Hemophilia from diagnosis to home care: Support for the journey

This publication is made possible by an unrestricted education grant from Bayer Inc.
BP401-00006
**Introduction**

These books were developed to help new parents work through the challenges of raising a child with hemophilia.

Parents will determine how they use Book 1 to record important information, events and discoveries for future reference.

Book 2 can be introduced to your child at ages 3 to 5 and given to your child at age 5 when he begins school.

These books are meant to complement the information parents may have received in the Step by Step Program and other CHS materials including All About Hemophilia: A Guide for Families and the Emergency Room Guide: Prepare To Succeed. As with all educational materials, the maximum benefit is attained when the content is reviewed and discussed with your nurse coordinator. It may also be helpful to discuss some topics with other parents.

**Commonly used terms**

CBS = Canadian Blood Services
HQ = Héma-Québec
CHS = Canadian Hemophilia Society
HTC = hemophilia treatment centre

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Thank you to the CHS Step by Step parent volunteers who reviewed the book and provided the parent quotes.

A special thank you to all the families who manage bleeding disorders in their family with courage and tenacity. You are an inspiration to us all.

A special thank you to the Bleeding Disorders Program at the Health Sciences Centre in Winnipeg for showing us the value of working in partnership to manage bleeding disorders.
Our support network

We learned that we are not alone and that there are many caring individuals and resources to help.

Medical contacts

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Part 1 – Beginning the journey

“The HIC was my backbone after my son’s diagnosis. Naturally I had many fears, like most parents when their child is diagnosed. The understanding I received from our HIC and nurse along with educational information, support and a soft hand was amazing. Slowly, one at a time, we are chipping away at my fears and questions together. We are growing as a team.”

A mom from New Brunswick

The first year after diagnosis is a year when parents begin to learn about hemophilia. When caring for a child there are always many unknowns, and hemophilia often adds to the challenges of parenting. Your hemophilia treatment centre, CHS and your local chapter will provide the necessary education and support you will need. This is where to begin recording what you learn.

The events that led to diagnosis

_________________________________________________________

My most important memories of that day

_________________________________________________________

_________________________________________________________

_________________________________________________________

_________________________________________________________

_________________________________________________________

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Managing common fears

This section deals with the things parents worry about most, immediately after their child is diagnosed with a bleeding disorder. Discussing your concerns with people who have experience with hemophilia – an HTC nurse and other parents – can help lessen these fears.

Common questions

How will I recognize when my child is bleeding?

Suggestions

Date discussed with nurse or other parent

What if I don’t recognize when he is bleeding?

Suggestions

Date discussed with nurse or other parent

As my child will bruise more than other children, will people think he is being abused?

Suggestions

Date discussed with nurse or other parent

How do I know who to tell, what to tell and when to tell others that my child has hemophilia?

Suggestions

Date discussed with nurse or other parent

What do babysitters or staff at daycare need to know for my child to be safe?

Suggestions

Date discussed with nurse or other parent

How do I teach my family not to be afraid of my child?

Suggestions

Date discussed with nurse or other parent

Suggestions

Date discussed with nurse or other parent

Suggestions

Date discussed with nurse or other parent
Coping strategies

What can we do to make our home safer?

________________________________________________________________________

________________________________________________________________________

Date discussed with nurse or other parent

________________________________________________________________________

How do I feel about my child’s treatment, specifically the needles and the nurses restricting my child’s ability to move?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

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________________________________________________________________________

Discussed with __________________ Date __________________

How do my feelings and other family members’ feelings (and how we behave) affect my child?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Discussed with __________________ Date __________________

How can I be more positive? (advice from other parents)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

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Discussed with __________________ Date __________________
"Waiting for the first bleed to happen was torturous, but we read everything we could get our hands on and were ready to deal with it. Educate yourself, then hemophilia doesn’t seem so intimidating.”

A mom from Southern Alberta

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**My first trip to the ER**

(For additional information please refer to the CHS resource *Prepare to Succeed: A Guide to the ER*.)

My most important memories of that day

1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
9. 
10.
Other important information for successful trips to the hospital

Basic first aid

In the early stages, parents can help manage the bleed with first aid measures.

What is basic first aid? How does the application of ice reduce the bleeding?
(my understanding of basic first aid and application of ice)

Date discussed with nurse or other parent

If my child does not like ice applied, how can I help him to cooperate?

What is the best ice pack to use?

When do rewards work, and which rewards are best?

Tips from a child life specialist

“Our lives would be easier if we didn’t spend so much time at the hospital.”
Part 2 – The journey to home management

"Life is so much better when you can treat at home." A mom of two children with severe hemophilia A

This section will help families, when they are ready, to begin this journey. There is no set time for beginning home management. Documenting your fears will help direct your nurse coordinator to better meet the needs of your family. Please work with the nurse coordinator to develop your individual plan for treating your child at home. A strong partnership of care with the nurse and the family provides the safest, most efficient care in the home setting.

