

12 Physical Activity, Exercise and Sports

This chapter explains how children with hemophilia can be physically active and, at the same time, minimize the risk of joint damage. It answers these questions:



- What are the differences between physical activity, exercise and sports?
- What are the benefits of physical activity, exercise and sports?
- What are the risks from some types of physical activity, exercise and sports?
- What needs to be considered when selecting a physical activity or sport?
- What is the role of the care team in helping your family choose the right physical activities and sports?
- Can't you simply consult one of the booklets that rank different sports according to their risks?
- If your child is on prophylaxis, do you need to worry about the risks at all?

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NOTES

■ What are the differences between physical activity, exercise and sports?

The terms *physical activity*, *exercise* and *sports*, are often used interchangeably. They are, however, different in some ways.



“I let the kids choose one activity per season and the other one is automatically swimming lessons. By booking in to lessons, they are all getting regular exercise each week in a safe way.”

Physical Activity

Physical activity can be defined as any activity that involves some form of physical exertion and voluntary movements that burn calories. Such an activity causes a person’s body to work harder than normal.

Examples of physical activity range from gardening, dancing, walking the dog, shoveling snow and raking leaves.

Exercise

Exercise also involves physical exertion, voluntary movements and burning calories. This form of physical activity, however, is specifically planned, structured and repetitive. It does not usually involve any kind of competition.

Examples of exercise include jogging, cross-country skiing, recreational swimming, cycling and aerobics.

Sports

Sports also involve physical activity and exercise but differ in that they also have a set of rules, or goals to train and excel in specific athletic skills. Some are individual sports such as golf and swimming. Others are played in teams — for example, soccer and hockey. Sports are often, but not always, competitive.

When doing a physical activity, exercise or individual sport, it is usually possible to control factors such as speed, length of time, intensity and movements as needed for the protection of muscles and joints.

But with competitive team sports like basketball and contact sports like tackle football, it is difficult and often impossible to predict the actions of teammates and opponents. This generally results in more injuries and bleeds that can be very serious for a child with hemophilia.

■ What are the benefits of physical activity, exercise and sports?

Physical activity, exercise and sports provide numerous benefits for *everyone*, young or old.

Physical Benefits

There are many physical benefits. Physical activity, exercise and sports help:

- develop strong bones and joints
- develop strong and flexible muscles (provides good support to the joints and reduces the risk of injury)
- keep in good physical shape (healthy weight reduces stress on joints)
- improve balance, reflex and coordination
- improve overall fitness
- promote healthy physical development

“Physical activity is important for everyone. It helps develop and maintain the strength of muscles, ligaments and tendons — together, they support and stabilize the joints. But you’ve got to be careful with aggressive physical activity, especially in adolescence because the sport often gets rougher than expected.”

Hemophilia-related research has shown that regular physical activity and exercise, when done properly and safely, are critical to the overall health, well-being and quality of life of children with hemophilia. Specifically, the research shows:

- Exercise is important for building healthy bones and strengthening muscles that support and protect joints.
- Regular physical activity actually helps prevent bleeds and joint damage.
- Strong muscles help to lower the frequency and severity of bleeding episodes in joints and joint pain.
- Strong muscles and good balance and coordination help to lower the frequency of bleeds in both joints and muscles. Strong and flexible muscles can better withstand overexertion or overstraining; they will be less prone to injuries or bleeds.



“He likes Irish dancing. The competitions give him a sense of achievement and confidence in himself because he is good at what he is doing.”

Muscles support joints. To have a strong knee joint, the muscles that surround the knee also need to be strong. Physical activity and exercise help strengthen muscles, which in turn helps provide better support to the joints. Balance and coordination are also important for joint support. Both are improved when a child is physically active.

Children with hemophilia can increase their strength and improve their fitness levels through physical training. In childhood this physical training occurs mostly through physical activities and sports.

