

Hemophilia

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HEMOPHILIA

A HANDBOOK FOR FAMILIES

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■ WHAT IS HEMOPHILIA?

The blood clotting system is made up of proteins that work together to prevent too much bleeding or too much clotting. There are a number of proteins (factors) which must work together to form a fibrin clot. This keeps blood from leaking out of the vessel.

Hemophilia is an inherited bleeding disorder. Hemophilia occurs when one of the factors needed to form a clot is missing or does not work well. Blood may flow out of the body, for instance, from a skin cut. Or it may leak into tissue around the vessel, causing internal bleeding. Any type of trauma, such as falling and bumping the knee, can cause a bruise, or hematoma. Bleeding into tissue can cause pain, swelling, and slow healing. A person with hemophilia does not bleed faster than someone without it, they bleed longer.

■ WHAT ARE THE TYPES OF HEMOPHILIA?

There are two types of hemophilia. *Hemophilia A*, also called classical hemophilia, is a shortage of factor VIII (8). Hemophilia A is the most common form of hemophilia, occurring in 80% of people with hemophilia.

Hemophilia B is a shortage of factor IX (9). Hemophilia B is sometimes called Christmas disease, named for the first person diagnosed with this disorder. Hemophilia B occurs in 20% of people with hemophilia.

The normal range of factor VIII and factor IX activity is 50%–200%. There are different levels of factor activity in hemophilia. In severe hemophilia, the factor level is less than 1%, or almost cannot be measured. Moderate hemophilia is a factor level of 1%–5%. Mild hemophilia is a factor level of 6%–49%.

People with severe hemophilia may experience *spontaneous bleeding*, or bleeding that starts with no injury. People with mild to moderate hemophilia are more likely to bleed with because of injury or surgery. They rarely have bleeding without injury.



■ WHAT ARE SOME OF THE SYMPTOMS OF HEMOPHILIA?

NEWBORN BLEEDING

Some babies with hemophilia may have bleeding that lasts longer after being circumcised or being pricked in the heel for blood tests. Newborns (and anyone) with hemophilia do not bleed any faster than others. However, people with hemophilia can bleed longer. How often your child bleeds depends on the level of the factor protein in their blood.

BRUISING

Young children with hemophilia often have bruises as they learn to crawl and walk, though these bruises usually do not need special treatment. Bruises can be seen on the chest or under the arms where caregivers pick them up. Sometimes these children are suspected of having been abused. When this happens, testing of factor VIII and IX levels can show that the child has hemophilia.

MINOR CUTS AND SCRAPES

Minor cuts and scrapes can be treated with normal first aid, but bleeding inside the body is more of a problem. The most common types of bleeding in children with hemophilia are bleeding into joints and muscles.

JOINT BLEEDING

Bleeding episodes happen more often as children become more active. The most common type of bleeding in children with hemophilia is joint bleeding. Children may feel “bubbling” or “tingling” in a joint. Young children may not realize that this is an early sign of bleeding. If they are not treated for the bleed at this point, they will start to feel pain. When children with hemophilia have pain in a joint, they usually try to protect the bleed by holding it in a flexed or bent position that is more comfortable. If you touch the area of the body where there is a bleed, it may feel warm to the touch. If the bleed goes on for a long time, you may notice swelling. You may not see any bruising since the bleeding is going on inside the joint or muscle. If you are not sure whether your child is bleeding into the joint, do not force him to move the affected arm or leg as this may cause more pain. Sometimes it is helpful to compare the affected limb to the one on the other side.

MUSCLE BLEEDING

Bleeding can often occur into muscles. Early signs of a muscle bleed might include fussiness in an infant or toddler or a refusal to use one of the arms or legs. You may not see any bruising because the bleeding is inside the muscle. The muscle may feel warm to touch. Over time, the muscle can also become swollen.

