
B2B
Learn From
Experience
A Guide for Mature Adults

*"All experience is an arch, to build upon."*[1]

*— Henry Brooks Adams, 1838–1918*

## Foreword

**The B2B (hemophilia B patient to hemophilia B patient) series began in 2005 as a vehicle to empower individuals with hemophilia B through peer support and education. The objective of the program remains to address the various challenges of having hemophilia B, especially those encountered when transitioning from one life stage to another. Another goal of the B2B program is to help strengthen the internal support system and educational network within the hemophilia B community. The B2B program is a sharing of firsthand accounts about everyday life from those living with hemophilia B.**

**This installment of B2B provides the mature adult with some helpful knowledge to make informed life decisions and to remain healthy not only today, but also in the years ahead.**

**On behalf of Pfizer Inc, The Coalition for Hemophilia B, Inc., and the B2B Advisory Board, we would like to extend our gratitude to the members of the hemophilia B community who contributed to this book. Your time, knowledge, and personal stories about life with hemophilia B are greatly appreciated:**
**Dan Bond, Jeff Kandt, and Joseph Logan**

**We would also like to thank the professionals involved with hemophilia care who shared their insights about hemophilia B:**
**Linda Gammage, MSW, LCSW, and Judy Bagato, RN, BSN**

The narrative and statements from health care providers in this book were provided prior to its initial publication in 2009.

The views and opinions expressed in this book are those of patients, parents, and hemophilia care specialists who are members of an advisory board within the hemophilia B community and not of Pfizer.

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# Introduction

As a mature adult living with hemophilia, you can reflect on the experiences that have molded you into the person you are today. You have endured the struggles of being a child with hemophilia B when not much was known about the condition. You persevered through the awkwardness of adolescence and the trials and tribulations of being a young adult. You have earned your stripes and have settled into a life you can call your own, a life in which you are reminded daily that you are living with hemophilia. With age can come additional challenges—physical ailments such as high blood pressure, diabetes, and arthritis; psychosocial issues such as depression and stress; and financial planning and retirement concerns.

Our goals in creating this book are to recognize the situations that may arise during a mature adult's life and offer suggestions that may help guide you. To achieve this, we have enlisted the help of people who live with hemophilia B, nurses, social workers, and community advocates to share their stories.

**Hopefully, you will find this book and the listed resources to be invaluable support for you and your family, now and in the future, as you continue to live with hemophilia B.**

**The objectives of this book are to:**

- Provide an overview of hemophilia B, including treatment issues and situations that may arise during your life
- Offer recommendations from hemophilia B community members and medical experts for meeting the challenges of everyday living
- Suggest resources to help you manage specific psychosocial and/or treatment issues that may arise

# What Is Hemophilia?

**Hemophilia is a congenital bleeding disorder. About 20,000 people in the United States have hemophilia and each year another 400 babies are born with the disorder. Hemophilia usually manifests only in males; however, there are exceptions.[2]**

**The term bleeding disorder refers to a wide range of medical conditions that lead to poor blood clotting and continuous bleeding. You may hear it referred to as coagulopathy or clotting disorder. A person with a bleeding disorder tends to bleed for a longer period of time following an injury to a blood vessel than someone who does not have a bleeding disorder.**

**People with hemophilia do not have enough clotting factor VIII or IX in their blood; sometimes, they do not have any. Clotting factor works together with other proteins and platelets to help blood clot. Platelets are small blood cells that are formed in the bone marrow. When a blood vessel is injured, clotting factors help the platelets stick together to plug cuts and breaks at the site of the injury to stop the bleeding. Without clotting factors, normal blood clotting cannot take place.[3]**

**There are two main varieties of hemophilia:**

- Hemophilia A—the most common type of hemophilia[2]
  - The body has little or no clotting factor VIII[3]
  - About 8 out of 10 people with hemophilia have hemophilia A[3]
- Hemophilia B—the second most common type of hemophilia, is also known as factor IX deficiency or Christmas disease[2]
  - The body has little or no clotting factor IX[3]
  - Hemophilia B occurs in about 1 in 25,000 male births[4]

