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Aging Well with Hemophilia

CVS Specialty Hemophilia Care Program



Anthony’s Story

Meet Anthony, a retired musician and now part-time music teacher. Anthony was diagnosed with hemophilia A at age two. His parents didn’t expect him to live long. But they tried to make life as normal as possible. Still, Anthony grew up always thinking of the next health hurdle. Now, decades later, Anthony calls his life “charmed.” He just celebrated his 33rd wedding anniversary and has three grown children who live nearby.

But there were extra health challenges along the way. Anthony was one of many people infected with both HIV and hepatitis C (HCV) from contaminated blood products. But medicine has helped Anthony manage his HIV and HCV. He also credits clotting factor concentrates (or “factor”) with saving his life. And he speaks highly of his CVS Specialty™ Hemophilia CareTeam and Hemophilia Treatment Center (HTC). Both have helped him manage each new health challenge.

Anthony is now 61, and he is facing the same health challenges as other people his age. This means he has to juggle his hemophilia, HIV, and HCV, along with the “normal aging” stuff. It’s getting harder to read the music notes his students are playing. Plus, his cholesterol and blood sugar are a little high. Then there’s the pain in his hips...

Are You Like Anthony?

If you are, you’re not alone. Many people are dealing with hemophilia, viral conditions like HIV or HCV, and the normal challenges that come with aging. The good news is that people with hemophilia are now living as long as people without hemophilia. Some reasons why are:

- More effective medicines to treat HIV and HCV
- Safer factor
- Care from hemophilia experts like your Hemophilia CareTeam and HTC

Meet Health Challenges—One Small Success At a Time

You have already succeeded in managing hemophilia long-term. This guide explains some of the health challenges you may have as you age with hemophilia. Staying informed is one of the best ways to meet any challenge, so read this guide with the goal of learning all you can.

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TIP

Take a major role in your care. The more you know about each health challenge you face, the more options you may have.

Hemophilia and the Health Challenges of Aging

Heart Disease

Heart disease includes health problems related to the buildup of plaque (fatty substances, cholesterol, and cell waste) in the arteries. Arteries are blood vessels that supply oxygen-rich blood to the heart muscle, brain, and other parts of the body. Hardening of the arteries (atherosclerosis) happens when:

1. Plaque builds up in the arteries
2. They narrow
3. Blood flow becomes more difficult

This leads to a higher risk for heart attack and stroke.

Some other types of heart disease are:

- Heart failure (this is not a single event, but a condition)
- Irregular heartbeat (arrhythmia)
- Heart valve problems

People used to believe that hemophilia protected you from heart disease. But research has shown that it does *not* protect you. In fact, heart disease is a common cause of death in people with hemophilia. Here are some facts about hemophilia and heart disease:

- Men with hemophilia get as much hardening of the arteries as men without hemophilia
- High blood pressure is more common in men with hemophilia compared with the general population
- High factor levels can increase clot formation. This is most common with APCC (activated prothrombin complex concentrate), a specific mix of factors. Increased clotting can put you at risk for heart disease.
- Some medicines used to prevent strokes, heart attacks and irregular heartbeats can affect blood clotting. Someone with hemophilia can bleed more on these medicines. This can make it difficult to manage heart disease.

TIP

Have regular check-ups. Routine screenings can help your doctor find conditions that lead to heart disease. Visit [heart.org/numbersthatcount](https://www.heart.org/numbersthatcount) for a list of screenings that you may need. Talk with your doctor about these screenings to stay heart-healthy.



What You Can Do

The American Heart Association (AHA) has 7 tips:

1. **Get active.** Aim for 2.5 hours of moderate physical activity each week. This is equal to about 20 minutes of walking each day. Always start an exercise program slowly.
2. **Manage your cholesterol.** Start with diet and lifestyle changes. If your doctor thinks you need medicine, take it.
3. **Eat better.** Make half your plate fruit and vegetables. Eat fish twice a week and fiber-rich whole grains every day. Limit your salt and sugary drinks.
4. **Manage blood pressure.** High blood pressure has no symptoms. Know your blood pressure and take steps to lower it if it's too high.
5. **Lose weight if you are overweight.** Losing even 10 pounds lowers your risk of heart disease.
6. **Lower blood sugar.** Diabetes is not a friend of the heart. When blood sugar is too high, this increases the risk of heart disease by 4 times.
7. **Stop smoking.** This can help you prevent heart disease, cancer, and chronic lung disease. Ask for help—there's no reason to do it alone.

Be sure to check with your hemophilia treatment team for special advice about the AHA tips to prevent heart disease. For example, your HTC physical therapist can give you examples of the right kinds of exercise for you. There might be other special instructions for you based on your current health.

