

PASSPORT TO WELL-BEING



Empowering people with bleeding disorders
to maximize their quality of life



Destination fitness

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Canadian Hemophilia Society
Help Stop the Bleeding

www.hemophilia.ca



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The Canadian Hemophilia Society is committed to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure.

The CHS consults qualified medical professionals before distributing any medical information. However, the CHS does not practice medicine and under no circumstances recommends particular treatments for specific individuals. In all cases, it is recommended that individuals consult a physician before pursuing any course of treatment.

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*Note: Bleeding disorders affect both men and women.
The use of the masculine in this text refers to both.*

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INTRODUCTION

We have all heard the statistics. Nearly thirty percent of Canadian children and youth (2-17 years old) are overweight or obese. This number increases to over 50% in adults. Today's youth and adults are both less fit and less active. Only 7% of children and youth and 15% of adults meet the Canadian Physical Activity Guidelines, and across the age spectrum individuals spend over 60% of their day in 'inactive' pursuits (TV, video games and computer, or 'desk jobs'). We all know that physical activity is important for weight control. As well, it can prevent heart disease, depression, cancer and diabetes. And, for people with bleeding disorders, physical activity can develop strong muscles to protect joints from twists and strains, and better coordination to prevent falls and injuries.

But what is physical activity?

Some people think of team sports, such as basketball, hockey or soccer, while others think of individual sports like golf, swimming and skiing. Quieter activities such as walking, snowshoeing, gardening, yoga and Tai chi are also excellent physical activities. So are the chores we all have to do: housework, climbing stairs, raking leaves, mowing the lawn and shovelling snow. Physical activity is anything that keeps you moving.

"I hate exercise for the sake of exercise. Don't ask me to lift weights! But I enjoy shovelling snow, cutting and pruning trees, and stacking firewood. Not only do these activities keep me in shape, but I accomplish something useful."

– a 60-year-old man with hemophilia

This booklet, *Destination fitness*, will provide guidance on not only how to keep moving, but also on how to do it safely. Physical activity will help you to achieve an active lifestyle, no matter how old you are or what type of bleeding disorder you have. You may find that the journey toward fitness is easier than you think!





BEING ACTIVE: AS NATURAL AS BREATHING

A perspective written by Raymond O'Shaughnessy, who grew up in Montreal in the 1960s when physical activity was discouraged for a boy with hemophilia.

As far back as I can remember, being active was as natural as breathing; physical activity was the way to get around and to get ahead, and the guarantee of long life and independence.

I was born with hemophilia in 1960. At that time, it took a strong dose of determination to become involved in physical activities. They were prohibited by my physicians because of the associated risks—repeated bleeding and hospitalizations. Despite these risks, how could I have refused my body's call, the irresistible need to "be like everybody else", the profound feeling that I could reach my potential while respecting the limits set by my hemophilia? I learned very early in life that it was up to me to begin this long journey by mastering the tools I needed, listening to and getting to know the marvellous machine of my body so different from that of others.

What didn't I try? I admit today that the results weren't always brilliant... but they were never catastrophic and certainly always educational. I learned through my own trials and errors, having no model to follow or support from my immediate entourage. Today, the context is completely different. Knowledge about hemophilia has advanced and, at the same time, the resources available to those affected have developed rapidly. It is now easier to evaluate the risks and the benefits of physical activity for a person with a bleeding disorder. As for me, all I had was my certainty that a fit body with strong and supple muscles would ensure a better future. How could I have "protected" myself and gained confidence in myself without "living in" this body and learning its finer points?

It was thus with confidence and assurance that activity became as normal and essential for me as eating and drinking. Touring by bicycle, sailing, canoe-camping, mountain hiking, cross-country skiing—to name just a few—became synonymous with independence and freedom. In my mind, they were associated with travel, but also with well-being because of the very real benefits they brought me, including an important decrease in bleeding episodes.

Hemophilia has not ruled my life. Through physical activity I have achieved independence, and health of body and mind. I have experienced adventure and found my place in this world.

– Raymond O'Shaughnessy



BENEFITS AND RISKS OF PHYSICAL ACTIVITY

Benefits

"I like Irish dancing. The competitions give me a sense of accomplishment and confidence in myself because I am good at what I am doing."

– an 8-year-old boy with hemophilia

"I felt so much healthier after starting exercise. I had more energy and felt so much better about myself."

