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Disclosure: The author has no relevant financial relationships to disclose.

doi: 10.3928/00904481-20121022-13


ter juvenile idiopathic arthritis (JIA), the fifth most common chronic disease of childhood. Attention to the health care transition for youth with JIA is essential, since about one third of these patients will be diagnosed during adolescence and more than one third will continue to have active disease as adults.

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CHALLENGES OF CHRONIC ILLNESS IN ADOLESCENCE

Transition can be defined as “a purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents to develop skills and build on their existing strengths.

Among the rheumatic diseases primary care providers (PCPs) will see in their practices, they are most likely to encounter juvenile idiopathic arthritis (JIA), the fifth most common chronic disease of childhood. Attention to the health care transition for youth with JIA is essential, since about one third of these patients will be diagnosed during adolescence and more than one third will continue to have active disease as adults.

In an ideal world, all primary care and specialty practices would have transition coordinators to implement and oversee the process of transition with patients and their families. The reality, however, is that the process of transition must often occur in the setting of limited staff, time, and resources. Making it a point to spend a portion of each visit with your patients on transition is invaluable work.

PREPARING FOR TRANSITION

While they learn to form friendships that are mutually close and supportive, teens with JIA must navigate how to explain their condition to others, and if and when to disclose their condition to friends. I have noticed in my work that a particularly challenging aspect of JIA management that teens deal with as they develop abstract thinking skills is the need to continue taking medications even when they are feeling well.

Point of View

Perspectives from practice.
ten transition plan to be signed by the patient, a parent, and the PCP. A clear outline takes the mystery out of what transition entails and makes it less overwhelming by dividing the process into smaller, more manageable steps. The plan can be broken down into the stages of adolescence (early, middle, and late) and should include the following tasks:6

**Early Adolescence (Females: 9 to 13 Years, Males: 11 to 15 years)**

a) Able to tell provider what is wrong.

b) Knows names of medication, dose, reason for taking medication and expected response.

c) Knows any allergies they may have.

d) Knows the difference between health care providers and their respective specialties.

e) Knows date and reason for next appointment.

**Middle Adolescence (Females 13 to 16 Years, Males: 14 to 17 Years)**

a) Knows basics of own health history, including family history.

b) Makes own health care appointments.

c) Calls pharmacy to refill prescriptions or calls providers about need for refill.

d) Has increasing responsibility in family.

**Late Adolescence (Females: 16 to 21 Years, Males: 17 to 21 years)**

a) Manages stable JIA independently.

b) Participates in discussions regarding health care options.

c) Keeps updated file of own health care records.

d) Understands own insurance plan.

e) Understands own insurance plan.

**Self-Management Skills**

Just as it takes years of practice to become a good doctor, nurse, or violinist, adolescents and their families need to practice self-management skills to be successful. I have observed that patients who transition most successfully are those whose providers:

a) Help their patients develop the skills necessary to manage their chronic condition.

b) Identify and build on patients’ existing strengths.

c) Provide constructive feedback.

d) Praise accomplishments along the way.

Eventually, a combination of the patient’s own readiness, insurance coverage, and respective pediatric provider’s practice policy will lead patients to the point where they must choose an adult rheumatologist and PCP and make their first appointment. The last appointment with the pediatric providers can occur before or after their first adult appointment and can serve as a time for reflection on how far the patient has come. This is a time of both closure and beginning in their lives.

A succinct summary of the patient’s medical history and problem list from the pediatric providers should accompany the patient to the first adult visit, along with an invitation to the adult provider from the pediatric practice for further discussion about the patient via email or phone.

Ultimately, transition is a process of helping youth learn to love, respect, and take good care of all aspects of themselves, not just their JIA. PCPs are in a unique position to offer hope to youth with JIA through their focus on anticipatory guidance and planning for the future. Routine adolescent visits with PCPs should acknowledge the youth’s JIA, but should focus on the common concerns of young people, such as growth and development, sexuality, mental health issues, substance use, and other health promoting and damaging behaviors. In this way, JIA becomes a particular, but not defining, aspect of the youth’s life. ■

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**REFERENCES**