**Hemophilia can range from mild to severe.[3] People with normal blood have factor IX levels between 50% and 150%.[5]**

- People with mild hemophilia (5% to 40% factor level), about 30% of the hemophilia B population, usually have problems with bleeding only after serious injury, trauma, or surgery. In many cases, mild hemophilia is not discovered until an injury or surgery or tooth extraction results in unusual bleeding. The first episode may not occur until adulthood[5,8]
- People with moderate hemophilia (1% to 5% factor level), about 40% of the hemophilia B population, tend to have bleeding episodes after injuries. They may also experience occasional bleeding episodes without obvious cause. These are called spontaneous bleeding episodes[5]
- People with severe hemophilia (less than 1% factor level), about 30% of the hemophilia B population, have bleeding following an injury and may have frequent spontaneous bleeding episodes, often into the joints and muscles[5]
  - Severe hemophilia causes severe bleeding throughout life, usually beginning soon after birth. In some babies, hemophilia is suspected with the appearance of a scalp hematoma after delivery or when a routine circumcision (removal of the foreskin of the penis) results in excessive bleeding.[6] Toddlers are at particular risk because they fall frequently and may bleed into the soft tissue of their arms and legs. These small bleeds result in bruising and noticeable lumps, but do not usually require treatment. As a child becomes more active, bleeding may occur into the muscles, a much more painful and debilitating situation[4,6,7]

**The age when hemophilia B is first diagnosed in a child who does not have a family history of the disorder and the frequency of bleeding episodes the child experiences are generally related to the factor IX clotting activity. In any affected individual, bleeding episodes may be more frequent in childhood and adolescence than in adulthood. This greater frequency is a function of both physical activity levels and vulnerability during periods of more rapid growth.[8]**

**There are several important considerations when caring for a person who has hemophilia. Prevention of bleeding episodes should be a primary goal. The second goal involves treating bleeding episodes early and aggressively. Additionally, supportive and adjunctive measures for each bleeding episode in the context of a multidisciplinary team approach should be used.[9]**

**Standard treatment is infusion of factor IX concentrate to replace the defective clotting factor. The amount infused depends on the severity of the bleeding, the site of the bleeding, and the height and weight of the patient.[10]**

**Following an infusion, the doctor may perform a blood test to measure the level of circulating factor IX activity in a patient's blood, also called recovery. Because factor IX recovery varies for each individual, knowing this important recovery value helps the doctor figure out the proper dose of factor needed.[11]**

## *What Are the Symptoms of Hemophilia B?*

**An accurate diagnosis of hemophilia is the first essential step to hemophilia care.**

**Bleeding is the most common symptom of hemophilia, especially into the joints and muscles. For a child with hemophilia, small cuts or surface bruises are usually not a problem, but deeper injuries may result in bleeding episodes that could cause serious problems and lead to permanent disability unless treated promptly.[12]**

**The symptoms of hemophilia bleeding depend on where the bleeding occurs. Young infants may have bleeding from their mouth when they are cutting teeth or if they bite their tongue or tear tissue in their mouth.[12]**

**Toddlers and older children commonly have bleeding into their muscles and joints. The symptoms of these types of bleeds include[12]:**

- Pain
- Swelling
- Loss of range of motion
- Inability to move or use the affected arm or leg

## MASAC Recommendations

In 1954, the National Hemophilia Foundation (NHF) formed a medical advisory council comprising scientists, physicians, and other treatment professionals who are regarded as experts in the field of bleeding disorders, to advance clinical care and promote hemophilia research. This group is now known as the Medical and Scientific Advisory Council (MASAC), and it establishes the quality-of-care guidelines for the treatment of hemophilia. The recommendations issued by MASAC are guidelines that are intended to set the standard of care and are referred to by physicians, medical schools, pharmacists, emergency room personnel, insurance companies, and others.[13]

In joint bleeds, there is usually no bruising or discoloration of the skin to indicate that the swelling and pain are due to bleeding.[12] Repeated bleeding into joints is a significant cause of disability in people with hemophilia. About 90% of all bleeding in individuals with severe hemophilia B occurs in the joints. Repeated bleeding into the same joint results in progressive damage and development of a condition called hemophilic arthropathy that can eventually lead to arthritis.[14]