Infants and toddlers may develop muscle bleeds in the buttocks because they often fall as they learn to stand and walk. Using two diapers at once for more padding may decrease this type of bleeding. Some caretakers also use a small piece of foam padding tucked into the toddler’s pants.



Some muscle bleeding can be more serious. For instance, bleeding into the large muscle in the groin/abdomen, the iliopsoas, is serious. When children have a bleed in the iliopsoas muscle they sometimes have symptoms similar to appendicitis. Children with hemophilia are missing a factor that is necessary to form a stable blood clot. Replacement factor can be given when bleeding is suspected. It is important to treat with intravenous factor products, to replace the missing factor, before any further testing is performed. This is in case the symptoms are being caused by a bleed.

Bleeding into the long muscles of the forearm, hand, or calf can put pressure on nerves and muscles. The pressure may cause severe pain or numbness below the bleed. This is called compartment syndrome. A compartment bleed is a limb-threatening bleed. It is important to report bleeding in these muscles and any of these symptoms to your physician and seek treatment immediately.

MOUTH BLEEDING

Children with hemophilia can have prolonged bleeding from the mouth when they injure their teeth, lips, or gums. Prolonged bleeding can also happen when a child gets new teeth or loses teeth. Mouth bleeding may happen after an injury or a dental procedure such as an extraction or root canal. Mouth bleeding may seem worse because the blood mixes with saliva, making it look as though your child is losing more blood than they are. Applying cold with an icy drink or popsicle can help stop the bleeding. Bleeding that continues for more than 30 minutes should be reported to the hematologist. Having hemophilia does not cause dental problems, but it is important to take care of any problems that can lead to mouth bleeds.

Children with hemophilia should have regular dental cleanings so that they can avoid dental issues that may require invasive procedures or cause bleeding.

NOSE BLEEDING

Hemophilia does not cause nose bleeds, but having hemophilia may make nose bleeds from other causes (allergies, injuries, etc.) last longer. Nose bleeds usually are not serious. Applying pressure to the nose for 10–15 minutes while your child sits upright usually helps stop the bleeding. Contact your physician if bleeding continues after 20 to 30 minutes despite pressure and other first aid measures. If your child has frequent nose bleeds, it may be helpful to find out if there is a reason. If you can identify the reason for the bleeds, you may be able to decrease the number of bleeds.

EYE BLEEDING

You should have any injury to your child's eye examined by your physician right away. Bleeding in the eye could result in blindness.

NECK AND THROAT BLEEDING

An injury to the neck or throat could lead to bleeding that will affect your child's ability to breath and/or swallow. Seek immediate medical care if your child's neck becomes swollen or if they have trouble breathing or swallowing.

If your child is vomiting bright red blood or what looks like coffee grounds you should call your child's physician immediately.

ABDOMINAL BLEEDING

Abdominal bleeding can go on for a long time before there are symptoms. Any trauma to the abdomen should be discussed with your physician. Symptoms of bleeding in the abdomen, stomach, or intestines include vomiting up bright red or "coffee ground" vomit. You may also see black or tarry stools. Because the bleeding can go on for a long time, your child may look pale and feel tired. Your child's abdomen may also be tender when you touch it. If your child has any of these signs or symptoms, you should call your physician immediately.

HEAD BLEEDING

Any trauma to the head should be considered an emergency even if there are no symptoms. Symptoms are a late sign of bleeding. Head bleeds can also happen without any known trauma (spontaneously) in children with severe hemophilia. Some signs that you may see include headache, feeling tired, difficulty waking up, or vision changes. Other signs include nausea, vomiting, dizziness, crankiness, seizures, uncoordinated walking, slurred speech, and confusion. Contact your physician with any head trauma before you see symptoms. You should also contact your physician if your child has any of these symptoms even if there is no history of trauma.