Psychosocial Benefits

In addition to the physical benefits, there are many psychological and social benefits. In general, physical activity, exercise and sport help to:

- increase relaxation
- improve self-esteem
- build positive self-image, partly due to improved muscle tone and appearance
- increase levels of hormones called endorphins (which can help improve mood and enhance feelings of well being)
- increase feelings of acceptance and belonging to a group of peers

The psychological and social benefits derived from physical activity and sport are well known to mental health specialists who work with children and youth. Physical activity has a positive impact on how children rate their own happiness and self-image.

Why is this? A recent study of children with hemophilia found the main reasons they participate in physical activity and play sports are:

- to interact with others and
- to have fun!

Group activities and sports offer the chance for children with hemophilia to be actively involved with their peer groups. This leads to feelings of acceptance and belonging. Combined with a healthy body image, the result is increased self-esteem.

“Meeting other parents and adults with hemophilia meant the world to me. Just seeing that hemophilia hasn’t dominated their lives really helped us cope.”



“We made a conscious decision to raise Mathieu to think of the things he can do, rather than the things he can’t. So we gave him the framework to make his own choices and decisions about activities. I’ll say: “Mathieu, you need to find a sport where you’re less likely to be injured, so that you can participate more.” But we encourage him to make these choices himself, as he’ll have to live with the consequences.”

The desire to belong and be accepted by a peer group is very powerful and not something to be overlooked. Sports can often provide an avenue for this. Children can test their skills, prove themselves, and achieve acceptance into a group.

The challenge is to select the activities and sports that will provide the psychosocial benefits, without putting the child’s joints at risk. The comprehensive care team at your HTC — especially the physiotherapist — have a lot of experience working with families with hemophilia to help them understand the benefits and risks. They can work with you and your child to select safe activities or sports, according to your child’s age, muscle and joint health, overall physical condition and interests.

Sometimes, children with hemophilia feel alienation, anger or sadness because they can’t participate, or participate as fully as others, in certain sports. In these situations, the HTC’s psychologist can work with the physiotherapist and the family to come up with satisfactory solutions.

The psychological and social benefits of sports participation are significant. At the same time, similar benefits can also be gained through involvement in various other activities. Children and teenagers can also find individual challenges and peer acceptance in activities such as math or debating teams, theatre, music classes and competitions, or through community centre activities.

While teenagers often like to take part in sports with their peers and friends primarily to gain social acceptance, young children often simply enjoy the game itself and interacting with other children, their siblings and their parents. Playing on the sidewalk, in the backyard or park, shooting hoops, playing pitch-and-catch with a softball, or taking shots on net can be safe, interesting, and fun for the young child.

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An alternative to team sports that involve a lot of body contact, or a sport that is not advised for a child or teenager with a target joint, is to combine a safer sport, exercise or physical activity with a fun social activity with friends and other people their age. (For example: leisure hiking, dance lessons, golf, bowling or billiards.) This can provide similar physical, psychological and social benefits. The physiotherapist and psychologist at the HTC as well as other members of the team are available to help guide you.

■ What are the risks from some types of physical activity, exercise and sports?

When recommending or discouraging certain physical activities, exercises or sports for a child or teenager with hemophilia, the HTC care team considers the risk and likelihood of these four different types of injury that can occur:

- **Joint bleed** – This is usually because of “pinch or twist” types of injury to the joint and the lining of the joint called the *synovium* or *synovial membrane*. A joint bleed can happen especially if the activity involves putting full weight and stress on a joint or forceful movements such as throwing and kicking.
- **Muscle bleed** – This can happen if a muscle is strained or stretched too much. A muscle bleed can be caused by a single serious trauma or small but repetitive trauma.
- **Early joint (osteo-cartilage) damage** — This can develop if someone already has a target joint or inflammation of a joint like arthritis.
- **Body collision or contact injuries** – This can range from minor and serious bruising (*hematoma*) to life-threatening bleeds that involve the head, neck, chest, or abdomen.



“All my friends are involved in football but I’ve learned to accept that I can’t play in rough sports like football and hockey.”

