IN THE DRIVER’S SEAT

A WORKBOOK DESIGNED TO GUIDE PERSONALIZED DECISION-MAKING ABOUT PHYSICAL ACTIVITIES
This workbook has been developed by members of the Canadian Physiotherapists in Hemophilia Care (CPHC) to guide adults with bleeding disorders through an organized and thoughtful approach to decision-making around physical activities.

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For more information:
Canada Fitness Guidelines

Identifying common joint & muscle bleeds
www.hemophilia.ca/en

Playing it Safe
www.hemophilia.org/Community-Resources/HANDI-NHFs-Information-Resource-Center/NHF-Publications

Exercise in Management of Musculoskeletal Pain
www.iasppain.org/files/Content/ContentFolders/GlobalYearAgainstPain2/MusculoskeletalPainFactSheets/Exercise_Final.pdf

Get Set - Train Smarter By International Olympic Committee
itunes.apple.com/au/app/get-set-train-smarter/id894609112?mt=8

Physical Activity, Exercise and Sports.
Chapter 12 in All About Hemophilia – A Guide for Families.
www.hemophilia.ca/en

Strategic Assessment of Risk and Risk Tolerance (StARRT) framework
www.ncbi.nlm.nih.gov/pubmed/26036678
About this workbook

Just as people with bleeding disorders have their own unique bleeding patterns, we recognize that each individual has unique interests, abilities and limitations when it comes to physical activity.

We hope that you will use this workbook to help you reflect on the role sports and physical activities play in your life, and use it to help you make a plan that works for you.

You have valuable knowledge about the condition of your body, your interests and your bleeding disorder. The objective of this workbook is to help you match your goals and physical condition with physical activities that are suitable for you.

This is a workbook, designed for you to work through on your own, or to use in collaborating with your physiotherapist or any member of your health care team, as well as coaches and trainers, and family members.

We expect that you will continue to use the skills you develop from this workbook as your life circumstances, physical abilities and interests change over time.

This workbook will not provide lists of activities that are considered “safe” or “not safe” for people with bleeding disorders. While they may be helpful to get you started in thinking about activities, a “one-size-fits-all” approach does not work for everyone. Many of us know people with bleeding disorders (maybe you are one of them) who participate in activities that could be considered “dangerous,” but still have very few injuries/bleeds. On the other hand, there is no activity that is 100% safe for all people all the time.

THIS WORKBOOK IS DIVIDED INTO FOUR SECTIONS

A. ASSESSING YOURSELF
- Assess your own current levels of activity and fitness and explore whether they are acceptable to you.
- Understand the many benefits of physical activity, exercise and sports.
- Identify goals that you may want to achieve by participating in physical activities.
- Identify barriers to participation in physical activity.

B. CHOOSING PHYSICAL ACTIVITIES THAT WORK FOR YOU
- Assess your own physical strengths and weaknesses.
- Assess the physical demands of specific activities.
- Match activities to your goals and abilities.

C. REDUCING THE RISKS
- Discuss your physical activities with your physiotherapist and bleeding disorder team.
- Determine ways you can reduce the risk to yourself and participate safely.
- Plan ahead in case of injury.

D. MAKING AN ACTIVITY PLAN
- Formulate a specific plan for your activity participation.

On the following pages you will be asked several questions. There are no right or wrong answers, only your answers.
SECTION A: ASSESSING YOURSELF

For adults aged 18–64, the Canada Fitness Guide recommends 150 minutes per week of moderate to vigorous activity in blocks of at least 10 minutes. This means you should set a target of a minimum of three 10-minute blocks every day. This includes activities like yard work, walking to the bus stop and active video gaming, as well as sports and other exercise.

Question 1: How much physical activity do you do?
Think about your usual amount of physical activity. How would you rate yourself based on the Canada Fitness Guide recommendation of 150 minutes of exercise per week?

