

TRANSITION TO ADULTHOOD

A common question from teenage patients and their families is “How long will I keep coming to this clinic?” As a pediatric team, we know that all of our patients will someday reach a point where they will be transferred to an adult-based clinic. However, we also know that readiness for this transfer and readiness to be an independent adult are not skills that come overnight. That is why we work hard to ensure that the process of transition – one that prepares you for that switch – is effective for our patients. Developing into adolescents and then into young adults takes children through a time in life that involves many changes. Even for those without a chronic medical issue such as a liver transplant, the path from childhood to adulthood is a challenging one. Late teenagers and young adults are at increased risk for injuries and serious health-related problems due to many different causes, and studies have shown that if they are also dealing with a chronic health problem such as liver disease or a transplant, the risk for poor control of that disease goes up as well. Our goal is to guide you through a transition process that decreases the risk of complications related to your transplant and increases the chances of you being successful once you ultimately transfer your care to an adult-based clinic.

What is “Transition”?

It is a word used to describe the process that takes you from being a child – whose parents do everything for them – to a young adult who is responsible for managing all aspects of their life, including medical needs. Transition is a process that occurs over many years, while transfer is the actual switch to a new clinic.

When Does it Begin?

There is no hard and fast starting point that works for everyone. In general, we start discussing transition-related issues at clinic appointments when you are around 10-12 years old. However, some patients are interested earlier while some may need more prompting later on.

Whether you received your transplant as a baby or as a teenager, our goal for the transition process is still the same – to ensure that you have the knowledge and skills you will need to be an independent adult when the time comes. The exact process is different for each individual patient.

If we do not talk about something you are interested in at your appointment, please ask! We start talking about these issues long before transfer so that you do not have to learn and master so many new things all at once later on.

When is it Over?

The transition process is different for every patient. However, we usually plan to keep seeing patients in this pediatric liver transplant clinic until they are in their early 20s. This is so you are not having to get to know a new doctor or clinic at the same time you are graduating high school, moving out of home and starting college or a job. Many patients who start going to the adult clinic in their 20s do better than those who transfer earlier. There might be reasons why some patients are transferred earlier, but just like you do not automatically become an independent adult at 18, we do not automatically send you to a new clinic when you turn 18.

What Will be Different About Your Appointments?

While we will always want to discuss how you are doing right then at clinic appointments, once you are 10-12 years old, we will also start spending more time talking about long-term issues related to transition. You will not be expected to develop all of these things right away. Rather, responsibility for them should be gradually shifted from your parents, to being shared between you and your parents, to eventually all your own.

We may occasionally ask to speak with you alone, without your parents in the room. This is not because we are worried about you or because you are in trouble. We do it because learning to discuss certain issues independently is an important part of someday being able to manage them independently.

What Kinds of Things Will We Talk About?

- Being able to describe what a liver transplant is.
- Knowing why you had a liver transplant.
- Knowing the names and doses of all of your medications, as well as why you are taking each one and potential side effects.
- Knowing which labs are important and why for monitoring the health of your transplant and your safety while on your medications.

Information about many of these points is discussed in other sections of this book.

What other types of things will we work to prepare you to be able to do? (Not all at once!)

- Helping remember when it is time to take your medicines. Think about setting an alarm on your watch or cell phone to help with this.
- Calling for your own refills – it is important to remember to do this well before you run out.
- Organizing your medications, like in a pillbox every week.
- Remembering when it is time to get labs drawn.
- Scheduling clinic appointments and remembering when they are scheduled.
- Knowing how your medical care and medicines get paid for – when you will need to get your own health insurance, where you will get insurance from, and what steps you will take to ensure you remain covered. Our social workers are available to help you with insurance-related issues.
- Call the office yourself with questions or concerns that need to be brought up in between appointments.
- Discuss issues yourself with your doctor during the appointment rather than always relying on your parents.
- Coming to each appointment with questions to ask the medical team about anything related to your care. This is important to get you engaged and thinking about your transplant and what we are doing to care for it. You can write down questions that come up before an appointment to help you remember them.

How Will We Help You Work on All of These Things?

Your transplant team will pick a few things to work on at each visit. We will discuss these with you, answer any questions you may have about them, and provide suggestions for how to work on them between then and your next appointment.

It is important to know that you will not be expected to master all of the issues in the previous two sections right away. Just as an 18 year-old who has not assumed responsibility for any of the above issues would be concerning, so too would be a 10 year-old who is unsupervised in managing his care. Remember, transition is a process that does and should take years!

You and a parent may be asked to fill out a survey when you come to clinic that asks about different things related to the transition process. These surveys help us identify areas in which you are strong and areas where we need to work to help you improve. We are always working with these surveys to make sure they, and the time we spend with you in clinic, are helpful and set you up to do well long into the future.

Just like it is important for the transplant team to prepare to see patients before we actually walk into the exam room, a successful transition process can only happen if you spend time preparing outside of clinic appointments. Schoolwork is always the most important, but you should try to spend time between appointments learning about your medicines, labs, other transplant-related issues, and thinking of questions to ask when you come to clinic.

What if you still have questions about transition, growing up with a liver transplant, or how much you should be doing for your own care?

Please ask! Talk with your parents, call us here at the office, have your parents call, or write down your questions to discuss when you are here for an appointment.

What Happens When it is Actually Time to Transfer?

For almost all patients, the timing of transfer is not a surprise. You will know ahead of time when your final appointment with us will be.

After your last appointment in the pediatric liver transplant clinic, the transplant nurse coordinator will work with the adult transplant clinic to schedule your transfer appointment. You will be notified when the appointment is scheduled. Until you are seen by the adult transplant provider, you will continue to be followed by the pediatric transplant clinic.

In rare cases – due to things such as family location, job, or college – some of our patients may wish to transfer their care to an adult clinic closer to home. We will work with you to arrange this if it is the best thing for you, but we may not have as much information about clinics or doctors outside of University of Michigan Health.