditions:

- Diabetic Nephropathy (type 1 & 2)
- CKD GFR 20 % or less
- ESRD on Renal Therapy
- Polycystic Kidney disease
- Lupus Nephritis
- Chronic Interstitial Nephritis

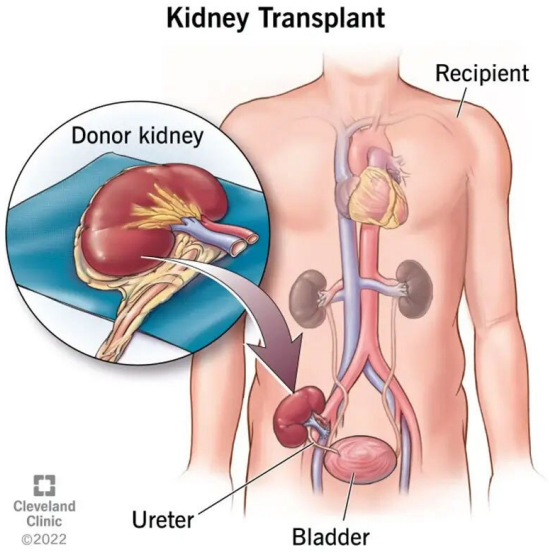


Challenges

- Progressive Uremic Symptoms (fatigue, pruritus, cognitive decline)
- Cardiovascular Complications (HF, HTN, and Acidosis)
- Anemia and mineral bone disorders
- Multiple hospitalizations
- Malnutrition, Sarcopenia and Fragility
- Reduce quality of life,

Timing for Kidney Transplant Evaluation Referral

- Progressive, irreversible kidney failure
- Expected need for dialysis within 6-12 months
- Decline of GFR despite optimized medical therapy
- High risk for ESRD progression based on disease trajectory
- Dialysis related complications such as vascular access failure, hypotension, poor dialysis tolerance
- Poor quality of life due to dialysis dependency (HD or peritoneal dialysis)



Role of Referring Providers (Primary Care/ Nephrologist)

- Identify CKD stage 4 patients early
- Monitor GFR trends, proteinuria and complications
- Educate patients on transplant as a treatment options not a last resort
- Initiate referral before dialysis dependency
- Initiate optimization prior to the need for immediate evaluation and transplant.

Case Presentation:
When to Refer for Pancreas Transplant Evaluation

- 42 year old female
- **PMH:** Type 1 diabetes mellitus since childhood
- **Current status:**
  - Recurrent severe hypoglycemia with loss of awareness
  - Multiple emergency visits for hypoglycemic events
  - Wide glucose variability despite insulin pump and continuous glucose monitoring
- **Clinical concern:** Brittle diabetes with life-threatening hypoglycemia and impaired quality of life
- **Next: Refer for pancreas transplant evaluation**

Advanced Pancreas Diseases That May Progress to Require Transplant

Common Conditions:

- Type 1 diabetes mellitus
- Diabetes with kidney failure
- Cystic fibrosis related diabetes
- Metabolic Complications leading to frequent hyper or hypoglycemia, DKA
- Other DM complications

Challenges:

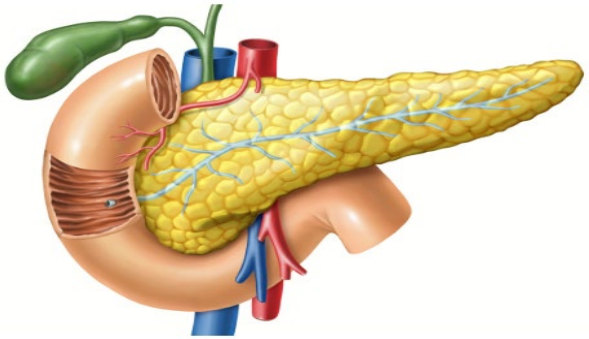
- Severe glycemic instability
- Hypoglycemia unawareness
- Malnutrition and weight loss
- High treatment burden
- Psychosocial stress

