

Inherited Illness Transition Resources

For all of us, life involves a series of transitions – birth takes us from our mother’s womb into the world. School takes us from home into a world full of ideas and peers. Jobs take us from financial dependence to increased self-sufficiency. Life involves lots of transitions! The word “transition” comes from the root word “transit”, which simply means to pass from one place to another. Transitions are unavoidable, and they are often good, but they can be frightening or difficult too. For people who have heritable illnesses and their families, transitions can sometimes require a significant amount of thought and planning. This website is designed for people who have inherited illnesses and for those who have loved ones with heritable illnesses. Our goal is to help you think about key transition points and to provide resources that may help you plan effectively for a variety of transitions that you may face. Of course, heritable illnesses are diverse, so the information provided here will necessarily be somewhat general, focusing on transitions that are common to many heritable illnesses. While we hope this information will be helpful to you, please remember that this information cannot replace competent medical care or advice from professionals. You may also find that national organizations that provide information for people with specific inherited illnesses may have additional resources that focus on the unique challenges of particular conditions. We encourage you to talk to your medical doctors, social workers, genetic counselors, and other specialists who can provide detailed information about your own concerns, and to seek information from reputable organizations that provide information about specific heritable conditions.

The information and resources that are available on this website are organized according to a developmental framework. In other words, information is organized beginning with transitions that might be identified earlier in life (such as when a parent finds out that their child has a heritable condition) to those that occur later (like going to school) to those that occur later in life (like planning for guardianship or independence). We structured the information in this way partly because it is important to remember that transition is a developmental process. To give just one example, think about what it takes for someone to be knowledgeable

about, and responsible for, his or her medical treatment as a young adult. For this to occur, parents and caregivers need to provide education about medical conditions and treatments over a long period of time and with increasing complexity commensurate with the child's capacity to understand. Likewise, parents need to gradually transfer increasing responsibility to their child over a long period of time, which may stretch over years or even decades. Because this website is currently under development, we decided to start by providing resources for transitions that affect young adults, so you will find that there are more resources for those areas than for others. Our hope, though, is to continue expanding this site so we can provide additional resources for other transitional phases as well.

We hope that you find this information helpful! Click on any of the links below for more information about one of these specific topics.

- Adjusting to diagnosis (focus: parents)
- Genetic counseling (focus: parents. Condition education, reproductive issues)
- Incorporating therapies into routine (focus: parents)
- Importance of adherence (focus: parents)
- Transition as a developmental process – begin early! (focus: parents)
- IEP / Educational Accommodations (focus: parents, resources for educators)
- Planning for the future – LTC / Higher Ed. / Jobs – ADA resources (focus depends on level of independence)
- Insurance: Aging out, Federal Health Care Reform, and other issues
- Importance of treatment adherence (focus: patient)
 - Education about specific condition, therapies, and medications
 - Building therapies and medications into one's routine

- Educational and occupational decisions (focus: patient)
- Access and transition to adult health care
- Social and relational issues (focus: patient)
- Reproductive decisions (focus: patient. Discussing one's condition with potential partners, discussing reproductive implications, reproductive decisions)
- Discussing personal health information with others
- Guardianship
- Life skills