## Managing the Transition From Childhood to Adolescence

## **Guiding Preteens With Hemophilia**



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Parents of a preteen with hemophilia may have concerns about preparing a child for life with a chronic condition. During the preteen years, children spend time away from family, attend school, and experience additional social influences. This is when children begin to form their own ideas and opinions. Preteens may be exposed to peer pressure to engage in risky behavior and/or forego treatment, making open communication essential.

Preteens are building life experience and taking steps toward independence, and it is important that parents set limits. Preteens may not handle their impulses and desires maturely. Guiding a child to make the right choices can help prepare him or her for the future and the many similar decisions he or she will make. Parents should find a balance between giving a child space to grow and setting boundaries.

Adolescence lasts longer today than in the past; children begin puberty earlier and leave home later. This gives parents and children more time to learn how to negotiate the transition to independence.<sup>2</sup>

## **Proactivity is Crucial**

Dr. Thomas Truncale ranks proactivity as the most important factor when managing hemophilia. Anticipating needs and putting together a plan ahead of time can have benefits when treating hemophilia, addressing parenting issues, and in seeking education.

Proactively educating children about hemophilia can improve their ability one day to begin managing their own medical care. At a young age, children can gather infusion supplies or even decide on the infusion site. This involvement can help prepare them for self-infusing. Dr. Truncale recommends that families attend summer camps where older children mentor younger children.

"Encourage your child to focus on what he or she can do, not what they can't do."

— Thomas Truncale

Education helps children living with hemophilia learn to make the right decisions. If a bleed occurs, proper education may help the child identify it as soon as possible so it can be treated early.

Dr. Truncale adds that proactivity should extend to school, church, and community. Create a package of educational information for the school nurse, teachers, church personnel, babysitters, and other families. Ask the hemophilia care team for materials available for this purpose, and don't forget to add relevant personal contact information.

Reference: 1. Cassis FRMY. Psychosocial Care for People With Hemophilia. Montréal, Québec: World Federation of Hemophilia; 2007. 2. Irish Haemophilia Society. Transition. https://haemophilia.ie/living-with-haemophilia/parents-of-children-with-bleeding-disorders/the-bridge-of-transition-for-adolescents-with-bleeding-disorders/. Accessed September 17, 2019.



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