Liver Disease

Many people treated with factor before the early 90s were infected with hepatitis C (HCV). HCV can cause chronic liver disease, liver failure, and the need for a liver transplant. Those infected with both HCV and HIV can have even more problems.

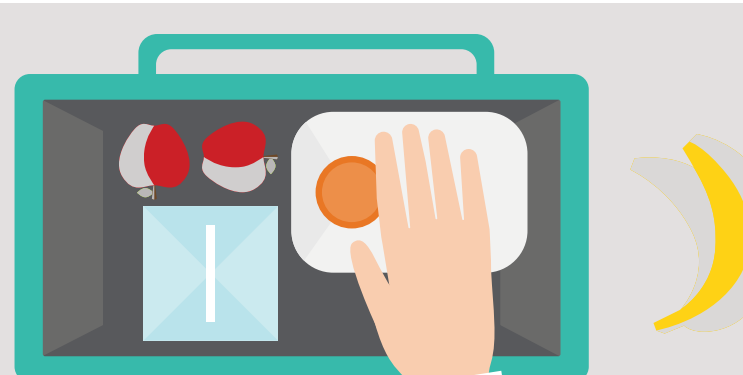
Chronic liver disease from HCV is the leading cause of death in people with hemophilia. This virus slowly destroys the liver. And because the symptoms can be mild, they are easy to ignore.

What You Can Do

1. **Get preventive care.** Blood tests and biopsies can provide information about your liver function. This is very important for people infected with HCV, HIV, or both. Check with your doctor about what tests you need to check your liver health.
2. **Manage other conditions.** Managing HIV and HCV will help support your liver.
3. **Be kind to your liver.** This means adopting habits that support the liver:
 - Avoid alcohol. It destroys liver cells. Even a small amount can make liver disease worse.
 - Know how all your medicines affect the liver. Check with your hemophilia treatment team before you take any new medicine. This includes over-the-counter (OTC) medicine and other products, like herbs, vitamins, and supplements.
 - Eat a healthy diet and stay at a healthy weight for you. This makes it easier for the liver to do its job. It may even help repair some damage. Limit sugar and salt. Do not eat uncooked shellfish like oysters or clams. An unhealthy diet can cause more liver damage.
 - If you also have HCV, limit foods with high amounts of iron. Don't use iron cooking pots. Again, limit salt.
4. **Treat liver disease.** Treatment can be difficult. But newer medicines may increase the response to treatment and decrease the treatment time.

TIP

Many of the healthy habits that support your kidneys also support your heart and liver, and may protect you against cancer too.



Kidney Disease

People with hemophilia have a much higher risk of dying from kidney disease than those without hemophilia. Three things add to this risk:

- HIV infection
- High blood pressure
- Bleeding in the kidney (as a result of high blood pressure)

Having HIV, HIV with HCV, and inhibitors are also linked to kidney disease.

What You Can Do

1. **Get preventive care and watch for symptoms.** This includes blood tests and biopsies, if needed. Check with your doctor about what tests you need to check your kidney health. Also watch for symptoms. Men with hemophilia may sometimes have blood in the urine (hematuria). But in aging people with hemophilia and diabetes, it may also be a sign of chronic kidney disease.
2. **Manage other conditions.** Some conditions are risk factors for kidney disease, like high blood pressure, HIV, HCV, kidney bleeds, and diabetes. Treat those conditions, and watch your progress.
3. **Be kind to your kidneys.** This means adopting habits that support the kidneys:
 - Don't smoke
 - Eat meals low in fat and cholesterol
 - Get regular exercise. Talk with your hemophilia treatment team before starting any new exercise. And start slowly.
 - Take medicine to lower your cholesterol, if you need it
 - Keep your blood sugar under control
 - Limit salt and potassium
 - Check with your hemophilia treatment team before you take any new medicine. This includes OTC medicine and other products, like herbs, vitamins, and supplements.
4. **Treat advanced kidney disease.** Treatment may include dialysis or even a kidney transplant.

TIP

Check with your hemophilia treatment team before you take any new medicine.

Cancer

People with hemophilia aren't more at risk of cancer than other people. But certain cancers are linked to hemophilia:

- **Liver cancer:** this can happen with chronic HCV and treatments to manage the virus
- **Colon cancer:** colonoscopies are recommended starting at age 50, but people may put them off because of the possible need for factor

What You Can Do

1. Many of the tips for heart health also work to lower your cancer risk:

- Avoid tobacco
- Stay at a healthy weight
- Be active
- Eat healthy
- Limit your alcohol
- Protect your skin
- Know yourself, your risks, and your family history



2. Get preventive care and watch for symptoms. You need general screenings, blood tests, biopsies, or procedures to find cancer early. Don't put them off. Here are some other tips for screenings:

- For people infected with HCV, HIV, or both, screening for certain cancers is very important.
- To find out when you should have routine health screenings for cancer, visit www.cancer.org/healthy/findcancerearly/cancerscreeningguidelines/american-cancersociety-guidelines-for-the-early-detection-of-cancer.
- Also remember to let your hemophilia treatment team know when you are preparing to have these screenings. They may want to recommend factor dosages and follow up with you after your screening.

