



There for you with
Patient Resources



The Power of Choices

TAKING CONTROL OF YOUR HEALTH

Baxter

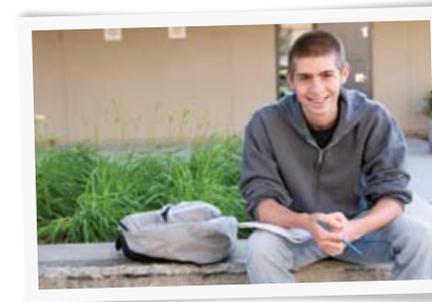
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Every day, you're faced with making choices. Some are big decisions that you know will affect your life. Others may seem less important. When it comes to hemophilia, *every* choice matters. The choices you make can help you take control of your health and can have a lasting impact on your life.



Knowledge is key to making the right choices about your health and enhancing your life. To help you make these powerful choices, this book focuses on 3 key areas:



Recognizing
Your Bleeds

When you know your body, you can make healthier decisions every day.



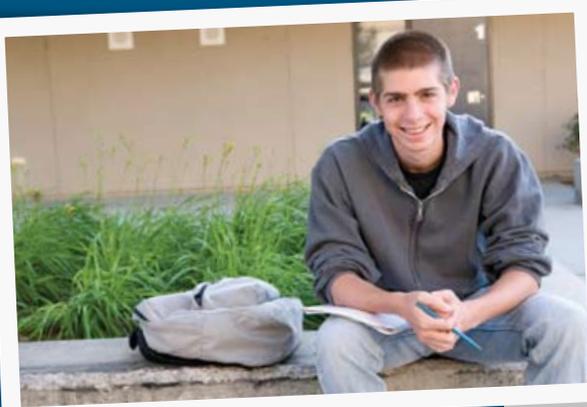
Understanding
Your Factor

When you know about your factor, you can make appropriate treatment decisions.



Monitoring
Your Health

When you know about prevention, you can live a fuller life.



Recognizing Your Bleeds

Sometimes it may feel like treating bleeds right away isn't that important. You might even think you have a good reason to not treat a bleed.

"I'll treat it next time."

"This doesn't feel that serious."

"My joints are already damaged—it doesn't matter if I treat."

Sound familiar? The truth is each tingle, each swollen joint, and each bleed can inflame and eat away at the joint. Treating your bleeds right away is the best way to help you prevent permanent damage.¹ It's a powerful choice you can make to enhance your life.

Know the effects of a bleed^{1,2}

After each bleed, some blood remains in the joint. Over time the joint lining, called the synovium, stops producing the slippery, oily fluid that helps the joint move. With time, the cartilage breaks down and some bone wears away. Joints can become severely restricted in movement.

Know the signs of a bleed

To help guard against joint damage, you can recognize the signs of a bleed and treat right away.

Common signs of a joint bleed¹:

- Tingling
- Swelling
- Heat
- Pain

Common signs of a muscle bleed³:

- Warmth
- Swelling
- Redness
- Tightness of skin
- Stiffness
- Numbness

SMALL STEPS >>>

Learning to recognize bleeds and treat right away can make a positive change in your life. You can start by making these simple yet powerful choices:

- > Think about your bleed patterns. Where were you? What were you doing? Tracking this can help you know your body better and be prepared to treat quickly.
- > Bring factor with you on your next outing and keep it easily accessible.
- > Treat at a first sign of a bleed, such as tingling or pain.
- > Know when to call your clinician.

"It's very important to recognize that every single person with hemophilia is actually born with normal joints."

- Dr. Mauricio Silva, Orthopedic Surgeon and Associate Medical Director, Los Angeles Orthopaedic Medical Center

EVERYDAY CHOICES

Think about your everyday decisions and habits. What choices do you make when it comes to recognizing bleeds?

I know the signs of a bleed

- Always
- Sometimes
- Rarely

I treat bleeds right away

- Always
- Sometimes
- Rarely

As you continue to read, you can determine what is working for you, and where you could improve.



Understanding Your Factor

There are times when knowing about factor and creating a treatment plan may not seem important or realistic. The key to sticking with your plan is to make sure you don't let any of the common misconceptions get in your way.