It’s probably impossible for a child with hemophilia to avoid ever having a bleed at all. But it’s still extremely important to prevent serious types of injury, and repeated bleeds into the same joint. Although most sports carry some risk, there are certain factors that increase the risk of getting a bleed or serious injury.

- **Body contact** – Sports such as hockey involve a lot more physical contact than something like team tennis because players fight for the puck and bump into each other and against the rink boards. The chances for an injury to occur are therefore higher.
- **Speed** – There is a bigger risk of injury with motorized sports that involve a lot of speed such as snowmobiling and dirt biking.
- **Force of impact** – Sports such as football and boxing are extremely risky even for people who do not have hemophilia because of the high force of physical impact.
- **Height** – Sports that involve big heights such as downhill skiing, snowboarding and hang-gliding come with more risk of serious injury.
- **Hard-to-predict conditions** – Waves in water skiing, and icy surfaces when downhill skiing, are examples of how unpredictable conditions can affect how risky some sports can be.

A child who has a target joint, arthritis or — most significantly — *inhibitors* in the bloodstream that fight against clotting factor as soon as it is infused and make it less effective, needs to be especially careful about selecting physical activities and sports that won’t harm his joints. This is more of a challenge for families. Individuals who have any of these complications require more careful assessment and should discuss what is safe and what’s not with the comprehensive care team.

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Parents of a child with inhibitors who has a high risk of bleeds and may already have several target joints must ask this question: Are the benefits of the sport or activity worth the risk? This can only be answered after thorough discussion with the child and his care team. Decisions must be made on an individual, case-by-case basis.

Choosing sports and physical activities carefully, preparing well for them, and knowing how long and hard it is safe to do the activity can help to cut down the risk of injury. Still, learning to make good choices, often by trial and error, is an important part of growing up and living with a chronic condition such as hemophilia.

■ What needs to be considered when selecting a physical activity or sport?

The key question is how to select the right physical activity, exercise or sport that will help provide many of the benefits, but at the same time do not involve a lot of injuries, bleeds, inflammation and joint deterioration.



Here are some important questions to ask...

- **What benefits are you seeking?** Strictly physical benefits? Social interaction? Interaction with peers? Competition? What are your child's goals? What do you value as important and how can this be met safely?
- **Is the activity something your family can do together?** For example, hiking and cycling are just a couple of the safe activities that the whole family can enjoy. What's more, you can closely supervise and manage injuries if they occur.

“He loved hockey but he never played except for ‘street hockey’ with his friends and Dad. That was one sport we had to say ‘No’ to.”

- **Does your child already have a target joint?** Are there realistic ways to protect the joint by using a brace for joint support, special footwear or by changing the exercise, activity or sport so that it’s safer? Any previous injury or chronic joint damage from prior bleeds will be more likely to get injured and start bleeding again.
- **What sports are risky for someone with a target ankle, knee or elbow joint?** A person with an ankle target joint should not play racquet sports such as competitive tennis and badminton. These sports involve a lot of fast and sudden back-and-forth and side-to-side movements. They are very demanding on the ankles, knees and elbows, and sometimes shoulders. Racquet sports are especially risky if the joint is already injured or chronically inflamed.
- **When is the best time to infuse factor to minimize bleeds from happening with a physical activity or sport?** If your child is on prophylaxis therapy, his treatment schedule should ideally be timed with his games and practices to make sure he has maximum protection.

There are also important factors...

- **Health condition** – If a child is overweight or not in very good physical shape, it may be less stressful on his weight-bearing joints to start with activities such as swimming, cycling and possibly even stationary cycling. Talk to the physiotherapist about how your child can safely build up his strength and coordination.