How would my child’s (and family) life be better with home management?

• More time to spend with my family
• Less stress by decreasing hospital visits
• Having control when my child receives treatment by managing my child’s care at home
• Prompt treatment

For us it would be better because

What is stopping me from treating at home? Fears? Difficulties?

• Fear of not being able to insert the needle in the vein
• Fear that I could harm my child

My fears

[Blank space for fears]

"When the hospital started talking about home care, we felt like we were being pushed out the door. However, with the support of the nurse coordinator of our NIC, home care was very successful. Our child being so active, it gave us freedom and independence to live a normal life."

A dad from Halifax
Conquering fears and problem solving

Sharing your concerns with a person who has experience providing care and treatment for children with hemophilia can often help you develop strategies to overcome the challenges and decrease your fears.

Fear: I won’t be able to access a vein.

Suggestions

Watch every time the vein is accessed by a health professional. Ask questions, review resources available and work with the nurse coordinator. Practice (not on you or your child) until you are confident.

Speak with other parents or teens that have “been there and done that.”

Fear

Suggestions

Date discussed with nurse or other parent ____________________________


Part 3 – My plan to succeed at home care

"I knew from the day my son was born that home care was right for us! I love the independence and would never look back. There are times I get frightened, but I know this offers the best care."

A mom from Saskatchewan

The goal of moving to home care can seem like an overwhelming task. There is so much to learn! Breaking up the learning into sections and outlining a realistic time frame to achieve the skills will make it much easier for you.

Review muscle and joint bleeds with a physiotherapist.

My goal is to do this by (date) _______________________

Review available literature on assessing bleeds. (List reviewed material.)

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My goal is to read the material and to have one place to keep the material by (date) _______________________

Practice makes perfect! Do a nightly assessment of joints and muscles. Many parents find bath time or pajama time a good routine time to examine their children.

☐ Week one  ☐ Week two  ☐ Becomes habit

My goal is to achieve this routine by (date) _______________________.

Gain confidence with assessing bleeds.

My goal is to achieve this skill with time and experience.
Attend clinic regularly and establish a good working relationship with the nurse.

My goal is to speak to the nurse about this by (date) ____________________

Learn to order the product.

☐ My goal is to do this by (date) ____________________

Read the package insert. Watch how the product is prepared.

☐ My goal is to do this by (date) ____________________

Prepare the product with supervision.

☐ My goal is to achieve this skill by (date) ____________________

Prepare the product safely and independently.

☐ My goal is to achieve this skill by (date) ____________________

Learning from the nurse how to do a venipuncture or access a port.

Practice date ________________

Key points learned

Practice date ________________

Key points learned

Practice date ________________

Key points learned

Practice date ________________

Key points learned
Review treatment plans with the HTC team.

Joint bleeds

Soft tissue bleeds

Learn to complete bleed sheets in a timely manner. Submit completed records (paper or electronic).
The goal is to achieve this skill by (date) __________________ .

Memorable moments


I did it!

My first success in treating my child myself.

Be confident. You're not alone!
Part 4 – Helping your child on his journey to independence

This section and the following sections can also be found in Becoming the captain of your own ship – Part 1.

This section will guide parents to direct their children to this new, sometimes challenging and always character-building, journey to self-care. Parents can journal in this book and help their child use Becoming the captain of your own ship – Part 1.

“My son learned how to self-infuse at the age of eleven when he attended the hemophilia summer camp. It was a great step in his self-confidence, but it took me time to feel comfortable with this.”

A mom from Quebec

Ages 3 to 5 years – helping Mom or Dad

Checklist

Please remember that children develop and mature at different rates.

The following are the early steps young children take while gaining an understanding and acceptance of their bleeding disorder. It is important for parents to continually assess their child’s understanding and adaptation to their condition. You or your child could use stickers when he demonstrates steps towards understanding and acceptance. (Your nurse will show you how to use Becoming the captain of your own ship – Part 1.)

Your child can describe what hemophilia means to him (no recess for a week following an injury, “I have to be careful,” “I have to slow down,” etc.).

Write down what your child says about hemophilia (exploring his perception).

Date

What was said

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What was said
Your child knows that when he is hurt, he must relax and play quietly. (When he does this with minimal prompting, he can be rewarded with a sticker.)

Description of events

Your child asks for ice when he is injured. (Reward with stickers.)

Description of events

Your child tells the caregiver when he is hurt/needs a treatment. (Reward with stickers.)

Description of events

Your child can get an ice pack or cool gel pack for the injured area (by age 5). (Reward with stickers.)