■ YEARLY SCREENING LABS AFTER DIAGNOSIS

Children with hemophilia should be screened every year for antibodies (called inhibitors) to factor VIII or IX. Some children with hemophilia make very little, if any, factor protein of their own. The immune system is supposed to get rid of proteins that do not belong. So some children with hemophilia will make these inhibitors to

the factor protein that we give to treat bleeds. When this happens, we must find other ways to treat bleeding while we try to get rid of the inhibitor. Your child should have a screening test for an inhibitor at least once a year. An inhibitor test should also be done if your child is not showing improvement when you are treating a bleed or if your child has suspected bleeding despite regular factor replacement (prophylaxis).

Some factor treatment products are made from human blood proteins. Other factor treatment products are stabilized in human blood proteins (albumin). Newer generation products are produced without albumin. It is important to make sure that your child receives immunizations to protect them from viruses like Hepatitis A and B that potentially can be transmitted through albumin. There are other viruses for which there are no vaccines available at this time. Your child may have a screening test every year for Hepatitis A, B, C, and HIV.

■ WHO GETS HEMOPHILIA?

Hemophilia is an inherited bleeding disorder. Genes (found in chromosomes) control the traits that each person inherits from their parents. Males have one X chromosome and one Y chromosome (XY). Females have two X chromosomes (XX). This pair determines the sex of the child. Each of these chromosomes contains hundreds of genes. Genes determine a person's height, eye color, hair color, and blood clotting ability. Just like eye or hair color, hemophilia is something a child is born with and has for life.

The gene that causes hemophilia is carried on the X chromosome. It is called a sex-linked disorder because that is the chromosome that determines the person's sex.

The hemophilia gene is recessive. Females have two X chromosomes, so in females, the hemophilia X chromosome is overridden by the unaffected X chromosome. That is why females rarely get hemophilia. They do, however, carry the hemophilia gene.

Because males only have one X, if they inherit the affected X chromosome, they will then have hemophilia. They do not have the unaffected X to overrule the affected one.

Hemophilia may not be seen in several generations. That happens when it is being passed down through female carriers. If the women had girl 'carrier' babies and no one had a boy with hemophilia for a few generations, then it looks like there is no history of hemophilia in that family. This can easily happen because the X is being passed on to the next generation by female carriers.

One other way that hemophilia can occur is from a spontaneous genetic mutation or modification (change) in the cell that happens for no apparent reason. The mutation (causing an affected X chromosome) can occur in the mother when she was conceived. The mutation can also occur when the child is conceived. Cells mutate as they are created. It is estimated that a mutation could account for about 30% of those affected by hemophilia. Once the mutation is there, then the rules for inheritance continue from that person onward.



■ HOW IS HEMOPHILIA INHERITED?

A father with hemophilia will give his Y chromosome to all of his sons. The Y chromosome is what makes them males, and the mutation that results in the factor deficiency is on the X chromosome. The Y chromosome does not have the hemophilia gene on it so the sons of a man with hemophilia will *not* have hemophilia and will not pass it on to his children. The hemophilia stops there.

A father with hemophilia will give the affected X chromosome to *all* of his daughters. The X chromosome is what makes them female, and because the X has the hemophilia gene on it, *all* of his daughters will be carriers.



■ WHAT IS A FEMALE CARRIER?

This is a female with an affected X chromosome, which she can pass on to her children. Although she does not have hemophilia, she could have normal levels of factor or she could have low levels of factor. Some female carriers may have factor levels low enough to fall into the mild hemophilia range. These women are often referred to as symptomatic carriers.

The female carrier has a one in four chance (with each pregnancy) of having a son with hemophilia. There is also a one in four chance (each pregnancy) of having a daughter who is a carrier.

If the fetus is male, there is a 50% chance the boy will have hemophilia.

If the fetus is female, there is a 50% chance the girl will be a carrier.

These odds apply for each pregnancy a woman carries. So, a woman could have four sons and *none* of them have hemophilia, or she could have four sons and *all* of them could have hemophilia.

Prenatal testing, or testing during pregnancy, can be done to determine if a fetus has hemophilia. Another way to determine if a child has hemophilia is to test a sample of umbilical cord blood immediately after birth.

