

Research Article Summary Transition from Adolescent to Adult Medical Care

Transition of Care

Transition is the term used in medical literature to describe the process of moving a person who has a chronic/life-long condition from pediatric care into the adult health care system. For people living with OI and other conditions that begin in childhood and last a life-time, transition is often complex, time consuming and very important. In their article *Osteogenesis imperfecta: Effecting the transition from adolescent to adult medical care*, Dr. Shapiro and Dr. Germain-Lee draw on their years of experience. Both authors who are from the Kennedy Krieger Institute in Baltimore, MD are experienced in the care of people who have OI. Dr. Shapiro is a member of the OI Foundation's MAC. This thought provoking article is important for parents to read no matter how young their children are, and for parents of teens to read and discuss with their young person.

This article presents a set of guidelines for pediatricians, physicians who care of adults, young people who have OI and their families. They present OI as a complex disorder that during the young adult years involves not only unpredictable instances of broken bones, but also the emergence of other health issues such as hearing-loss or heart valve disease. Their guidelines point out the importance of four sets of topics.

- Maintaining health
- Preserving or improving function
- Continuity of medical and surgical care
- Psychosocial support

The authors stress the importance of staying informed about the medical aspects of managing OI especially the symptoms that emerge during late adolescence. Beginning well before age 18, they encourage addressing the physical activity questions that young people face as they begin to live more independently, go to college, and face the rigors of the working world. Continuity of care becomes more complicated as the child with OI becomes too old to be treated at a pediatric center and as his/her health insurance changes. While pediatric care often focuses on forming teams and being comprehensive, the adult system is much more fragmented. This requires the young adult to learn to be proactive about his/her health care needs, to understand their health insurance, and to know how to keep track of their health records. The importance of connecting with new doctors well ahead of an emergency is stressed in this article.

Identifying the issues is an important first step. How to address these needs will differ depending on the severity of the person's OI and the community they live in.

This article appeared in the Summer 2012 issue of Breakthrough, the OI Foundation newsletter.