When there is bleeding into a joint, the blood is gradually resorbed and significant permanent damage is unlikely. If this occurs repeatedly, materials contained in red blood cells (iron and other substances) begin to accumulate in the joint, which leads to inflammation that contributes to progressive joint damage. Repeated bleeding into a joint may also decrease the activity of cells that form new bone, a process that normally occurs throughout life and keeps joints healthy.[14]

In the majority of patients, hemophilia is diagnosed at birth because of a family history. In approximately one-third of patients, the occurrence of hemophilia represents a new genetic event or mutation.[12] When hemophilia is suspected on the basis of either clinical findings or a positive family history, diagnostic studies may be done to confirm the diagnosis.[15]

## Preventing the Preventable

**After years of caring for themselves, older men with hemophilia B have become quite adept at managing their condition. However, as with the general population, they must also face other ailments and health issues that may come with age. As an older man with hemophilia, meeting this challenge may be more complex due to complications related to hemophilia, such as joint damage and coinfections.[16] These additional issues may add stress for you and your family.**

**The fact that you were born with hemophilia was never in your control, but living a healthy lifestyle is. For various reasons, you may have fallen out of the habit of visiting your hemophilia treatment center (HTC) as frequently as you did in your younger years. Yet your HTC medical team continues to be a crucial part in maintaining your health. With the additional health issues that can come with age, you may need to seek medical help from a primary care physician to help you manage your overall health. If you have never consulted a primary care physician before, you may find that the primary care physician is inexperienced in treating patients with hemophilia.[17] Nonetheless, it is important to see your primary care physician for routine checkups and your additional health issues.**

**Although certain health issues are more prevalent in men with hemophilia, a healthy lifestyle and routine medical attention and screenings can help prevent these conditions. The following suggestions, although not extensive, are meant to be something for you to think about and discuss with your medical team to help manage your overall health.**

- Obesity—Keeping your weight under control is necessary for protecting your joints.[18] It has been noted that obesity is now more prevalent in the hemophilia population than in previous generations, with rates as high as or higher than those in the general population. Increased body weight can result in decreased joint range of motion, which is more pronounced in hemophilia patients[19]
- Alcohol use—There are important risks for people with hemophilia who choose to drink alcohol[20]
  - Accidents tend to occur when people drink alcohol. People with hemophilia would be at greater risk for serious injury from an accident because their blood does not clot normally

– There are also risks related to the effect of alcohol on the liver. Some people with hemophilia who received blood-clotting products before 1990 were infected with the hepatitis C virus (HCV). People with HCV who drink alcohol significantly increase the risk for developing cirrhosis of the liver, which further impairs the production of coagulation factors[20]

- Cardiovascular disease—People with hemophilia may have lower mortality from coronary artery disease than the general male population. This may be due to the fact that a reduced ability to form blood clots decreases the risk for heart attacks and other conditions (eg, angina) associated with blockage of coronary arteries. However, this protection is not complete. There are many risk factors for atherosclerosis, including aging, smoking, extra weight, hypertension, physical inactivity, and chronic renal disease.[21] Some of these may be more common and severe in people with hemophilia than in other people. Therefore, it is important to manage these potential dangers

  – Cholesterol—Your body produces this waxy-like substance naturally. Too much cholesterol can lead to heart disease. Strive to raise your "good" cholesterol level (referred to as high-density lipoprotein [HDL]) while lowering your "bad" cholesterol level (referred to as low-density lipoprotein [LDL]).[22] A simple blood test can measure your cholesterol levels[23]

  – High blood pressure—Stress, obesity, and other factors can make the heart work harder than normal, causing elevated (high) blood pressure. This, in turn, can lead to an increased risk for stroke or heart disease. High blood pressure occurs more frequently in people with hemophilia than in the general population.[17] Early detection and treatment are vital. The healthy standard for blood pressure is 120/80 mm Hg; hypertension is defined as a blood pressure of 140/90 or greater[24]

- Cancer—Adult hemophilia patients who became infected with HCV or human immunodeficiency virus (HIV) due to the use of contaminated plasma-derived replacement products are at increased risk for certain cancers. Those with HCV infection are at increased risk for hepatocellular carcinoma and those with HIV infection have increased risk for non-Hodgkin's lymphoma. In contrast, most studies have not found an increased incidence of other cancers among individuals with hemophilia versus the general population.[25] Nevertheless, it is important to be aware of cancers that have become more frequent in older individuals

