

Parents:

The years of watchful care and planning for safety now meet with the teens' drive for independence and their belief in invulnerability and immortality! This may result in family conflict. If parents can't let go, teens may become dependent, resentful adults who don't grow up. If parents let go too fast, or too soon situations can add to parents' guilt when there are bleeds.

Complex feelings may surface in times of stress. Teens have been known to blame their parents. Remind them they inherited their good looks and brains from you too!

Remember that most families find it challenging to parent teens. Consider taking a course and do some research or reading about talking with adolescents. Be aware that body language speaks louder than words.

Speak to the team and Social Worker to discuss ways to deal with emotional behaviour.

In learning to self-infuse, use this checklist to consider their readiness for independence: It's hard for teens to think about the long term consequences. They don't think about what today's bleed can mean for their joints as they age. Adults with joint damage from their bleeding disorder can educate by sharing their experiences.

Do they:

- promptly and consistently identify bleeds
- self infuse, at home or away from home
- treat bleeds appropriately, and do follow-up physiotherapy as recommended
- keep track of and order their own factor and infusion supplies
- send in infusion logs by post or email.
- make and keep clinic appointments, including calling to reschedule
- always wear a medic alert bracelet, carry a Factor First card and make their own list of questions for SBDP staff

- understand the roles of all SBDP staff, and follow the advice of medical staff
- know how to call Emergency

Pillars of Chronic Disease Management Program Design

Exercise

- Community based supervised exercise and rehabilitation programs providing personalized exercise prescription
- Education sessions
- Group and social support

Disease-Specific Management

- Inter-professional team working closely with individuals, their family, Family Physicians and Specialists.
- Evidence-based optimal care delivery.

Self-Management

- Individualized plan of action for patients
- Peer-led support classes through the LiveWell with Chronic Conditions Program
- Enhance self-management skills

Provincial Program

- Saskatoon and Regina Clinics
- Pediatric and Adult
- Hospital and Community

For more information:

Saskatchewan Bleeding Disorders Program
655-6504

<http://www.saskatoonhealthregion.ca> - click on "Your Health, Patient Services", and look for Chronic Disease Management and then Saskatchewan Bleeding Disorders Program.

Hemophilia Saskatchewan
1-866-953-4366
Or
653-4366
www.hemophilia.ca



Saskatchewan Bleeding Disorders Program (SBDP)

Paving the Way to Independence
12 – 18 years of age



Education and Understanding:

- Adolescents are sorting out issues of privacy, independence and separation from parents. Those with a chronic condition may have trouble accepting this difference, and resent the restrictions.
- Teens may let a bleed get “out-of-hand” because they don’t want to draw attention to themselves or stop their activity.
- Some do everything despite the pain; others isolate themselves so they don’t have to tell anyone. Help them see the value of the middle ground.
- Teens look to their peers for praise, acknowledgement and belonging. Connecting with a peer support group of youth with similar health and lifestyle issues can be an important influence. Hemophilia Sask. offers peer support.
- Some adolescents think they are both invulnerable and immortal! They don’t think about what today’s bleed can mean for their joints as they age. Adults with debilitation from their disease can educate by sharing their experiences.
- Discuss puberty changes; offer information and support about sexual health. Make sure they know about refusal skills, safer sex practices, and contraception/ pregnancy.
- Be aware there are scholarships that are funded for people with bleeding disorders.

Preparation for School and Outside Activities:

- At this stage your child must decide who and what to tell about his bleeding disorder. This is individual and can change over time. For some, having everyone know is easiest. For others, telling a few close friends makes them feel more in control. For safety, be sure that someone responsible (teacher, sports coach, group leader) in each situation knows about your child’s bleeding disorder.
- Health information is confidential; talk with your teen about who you can discuss it with and respect their wishes. Stress this with all family members.
- Prepare them for the occasional strange response – over concern to avoidance. People are often afraid or have old information about bleeding disorders.
- Dating – if it’s someone your teen will be seeing on a regular basis they will need to be told.
- Encourage them to think ahead 24 hours – if they wish to take part in something vigorous tomorrow, encourage them to plan to treat with factor in advance.
- Teach and model good nutrition. A healthy diet helps a growing person stay strong for when the body is challenged by a bleed.
- Plan for lifelong activities, like swimming, walking or skiing – after team sports.
- Educate them about the blood thinning effect of alcohol.

Preparation for Treatments and Clinic Visits:

- Adolescents gradually take on self care responsibilities in the following pattern
 - 1) mix product and keep treatment records
 - 2) self-infuse
 - 3) order factor
 - 4) handle their own clinic appointments.
- By age 13, youth are encouraged to increase communication with program staff – e.g. 10 minutes alone with the staff and increase it each year to practice speaking for themselves.
- Talk about your goals to manage their own health care. Your child can request that information they share with staff remain confidential. Staff have a professional responsibility to respect confidentiality unless there is a risk of harm to self or others.
- The Genetic Counsellor is available to discuss genetic factors and adult family planning.
- Summer camps are a great place to begin developing self infusion skills and to develop into the role of mentor.
- The hard job for parents is managing the emotional tasks involved in “letting go”. Many youth with a bleeding disorder identify at least one parent as “over-protective”.