"I know how best to treat—I don't need a treatment plan."

"I don't carry my factor with me all the time."

"I don't have the resources to stick to my plan."

Sound familiar? The truth is a treatment plan is something you develop with your clinicians, about you and for you. You can make a powerful choice to come up with a plan that works for you and your life.

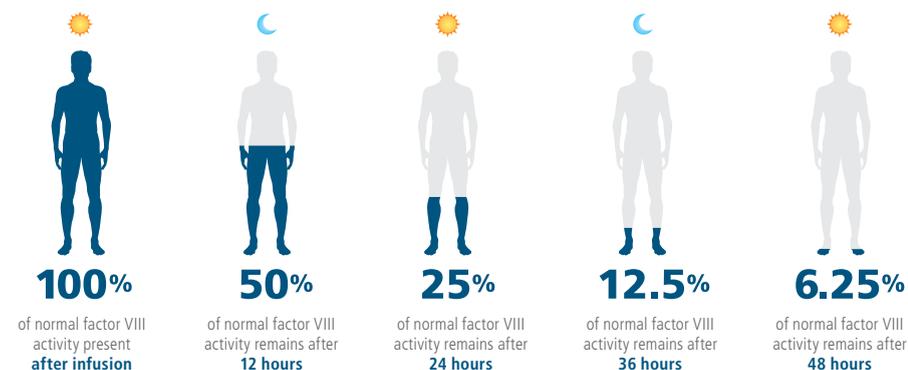
Infusing factor: what really happens^{2,4,5}

When you have a bleed, infusing your factor replaces missing factor protein to help stop bleeding. Infusing factor also:

- Decreases pain that results from bleeding
- Preserves joint health
- Prevents further complications

After infusing, factor VIII activity gradually drops according to its half-life, the rate at which factor is eliminated from your body (Figure 1).

Figure 1. The half-life of factor VIII is 8 to 12 hours, which means the amount of factor VIII activity in the body drops by half in 8 to 12 hours. Note: Factor IX's half-life is 18 to 24 hours. It is important to remember that these numbers will vary from one person to another.



Elements of a successful treatment plan^{1,5}

To get the factor you need, start with a good treatment plan. It will include:

- Infusing at the first sign of a bleed. Every bleed. Every time.
- Monitoring weight changes. Weight gain or loss may affect your dose.
- Recording your infusions and bleeds. Keeping track can help you and your clinician monitor your treatment plan.

SMALL STEPS >>>

Here are some small but effective steps you can take to help you and your doctor make right treatment choices:

- > Write down your brand of factor and your current dose. Keep it someplace accessible.
- > Log your next few infusions. You may be surprised at the patterns you note and how easy it is to do.
- > Follow your treatment plan and remain in contact with your clinician.

When you know your factor dose, brand, and instructions, you can better prepare for daily life and emergencies.

EVERYDAY CHOICES

Think about your everyday decisions and habits. What choices do you make when it comes to your factor and treatment plan?

I know my factor dose

- Always
- Sometimes
- Rarely

I follow the treatment plan my clinician and I made

- Always
- Sometimes
- Rarely

As you continue to read, you can determine what is working for you, and where you could improve.



Monitoring Your Health

In our busy lives, proactive health activities like exercise, eating healthy, and visiting your clinician or hemophilia treatment center (HTC) can often be pushed off. Everyone has found an excuse at one time or another.

- "I don't have the time or energy to add exercise to my life."*
- "I don't want to think about my hemophilia—why go to the doctor when it's not necessary?"*
- "My joints are already damaged—why bother?"*

Sound familiar? The truth is every little step you make toward building strength, eating well, and working with your clinician or HTC adds up to better joints and an improved life. They're powerful choices you can make.

Exercising and eating well – why it matters^{6,7}

Everyone knows that exercise and eating well are important. But they're especially important if you have hemophilia because:

- Maintaining a healthy weight is good for your joints. Extra weight means extra stress on the joints.
- Building strong muscles helps reduce stress on the joints and reduce the likelihood of bleeds.
- Eating well gives you energy for daily life and good nutrition for healing.

