HAEMOPHILIA SUPPORT

HELPING YOU NAVIGATE LIFE WITH HAEMOPHILIA AND INHIBITORS
If you or a loved one has been diagnosed with inhibitors, you may have questions or worries about what this means. It’s important to know that you are not alone, and help is available.

When someone with haemophilia has inhibitors, it means that bleeds may be more difficult to control. Living with inhibitors can be easier with knowledge, planning, a few trade-offs, and support. Use this brochure to gather facts and support for living with or caring for someone with inhibitors.
INHIBITORS: THE BASICS

Some people with haemophilia develop inhibitors because their body doesn’t recognise the factor replacement therapy they receive to help their blood to clot. As a result, the inhibitors prevent the factor VIII or factor IX found in normal haemophilia treatment from working.

It is not known why some people get inhibitors and others do not. Inhibitors develop in about 20% to 30% of people with severe or moderately severe haemophilia A. Only about 1% to 5% of people with haemophilia B develop inhibitors.

Inhibitors are suspected when there is a decrease in how well a haemophilia treatment works or an increase in the number of treatments needed to control a bleed.

INHIBITOR TREATMENT

The amount of inhibitors in the blood varies from person to person and within the same person over time. A blood test called the Bethesda inhibitor assay will measure the amount of inhibitors in a person’s blood. Results of this test tell the haemophilia care team whether the amount of inhibitors is low- or high-titre. Knowing the titre can help the haemophilia care team decide on the best treatment plan for inhibitors.

Some people with inhibitors can continue receiving factor VIII or IX replacement to manage haemophilia. However, others may need additional or different treatments.

Your haemophilia care team will watch for changes in inhibitor levels to decide the best treatment plan for you or your child.

DID YOU KNOW?

INHIBITORS MAKE IT MORE DIFFICULT TO CONTROL BLEEDS, BUT DO NOT CAUSE BLEEDS TO BE MORE FREQUENT OR SEVERE.
DID YOU KNOW?
The higher the titre, the greater the amount of inhibitors in the blood.

TREATMENT CHOICES

It is important to talk with your haemophilia care team about your inhibitor levels and the treatment choices that may be right for you or your child. For some people with inhibitors, treatment plans may include immune tolerance induction (ITI) or bypassing agents.

**Immune tolerance induction:** When inhibitors are first identified, your haemophilia care team may try to stop them by infusing high doses of factor VIII or factor IX on a regular basis, such as every day or every other day. The goal of ITI is to get the body’s immune system to accept treatment from the missing clotting factor.

**Bypassing agents:** Bypassing agents are given into the bloodstream and work by bypassing the need for factor VIII or factor IX concentrates. Two bypassing agents currently are available to treat haemophilia with inhibitors. These treatments work in different ways, and patients may respond differently to each of them. A complete treatment plan should include both bypassing agents. Bypassing agents should not be given at the same time, however.

PREVENTING JOINT DAMAGE

**Bypassing agents can be used to keep bleeds from happening (prophylaxis) or to stop bleeds when they occur (on-demand).** The goal of treatment is to protect against joint damage.

**Prophylaxis:** To keep bleeds from happening, your haemophilia care team may recommend prophylaxis as a treatment goal. Prophylaxis has been used for some time in the haemophilia A community. Use of prophylaxis for managing inhibitors is growing.

**On-Demand:** Treatment is given as a bleed occurs to stop the bleed as quickly as possible. Quick, effective treatment of joint bleeds is very important for helping to prevent long-term joint and muscle damage. Work closely with your haemophilia treatment team and contact your healthcare provider if bleeds get worse or do not stop within 24 hours.
CARING FOR SOMEONE WITH INHIBITORS

If you are caring for a child with haemophilia and inhibitors, you may have some of the signs that could indicate caregiver burnout. These include:

- Feeling very tired.
- Not wanting to be with people.
- Feeling lonely.
- Feeling helpless.
- Having a hard time sleeping.
- Losing patience easily.

At times, people who care for a loved one with inhibitors may feel anxious and overwhelmed because of the heavy demands placed on them and their families. Here are some tips that may help.

Accept your feelings: You may feel financial, social, and other pressures as you adjust to the reality of having a child with haemophilia and inhibitors. Don’t deny your feelings. Talk about them instead.

Educate yourself: Learn all you can about inhibitors and their treatment, how to keep bleeds from happening, and what to do in an emergency. The things you learn can go a long way towards helping you feel that you have control of life.

Take time out for you: Do things that help you and your health. Go to the gym. Eat well. Go to bed on time so you can get enough sleep. Meditation, music, and even a walk around the block can be a great way to reduce stress.

Ask for help: Your haemophilia care team is there to help you with education and support. The social worker on the team can help you reduce your stress, help with financial issues, and even find ways to get to doctor’s appointments.

Reach out to others: Look to family, friends, and social groups. The Internet is a great source for facts and support. A list of groups and Internet sites that may be helpful is included in this brochure.

