

# Family Education Sheet:

## Family Guidelines for Transition and Transfer at the Liver, Intestine & Multivisceral Transplant Program



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This family education sheet explains the steps that will happen as your family participates in the different steps of transferring to adult care. It also explains some common terms you're likely to hear.

The Liver, Intestine and Multivisceral Transplant Team at Boston Children's Hospital is committed to providing family-centered and high-quality care throughout your entire transplant experience. Supporting you so you're prepared to move to an adult transplant center is part of that commitment.

### Key terms

- **Transition:** Transition is a process that helps you build skills and confidence so you're ready to be in charge of your own transplant care when you're an adult. This process can start when someone is as young as 12 years old. By starting early, we hope to give you and your family the tools you need to prepare for these changes, including ways to practice skills to build confidence.

Important transition skills include:

- Learning more about your transplant history and current health
- Practicing important tasks in managing your transplant care
- **Transfer of Care:** Transfer is the act of moving your transplant medical and surgical team to an adult transplant center. At age 18, you're a legal adult and you'll start to make your own medical decisions.

When the time is right, our team will connect you to an adult transplant center. Most young adults transfer to an adult transplant center between age 18–22. Once you're connected to an adult transplant center, you'll be expected to manage your own care and engage with your new transplant team.

### What are the steps of transition?

It's important for families and the transplant team to work together and talk about an eventual transfer of care during your clinic visits. Below are some examples of important steps.

#### Step 1: Actively participate in your care

When you're about 12 years old, we may begin speaking with you privately during clinic visits. We'll help you practice doing all of the tasks needed to take care of your transplant medical care.

We'll start to talk about ways to prepare for your transfer to an adult transplant center. This may mean helping you

learn more about your medications and health insurance. It might also mean talking about your mental health or sexual health.

- Here are some examples of questions we'll start to ask you:
  - Do you know why you had a transplant?
  - Do you know what your transplanted organ does for your body?
  - Do you know what organ rejection is?
  - Do you know the names of your medications and what they do?
  - Do you know the doses of your medications?
  - Do you fill your own pillbox?
  - Do you take medications correctly and on your own?
  - Do you know how to call for refills and make medical appointments?
  - Do you know how to contact your medical team?

#### Step 2: Learn what happens at age 18

By law, you're an adult at age 18 and you make your own medical decisions.

This means:

- You'll sign medical consent forms that give your permission for medical treatments and procedures.
- We need your written permission to speak with your parents or other caregivers about your health after you turn 18. To give this kind of permission, you need to complete a release of information form and send it to our Medical Records Department.
- Some young adults have conditions that prevent them from fully understanding their healthcare needs. In these situations, we can help your family think about official legal options for medical decision-making support before your 18th birthday.
- Here are some examples of questions we may start asking you when you turn 18:
  - Have you filled out a healthcare proxy form and other forms for people 18 and older at the hospital?
  - Do you know what legal guardianship is and if this is something your family should learn more about?

### Step 3: Transfer of care

When you're 18–22 years old, you'll transfer all of your transplant care from Boston Children's Hospital to an adult transplant center at a different hospital. This means that all of your transplant questions, medications, blood work, and appointments will be managed by an adult transplant team.

It's important to work with your Boston Children's transplant team and your health insurance company to find the best adult transplant center options for you. Once you've found the right transplant center for you, we can help you with the different steps.

Here are some examples of questions we might ask you:

- Do you know how to request your own medical records?
- Do you know how to call your health insurance company to ask questions?
- Do you know who the primary cardholder is on your health insurance?
- Do you have an adult primary care physician?

We hope these guidelines are helpful for your family. Please call us (617) 355-4837 if you have any questions.