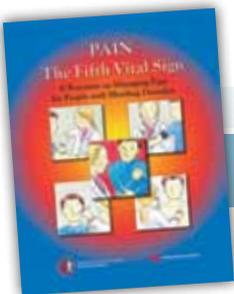
– a 15-year-old girl with severe von Willebrand disease

Physical activity makes us feel more alive. It increases our self-esteem and self-confidence, and develops our interests and hobbies. Physical activity provides a sense of well-being and involvement through the development of social skills, interaction with others, cooperation and healthy competitive spirit. Beyond these very real psychological benefits, physical activity is essential for healthy growth and development. It...

- develops cardiovascular fitness and reduces the risk of heart disease and stroke in later life.
- enhances bone formation and reduces the risk of osteoporosis. Thirty-five to forty percent of a person's total bone mass is formed during adolescence, so this time is particularly important.
- helps maintain a healthy body weight, which reduces stress on joints.
- positively affects aerobic power, agility and strength.¹

"Dietary interventions designed to reduce weight among persons with bleeding disorders may be the most effective prevention for range-of-motion loss besides avoidance of joint bleeds."¹¹

- decreases the chances of diabetes and high blood pressure.
- develops strong muscles. Between 12 and 17 years of age, boys rapidly gain muscle mass and lose 3–5% of body fat. Good muscle strength and endurance help protect joints from injury. Active children are more likely to become active adults!¹¹¹
- temporarily increases endorphin levels, leading to feeling better and happier.
- even helps to reduce/manage chronic pain.



Pain | The Fifth Vital Sign
A Resource on Managing Pain for People with Bleeding Disorders





"The Pain Service at the Hospital for Sick Children always recommends appropriate exercise to our patients. We know that exercise makes the body release chemicals, called endorphins, that not only make us feel less pain but also make us feel good. It's something you can control and do for yourself."

– Dr. Michael Jeavons, Psychiatrist, HSC Pain Service

- maintains or improves muscle flexibility. This reduces the risk of strains, decreasing the chance of a bleed.
- helps maintain joint mobility by maintaining joint and cartilage lubrication and health.
- maintains or improves joint proprioception (the body's ability to know where it is in space) which helps prevent injury.
- improves coordination and reflexes which shorten reaction time and help to avoid injury.
- develops motor skills. The more experience of activity a child has, the better his motor skills are likely to be, leading to better balance and coordination.
- maintains or improves general mobility and function, and long-term autonomy.

"The older I get, the more I think about this question of autonomy. I am spurred on to maintain my activities and to keep the autonomy I have."

– a 43-year-old man with hemophilia

- increases blood flow which helps to repair damaged tissues (tendons, muscles, cartilage and bone).
- reduces mental and muscular tension, and increases concentration and energy levels.

"I have often observed that periods of sustained exercise, for example, a bike trip, reduce the number of bleeds greatly, while at the same time providing a sense of general well-being, no doubt associated with the endorphins secreted by my body."

– a 43-year-old man with hemophilia

The key is to choose the right exercise. The wrong activity can lead to increased rather than decreased pain. The best advice is to talk to your physiotherapist.





For a person with a bleeding disorder, participating in the right activity has a whole range of benefits. But most of all, **PHYSICAL ACTIVITY IS FUN!**

Risks

Avoiding all bleeds is probably impossible for a person with a bleeding disorder. Avoiding the most serious ones, and repeated bleeds into the same joint, however, is extremely important.

Although most activities carry some risk, there are certain factors that increase the chance of bleeding... and the risk of serious injury.

- *Contact and collision* – Sports in which there are deliberate collisions—such as rugby and football—are riskier than sports where contact is unintentional.
- *Repetitive motion and extremes of motion* – Activities that use the joints at the limits of their range of motion can pinch the synovium and start a bleed. Examples are racquet sports, where the elbow may be hyperextended many times, and running and jumping where the ankle is repeatedly dorsiflexed (foot towards shin).
- *Speed* – Motorized sports like snowmobiling and dirt biking carry a greater risk of injury than regular biking because of their speed.
- *Force of impact* – Football and boxing, for example, are extremely risky, even to people without a bleeding disorder, because of the high force of impact and the fact that impact is frequent and deliberate.
- *Height* – The more height involved, such as in downhill skiing, snowboarding and hang gliding, the greater the risk of serious injury.
- *Unpredictable conditions* – Waves in water skiing, and icy surfaces when downhill skiing, are examples of how unpredictable conditions can affect the degree of risk. Players' movements in team sports are also unpredictable and lead to collisions.