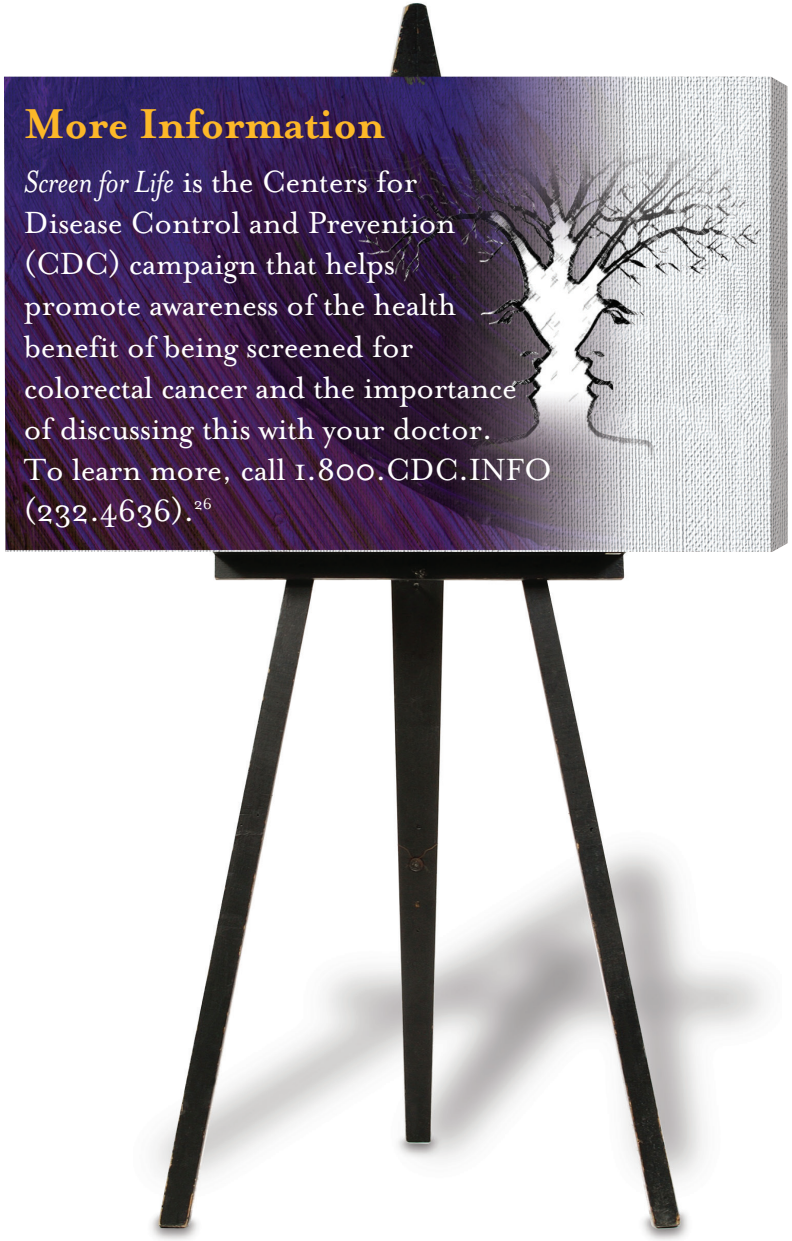
  – Colorectal (colon) cancer—Beginning at age 50, regular screening for precancerous growths is recommended.[26] Each year, there are approximately 136,000 cases of colorectal cancer in the United States. The incidence of occurrence rises sharply around age 40 to 50[27]

– Prostate cancer—The prostate is a small gland located near the bladder that tends to increase in size as men age. An enlarged prostate may affect urination. Although no one set of guidelines exists for who should be screened and when, it is generally recommended that men over the age of 50 receive screening for prostate cancer, which might include a digital rectal exam and a blood test for prostate-specific antigen (PSA)[28]

- Osteoporosis—Hemophilia has been associated with low bone mineral density (BMD), and it has recently been shown that men with this disease are at an increased risk for osteoporosis. A study of men ≥50 years old with hemophilia indicated that 38% had osteoporosis[29]