- I achieve or exceed the target almost every week.
- I reach the target about 75% of the time.
- I sometimes reach the target 50% of the time.
- I rarely reach the target (25% of the time or less).

Question 2: How satisfied are you with your current level of physical activity?
Regardless of how much physical activity you do, the more important question is whether you feel this is the right amount for you.

Do any of the following statements apply to you?

- I've been told by ______________________ (doctor, sibling, friend, parent) that I should be more active, and I agree.
- I used to be fairly active and would like to get back to that level of activity again.
- I've never been really active, but have been thinking I would like to be more active than I am now.
- I would like to try some new or different activities.
- I am satisfied with my current level of activity.

Question 3: What are your goals?
This is a list of the many benefits of an active lifestyle. Are any of these your goals?

You may have reasons to be physically active, not related to your bleeding disorder, that you may not have considered.

- Improve my balance/coordination
- Control my blood pressure
- Control my blood sugar/prevent diabetes
- Improve my sleep pattern
- Improve my mood
- Improve my endurance/stamina
- Keep up with my kids
- Decrease the frequency of my injuries
- Join a team
- Get people to stop bugging me to be more active
- Participate in an activity that I was told not to do
- Prevent injuries
- Achieve/maintain a healthy body weight
- Decrease the number of bleeds I have
- Decrease my pain
- Decrease my stress level
- Have fun with friends
- Decrease the risk of bleeds
- Meet new people
- Compete with myself or others
- Improve my appearance/self-image

Are there any other reasons that you are thinking about changing your physical activity patterns?
Question 4: What activities do you do now?

List any physical activities you do. Then, looking across the table, make a check mark in the column that best describes how you feel about and how your body reacts to that activity.

<table>
<thead>
<tr>
<th>Activity</th>
<th>I enjoy it and never have any pain or bleeds from this activity</th>
<th>I enjoy it but sometimes have pain or bleeds</th>
<th>I enjoy it but am having lots of pain/bleeds; maybe I should stop this one</th>
<th>Don't love it; would like to find something else</th>
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Summary: Before moving on to the next section, consider the following statements, answering yes or no to each one.

- I am not completely satisfied with my current level of physical activity
  - Yes
  - No

- I have identified some goals that could be addressed by physical activity
  - Yes
  - No

- I have identified that some of my current physical activities may no longer be suitable
  - Yes
  - No

- I would like to try some new or different physical activities
  - Yes
  - No

The above statements can help you gauge if you want to make some changes in your physical activities.
SECTION B: CHOOSING PHYSICAL ACTIVITIES THAT WORK FOR YOU

Assessing your own fitness
Physical fitness has many components. You may be fit in some areas, and not so fit in others. Your ability to participate successfully in and enjoy certain physical activities may be affected by your bleeding pattern, chronic joint damage and/or pain.

In this section, you will outline your strengths and weaknesses and weigh them against each other. This information will be useful when you are deciding which activity is good for you.

Part I: For each of these descriptions, put a mark on the line that describes your situation. There is space at the bottom to make more detailed notes.

Notes:
0 = not a problem at all for me
5 = some times a problem for me
10 = a problem for me and really limits my choices

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<thead>
<tr>
<th>Description</th>
<th>0</th>
<th>5</th>
<th>10</th>
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<tbody>
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<td>Pain when I do certain activities</td>
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<td>My overall strength</td>
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<td>My ability to get around</td>
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<tr>
<td>The frequency of my bleeds</td>
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<td>Pain at rest (even without activity)</td>
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<tr>
<td>My overall muscle strength</td>
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<td>My joint range of motion</td>
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<td>My flexibility</td>
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<td>My balance</td>
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<td>My coordination and reaction time</td>
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<td>My running ability</td>
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<td>My endurance/stamina</td>
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<tr>
<td>My ability to walk</td>
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<tr>
<td>Other:</td>
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NOTES:
*Use this space to describe any concerns in more detail.*