All newborns have somewhat low levels of factor IX. This does not necessarily mean they have Hemophilia B. Retesting should be done at 6–9 months for a more definitive answer.

For families without a history of hemophilia, the diagnosis is often made

- after prolonged bleeding from a circumcision, the mouth, a heel stick, or other lab draw
- when unusual raised bruises or large amounts of bruising are noted
- a joint or muscle becomes swollen and painful.

■ WHAT TESTS AND PROCEDURES WILL MY CHILD NEED?

If there is no family history of a bleeding disorder, but your child has prolonged bleeding, screening tests may be performed. A *prothrombin time* (PT) is a screening test for some of the clotting factors. The PT should be normal for age in a child with hemophilia. The *partial thromboplastin time* (PTT) screens for low factor levels that are seen in hemophilia. A prolonged PTT may mean that one of the factor proteins that cause hemophilia is low.

If hemophilia is suspected, specific factor assay studies can be done right away. Blood can be taken from the umbilical cord or from the baby's vein. The factor assay will be listed as a percentage. The percentage of factor protein will determine how severe the disease is.

If hemophilia B is suspected (factor IX deficiency) the results should be compared to levels that are normal for newborn babies. Factor IX levels are lower in new babies and go up in the first 6 months of life. If levels are lower than the normal range for a baby it is likely that he or she has hemophilia. Repeat testing will not show a change in the level.

Normal factor assay levels are between 50% and 200%. It is important to know your child's factor level since this will tell you how severe the hemophilia is and give you an idea of what type of bleeding to expect. Factor levels do not change as your child gets older.

■ HOW CAN HEMOPHILIA BE TREATED?

Hemophilia results from decreased or absent amounts of factor (FVIII or FIX), so treatment involves replacing the missing protein (factor concentrates). There are several factor concentrates on the market that fall into two categories:

- Plasma-derived: factor made using human plasma donations. They are then purified.
- Recombinant: factor made using human genes placed into other cells that make human proteins – FVIII or FIX. They are then purified.

Factor concentrates are given intravenously (IV). This may be done using a butterfly needle or a venous access device (VAD). You should discuss the benefits and risks of each type with your child's healthcare team. Since 1997, none of the factor concentrates licensed in the U.S. have had a documented case of viral transmission. Your healthcare team will work with you to determine the best treatment product for your child, as well as the best way to give the drug.

People with mild hemophilia A (FVIII levels >5%) and hemophilia A carriers have other treatment options. These individuals may increase their factor levels using a product called desmopressin acetate (DDAVP). DDAVP can be given through an IV, sub-cutaneously (under the skin, similar to insulin injections), or as a nasal spray. DDAVP can cause release of FVIII stored in cells that line the blood vessels. This medicine should not be used to treat severe or life or limb-threatening bleeds. Often, a blood test called a DDAVP challenge is done to see if high enough levels of FVIII are achieved when this medication is used. Your healthcare team will teach you about side effects and how to use DDAVP correctly if it is prescribed for your child. Children with hemophilia are missing a factor that is necessary to form a stable blood clot. Replacement factor can be given when bleeding is suspected. It is important to treat with intravenous factor products, to replace the missing factor, before any further testing is performed. This is in case the symptoms are being caused by a bleed.



The main goal of treatment in hemophilia is to stop or prevent bleeding. Treatment given to stop bleeding is called on-demand, or episodic, therapy. Prevention of bleeding is referred to as prophylaxis, which is a planned treatment given on a regular basis. It also can be used prior to a specific activity such as surgery, dental or medical procedures, sporting events, and school outings. Prophylaxis is given to minimize the long-term effects of repeated bleeding, such as joint damage, which can lead to joint disease.