Target joints, arthritis, chronic hepatitis, HIV and—most significantly—*inhibitors* can make selecting and participating in physical activities more of a challenge. Individuals who have any of these complications will require more careful assessment and discussion with the members of the comprehensive care team to determine safe and appropriate physical activities.

Choosing the activity carefully, preparing for it well, and knowing how long and hard to practise it, can help to reduce the risk of injury. Learning to make good choices, armed with good advice from the members of the treatment team and, yes, sometimes by trial and error, is an important part of growing up and living with a chronic condition such as a bleeding disorder.

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

– a mother of children with hemophilia

People with inhibitors, who are at high risk of bleeding and who may already have several target joints, must ask this question: Are the benefits of certain physical activities worth the risk? This can only be answered following a thorough discussion between the person with an inhibitor and his comprehensive care treatment team. Decisions must be made on an individual, case-by-case basis.



COMPONENTS OF A FITNESS PROGRAM

There are several components that make up a well-rounded, complete fitness program. Ideally, as you map out your road to fitness, aim to include all three of the following components on your journey to healthier living.

Endurance or cardiovascular activities improve the heart's and body's ability to pump blood and carry oxygen and energy to the various organs and tissues. Benefits also include a decrease in life-threatening diseases such as stroke, diabetes, heart disease and high blood pressure. Good examples are swimming, brisk walking and cycling.

Muscle strengthening improves the ability of muscles and tendons to exert themselves or resist forces for relatively brief periods of time, without sustaining injuries. Good examples of activities are resistance training using weights or stretchy bands and calisthenics which specifically promote muscle strengthening.

Flexibility exercises help muscles and tendons to attain their maximal range of motion. Experts believe that improved flexibility also helps in the prevention of musculoskeletal strains/sprains. Activities such as yoga, tai chi and specific stretching exercises help to improve flexibility.

Many activities or exercises involve only one—or at most, two—of the above components. For example, jogging mainly improves cardiovascular endurance, body building increases strength, and yoga promotes flexibility. Therefore, a person may benefit by combining two or three complementary activities.

Finally, one should also add proper nutrition and sleep (or rest) to this list of components comprising a well-rounded fitness plan.





ROADBLOCKS TO PHYSICAL ACTIVITY

Many people, whether they have a bleeding disorder or not, find reasons to avoid physical activity. Do any of these statements sound familiar?

- I'm just not in good enough shape.
- My joints hurt so much I can't do any physical activity.
- My knees, ankles and elbows are so badly damaged, there's no point in trying to get in shape.
- I am too busy to exercise.
- I have a bad knee and I am afraid of hurting it.
- I don't know where to start.
- I had a bad experience the last time I tried.
- I have no one to exercise with.
- I don't like exercise. I prefer quiet activities.
- I can't find the motivation to keep at it.
- My doctor/nurse/ mother/father won't let me.
- It's too far to go.
- It's too cold. (It's too hot.)
- There's not enough snow. (There's too much snow).
- It costs too much.
- There are no facilities where I live; the hours of operation don't suit my schedule.
- Instructors/coaches are not knowledgeable about the risks to me.
- I know someone who tried_____. He had a bad experience so I'm scared.
- I have an inhibitor.

Each of these statements contains an element of truth, a reason why physical activity may be more difficult and require more thought. Keep your own reasons in mind as you read the next section on choosing the right activities.





STARTING OUT ON THE JOURNEY TO FITNESS

How much activity?

Health Canada has published guidelines regarding recommended amounts of physical activity for different age groups. (www.csep.ca/english/view.asp?x=949)

For example, toddlers and preschoolers (ages 1–4) should have 180 minutes of physical activity throughout the day. Children and teens (5–17 years of age) should engage in 60 minutes of moderate to vigorous activity every day, and ensure vigorous activity at least three times a week. Activities that strengthen bones and muscles should also be done three days per week.

Adults of all ages should have at least 150 minutes of moderate- to vigorous-intensity aerobic physical activity per week, in bouts of 10 minutes or more.

Conversely, Health Canada also has guidelines regarding how much SEDENTARY time is acceptable for different age groups. They discourage prolonged sitting (more than an hour) and 'screen time', that is TV, computer, and electronic games.