  – Multiple factors may contribute to increased risk for osteoporosis in people with hemophilia, including hemarthrosis and arthropathy, long periods of immobility that contribute to increased bone resorption, and inflammation associated with HCV and/or HIV infection[30]

  – Management of osteoporosis includes improved diet, the use of supplements, lifestyle changes, and medication. Vitamin D and calcium supplementation are both important and treatment with a drug that prevents breakdown of bone may also be recommended. Bisphosphonates inhibit cells called osteoclasts from breaking down bone tissue, increasing density and making bones stronger and less prone to fractures. Strength training (lifting weights) can also increase bone density and even walking can help build bones[31]



**There are also a few things to remember about sex and risk for bleeding.**[32]

- Sex involves parts of the body that have a lot of blood vessels, and you can get a bleed anywhere your blood flows
- Sex is like most other strenuous physical activities for a person with a bleeding disorder, and it could potentially cause a bleed in any part of the body or in any joint
- After sex, some men experience lower back, abdominal, pelvic, and/or upper thigh-groin pain, and tingling or numbness in the affected thigh if they bleed into their deep pelvic muscles
- The deep pelvic muscles are large, and as with any large muscle bleed, a lot of blood can be lost into the muscle, leading to low blood volume and potentially serious problems with circulation
- Deep pelvic muscle bleeds can be limb and/or life threatening and should be considered a medical emergency. Call your doctor as soon as possible for help and treatment instructions

**Men should look out for any injury to the penis, which may be marked by external bleeding, swelling, pain, and discoloration of the urine. If you have any of these signs and symptoms, call your doctor as soon as possible.**[32]

**Over the years, you have probably had various medical procedures and tests. In this stage of your life, they continue to present a challenge because of hemophilia. Yet you should seriously consider certain procedures and tests to maintain your overall health.**

**Remember! Speak to your health care provider about proper preventive measures, which could help lessen the chance of excessive bleeding during a medical procedure or test.**

## Be Smart

Practicing safe sex does not end once you have reached a certain age. Whether you are in a committed relationship or just dating, you should always take proper precautions to prevent sexually transmitted diseases (STDs), such as herpes, HIV, and hepatitis. Of course, disclosing the fact that you have hemophilia is your decision. However, disclosure of any other resulting complication is a moral and ethical decision that needs to be carefully thought through. These and other sexual matters should be discussed with a trusted health care professional.

**You may need dental care or even a skin biopsy as part of your preventive health care.**

- Dental care—Health issues in the mouth and throat range from tooth decay to cancer. Many of these afflictions are preventable when detected early. You should visit your dentist for cleanings, fillings, and preventive sealants. This kind of regular care can help you avoid having extractions.[33] Other actions that can decrease your risk for tooth decay include[34]:
  - Reducing the frequency and amount of sugars in the diet
  - Avoiding smoking
  - Using fluoride
  - Practicing regular oral hygiene (at least twice daily)
- Skin exam—For years, the medical community has stressed the importance of protecting your skin from the sun. Even moderate, repeated sun exposure causes visible skin damage. The damaging effects of unprotected exposure to the sun build up over time and cause permanent changes. A more serious effect of sun damage is skin cancer.[35] Talk with your doctor if you notice any abnormalities or changes in your skin

**To test for skin cancer or other abnormalities, your doctor may recommend that you have a biopsy. This involves taking a sample of the section of skin in question and sending the sample to a laboratory to be examined. Because your skin will be cut, the nurse at your HTC or other facility will speak with the dermatologist or plastic surgeon to find out how involved the procedure is. Usually, it is recommended that you infuse factor before the procedure and contact your HTC afterward for any additional care.**

- Chronic pain—If needed, talk to your HTC about drug (pain medicines) and nondrug treatments for pain. These can include acupuncture, biofeedback, exercise, hydrotherapy, physical therapy, and more.[36]

With today's technology, smartphone apps serve many purposes. For example, HemMobile® is a free app that lets you keep track of your infusions and any bleeds you might have. This information may be helpful to share with your doctor at your next appointment.