The type of treatment that the doctor prescribes—on-demand versus prophylaxis—depends on several elements, including the severity of hemophilia and the amount of bleeding a person has. Other medical conditions may also be noted. Both on-demand and prophylaxis infusions can be done in different ways. Your treatment team will help you decide which option is best for child. The National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council (MASAC) makes recommendations for treatment for hemophilia. They determined prophylaxis as the treatment of choice for all persons with severe hemophilia A or B. A recent study compared treatment modes in severe hemophilia patients. In this study, patients who had prophylaxis showed significantly improved joint outcome scores (Manco-Johnson, 2007).

Hemophilia can also be treated using other methods. Antifibrinolytics (amino-caproic acid, Amicar®) are drugs used to slow the body's clot-dissolving enzymes. These medications are particularly helpful for mouth and nose bleeding. Hormones can be used for control of heavy menstrual bleeding in symptomatic carriers. Topical clotting agents may be used to treat nosebleeds, some dental procedures, and small cuts or abrasions. Rest, ice, compression (using an ace wrap), and elevation (RICE) can be helpful when treating hemophilia. Your healthcare team will educate you about each treatment strategy when it is needed.

One of the most important treatment strategies for individuals with hemophilia is comprehensive care. Comprehensive care began in 1975 with the support of government agencies. Comprehensive care is provided by a team of specialists, including a doctor, nurse, social worker, and physical therapist, who treat hemophilia. People with hemophilia are best treated with prevention and a team approach. Studies show that persons treated in comprehensive treatment centers have lower risk of death. They also spent less time in the hospital and had better work and school attendance and fewer health complications than persons treated through a different source of medical care.



■ ARE THERE ANY TREATMENT-RELATED CONCERNS I SHOULD KNOW ABOUT?

Yes. Like with all treatments, some side effects should be noted. Infusion of factor concentrates can cause local irritation at the site of infusion. They can also lead to allergic reactions that require immediate medical intervention. For this reason, early factor infusions should be given in a medical facility.

Another concern with using factor concentrates is the development of an inhibitor. An inhibitor is an antibody. Antibodies form in everyone and are used by the body to fight infections and foreign proteins. The body can sometimes mistake infused factor as one of those foreign proteins, which causes inhibitor formation.

Inhibitors can develop in about 15%-30% of persons with hemophilia A and 1%-5% of those with hemophilia B. While the rate of inhibitors is lower in hemophilia B, patients with severe disease can have serious allergic reactions to factor concentrates when they develop an inhibitor. For this reason, early factor infusions should be given in a medical facility. Inhibitors make treatment more difficult and other strategies often are needed to stop or prevent bleeding. Other factor concentrates known as by-passing agents may be needed. These products contain other factors that are intended to bypass the need for factor VIII or IX. Currently, there are two bypassing agents that can be used to manage bleeding in children who have developed inhibitors. One product is made using blood that is donated and pooled (plasma-derived), the other is manufactured using recombinant technology. If an inhibitor develops, your healthcare team will work with you to determine which treatment strategy is best for your child.

■ HOW OFTEN WILL MY CHILD NEED TREATMENT?

How often your child will need to be treated depends on which treatment regimens they receive and the number of bleeds they have. Regardless of the type of treatment (prophylaxis or on-demand), all bleeds will need treatment at the time they occur. This is especially true when your child has a head injury. Head injuries are considered emergencies and you should seek medical care immediately.

The amount of factor that your child will need depends on the type of bleed and the increase in factor activity that is desired, as well as your child's weight. This depends on the seriousness of the bleed and is calculated using the child's weight. Some bleeds, like mouth and nose bleeds, can be treated with anti-fibrinolytics such as amino-caproic acid or some other nonfactor medication. Your child will not need treatment for minor bruises, unless they increase in size and cause pain. Generally, a joint bleed will likely not need a dose as big as one given for a head bleed.

If your child is on therapy as needed (on demand) and begins to have too many bleeds, your hemophilia care team may want to place your child on prophylaxis. This is the best method known for keeping joints healthy, so it is very important that you keep track of all bleeding episodes. If keeping a diary is difficult for you, speak with your hemophilia team. There are new ways to keep track of bleeds that might make it easier for you.