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- **Reflexes and coordination** – If your child has not yet developed good reflexes and coordination, he will have a bigger risk of getting injured. Injury can happen with any sport that someone is not yet ready or prepared to do. Always consult the HTC physiotherapist for help in choosing the right sports that match your child's level of coordination. She/he will also teach you and your child ways that he can progressively improve his reflexes and coordination.
- **Team vs. individual sports** – Some individual sports like cross-country skiing, cycling, swimming or paddling are generally easier to control because they do not involve contact with other players or team members.
- **Supervised vs. unsupervised activity** – An easy mistake is to think that playing on a competitive sports team is more risky than an informal game with friends. But studies have shown that this is not always the case. Team sports are usually supervised and the players and coach need to pay attention to proper equipment and technique — plus the referee is there to make sure everyone follows the rules.
- **Speed** – The faster your child is going, the more likely it will be for him to have a serious accident and injury. Always ask yourself if a sport or activity has a high risk of injury. Some involve repeated twist and turns that cause stress on the joints. Have an open discussion with your child about the risks and dangers, and whether they are really worth it.
- **Amount of contact** – Any sport that requires body contact as part of the game (football, rugby, hockey) is more dangerous.



“It’s a matter of letting them gradually move along as their experience and knowledge allows them to. But at times you basically still have to put your foot down and say, ‘No, this can’t be, we cannot do that.’ We’ve had our little skirmishes but for the most part there haven’t been really major issues.”

- **Skill levels** – Sports are not necessarily less dangerous when played at a young age. For example, hockey does not allow body-checking at a young age — but young players usually have very poor stick control. This results in many slashing injuries. As athletes grow stronger, so do their skill levels, how fast they play, and their reflexes and coordination. They get better at controlling their actions and the situations around them. Teammates are better able to protect each other — but this only happens with time, practice and learning. Sometimes, no matter how skilled your child is at a sport, it can still be very unpredictable and risky. Discuss the risks and issues openly as a family and with the HTC team.
- **Game plan** – What will your child and family do when he reaches a higher and more competitive and less safe level of sports? Will he have to quit his sport? Would it make him feel left out from the team and friends, and a sport that he is very passionate about? Can something be done to keep the sport as safe as possible for him, even at the higher levels? How hard will it be to stop an unsafe competitive sport once he has grown to love the game, and the camaraderie of his friends and teammates?
- **Position on the sports team** – In many sports, players have different positions and each one has a different role. The centre or “low post” in basketball stands under the net and watches so that he can grab the ball if it rebounds. Therefore, this position involves more contact than the point guard, who plays further from the net. Similarly, a baseball pitcher will have to throw much more during a game than a shortstop. This puts a lot of stress on the shoulder, elbow and wrist joints — and can lead to a type of injury called “pitcher’s arm” that is common in Little League baseball. For a child with hemophilia, this type of injury could easily cause repeat bleeding and development of a target joint.

- **Cost of good protective gear and footwear** – Proper protective gear is important for anyone practicing a sport. It is doubly important for a child with hemophilia. Your child will need high-quality equipment that fits his growing body, and gets replaced every now and then as he outgrows the protective gear and footwear. That equipment can be costly.
- **Access to proper training** – If your child is interested in a program to help him develop specific skills, it is important to consider who can best help you set that up. The HTC physiotherapist will teach you and your child the proper techniques involved, taking into consideration the child's overall *musculoskeletal* status, fitness level and whether he has a target or arthritic joint. Remember! Hemophilia is rare. Very few physiotherapists or physical trainers are familiar with the condition. What is perfectly appropriate for most children may not be good for your child with hemophilia. Seek advice from your HTC.
- **Access to the activity and family budget** – For example, if swimming is chosen as the activity, is there a pool within reasonable distance? Are membership, coaching and traveling costs to and from the pool too high?
- **Modifications to an activity or sport** – Your child's physiotherapist may be able to recommend ways to make an activity or sport safer for him. He may suggest equipment that will support joints or muscles. While not entirely eliminating the risk of injury, these modifications may make the activity or sport safer and more enjoyable.

■ What is the role of the care team in helping your family choose the right physical activities and sports?

Clearly, there are many factors to take into consideration when guiding your child on the choice of physical activities and sports. The members of your comprehensive care team can be like good coaches — they are there to help your family decide what is realistic and safe.