Description of events
Your child can take the treatment out of the fridge, if all stock is the same and only one box is needed. (The child may still require supervision.) (Reward with stickers.)

Description of events

Your child may still require supervision.

Reward with stickers.

Your child always washes his hands first if he helps with cleaning his skin with alcohol. (Check this off when he does this without prompting.) (Reward with stickers.)

Description of events

Your child is beginning to tune in to his body.

Reward with stickers.

Your child can sit still for his treatment most of the time. (Positive reinforcement helps!) (Reward with stickers.)

Description of events

Your child can tell you when the injury is better.

Reward with stickers.

Once this section is completed in Becoming the captain of your own ship – Part 1, your child is ready for the next level.
Memorable moments: ages 6 to 8
Memorable moments: ages 9 to 11

The HTC will work with your family through discussions and meetings with the staff of the adult programs to prepare the adolescent for the transition to adult care.
Learning to let go

“One of my biggest challenges as a parent has been letting go. When my son left home for university, I was very concerned about his well-being. My fears were soon lessened by the care and concern he received at the hemophilia care centre. The nurses were like mother hens and kept in touch with me at home.”

A mom from Newfoundland
Looking ahead...

Some people say that as a result of hemophilia in their family, they have made new friends and become closer as a family.

For us, the “silver lining” has been
Becoming the captain of your own ship – Part 1
Welcome aboard, Mates!

This book was written to guide you on your adventure. There are 5 levels to this adventure, and you must complete the jobs in each level before going on to the next level. Your parents and your nurse will help you. When you can show that you understand what you have learned, you will then be able to go to the next adventure.

Learn lots and have fun!!

This book belongs to:
Off we go! It’s time to start on your fun trip to learn more about your hemophilia. When you can do the jobs below, you will get stickers to place in your book. When you are all done, you will advance to Level 2. Remember, you can get lots of help from your family and your nurse.

Having hemophilia means:

1. ___________________________________________
2. ___________________________________________
3. ___________________________________________

I relaxed and played quietly when injured.

I asked for ice when injured.

I washed my hands before helping to clean my skin with alcohol.

I sat still for my treatment.

I told Mom or Dad when the injury was better.

Congratulations! You have successfully completed Level 1, and you can now go to Level 2.
Level 2 – Welcome aboard, Mate!

It is time to begin your new jobs. Your parents and nurse will tell you where to put the sticker after you complete each job. Learn lots, work hard and have fun!!

I washed my hands first, then took my treatment out of the fridge, while my parents watched.

I got a cold pack out of the fridge and used it for a bleed.

I watched my parents mix my factor at home.

I helped with the tourniquet, cleaning my skin, and infusing my factor.

I helped record my treatment.

I talked to the physiotherapist about muscle and joint bleeds.

I understand more about hemophilia, and I ask questions if I am not sure.

Congratulations! You are now ready to start Level 3.
Becoming the captain of your own ship
Part 2
**Important Contact Numbers**

Your nurse will help you fill in the blanks. John and David say, “Go for it!”

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CHS = Canadian Hemophilia Society
HTC = hemophilia treatment centre
Level 3 - All hands on deck!

Avast, young mate! You need to do the following tasks at least four times each. When you have been signed off on all tasks, you will begin training to be the captain of your own ship.

Please sign off the date and the type of bleed treated to complete sections 1, 2 and 3.

1. I tell my parents when I need a treatment.

- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed

2. I know when and how to use RICE (Rest, Ice, Compression and Elevation) and do this independently.

- I used RICE when:
  - Date: Bleed
  - Date: Bleed
  - Date: Bleed
  - Date: Bleed
  - Date: Bleed
  - Date: Bleed

3. I washed my hands, took my treatment out of the fridge, and mixed my factor with my parents or nurse watching.

- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed

I did everything except put in the needle.

- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed
- Date: Bleed

I order product when I have 2 or 3 treatments left.

- Telephone: #
  - I ordered my product on (date)
  - I ordered my product on (date)
  - I ordered my product on (date)
  - I ordered my product on (date)
  - I ordered my product on (date)
  - I ordered my product on (date)

I recorded my treatment by (electronic or paper) and sent them to my nurse.

- Date sent
  - Date sent
  - Date sent
  - Date sent
  - Date sent
  - Date sent

Congratulations on successfully completing Level 3. You are now ready to begin Level 4 to become captain of your own ship, which includes learning to insert the needle into your vein. Don’t worry, everyone is a little scared about giving himself or herself a needle. That’s normal.
Level 4 - Myth busters

The following myths are often the cause of fear, but they are not true.

1. You're really going to hurt yourself if you do it wrong.
2. It hurts more when you do it yourself.
3. If you are older it should be easier.
4. Everyone is successful every time.
5. Some people can never learn.
6. It's no big deal if you never learn.

