

Recreation, Physical Growth and Independence:

- Family activities that are good for general physical development include hiking, swimming, skiing. Discuss the importance of protective equipment - e.g. helmets for skating or bike riding.
- Children need to fit in with other children - risk taking is part of the adventure and fun.
- Try not to forbid an activity. Children may try them on their own and not tell you.
- Guidance helps children learn self control. Consequences can be positive, such as rewards, ignoring bad behaviour or praising good behaviour.
- Negative consequences can be time outs, taking away privileges or logical and natural consequences.
- Choose a non-physical discipline plan for all children in the family.
- Behaviour: ensure they know what you expect and always be consistent.
- Be sure they know you always love them.
- Parenting is a big job, and we all learn as we go. Be sure to take time for yourself each day.

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

LiveWell

Saskatchewan Bleeding Disorders Program (SBDP)

Paving the Way to
Independence
5 – 8 years of age



Our goal is to support the next stage in your child's growth to independence.

Education and Understanding:

Children understand things differently than adults. At this age, they may think of illness as punishment.

"Interview" your child to learn how they think about their bleeding disorder, then provide a little information at a time. You are building a foundation of knowledge as they grow.

Children will ask "why?" they have this disorder. At this age the simplest explanations are those with no cause attached – "you were just born that way".

Your child will have feelings about their bleeding disorder. One useful technique is to describe what you see and give it a name – "you're crying – are you sad?" Acknowledging feelings without judgement is a very powerful tool to help your child feel heard, understood and valued.

Teach your child ways to share feelings, and manage their emotions – play music, go for a walk, build/make something with their hands, draw, take some deep breaths.



Preparation for School and Outside Activities:

- Talk to your child's teacher and principal. Suggest an inservice or teleconference with program staff. Provide information about the disorder, signs of bleeding, basic RICE (Rest, Ice, Compression, Elevation), your contact information and a back up plan.
- Discuss ways your child can take part in activities if he has a bleed.
- Encourage music, sports, clubs, faith-based or other social groups.
- Discuss and rehearse different situations that may arise around an injury or need for a treatment.
- Provide an opportunity to socialize with others with a bleeding disorder (Hemophilia Saskatchewan holds regular get-togethers, and plans special activities, including a "guys" summer camp, and a family weekend).
- Rehearse how to handle uncomfortable comments, dares, or bullying situations.
- Have a routine for homework, responsibilities at home, and how you'll handle allowances.
- Discuss the future, their interests and how bleeding disorders may affect their choices.



Preparation for Treatments and Clinic Visits:

- Discuss signs and symptoms of bleeding/pain, and review the names/ways you talk about it.
- Teach your child RICE.
- Involve them in the home treatment process. Have a routine. The child can gather supplies, wash their hands, clean their skin site, choose the vein, pick out the band aid, and choose their distraction method.
- Encourage involvement with record keeping – document treatments or note appointments on a calendar.
- Set small manageable, measurable goals to help your child see and feel good about their progress.
- Explain the Factor First Card & System.
- Have a Medic-Alert system in place.
- If your child has a port, talk to SBDP staff about the transition to venipuncture.
- Encourage them to ask questions.
- Allow your child to observe someone else being infused. It can help to normalize the experience.
- Be matter of fact about treating bleeds – avoid blame. Your child is responsible for the behaviour, but not the seriousness of the bleed.
- If your child has a strong needle fear, talk to Program staff about making a "Better Needles Plan".