DID YOU KNOW?
PROTECTING JOINTS IS AN IMPORTANT TREATMENT GOAL FOR MANAGING INHIBITORS.
FINDING SUPPORT

It’s important to know that you are not alone. Meeting with other families going through the same thing can be helpful. Your haemophilia treatment centre can put you in touch with families and tell you about local support groups and programmes. The following organizations also can provide facts and support.

International Organization
• World Federation of Hemophilia, www.wfh.org. Official site of the World Federation of Hemophilia, an international not-for-profit organization dedicated to improving the lives of people with haemophilia and related bleeding disorders. Local haemophilia groups also can be found through the World Federation of Hemophilia site.

National/Regional Organizations
Australia
• Haemophilia Foundation Australia, www.haemophilia.org.au. Website offering information about inherited bleeding disorders. The Foundation is committed to improving treatment and care through representation and advocacy, education, and the promotion of research.

Asia

Europe
• The Haemophilia Society, www.haemophilia.org.uk. The only national and independent organisation in the UK providing information and support for all people affected by bleeding disorders.
• European Haemophilia Consortium (EHC), www.ehc.eu. A European patient group representing national member organisations from 43 countries in Europe.
• European Association for Haemophilia and Allied Disorders, www.eahad.org. A multidisciplinary association of healthcare professionals providing care for individuals with haemophilia and other bleeding disorders. The purpose is to promote clinical care, education, and research for this group of patients across the continent.
• Haemophilia Alliance, www.haemophiliaalliance.org.uk. A UK-wide partnership between patients with inherited bleeding disorders and healthcare professionals involved in the delivery of their care.

North America
• Canadian Hemophilia Society, www.hemophilia.ca. The official site of the Canadian Hemophilia Society, which strives to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure.
• US National Hemophilia Foundation, www.hemophilia.org. The US National Hemophilia Foundation is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy, and research.
• Centers for Disease Control (CDC) Hemophilia home page, www.cdc.gov/ncbddd/hemophilia/index.html. The mission of CDC’s Division of Blood Disorders is to reduce the morbidity and mortality from blood disorders through comprehensive public health practice.
• Hemophilia Federation of America, www.hemophiliafed.org. The Hemophilia Federation of America (HFA) champions the rights and protection of people with bleeding disorders by delivering information on product safety, accessibility, affordability, and availability of required treatments.
JOINT BLEED SIGNS

Sometimes patients will have a “sixth sense” that a joint bleed is about to start. Other times, it may be possible to recognise a joint bleed by these common signs:

- A tingling sensation.
- Warmth or tightness in the joint.
- Pain or swelling.
- Joints that are a little hard to move.
- Difficulty moving or walking.
BAXTER AND THE 
HAEMOPHILIA COMMUNITY

Baxter International Inc. is committed to supporting the haemophilia community through its involvement in a variety of important activities and programmes for patients* and healthcare providers, including the following:

• Offering new therapies to help more people with haemophilia.
• Improving care of people with haemophilia through financial support of programmes that find better ways to treat inhibitors.
• Supporting community groups through patient and clinician education to make sure patients can get the treatments they need.
• Developing online information and tools for the haemophilia community.
• Donating millions of dollars in healthcare products, including haemophilia treatments, to people in countries where treatment is hard to get.
• Providing ongoing support to the World Federation of Hemophilia’s Global Alliance for Progress (GAP) programme, a 10-year healthcare development project launched in April 2003.

* Programmes may not be available globally.
If you or your child has been diagnosed with an inhibitor, it is important that you take an active role by working with your treatment team and asking questions of them. However, sometimes it can be hard to think of the right questions to ask.

Get started by using this guide during the next appointment with your haemophilia care team. Never be afraid to voice your concerns or ask questions. That’s why your haemophilia care team is there.

DID YOU KNOW?
The social worker on your haemophilia care team can help with ways to reduce stress and other worries.
A GUIDE TO ASKING THE RIGHT QUESTIONS

Health and Safety
• How do I know if a bleed is happening?
• How long should it take for the bleed to stop?
• How do I know if my treatment is working?
• What should I do if my treatment doesn’t work?
• How do I know if there is an emergency and what should I do?
• When should I call my haemophilia care team?
• How long should I wait to call my haemophilia care team if my treatment does not work?

Treatment
• How often should I see my haemophilia care team?
• How will my health or my child’s health be watched over time?
• Which kind of treatment is right for me (prophylaxis or on-demand)?
• What dose should I or my child be taking?
• How often should my treatment be taken?
• What are the venous access options?
• What should I consider when choosing one venous access versus another?
• What is a target joint and how should I treat it?
• What are the signs of joint damage?

Physical Activity and Lifestyle
• Which activities are safe for me or my loved one to do?
• Which activities should I or my loved one not do?
• What can I do to keep bleeds from happening?
• What can I do to help my child live as normally as possible?
• How can I keep my joints as healthy as possible?

For Parents or Caregivers
• How should I work with my child’s school to meet his/her needs?
• Who should know that my child has haemophilia and inhibitors?
• Are there any support groups or summer camps for children with haemophilia and inhibitors?