

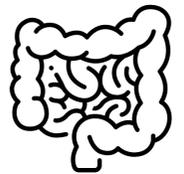
Adult Intestinal Transplant First Appointment Checklist and Questions

The first appointment with your intestinal transplant team may feel overwhelming. This guide provides a starting point of information to share with the care team and questions you may want to ask the team during the appointment.

Information To Tell The Care Team

Cause

- Tell the care team the cause of the short bowel syndrome or intestinal failure, if your child has already been diagnosed.
- If your child has not been diagnosed, provide a reason for referral to the care team.



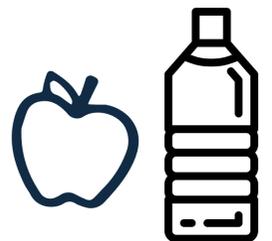
Medical History

- Provide the care team with a detailed review of surgical procedures and any related complications.
- Review of hospitalizations, including the reason for the stay, how long, what was done, and where it was.
- When you started noticing signs and symptoms of your gastrointestinal condition.
- History of your weight.
- Immunization record.
- Any medications you have been given.
- Known allergies, including medication, food, and environmental.



Hydration and Nutrition

- Hydration and nutritional needs.
- If you are on parenteral nutrition (PN), intravenous (IV) hydration, or enteral nutrition (tube feeds).
- Do you eat anything by mouth?



Bowel and Liver Function

- Questions related to bowel function: Diarrhea, nausea, recurrent vomiting, bloating, appetite, heartburn
- Questions related to malabsorption: Diarrhea, weight-loss, fatigue
- Signs of liver dysfunction- yellowing of the skin (jaundice) or fluid in the abdomen (ascites)



Central Lines

- The number of central lines you have had and the type of each line (i.e Hickman®, Broviac®, Port-a-Cath, Single or Double Lumen).
- Reasons why your central line was changed (i.e. blood clot, infection)
- If there was an infection, the type of organism caused the infection (fungus, bacteria).
 - Indicate if a hospitalization, IV antibiotics, mechanical ventilation, were needed.
- Your current central line (i.e Hickman®, Broviac®, Port-a-Cath, Single or Double Lumen).



Questions to Ask The Care Team

What are my choices other than transplant?

What are the risks and benefits of transplant?

What does the evaluation process include?

How long do most patients with my blood and organ type wait at this center for an intestinal transplant?

How long has this center been doing intestinal transplant?

How many intestinal transplants does this center perform each year?

Questions to Ask The Care Team

- Am I allowed to be listed at more than one transplant center (e.g. multiple listing)?

- What are the organ and patient survival rates for intestinal transplant at this center and how does that compare with the survival rates of the rest of the country?

- Do we have to relocate to the area before my transplant while on the waitlist?

- How long will we have to stay in the hospital and the area after my transplant?

- What are the costs I should expect associated with transplant and what financial assistance is offered?

- What are the expected outcomes of my transplant? (i.e. wean from PN, tube feeds, eat orally)

Your Questions to Ask The Care Team

Additional Notes or Questions:



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