Timing for Pancreas Transplant Evaluation Referral

- Frequent acute and severe Metabolic Complications leading to frequent hyper or hypoglycemia, DKA
- Progressive diabetic complications
- Poor quality of life
- End-organ damage

Role of Referring Providers
(Primary Care/Endocrinologist)

- **Identify patients with severe or unstable diabetes**
- **Optimize diabetes treatment** (insulin, pump, continue glucose monitor)
- **Watch for referral triggers** (recurrent severe hypoglycemia, poor control)
- **Monitor kidney function** to guide transplant type
- **Manage other medical conditions** affecting transplant eligibility
- **Educate patients** about transplant as a treatment option



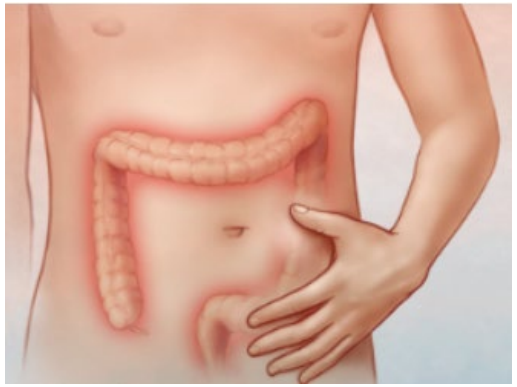
Case Presentation:
When to Refer for Intestinal Transplant Evaluation

- 52 year old male
- **PMH:** Short bowel syndrome after multiple abdominal surgeries for mesenteric ischemia
- **Current status:**
  - Dependent on long-term parenteral nutrition (PN) for >3 years
  - Recurrent central line infections (≥2 episodes of sepsis in the past year)
  - Progressive cholestasis and rising bilirubin consistent with PN-associated liver disease
  - Frequent hospitalizations for dehydration and electrolyte imbalance
- **Clinical concern:** Failure of intestinal rehabilitation with worsening liver function and limited venous access
- **Next: Refer to intestinal transplant center for evaluation** (consider intestine ± liver transplant)

Intestinal Diseases That May Progress to Require Transplant

Common Conditions:

- Crohn's
- Trauma, or tumors
- Short Bowel Syndrome
- Intestinal failure
- Patient on TNP with life threatening complications related to TPN: infections, liver disease, fluid and electrolytes imbalances

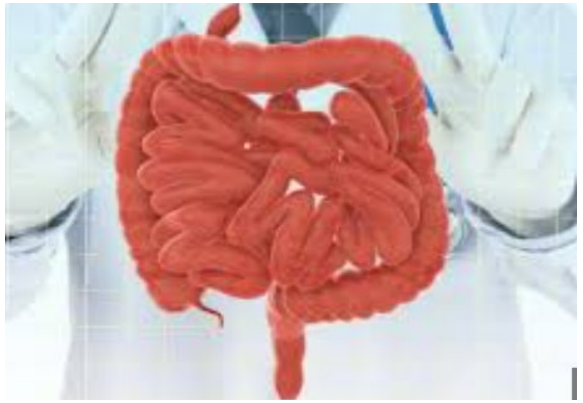


Challenges:

- Frequent infections and long term dependence of parental nutrition
- Recurrent catheter-related bloodstream infections
- Dehydration from chronic diarrhea or fluid losses is life-threatening or extreme
- Malnutrition and high hospitalization burden

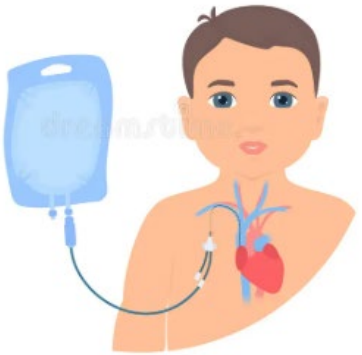
Timing for Intestinal Transplant Evaluation Referral

- **Progressive organ dysfunction** - Liver, kidney, or cardiopulmonary complications
- **Failure of intestinal rehabilitation** - Unable to maintain nutrition or hydration
- **Long-term parenteral nutrition with complications** - Liver dysfunction, recurrent line infections, loss of central venous access
- **Recurrent severe dehydration or electrolyte imbalance** despite optimal therapy
- **Progressive liver disease** related to intestinal failure or PN
- **Severe malnutrition or growth failure**
- **Frequent hospitalizations** related to intestinal failure
- **Irreversible intestinal disease** with no surgical or medical alternatives