Following the guidelines suggested so far, including consulting a primary care physician, is only one part of managing your health. Another part includes proper diet and exercise, which can help maintain a weight that is appropriate for your body to function at its best. Everyone is susceptible to grab-and-go eating habits—picking up a doughnut on the way to work, raiding the candy machine during a 3-o'clock slump at the office, or indulging in those appetizer specials at happy hour. When these behaviors occur frequently, the pounds start to add up. The extra pounds may not only cause a bulging midsection, but can also contribute to complications, such as diabetes and excess stress on joints. Losing as little as 7% of your baseline body weight, along with moderate physical activity, may reduce the incidence of diabetes in high-risk people by >50%.[37]

Regular exercise can help maintain a healthy body and reduce the risk of age-related disease. It is recommended that adults participate in at least 30 minutes of moderate physical activity 5 days a week to improve their general health.[38] If you have a busy schedule and a family to care for, having the time and patience to carry out a formal exercise routine may not be something that you feel you can accomplish. Try incorporating physical activity into your daily routine, such as taking the stairs instead of the elevator.

If you were physically active as a child, it is likely you will continue to stay active into your adult years. However, you may need to switch from one activity to another as you grow older. For example, some sports become more physical and possibly more dangerous in adulthood. Soccer and basketball may be safe for children, but these sports can result in serious knee and ankle injuries in adults.[39]

Physical activity does not have to be high-impact in order to reap benefits from it. You may want to consider swimming or yoga. You can improve your health through the accumulation of shorter times of moderate activity. However, greater levels of activity do produce greater health benefits.[38]

As always, talk with your doctor and HTC team before participating in a new exercise or sport. Also ask about preventive treatment regimens that may help you get the most out of your exercise routine.

Jeff K., a 46 year old with moderate hemophilia B from Minnesota, stays active and youthful by taking advantage of the great outdoors. Jeff loves spending time with his children, boating and coaching their soccer teams. Exercise and staying fit were never a problem for Joseph L., a 49 year old with severe hemophilia from New Jersey, who has been an avid athlete for most of his life. Running, basketball, baseball, and touch football were just a few of the activities he took part in. Although he does admit his active lifestyle may have caused a few bleeds, it also made his muscles stronger, which provided greater support for his joints. He remembers the frequency of bleeds actually diminished as he aged, a fact he attributes to his staying active.

### *Be Proactive*

As a result of growing up before much was known about hemophilia treatment, many older men did not have the opportunity to maintain a preventive treatment regimen or even treat bleeds as quickly as was needed. These men are living examples of the physical consequences of suboptimal factor replacement therapy. When Jeff was growing up, treating preventively was not an option. "My late teens and early 20s were during the dark years when blood supplies were not always safe." His treatment protocol was "just enough to get by." Today, Jeff believes that being proactive and treating preventively is a smart idea. Before certain events, such as a trip to Disney World with his family, he infuses factor because he knows he will be doing a lot of walking and carrying luggage. He also infuses factor before doing outdoor chores like raking leaves.

## Need a Rush?

If it takes more than a daily stroll through the park or a game of catch to get you motivated, you might want to explore outdoor adventure companies that specialize in safe, fun, and educational wilderness trips for people with special medical considerations, such as a bleeding disorder.

## Surgery

**Surgery can be a serious matter for anyone with hemophilia because excessive bleeding is always a concern. If you choose to undergo elective surgery, there are a few things you should know.**[40]

- Surgical procedures should be performed in coordination with a team experienced in the management of hemophilia
- Procedures should take place in a center with adequate laboratory support for reliable monitoring of the clotting factor level
- Preoperative assessment should include inhibitor screening
- Surgery should be scheduled early in the week and early in the day for optimal laboratory and blood bank support, if needed
- Availability of sufficient quantities of clotting factor concentrate should be ensured before undergoing major surgery
- The dosage and duration of clotting factor concentrate coverage depends on the type of surgery performed

**Remember that in certain cases, you and your doctor may not at first see eye-to-eye on whether to have a procedure such as a joint replacement (arthroplasty) or a joint fusion (arthrodesis). Dan B., a 55 year old with severe hemophilia B from Texas, discussed the possibility of surgery with his doctor to help correct the debilitating pain in his elbow and ankles. Five joint replacements later, Dan is now happy about having had the surgeries. Because the decision to have surgery is a personal one, he would encourage you to be your own advocate when it comes to your medical needs.**

# The Unexpected

When Joseph L. went into the hospital for a splenectomy (surgery to remove his spleen), his doctors made sure he received the appropriate amount of factor to maintain his levels during and after the surgery. He emerged from surgery, stitched up and ready to recover. What he did not plan on was suffering a seizure (due to an underlying epileptic disorder) several hours after surgery as he was walking the hospital halls.