■ WHAT NEW METHODS OF THERAPY EXIST?

There are studies being done testing several longer-acting factors. This means that if someone is on prophylaxis, the factor given to them will last longer in their body, and they will be able to infuse themselves less often.

Scientists are also working to develop therapy that will alter the hemophilia gene, which will allow the body to produce more factor on its own.

New ways to treat inhibitors, antibodies that the body makes against factor VIII or IX, are also being studied.

■ HOW CAN I WORK WITH MY CHILD'S HEALTHCARE TEAM?

Hemophilia treatment centers (HTC) are located in cities across the United States and other countries. The goal of the hemophilia treatment center is to keep your child healthy and strong and to help limit problems from bleeding. The center provides specialty care and is available as a resource to your family's regular doctor or dentist. They can help prepare for surgery or dental extractions. Your child's HTC healthcare team can provide you with tips for keeping younger children safe. You and your child are also members of the treatment team. The staff needs your help to develop a plan of care that will keep your child healthy, active, and able to live successfully with the challenge of hemophilia.

HTCs can also help daycare providers, teachers, coaches, and healthcare providers teach lessons and give out materials about hemophilia at your child's school.

Members of HTC care teams include:

- Hematologists: doctors who specialize in blood disorders.
- Pediatricians: doctors who care for infants, young children, and teenagers.
- Nurses specializing in hemophilia care. Nurses often coordinate the treatment team and are likely the people you will see most often.
- Social workers who assist with the issues of daily living. They can help with adjusting to hemophilia and finding help (e.g., insurance, transportation, housing, etc.).
- Physical therapists, who work with you on activity, exercise, and joint health.
- Orthopedists: doctors who are experts on bones and joints.
- Dentists: doctors who treat tooth and gum problems. There can be dentists at the HTCs who are very familiar with treating children with mouth bleeding problems. The HTC also may work with dentists in the community.

Speaking up for your child in the emergency room (ER) is perhaps one of the more important roles you have as the parent of a child with hemophilia. You must ensure that your child is seen promptly upon arrival. The ER has a process of picking which patients need to be seen the fastest. You must advocate for your child by educating the staff once you arrive. How do you respectfully advocate for your child in the ER? Make your trip to the hospital less stressful with some advanced planning.

- Visit the emergency department before your child needs to be seen. Many smaller hospitals may not see very many hemophilia patients.
- Come prepared to teach the staff. Some will know more than others about hemophilia. Remember, the staff you teach on the day of your advance visit may not be on duty at the time of your emergency visit.
- Ask if they have a policy that allows you to bring factor with you in an unopened box. Some ERs will not allow patients to bring in factor.
- When an unscheduled trip to the ER occurs, call your HTC on the way to the hospital. The professionals can help smooth the process, educate the ER staff, and encourage speedy treatment of your child.
- If you are going to the hospital for a while, you could make a list of the things you want to take with you, like a favorite toy, game, or book.

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- Talk with doctors and other healthcare providers about treatment, prevention of bleeding, and what to do in emergencies.
 - Take advantage of the care teams at the HTC for education and support as well as treatment. The social worker on the team can help with emotional issues, as well as financial and transportation problems and other concerns.

To find an HTC near you, contact HANDI, the National Hemophilia Foundation's resource center, at 800.42.HANDI or handi@hemophilia.org.

■ ARE MY FEELINGS NORMAL, AND WHAT DO I DO ABOUT THEM?

You have just been told your child has hemophilia. Both parents may feel shock, anger, fear, resentment, guilt, depression, and confusion to name a few. There also are questions. Will my child be healthy and have a normal life? How can I handle this? Even if a bleeding disorder runs in your family, the diagnosis and realization of it actually happening to your child can cause emotional stress. You cannot buy a book and learn everything about hemophilia overnight. It takes time. The feelings you are experiencing are legitimate and very real. Hemophilia will become a reality in your life when your child experiences a bleed. You need to know what to do to make the experience less traumatic for your child and your entire family.