Here is an example: Carl has hemophilia. He used to really like golfing but now he has a lot of pain in his ankles when he walks and also he knows he is not as strong as he used to be. Carl might answer these questions like this:

Pain when I do certain activities
0 ____________________________|___________ 10
My overall strength
0 __________________________________|_____ 10
My ability to get around
0 _______________________|________________ 10
Notes: Sore during golf, starts about the 4th hole; still a bit sore the next day but I don’t think it’s a bleed.
Assessing your own fitness

Part 2: Now use the body diagram to describe how your joints and muscles might affect your choices. Use these symbols to indicate your strengths and areas that might need work.

**KEY**

- P = Pain
- O = Swelling
- B = Prone to bleeds
- ★ = Strong
- # = Stiffness
- W = Weakness

### Signs of joint damage include:
- swelling
- frequent bleeding
- pain
- stiffness

### When a muscle bleed heals, scar tissue is formed. This can make the muscle stiffer, weaker and more likely to rebleed.
Evaluating physical activities

You have probably been told that, because you have a bleeding disorder, there are certain activities you should avoid. What was your reaction? Did you secretly try some of these activities and hope no one found out? Did you "obey" but regretted or resented that you were prevented from doing the activity? Did you openly defy your parents and health care team and do them anyway? What was the result?

At the beginning of this workbook, we said that we were not providing lists of activities considered "safe" or "risky." This is because all activities come with some risk, and each person’s risk factors are different and can change from day to day. For example: someone with an inhibitor, someone with a weak ankle, and someone who is trying a brand new sport for the first time all have different levels of risk associated with the same activity, and also have to think of different ways to deal with the risks.

When deciding if an activity is right for you, start by taking a step back and look honestly at your bleeding patterns, your level of fitness, your skills and abilities, and how well you take care of yourself. You did this in the first and second parts. Use this information to find a sport or physical activity at your level.

This section is designed to help you evaluate the many aspects of physical activities that may be associated with risk, and decide if the activities that interest you are, in fact, a good match. Think of some different activities that you like to do, or want to try. Then work through these questions for each activity to see how you can be safe while participating (and still have fun).

The activity that I am interested in is:

Question 6: Now think about how your body has to move during the sport or activity.

Which joints/body parts need to move during the sport or activity? Do these joints move easily for me?

- Yes
- No
- Unsure

Which joints/muscles/body parts need to be strong? Are MY muscles strong?

- Yes
- No
- Unsure

Do I need good balance or coordination? Do I have good balance for this activity?

- Yes
- No
- Unsure

Does this activity involve repetitive motion? Will my joints withstand that strain?

- Yes
- No
- Unsure

Does this activity require endurance? Do I have the endurance to do this activity?

- Yes
- No
- Unsure

Do I need to be able to change directions often or quickly? Can my knees and ankles handle the stress of quick changes in direction?

- Yes
- No
- Unsure

Am I fit enough right now to do this activity?

- Yes
- No
- Unsure

If you answered "No" or "Unsure" to any of these questions, consider talking to your treatment centre physiotherapist for advice.
Question 7: Now think about the activity itself:
Is there a chance of collision in this activity?
☐ Yes  ☐ No  ☐ Unsure
Could I be hit by another player, either accidentally or on purpose?
☐ Yes  ☐ No  ☐ Unsure
Could I be hit in the head?
☐ Yes  ☐ No  ☐ Unsure
Could I run into something at high speed?
☐ Yes  ☐ No  ☐ Unsure
Does the activity take place in a remote location?
☐ Yes  ☐ No  ☐ Unsure
Is there medical help if I need it in an emergency?
☐ Yes  ☐ No  ☐ Unsure
Is the terrain uneven, or hard? Can it be slippery such as wet floor or ice during the winter?
☐ Yes  ☐ No  ☐ Unsure
Will my knees/ankles/back and muscles like this?
☐ Yes  ☐ No  ☐ Unsure
What equipment is used for this activity?