Role of Referring Providers (Primary Care/ Gastroenterologist)

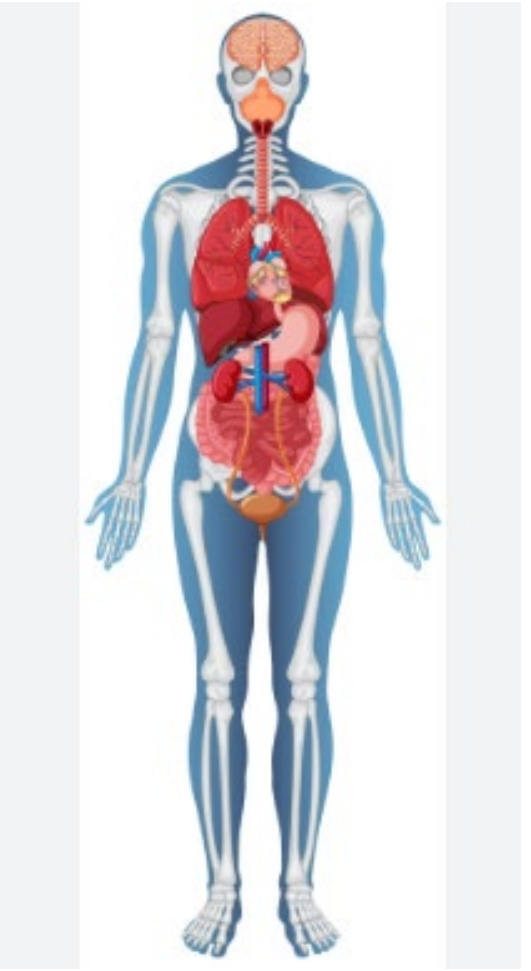
- **Optimize intestinal rehabilitation** (nutrition support, anti-motility agents, acid suppression, surgical options).
- **Manage and monitor parenteral nutrition (PN)** to maintain hydration, nutrition, and metabolic stability.
- **Monitor for transplant referral triggers -** PN associated liver disease, recurrent catheter-related infections, loss of central venous access
- **Recurrent dehydration or electrolyte imbalance**
- **Prevent and treat complications** of intestinal failure (malnutrition, micronutrient deficiencies, infections).



Transplant Evaluation Overview

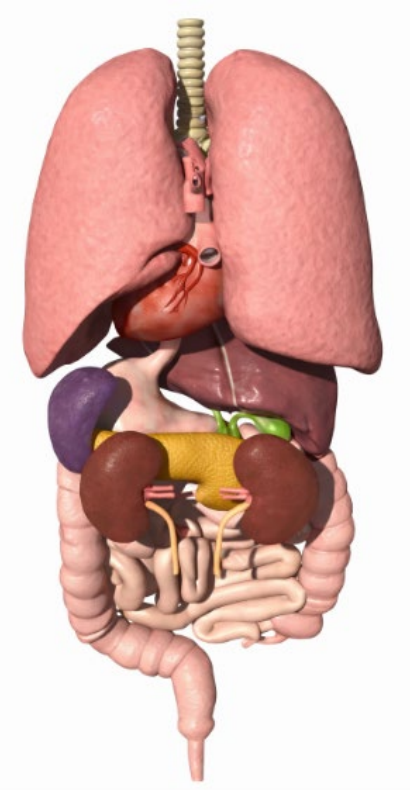
Comprehensive assessment includes:

- Organ disease severity and anatomical findings
- Nutritional status and degree of frailty
- Comorbidities and overall functional status
- Psychosocial support and health related behaviors
- Immunization history and vaccine needs



An Early Referral is Always the BEST Strategy to Facilitate Access to Transplantation

Preemptive Referral - Refer before the patient reaches End Stage Organ Failure and develops irreversible complications



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Thank you!

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