Where do you start? Getting support from those who have been living with a bleeding disorder is a good start. Understanding what lies ahead for your family and accepting that hemophilia is treatable is a step toward acceptance. Emotional overload is one way to describe how many parents feel when they bring their child home from the hospital.

The most important thing to do upon diagnosis is to empower yourself. Making an appointment with the local HTC is a good start. Read about hemophilia, contact your local hemophilia chapter, and ask your HTC for online resources. Sorting through the wealth of online information on hemophilia can be a daunting task. Your HTC can help you sort this out what's worth reading, and what's a waste of time.

Once you choose an HTC, the staff can also put you in contact with other parents of children living with hemophilia. This support service will make an impact on your ability to successfully live with hemophilia. These is a network of moms and dads who understand what you are going through and are available to help. You will not have all of the answers at once! It takes time.

As a mother or father, you may wonder how you will manage your new roles as a parent. Will you need to learn to infuse? Should you give up your love of football because your child won't be able to play? Parents can have the same whirlwind of emotions such as sadness, hurt, and anger at the diagnosis of hemophilia.

Joe Caronna, the father of a son with hemophilia, writes that parents may often have different opinions on how to raise their child. One parent, usually the mother, is the protector. The other parent, most often the father, is trying to prepare the child for the real world. A child needs both protection and the encouragement to explore. It is important to communicate with each other what activities are considered safe and allowable before a situation arises. One parent doesn't need to be perceived as the "bad guy," always saying no. Your goal is to teach your child to make smart choices on his own. This may prevent him from doing something without asking because he expects you to say no, but he will not always be under parental supervision. It is important to recognize that at some point the time will come when he needs to decide for himself if an activity is safe. Empowering your child to make smart, safe decisions early on will relieve some of your stress when he is on his own.

At first you will want to wrap your arms around your child and not let go. But someday you may feel secure and confident enough to send your child to a camp for children with a bleeding disorder. With today's treatments, hemophilia is a manageable condition. If you grew up with hemophilia in your family, you may remember the wheelchairs, crutches, hospital stays, and the things in life that were missed out on. This was back when hemophilia care and treatments were not what they are today. Since then, the world of hemophilia has changed for the better. Current HTCs look at your child and think, "He's a normal, healthy boy who happens to have hemophilia." Hopefully with time and education that will be your philosophy, too.

■ HOW CAN I HELP MY CHILD?

Teach your child about hemophilia using words and teaching methods that fit their age and stage of development. Use positive words and phrases about hemophilia and its treatment. Allow your child to share their thoughts and feelings about having hemophilia without judgment.

Try to control how you express negative emotions when dealing with the challenges of raising a child with hemophilia. Because it is a genetic condition, many parents feel guilty, thinking that they gave the disorder to their child. Expressing this guilt to your child will affect their self-esteem. Find support to help you cope with negative emotions so that you will be better able to meet your child's needs.

You can help your child cope with factor infusions by making sure they are hydrated and warm prior to receiving the infusion. When possible, give your child realistic choices and duties before, during, and after the infusions. Your child will begin to learn and take control of their treatment and will develop self-esteem in the process.

Try to allow your child to participate in as many normal childhood activities as possible. When possible, provide protective equipment for him or her to limit injuries and bleeding during his favorite activities. Use positive words so that you can help your child focus on what they can do instead of what is not safe.

Find and participate in local hemophilia support groups and activities. There may be a local chapter of the National Hemophilia Foundation or a First Step group. This will give you and your child the opportunity to meet others affected by hemophilia. Your child will realize that they are not alone in having hemophilia, which may help to develop coping skills for living with the condition.

■ CAN MY CHILD GO TO SCHOOL?