In addition, remember to talk to your clinician or HTC for advice on the right physical activities for you.

Making sure you develop good habits early

Adolescence is a time of growth, independence, and risk taking. It's a tempting time to become less committed to your treatment plan and all of the good habits that you have developed over time.

This time of transition is also a critical time for your joint health. Developing a good relationship with your clinician or HTC during this time can help. Together you can evolve your treatment plan to your changing needs.

SMALL STEPS >>>

Monitoring your health shouldn't be overwhelming. You can choose to live a fuller life by taking small, simple steps:

- Exercise with simple but functional activities that fit your schedule, like taking the stairs instead of the elevator, parking a little farther away, going on a bike ride, or walking with family or friends. Remember, talk to your clinician or HTC about exercise options for you.
- Add some vegetables to your dinner, limit portions, or limit desserts to once a week.
- Establish a good relationship with your clinician or HTC by keeping your yearly appointment. Commit to calling them with any questions you may have about your health or your treatments.

Your HTC is a resource, with hematologists, nurses, social workers, physical therapists, orthopedists, and even dentists on hand.

EVERYDAY CHOICES

Think about your everyday decisions and habits. What choices do you make when it comes to monitoring your health?

I exercise at least 3 times a week

- Always
- Sometimes
- Rarely

I visit my HTC at least once a year

- Always
- Sometimes
- Rarely

As you continue to read, you can determine what is working for you, and where you could improve.

Setting Goals

Now is the time to set a goal or two, putting all that you've learned to work.

Think about what you said in your self-assessment. Think about what you've learned about bleeds, factor, and monitoring your health. What would you like to do differently? What could you improve in your life with a few different choices? What are some small steps to which you can commit?

Use this space to set one or more goals. Make it realistic, but also think about what you really want to accomplish.

Here are some examples to think about:

- *I will treat with factor at the first sign of a bleed every time.*
- *I will ask my clinician what he/she would do differently if he/she were me, and try it for 3 months.*
- *I will exercise 3 times a week for 3 months or find other ways to stay active.*
- *I will visit the HTC every year to stay on top of my health.*



My Goals

Recognizing My Bleeds

Understanding My Factor

Monitoring My Health

References: 1. Gilbert MS. Musculoskeletal complications of hemophilia: the joint. In: *The Treatment of Hemophilia*. Montreal, Quebec, Canada: World Federation of Hemophilia; 1997. http://www.wfh.org/2/docs/Publications/Musculoskeletal_Physiotherapy/TOH-6_English_%20Joint.pdf. Accessed May 4, 2010. 2. Complications of hemophilia. In: *All About Hemophilia: A Guide for Families*. Montreal, Quebec, Canada: Canadian Hemophilia Society; 2001. <http://www.hemophilia.ca/files/Chapter%2008.pdf>. Accessed May 25, 2010. 3. Butler RB, Crudder SO, Riske B, Toal S. *Basic Concepts of Hemophilia*. Atlanta, GA: Centers for Disease Control and Prevention; 2001. 4. Management of bleeds. In: *All About Hemophilia: A Guide for Families*. Montreal, Quebec, Canada: Canadian Hemophilia Society; 2001. <http://www.hemophilia.ca/files/Chapter%2004.pdf>. Accessed May 25, 2010. 5. Clotting factor therapy. In: *All About Hemophilia: A Guide for Families*. Montreal, Quebec, Canada: Canadian Hemophilia Society; 2001. <http://www.hemophilia.ca/files/Chapter%2005.pdf>. Accessed May 25, 2010. 6. LaFranco J, Delorm D. Making better food choices. HemAware Web site. <http://hemaware.org/health-wellness/fitness-nutrition/making-better-food-choices>. Accessed May 26, 2010. 7. *Playing It Safe: Bleeding Disorders, Sports, and Exercise*. New York, NY: National Hemophilia Foundation; 2005.

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Your choices matter. They can affect you today and tomorrow, helping you take control of your health and enhancing your life. Remember these tips to make powerful choices:

- Recognize the signs of a bleed and be prepared to treat early, every time
- Know the details of your factor and work with your HTC to develop a realistic treatment plan
- Understand all the other ways you can help promote overall good health

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