Does it offer protection, or could it put extra stress on my body?
☐ Yes  ☐ No  ☐ Unsure
If this is a team sport, what position will I be playing?

Is this position the best fit for my abilities?
☐ Yes  ☐ No  ☐ Unsure

Did you know?
A concussion is an injury to the brain. Symptoms of a bleed into the brain include headache, blurry vision, nausea, sleepiness, poor balance/coordination and can progress to seizures and unconsciousness.
These symptoms are an EMERGENCY.
Call 9-1-1 and get to the closest emergency department as soon as possible!

Question 8:
It may be unpleasant to think about the potential serious consequences of participating in higher risk activities. However, it is a necessary part of making a fully thought out decision.

Ask yourself:

What would happen if I had an injury from this activity?
- Could I take time from work/school to recover?

What if I had a concussion?
- Do I know how to manage a concussion?
- Do I have a health care provider that will help me return to activities?

Do I have “target” joints that could become more painful if I do this activity? How would that impact me?

Am I setting myself up for long-lasting joint damage in the future?

NOTES:

Now that you have thoroughly thought about your capabilities and your interests, and carefully examined the demands and potential consequences of a particular activity, ask yourself:

Does your choice of activity seem safe for you?

YES
Great!
Continue to next section.

NO

Now what?

Can you make some changes to make it safer?
Consider competition level, different team position, indoor vs. outdoor, team vs. partner or solo activity, etc.
Is there a different activity that might also achieve the same goals?
SECTION C: REDUCING THE RISKS

Now that you have matched an activity to your abilities and interests, there are a few more things to think about. Your bleeding disorder treatment team can help you with all of these.

Managing Injuries

Question 1: Do you have an injury management plan?
- Yes  
- No  
- Unsure

Do you have a FactorFirst card? Medical ID bracelet?
- Yes  
- No  
- Unsure

Do you have a workout partner or teammate who knows you have a bleeding disorder?
- Yes  
- No  
- Unsure

Do you need to carry a travel letter? (i.e. will you be out of reach of your usual treatment centre?)
- Yes  
- No  
- Unsure

Do you know what first aid measures to use? And why?

Question 2: How will you get the factor replacement you need if you have an injury?

If you usually infuse factor yourself, what is your plan if you can’t?

Who will help you where will you go for treatment?

Question 3: What is your agreement with your treatment centre about when to notify your team about bleeds that you have?

Are you supposed to call the nurse? The doctor?
The physiotherapist?

Do you have their numbers handy?
- Yes  
- No  
- Unsure

Question 4: What is your injury recovery plan?

How will you know if you are ready to resume the activity?

Where will you go for rehabilitation?

Preventing Injuries

Question 1: Should you be talking to your hemophilia treatment team about your clotting factor infusion schedule?
- Yes  
- No  
- Unsure

If you use factor regularly, it is important to coordinate your infusions with your activities.
The risk of bleeds and injuries can be decreased by collaborating with your team to create a treatment regimen that works with your activity schedule, your joint health and your disease.

Question 2: Besides factor, are there other things you can do to prevent injuries and bleeds?
- Yes  
- No  
- Unsure

Do you have an old injury that needs some rehabilitation?
- Yes  
- No  
- Unsure

Do you have the right equipment?
- Yes  
- No  
- Unsure

Should you take some lessons? Or practice on your own a bit first?
- Yes  
- No  
- Unsure

Do you need to do some preconditioning?
- Yes  
- No  
- Unsure

Your physiotherapist may be able to help with stretching, strengthening or endurance exercises. They can also help you improve your coordination and balance and may be able to suggest additional protection (such as braces, taping) for your joints.

Question 3: Are you able to tell the difference between pain from bleeds and other pain (e.g. inflammation?)
- Yes  
- No  
- Unsure

Your physiotherapist can help you assess your pain, swelling and movement and make sure you are not missing bleeds that need to be treated, or treating bleeds that are not bleeds.