Yes! Your child should go to school as regularly as possible. Sometimes they may need to use crutches or a wheelchair while at school to rest an injured body part. Work with your child's school to obtain an individualized healthcare plan (504 plan) to ensure all educational needs are met.

Ask for help from the hemophilia treatment center staff to provide education for the school staff about hemophilia. They can also assist with challenges encountered in dealing with the school staff. HTC doctors, nurses, and social workers can provide support to ensure that your child gets the best possible education.

■ WHERE CAN I GO TO GET MORE INFORMATION?

RESOURCES

The National Hemophilia Foundation

116 West 32nd Street, 11th Floor

New York, NY 10001

212.328.3700

www.hemophilia.org

The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for bleeding and clotting disorders. They also work to prevent complications of these disorders through education, advocacy, and research.

The NHF has an information resource center called HANDI. HANDI's mission has always been centered on service—answering specific questions, fulfilling information requests, providing quality educational publications, making referrals to additional sources of assistance, and immediately responding to the needs of the bleeding disorders community.

<http://www.hemophilia.org/Community-Resources/HANDI-NHFs-Information-Resource-Center>

Hemophilia Federation of America

820 First Street NE, Suite 720

Washington, DC 20002

Phone: 202.675.6984

Toll Free: 800.230.9797

www.hemophiliafed.org

World Federation of Hemophilia USA

PMB 142

911 Central Avenue

Albany, NY 12206

www.wfhusa.org

The World Federation of Hemophilia (WFH) is an international not-for-profit organization. They are dedicated to improving the lives of people with hemophilia and related bleeding disorders.

Centers for Disease Control and Prevention

National Centers for Birth Defects and Developmental Disorders

<http://www.cdc.gov/ncbddd/hemophilia/people.html>

The Center for Disease Control and Prevention (CDC) helps support HTC's. The network finds ways to treat and prevent complications from bleeding disorders. CDC has established the Universal Data Collection Project to monitor blood safety and to conduct research.

Provider Guide for the CDC book (purple book)

Basic Concepts of Hemophilia: A Self Study and Planning Workbook for Families with a New Diagnosis of Hemophilia <http://www.cdc.gov/ncbddd/hemophilia/documents/providerguide.pdf>

The CDC has a checklist for families to use in the event of a natural disaster or emergency.

<http://www.cdc.gov/ncbddd/hemophilia/documents/familyemergencykitchecklist.pdf>

National Heart, Lung, and Blood Institute

Diseases and Conditions Index (DCI). This online health index provides a quick and easy way to get complete and dependable information about heart, lung, and blood diseases and sleep disorders.

http://www.nhlbi.nih.gov/health/dci/Diseases/hemophilia/hemophilia_what.html

Medline Plus

Medline Plus gathers information from government health organizations to help you find information to help answer health questions. MedlinePlus also has information about drugs, an illustrated medical encyclopedia and latest health news.

<http://www.nlm.nih.gov/medlineplus/hemophilia.html>

eMedicineHealth

Information on first aid, emergency care, and consumer health.

http://www.emedicinehealth.com/hemophilia/article_em.htm

WebMD

The staff works to provide the best health information available.

<http://www.webmd.com/a-to-z-guides/hemophilia-topic-overview>

HemophiliaMoms.com

Shares real-life stories along with practical information to help meet the day-to-day challenges of raising a child with hemophilia.

<http://www.hemophiliamoms.com/>

MedicAlert Foundation®

Information on how your child can get a medical-alert ID.

<http://www.medicalert.org/Main/ConditionsHemophilia.aspx>

VENDOR RESOURCES

Pfizer

<http://www.hemophiliavillage.com/index.asp>

Baxter

<http://nava.baxter.com>

CSL Behring

<http://www.cslbehring.com/s1/cs/enco/1151517258330/page/1151517258314/ProductListByCategory.htm>

Bayer Healthcare

<http://www.livingwithhaemophilia.com/>

NovoNordisk

<http://www.myinhibitor.org/>

Grifols

<http://www.grifols.com>



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