

Moving from Pediatric to Adult Care

Introduction

Teen and young adult years are a critical time for major life changes. An important adjustment for youth who have OI is moving from pediatric care into the adult care system. Children's hospitals tend to have a multidisciplinary team who understand OI. The adult system is much less organized. The young person will need to find a new team of doctors, take responsibility for communicating with them, and prepare for emergencies.

Planning

Transition into the adult care system usually happens between ages 18-21, but planning for it should begin much earlier. Here is a list of some of the skills, knowledge and habits that young people need to acquire.

- The ability to communicate confidently with doctors and other health care providers.
 - Make and keep appointments and arrive at appointments prepared to ask and answer questions.
 - Take responsibility for renewing prescriptions.
- Knowledge of OI and their personal OI history. ○ The OIF worksheet "**Know Your OI: A Basic Health History**" is a place to start.
- Find an adult primary care doctor and an adult orthopedist before one is needed.
 - Pediatricians and pediatric specialist may be able to make referrals.
 - In many cases the OIF can help locate doctors with OI experience.
- Develop healthy habits that promote general health and minimize OI complications. These include regular exercise, not smoking, a healthy diet and avoiding illness. The OIF fact sheet "**Take Charge of Your Health**" offers a summary.
- Be prepared for OI related injuries and other health emergencies
 - Carry a state photo ID, insurance card(s), medication list, allergy list and a health problem list.
 - Consider medical alert options and cell phone apps.
- Understand your health insurance. Know what is covered and how to make a claim.
- Youth who are working, traveling or going to school away from home have additional needs.
 - College students need to understand the Healthcare Services provided by their school and how to access them.
 - Anyone living temporarily away from home will need to find a local doctor; learn about the local hospitals and have an emergency plan.
 - People who are not married need to provide permission in writing for parents or another trusted person to have access to their medical information.

Many pediatricians and children's hospitals offer formal Transition Programs that include all of the skills mentioned above and workshops on independent living skills, education/vocational options, dating and relationships and understanding health insurance options. These programs can be very helpful.

Resources from the OI Foundation

- OI Foundation Information Center and Youth Leadership Council
- Send questions to the OIF office via phone or email
- See the series of fact sheets under the Materials for Adults with OI tab on the OIF website

Resources from Nemours AI duPont Hospital for Children -- A YouTube Video Series

Videos cover topics related to transitioning such as self-advocacy, independent living, vocational rehabilitation, and other community-based resources. Search "Nemours Becoming an Adult" on YouTube for a list.