“I would enjoy life a lot more if I could do all the sports I wanted. I know if I could join the sports teams, I’d have a much better time in my high school years. But I know that I can’t so I’m not going to dwell on what I can’t do.”

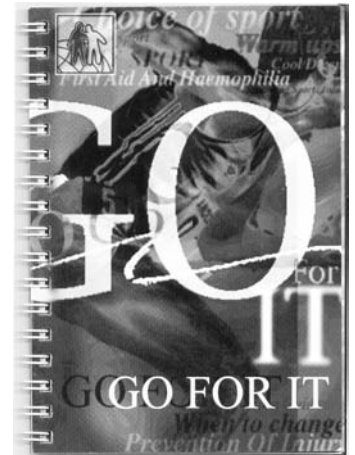
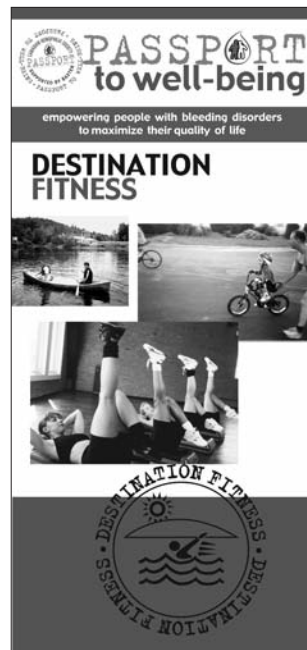
- The **hemophilia nurse** can help you coordinate his clotting factor therapy and monitor any changes in factor usage after your child starts a new activity.
- The **physician** can explain whether specific anti-inflammatory medications or pain medications would be helpful or harmful.
- The **physiotherapist** can show your child some warm-up exercises, and different tips and ways that he can adjust his physical activities to protect his joints. The physiotherapist will also tell you what to do if your child has a bleed, and advise you when he is ready to go back to the activity.
- The **HTC’s psychologist** can suggest coping mechanisms to help your child deal with feelings such as stress, alienation or anger because he’s not allowed to do certain activities and sports.

■ Can't you simply consult one of the booklets that rank different sports according to their risks?

Yes and no. Booklets do exist that try to rank various physical activities and sports by level of risk for children with hemophilia. Your HTC or your local CHS chapter can provide you these resources.

- *Go For It!* – published by World Federation of Hemophilia
- *Playing It Safe* – published by U.S. National Hemophilia Foundation
- *Fit for Life: A Guide to Fitness, Games, Sports and Dance for People with Hemophilia* – written by Anatol Kurme and Axel Seuser, Germany
- *Passport to Well-Being: Destination Fitness* – published by the Canadian Hemophilia Society

The guidelines in these booklets can be helpful. But you must keep in mind that no book can take into account **your child's** particular physical condition and circumstances. It is very important to select sports and activities that are based on **his** particular interests, needs and limitations.



“You can find a lot of information in books and the sports are often graded by risk. But really, the best way is to try some sports once or twice — if you have bleeds every time, realize that it's not worth it.”

“I remember going to a meeting back when my son was about two years old, and another mother told me that they develop a sense of danger. I find it true too — that’s part common sense and part experience.”

■ If your child is on prophylaxis, do you need to worry about the risks at all?

Yes, you definitely do. Even with today’s best preventative therapies, the fact remains that children with hemophilia do experience joint bleeds and to a lesser extent, muscle bleeding. These bleeds can still cause long-term musculoskeletal damage.


Factor levels on prophylaxis

Prophylaxis certainly helps decrease the frequency and severity of joint and muscle bleeds, as well as early joint damage. But it does not prevent all bleeds, nor can it give a child with hemophilia the normal factor levels like in children who do not have a bleeding disorder. He will not be nearly as well protected from bleeds as most of the children he plays with.

Consider this information on factor levels...