Your nurse and parents will help you to succeed, because they know you and are confident that you can do this. Remember, practice makes perfect.

"I knew I was ready for home management when I realized how easy it can be with a little practice. Nobody likes the idea of poking themselves with a needle, but it is much easier when you know that learning to self infuse will open your life to opportunities such as travelling that would otherwise not be possible."

Quote from a 20-year-old who began self-infusion at 11 years of age

I have done my own needle.

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What if I'm uncomfortable?
It's okay to be uncomfortable.

What if I mess up?
You'll have lots of chances to practice.

I don't think I can do this alone...
Your nurse will always work with you.

Will anyone help me?
Yes, you can always count on family.
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"It took me a couple of months to be comfortable doing my needles on my own even after being consistently successful."

Quote from 20-year-old who began self-infusion at age 11 and traveled away from home for competitive swimming meets.

Your physiotherapist knows the most about your joints and muscles. He or she can teach you a lot about how your joints and muscles work and how to prevent new bleeds and rebleeds.

I talked with my physiotherapist.

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<th>What I learned</th>
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“Being able to treat myself at home allows me to be in full control of my hemophilia. For me, learning to treat myself at home was the first step to becoming independent.”

Quote from 20-year-old who participated in many sports

---

I discussed preventative treatment with my nurse.

Date

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<tr>
<th>Date</th>
<th>Activity</th>
<th>Result</th>
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I used preventative treatment and took control.

Date | Activity     | Result |
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Important things I learned about having hemophilia

My type of bleeding disorder is ____________________________
My factor level is ____________________________
My treatment product is ____________________________

After a treatment, if my factor level rises to 50%, my factor level should stay over 25% for _______ hours.

My local bleeding disorders organization is ____________________________
Address ____________________________
Phone number ____________________________

Provides the following services:

1. 
2. 
3. 
4. 
5. 
6. 

**You and your hemophilia: control your body and put your mind at ease**

**Important facts you need to know**

- When you bleed into a muscle, it contracts or gets smaller. It can't work properly, so you lose range of movement.
- Muscles can re-bleed easily if they are used before you have recovered full range of movement. It is important to check with your physiotherapist before returning to full activity.
- Joint bleeds can and often recur if normal activity is started before the joint is completely healed, or has full range of movement.
- It is best not to treat alone whenever possible, just in case you have a reaction.

... also:

---

Congratulations! You are now on the last and most important part of your journey to become captain of your ship.

When you complete this level, you will be ready to be in charge of your hemophilia.
Level 5 - Are you ready to take charge of your hemophilia?

Do you see yourself

☐ Travelling without your parents?  ☐ Living away from home?
☐ Going to school or work in a different city?

If you answered yes to any of the above questions, you will need to complete the following.

Examples of how I assessed my bleeding episodes are:

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<tr>
<th>Date</th>
<th>Assessment</th>
<th>Actions</th>
<th>Results</th>
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If I were having a bad day with needles, I would get help from

Since I started doing my own treatments, my life has changed for the better because now

More positive effects of treating myself include

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I record all my bleeds and treatments and send them to the clinic at least once a month.

Month ______________________
Month ______________________
Month ______________________

I contacted the HTC prior to travel, and was sure I had a travel letter for my trip.

Date _______________ Trip to ______________________

“*It is a good idea to talk to whoever you are travelling with about some things they should do in case of emergency. Let them know where all of your emergency information is and provide them with information about hemophilia.*

“*It is extremely important to have all your medical info with you including Factor First card, medic alert and any emergency contact information. Make sure that you are prepared in general for the trip, including a good supply of factor. It is important not to rush this part of getting ready.*

Quotes from 20-year-old who travelled through the USA

I contact my nurse before any dental work or surgery to discuss treatment requirements.

Date: __________________________________

I always wear medic alert and carry a Factor First card.

Signature: ________________________________
### Important Contact Numbers

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<th>Name</th>
<th>Specialty</th>
<th>Phone Number/ Availability</th>
<th>E-mail</th>
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<tbody>
<tr>
<td>HTC nurse coordinator</td>
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<td>HTC hematologist</td>
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<td>Physiotherapist</td>
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<td>Social worker</td>
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<td>Home care</td>
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<tr>
<td>Canadian Blood Services/ Héma-Québec</td>
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<td>Dentist</td>
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### Friends and other non-medical supports:

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### CHS contact information:

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### Other important contacts (e.g., taxi and other transportation):

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CHS = Canadian Hemophilia Society  
HTC = hemophilia treatment centre
Congratulations!
You are now a full partner in managing your hemophilia and are ready to take charge of your bleeding disorder.