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The Bridge of Transition for Adolescents with Bleeding Disorders
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The change an adolescent is making when growing into an adult is complex and for an adolescent with a bleeding disorder there are additional changes to consider. Parents and adolescents might better understand that change by considering the following question. Could you drive across a very narrow bridge that is high above a river, if it did not have rails? Most people after careful consideration would conclude that they could, but that they would be very frightened. So, then, why are railings necessary? They are boundaries that guide us. They make us feel safe and if we do run into them, they should stop us from falling.

Adolescents have the job of crossing that bridge as part of growing up. The parents have the role to decide when railings (limits or boundaries) are necessary. Many new experiences must occur for the adolescent to cross that bridge. First is the need to have the physical abilities to drive the car. As the adolescent's body grows into puberty, so does the desire to get to the other side of that bridge to meet new people. The adolescent begins to develop the physical features of an adult. He is taller, developing sexually, and his body is stronger and more able to perform complex physical tasks. He is also developing intellectually and emotionally. He has to make decisions about how fast to go, when to break, should he get closer to the rail to let others pass him or should he hog the road. Some examples of these decisions are: future school and career choices, learning to drive, how to earn, use and save money, how to take care of personal hygiene, clothing, cooking, who to choose as friends, how to take care of his medical needs, how to get a date, who to date, how to plan a date, who and when to tell others about his hemophilia, etc.) Each of these decisions are important in that they set patterns for how he will handle decision making as an adult. It is a time of experimentation, so mistakes are made and learning occurs from those mistakes.

Parents have to decide when the railings should go up, how far out the railings should extend and when to let the adolescent drive without railings as the adolescent moves toward independence. These are difficult decisions, but they are best made with the adolescent's input. It is important to remember that teens do want parents in their lives. In fact, parents are the number one influence in their lives. Friends influence them when it comes to things like clothes, hair and music, but parent's are the ultimate source for values. Adolescents want to be guided and to know that parents are watching them.

Another consideration is that adolescence lasts longer today than it did in the past. Children begin puberty earlier and leave home later. This means that the bridge is longer than it was in the past. So the good news is that parents and the adolescent have more time to practice and learn how to negotiate the transition. For the parents of the adolescent with a bleeding disorder it may be more difficult to determine where the rails should be placed and when they can let him go on his own. For the adolescent with a bleeding disorder some of the additional issues of transition to adulthood will be:

- learning self-infusion
- managing self-infusion when away from home
- maintaining infusion supplies
- inventorying factor
- calling for more factor
- if on prophylaxis, taking his infusion in the morning
- learning to consistently and promptly identify bleeds
- infusing within one hour of beginning a bleed
- completing infusion logs at the time of each infusion
- making and keeping clinic appointments (calling to reschedule when he can't keep one)
- doing home exercises as instructed
- following what the doctors and nurses advise him to do
- coming to clinic with a list of things he wants to talk about

Parents and the Hemophilia Treatment Center staff can help the adolescent to learn these skills, by first identifying them to the adolescent and then praising, setting limits and encouraging him as he learns to practice them. Hemophilia Summer Camp is a great place for the adolescent to model these skills to the younger children, which then helps him to practice these adult behaviors.