- During intense exercise or physical activity, a person’s natural factor VIII levels can temporarily double or triple. This also happens when someone with hemophilia A does intense physical activity — but often the effect is still not enough to increase his factor VIII level to within the normal range. For example:
 - A child with severe hemophilia A with 0.5 to 1 percent factor VIII level can temporarily increase his factor level to only 1 to 3 percent, which is still significantly below normal range.
 - A child with mild hemophilia A and a factor VIII level of 10 percent can temporarily increase his factor level to 20 or 30 percent, which is still not within the normal range.

- **Important Note:** Factor IX levels are not affected by physical activity, exercise and sports. Factor IX levels do not change no matter how much physical exertion or intense exercise someone does, and regardless of whether or not the person has hemophilia.
- Unlike natural factor VIII levels, infused factor VIII is not affected by sports and exercise.

Typically, prophylaxis raises a child's factor VIII or IX levels to only 20 or 30 percent of normal immediately following the infusion. Even if he infuses clotting factor right before a game or physical activity, the level of infused factor circulating in his bloodstream will already be starting to decrease.  See **Chapter 5, Clotting Factor Therapy**. If he infuses clotting factor several hours before the activity, his circulating levels of factor will be much less than the initial 20 or 30 percent increase. Two or three days later, those levels will drop back down to around 1 percent — providing very little protection.


Additionally, if a child gets an injury or has minor but repeated bleeds while playing a sport, his factor levels will drop because they get used up to stop the bleeding.

This clearly shows that prophylaxis does not make a child with hemophilia normal in terms of having blood that clots properly.

Prophylaxis is a huge advance and has been shown to dramatically reduce risk and damage to the joints – but it does not raise factor levels to within the normal range. It is not a guarantee against bleeds and joint damage.

“I think the important thing is to make your child aware that you’re not the authority. What helped us early on were the guidelines published by the CHS on participation in physical activities. As you get older and more experienced, you start to understand that common sense plays a very important part.”

Repeated bleeds into a joint can lead to early and permanent joint damage. Once bleeding into a joint happens a few times, the joint lining can become inflamed and thickened. This type of joint disease is called *synovitis*. This in turn can lead to more bleeding and more joint damage. Furthermore, putting full weight on a joint that has recently bled or returning to physical activity too fast also contribute to early joint damage.

 For more information, see **Chapter 8, Complications of Hemophilia.**

Conclusion

It’s not always simple and easy to decide which sports and physical activities are good for your child. The challenge is to choose a safe activity or sport that will provide benefits while keeping down the risk of bleeds and early joint damage.

Sometimes, despite the recommendations and advice from the HTC, children and teenagers may try to test their limits for themselves to find out what they are and are not capable of doing safely. Some people consider this a normal part of the learning process and growing up.

But are you or your child willing to accept the certain risk and likelihood of early joint damage, and perhaps more serious joint disease in the future, in exchange for some of the psychosocial benefits of doing high-risk activities, exercises or sports? This is not an easy question to answer.

Fortunately, you and your child are not alone. The HTC team is available to guide you on how to select safe sports and activities that are right for your child’s particular situation. It’s also helpful to meet other families living with hemophilia who can share their experiences and how they deal with these issues.

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Some important points to remember:

- There isn't a single best activity or sport that is perfect for everyone but swimming, cycling, walking, tai chi and specific exercise programs are often recommended by HTCs.
- Even if there was an ideal sport or activity for children with hemophilia, not all would be interested in it. Everyone is unique.
- Sports do not always cause the same problems or have the same benefits in all children.
- It's important to review your child's treatment diary with the care team to see if there are any bleeding patterns. This will help you judge if the activity was a good choice or if you need to reconsider. If you chose well, you might notice that your child has fewer bleeds and needs to infuse less factor, less often. If not, you may discover that the activity has caused more bleeds than before.
- Keeping a treatment diary is an especially good strategy with teenagers, who may be so keen to try a sport or activity that they don't listen to parents and HTC team members who try to convince them to stop. They need to see the hard evidence for themselves. The diary will show his bleeding patterns when he participates in the sport or activity.



In the end we all have the same goal — to help your child enjoy the benefits of being active while having fun and being as safe as reasonably possible.