For people with bleeding disorders, who often need periods of rest to recover from bleeding episodes, it can be quite challenging to meet these guidelines.

It is therefore important to have a variety of activities to choose from, to minimize sedentary time and to allow you to meet the targets for aerobic activity and strengthening most of the time.

Choosing the right activities

"I recently started an exercise program. I feel more fit and I can do more. I am doing yoga, too. It has made me stronger and more flexible."

– a 15-year-old girl with severe von Willebrand disease

Choosing the right activities may take some thought, just as planning a trip requires careful research. Before deciding where to travel, the first questions you might ask yourself are:

- What places sound interesting?
- Can I travel with my family or friends?
- Do I know anyone who has been there before?
- How much will the trip cost?

These are almost the same questions you need to consider when choosing fitness activities for yourself or your child.

- What do you like to do? You will be much more likely to stay with an activity if you find it enjoyable.
- Can your family and friends participate? Most people are more likely to continue an activity if they can do it with a buddy or a group of friends. Keep in mind, however, that people may push themselves past their limits to prove they are as good as everybody else. Education and preparation are the best ways to limit the risk.



- Have you talked to people who have tried this activity? Get their tips about when to go, where to go, what clothes to wear and who the best “tour guides” are... just like for a real trip.
- Have you done your homework? Travel to a new place can be exciting, but also a bit scary. Advance preparation always pays off. Just as you might read a travelogue or a travel magazine, find magazine or web articles (parents' magazines, fitness magazines, fitness Web sites) and see what others say about the activity.
- Have your parents talked to others? Parents may be reluctant to let their children be too active, and may find it very helpful to talk to other parents or clinic staff.

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

– a mother of a child with hemophilia

- Teenagers may be keen to try the latest activity so they can be part of the crowd. But is this really a safe “travel destination”?
- If you are thinking about joining a fitness class or a sports team, observe a few sessions before you commit yourself. See if the pace of the activity suits you. Watch how the instructor or coach deals with those who might be having trouble keeping up; you might have days when you are recovering from a bleed and need to slow down a bit. Will the instructor be considerate of this or will you be pushed past your comfort level?
- What special preparations (or equipment) are needed? Do you need to coordinate your fitness days with prophylactic infusions? Do you need to use anti-inflammatory medicine? Do you need to use a brace or support for a target joint or weak muscle? Is there a treatment facility nearby in case you have a problem, or do you need to take treatment supplies with you?

“When engaging in physical activity, my first concern is ensuring I have my factor products close at hand, as well as knowing where the closest medical facilities can be found.”

– an adult with hemophilia

- How much will this activity cost?
 - A fitness activity does not have to cost any money at all. Gardening, playing badminton in your back yard, shovelling snow or walking to the corner store instead of taking the car are all activities that can improve fitness. If the weather is miserable, a brisk walk in the local mall can be a good activity. Or turn up the stereo and dance in your living room.
 - Can you afford the time it takes? Can you exercise on your lunch hour or on the way home from work? If you take the bus to and from work, get off one stop early and walk. Increase this to two stops... or more.
 - Is equipment required? Is the equipment expensive? Can you rent the equipment while you try out the activity? Is good used equipment available?



- Beware of “packages”. There are lots of exercise machines on the market that sound too good to be true, and usually are! Many fitness clubs want you to commit for a full year or more. What happens if you get injured and cannot continue? Can you get a refund?

The members of your comprehensive care team are like good *travel agents*.

- They can help you decide what is realistic for you. Do you have a target joint or an inhibitor that will influence what you can do? If you’ve had a recent joint bleed, how long do you need to rest it before resuming activity?
- The nurse can help you coordinate your factor replacement and monitor any changes in factor usage after you start a new activity.
- The physician can discuss with you whether anti-inflammatory medications or pain medications would be helpful or harmful.
- The physiotherapist (along with other team members, including other patients or parents) can help you select safe activities and modify them if necessary, according to your joint health status and fitness level. He/she can show you warm-up exercises or certain equipment or devices to protect sore or stiff joints during different activities. The therapist can also tell you what to do if you get hurt, and advise when you are ready to go back to the activity following a bleed or an injury.