NOTES:
**SECTION D: MAKING AN ACTIVITY PLAN**

Writing out a specific plan is a way to determine whether you are fully prepared. It can also be a good way to show that you have thought carefully about participating in an activity.

### SAMPLE ACTIVITY PLAN

**Activity:**
- Indoor soccer

**Details (position, competition level, etc.):**
- Rec league at the YMCA, in the gym. Guys play different positions - I will probably mostly play defense, at least to start. Gym supervisor is there all the time and also acts as the ref.

**Schedule:**
- Mondays and Thursdays, 7–9 p.m. - league runs September–December and again January–March.

**Factor replacement:**
- Ask to treat on Mondays and Thursdays, just before soccer. Consider treating 2x per week.

**Preconditioning:**
- Haven’t played in a while. Going to start walking/running on the indoor track 2–3x/week until the season starts. Play defense until I’m feeling comfortable with how it’s going. Go see physio about my knees and get some exercises to make them stronger.

**Safety gear/equipment:**
- The gym has a rubber floor so I’ll get new runners for indoor use. I will get some shin guards in case I’m taking balls to the legs.

**Lessons/tune-up:**
- I played in high school, so know the sport pretty good. I might talk to one of the trainers at the gym about how to get my feet moving faster.

**People who can help me:**
- My buddy, Joe, knows about my bleeding disorder and when I might need help. I have my FactorFirst card on me just in case.

**Contract:**
- I agreed with my girlfriend that I will try September to December and see how it’s going. If I start having bleeds (despite proph) I agree that I will stop playing soccer and try something else. If there is no change in my bleeding pattern, I will sign up for the winter session too.

### MY ACTIVITY PLAN

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<tr>
<th><strong>Sport or activity:</strong></th>
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<table>
<thead>
<tr>
<th><strong>Details (position, competition level, etc.):</strong></th>
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<table>
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<tr>
<th><strong>Pre-participation training/rehabilitation:</strong></th>
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<th><strong>Safety gear, new equipment:</strong></th>
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<th><strong>Coaching, lessons or a technique tune-up:</strong></th>
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<tr>
<th><strong>Support people:</strong></th>
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<td>(Emergency contacts/people who help me, people who are aware I have a bleeding disorder)</td>
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<th><strong>Schedule:</strong></th>
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<th><strong>Frequency, time of day:</strong></th>
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<th><strong>Factor replacement timing:</strong></th>
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——— www.hemophilia.ca ———
When a contract is helpful...

Once you have answered all these questions and carefully chosen an activity, you, a family member, a friend or a health care team member may still have concerns. This is when having a "contract" can be helpful in setting boundaries or limits, and to help you decide when it's time to try something else.

Contract ideas:

- Think about what could happen:
  - more bleeds, more pain

- How can you make the sport safer?
  - e.g. less competitive, don't play as often, wear safety gear, play on a bigger team for more breaks, etc.

- How long will you try the activity?

- What would make you stop the activity or change to something else?
  - e.g. if non-contact becomes contact
  - more bleeds than before – missing work, school or games due to bleeds; using more factor
  - feeling that joints are becoming more painful
  - league getting too competitive, pressure to return too soon after injuries.

- Who will you make this contract with?
  - Spouse/partner, self, health care team

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**NOTES:**

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Chris is a 19-year-old with severe hemophilia A. He's decided to play recreational volleyball and to work out at a gym. He thought about playing hockey or basketball, but with a past shoulder injury, thinks that a team sport with less contact would be a better choice. Chris knows that playing the middle “blocker” position will be easier on his shoulder, and he’s looking forward to playing as part of a team. For Chris’ gym workouts, before he gets started at his new gym, he’ll do the intro session to the equipment offered by the trainer. He can make sure he gets a good workout that’s also safe, and let the gym staff know about what to do in case he gets injured.