The resulting fall caused Joseph to bleed internally and his sutures to tear. An additional 2 weeks of recovery was needed, along with more infusions of factor and the risk of returning to surgery to restitch his abdomen. Because an event like this can happen at any time, it is crucial that the doctors involved in your surgery know your complete medical history and any ailments or conditions that may complicate your care and recovery. The doctors should ensure that all necessary medications are being properly administered.

## Stick With It

Of course, surgery is not all it takes to restore your body. In the postoperative period, you must maintain appropriate factor levels and adhere to the physical therapy routine the health care team designs for you. Physical therapy aids the healing process by strengthening the muscles to help keep the joints active. Not adhering to your workout or becoming lax about it could mean longer recovery time or the possibility that the joints that were operated on might not function properly.

**Jeff K. said that his ankle fusion and hip replacement (at 32 and 41 years old, respectively) "changed his life." Major surgeries like this require discussion with your treatment team. If you are considering surgery as an option, it is important to thoroughly explore it with your doctors.**

## Psychosocial Issues

Older men with hemophilia B often have experienced quite a few challenges related to their disease over the course of their lives. In some cases hardships can contribute to the development of clinical depression, which is much more common among people with hemophilia than in the general population. All of these factors may contribute to increased risk for the development of clinical depression, which is much more common among people with hemophilia than in the general population. Results from one study showed that 37% of a sample of patients with hemophilia met the criteria for depression, 20% of these had moderate to severe symptoms, and 66% suffered functional impairment due to their depressive symptoms.[41]

**Education and support for men with bleeding disorders and their families is very important, as well as being in control of their own lives and being their own advocates. Some men use what has happened to them as a way to motivate themselves. Other men have more difficulty. Through seminars and discussion groups, these men can be helped to set and attain realistic goals.**

**Some men who acquired HIV and HCV from virally contaminated blood products have carried their anger and resentment for years. Other men carry resentment for not having family or social support when they were younger. Some resent the current changes in their lives, such as early retirement or altered family dynamics. Linda Gammage, MSW, LCSW, a retired social worker/consultant from Illinois, recognizes how difficult it can be to let go of issues. It is important to seek help in dealing with these negative emotions.**

**Older men with hemophilia may also be dealing with stress due to monetary and/or insurance issues, depression, and pain. These situations can become more serious if not dealt with properly. If you are experiencing psychosocial issues such as these, it is important to seek help. Reach out to your treatment team to discuss your feelings and learn more about next steps.**

## Career/Financial Planning/Retirement

**Because economic conditions fluctuate, job security, financial stability, and retirement plans are constantly on our minds. In your younger days, you probably had your fair share of jobs and struggled with how to best manage your money. You also may have had to decide whether or not to tell a prospective employer that you have a chronic condition.**

**Hopefully, you have a career that is satisfying, pays the bills, and affords you decent health benefits. Joseph L. admits that after leaving his family's business and taking a job with another company, his top priority was researching the company's health insurance policies to make sure he would have proper coverage for his condition. Joseph has since started his own consulting firm with his wife and says it was an extremely prudent decision. If you have the means and the drive, Joseph highly recommends exploring the idea of starting your own business. Jeff K., who is also self-employed, echoes these sentiments.**

**Not everyone has a job that is very satisfying. However, Linda Gammage points out that some people might feel trapped in their jobs just because it is easier to stay than to look for another opportunity. She recommends speaking with a social worker or reimbursement specialist for help with the process. Programs such as Medicare, Social Security Disability Insurance (SSDI), and Supplemental Security Income (SSI) are a few options available to older adults.**

**No one can predict the future, but you can project how much money you will need when you retire. A financial planner or analyst can help you estimate your needs based on your current assets, health care requirements, preferred lifestyle, and other issues. The financial planner can also advise you on saving for retirement through contributing to a 401(k) or other retirement fund.**