Keep a *travel journal*

- Most people take pictures when they go on a trip. These pictures help them remember what was good (and maybe not so good) about their trip.
- Keep copies of your treatment diary to see bleeding patterns. You will be able to tell if the activity was a good choice or if you should reconsider. If you chose well, you might notice that you use LESS factor. Or you might discover that the activity you really wanted to do has caused more bleeds than you had before. (The diary is an especially good strategy for teenagers, who may be so keen to try a sport or activity that they don’t listen to parents and team members who try to convince them to stop.)

The *armchair traveler*

Being able to participate in activities with friends is an extremely important part of a person’s life. What happens when a person’s condition means that he cannot join in? Here are some alternatives.

- He can be the team statistician or equipment manager.
- He could take a first aid course and be the team “trainer”.
- He could take responsibility for organizing the activity.
- He could learn to excel in another sport or activity and invite friends to try their hands at something new.

Supervised or unsupervised activity?

- You may think that playing on a regular team is more risky than a “pick-up” game with friends. Some studies have shown that this is not always the case. Supervised teams usually pay attention to proper equipment and proper technique, and the referee is there to make sure everyone follows the rules. On the other hand, some players, coaches and parents are so concerned with winning that the game is no longer fun.



"He loved hockey but he never played except for 'driveway hockey' with his friends and dad. That was one sport we said 'no' to."

– a mother of a child with hemophilia

- There are some merits to following an exercise program in your own home. There are many books and videos that provide instruction. The advantages of this approach are that you do not have to leave your house, the cost is minimal, and you don't have to buy the latest sportswear. The downside is that you do not get feedback if you are doing an exercise incorrectly. Some of the exercises may be too hard or too easy, and you may be unsure how to modify them to suit your needs. Discuss these issues with your physiotherapist.

It might take you a while to find just the right itinerary for your trip, but keep trying! Remember: it's never too late to start.





THINKING ABOUT ACTIVITIES?

People with bleeding disorders can participate in many activities safely, but some are riskier than others. Before you choose one, use your head!

THINK ONCE!

These activities are usually safe choices for you:

- Swimming
- Golf
- Yoga
- Hiking
- Sailing
- Canoeing
- Kayaking
- Bicycling
- Tai Chi

THINK TWICE!!

These activities can cause some injuries, but can be fun to do with friends. If you pre-treat, use the proper equipment and have learned the skills you need, go ahead and participate in:

- Badminton
- Basketball
- Baseball
- Bowling
- Tennis
- Skating
- Volleyball
- Cross-country skiing
- Running
- Soccer
- Hackeysack

THINK AGAIN!!!

These activities can cause injury even to people who do not have a bleeding disorder because they involve speed and/or body contact. Even though they might seem fun to do, you need to ask yourself if they are worth the risk of getting hurt. They include:

- Football
- Hockey
- Downhill skiing
- Rollerblading
- Skateboarding
- Karate/Judo
- Snowboarding
- Wrestling
- Boxing
- Taekwondo
- Dirt bike racing
- Racquetball
- Snowmobiling

There are many things to consider when you choose a sport. Your physiotherapist can help you decide if you should think once, think twice... or think again.

A word of caution: Even activities in "Think once" may be too risky for certain people at certain times, and therefore would become a "Think again" activity. For example, golf may not be appropriate for a person with a target elbow joint. And activities in "Think twice" may be "Think again" activities for a person with serious limitations to movement in a knee joint.

"I like this system of "Think once... Think twice" way better than an adult just telling me what not to do, which, I admit, I usually ignore anyway. It encourages me to be responsible and decide what works for me."

– a 16-year-old boy with hemophilia



CONCLUSION

On a trip, we usually have a destination in mind. Everybody knows, however, that half the fun is getting there. The places we discover, the people we meet and the experiences we have along the way are what we remember. Sometimes, we even find a new destination and end up somewhere we never planned to go.

It is the same with the journey along the road to fitness. We may or may not reach the level of fitness we dream of. But in starting down that road—in taking that first step of a long journey—we are immediately more alive, more involved in the world around us and on the way to reaching our potential. And who knows what surprises we will encounter along the road!





RESOURCES

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3. *Identifying Common Joint and Muscle Bleeds.* Kathy Mulder, Physiotherapist, Manitoba Bleeding Disorders Clinic.
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Footnotes

- I) Musculoskeletal fitness: the keystone in overall well-being and injury prevention. Hunt A. *Clin Orthop.* 2003 Apr;(409): 96-105.
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