## Remember

Based on the Americans with Disabilities Act (ADA), employers are not allowed to discriminate against people with disabilities, which in certain cases can include those with chronic illnesses such as hemophilia or diabetes. The act also states that employers must make a "reasonable accommodation" for a person's disability. If you know that you are able to successfully perform the required job duties with reasonable accommodations from your employer, you are protected under the law as long as you disclose your condition before being hired. If you choose not to disclose this information, you may not be protected under the law.[42]

## Insurance/Disability

**Maintaining health insurance coverage can sometimes be more difficult than getting it in the first place. Certain circumstances in life, such as losing a partner, losing a job, or changes in your health status simply due to growing older, can lead to interruptions in health care coverage. A few options are designed to help individuals in these situations. These include the Consolidated Omnibus Budget Reconciliation Act (COBRA), state-sponsored plans, individual Health Insurance Portability and Accountability Act (HIPAA) insurance plans, and Medicaid.**

**You can also explore these areas:**

- Local chapters of the National Hemophilia Foundation (NHF)
- National advocacy groups, such as the Hemophilia Federation of America (HFA) and The Coalition for Hemophilia B, Inc.
- State and local governments with programs and funds dedicated to hemophilia care
- Nonprofit agencies
- Pharmaceutical manufacturers

**Judy Bagato, RN, BSN, reminds older adults that there is always somewhere to turn, even in times of immense hardships. All you need to do is ask, and you should never feel ashamed for doing so.**

## Travel Tip

Whether you are packing the family up for a weekend adventure or flying somewhere for business, it is always important to be prepared when you travel. Accidents can happen anywhere, and it is better to be safe than sorry.

Judy Bagato encourages patients to inform their HTC nurse coordinator as to where and when they will be traveling. In Judy's center, once she knows a patient's travel plans, she supplies them with a travel letter explaining why they need to carry factor and an emergency room introduction letter. She also provides her patients with a complete list of HTCs located along their travel route. Judy recommends that they carry all of their important papers together in a folder that is easily accessible.

## Conclusion

**Despite the challenges many people with hemophilia B may have experienced in their lifetimes, it is important to remain positive about the future. Despite having endured five joint replacements, cancer treatment, and most recently, a cartilage tear in his shoulder, Dan B. continues to maintain a positive outlook on life and reminds himself every day how lucky he truly is to be alive.**

**Dan B. feels that part of the reason he has been able to reach the "ripe old age of 55" is due in part to caring and generous individuals within the hemophilia community. His advice is to never forget those who helped you get where you are today. Dan says, "You owe it to all the people who helped you survive to make the most of what you have and to give something back." Volunteering in any arena can touch the lives of others and gives you a sense of pride and accomplishment. It is also important to realize that once your generation is gone, so are many lifetime collections of wisdom and experience. Some of these may never be known by the younger generation growing up in such a medically advanced world. Tell your story and be remembered.**

# Resources

**Pfizer Hemophilia Connect**

We're committed to helping the hemophilia community.

For the past two decades, Pfizer has been a part of the hemophilia community. We recognize it can be difficult to understand what support is available to help families with bleeding disorders, and to help address this challenge, we created Pfizer Hemophilia Connect.

Pfizer Hemophilia Connect is a one-stop destination to access all of our resources for eligible patients.

**Soozie Courter Hemophilia Scholarship Program**

Pfizer provides scholarships to students with hemophilia A or hemophilia B who are high school seniors, have a graduate equivalency diploma (GED), or are currently enrolled in an accredited junior college, college (undergraduate or graduate), or vocational school. Awards are based on academics, recommendations, and a personal statement from the student.

Visit www.HemophiliaVillage.com to download an application.

**HemophiliaVillage.com**

The Pfizer-sponsored website, www.HemophiliaVillage.com, provides information for the hemophilia community. Consumers and professionals alike can find product information and learn about programs and services.

**B2Byourvoice.com**

The Pfizer B2B Consumer Advisory Board was developed to directly connect Pfizer to hemophilia B patients and caregivers in order to gain firsthand feedback from the hemophilia B community. As a result, the B2B program has created tools and resources to support the community and continues to evolve to address needs as they change. Visit www.b2byourvoice.com for more and to check out a series of books, videos, patient stories, and other resources for people living with hemophilia B.

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This book was funded by Pfizer Inc
and distributed in partnership with The Coalition for Hemophilia B, Inc.

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