Take any symptoms seriously. Don't overlook symptoms that you assume are related to hemophilia. For example, men with hemophilia may sometimes have blood in the urine or stool. But new bleeding can also be the first sign of a problem, like colon cancer. Tell your hemophilia treatment team about new bleeding right away.

TIP

If you do have cancer, it's better to know sooner than later. Prevention and screening can make all the difference.

Joint Disease

Your joints age, along with the rest of your body. Today, children begin treatment with factor to prevent bleeds. This is called prophylaxis. But you probably didn't receive this preventive treatment as a child. So you may have damaged, painful joints if you are over the age of 40 with severe hemophilia. Two types of arthritis may affect you now and in the future:

- **Chronic hemophilic arthropathy:** from previous joint bleeds due to lack of early prophylaxis
- **Osteoarthritis:** from normal wear and tear on the joints as people age

Arthritis can cause pain, deformity, and loss of function. This increases the risk of falling.

More adults are starting factor with existing joint disease. This is called secondary prophylaxis. It won't reverse the disease, but it may:

- Decrease bleeding
- Relieve pain from bleeding
- Allow you to exercise
- Improve your quality of life
- Slow joint damage

Those are some benefits of prophylaxis. But these issues may keep people from getting the best results:

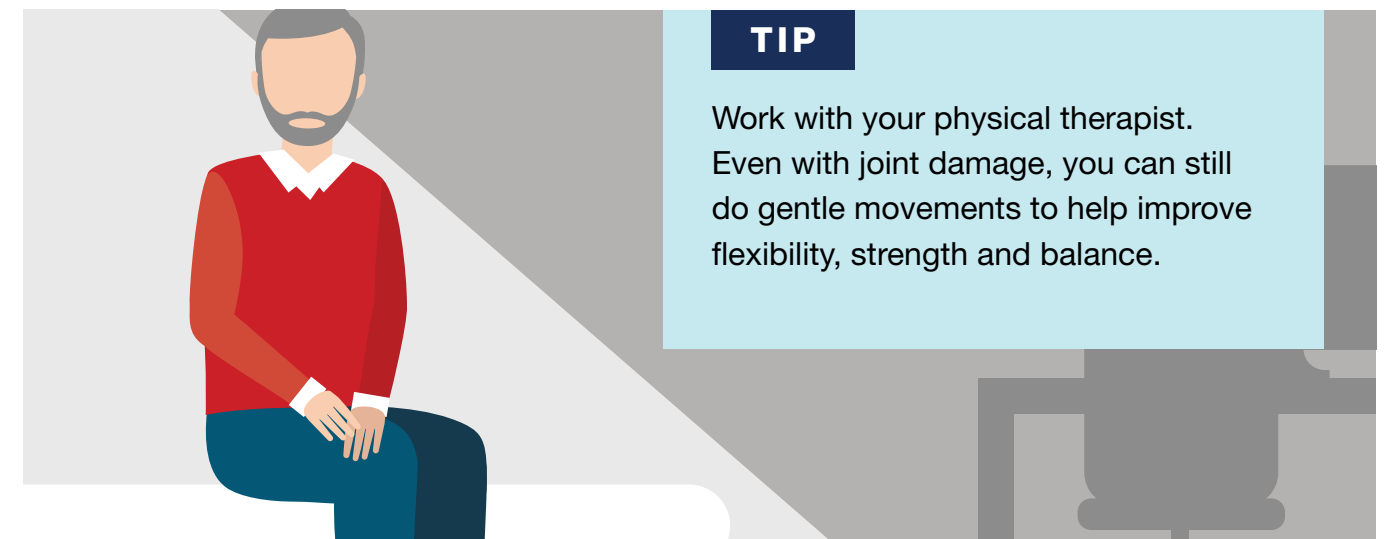
- **Inhibitors** are antibodies that your body can make in response to factor. Inhibitors destroy the factor before it can work. If you use factor for prophylaxis, your doctor needs to watch you closely for inhibitors.
- **Adherence** means how well you stick to therapy. This can be hard. Skipping doses can cause factor levels to fall. Low levels increase bleeding risk.
- **Vein access** is needed to give factor. Repeat injections in the same vein may have caused scar tissue. This can make it harder to get access to veins.

More research is needed to find out how much prophylaxis with factor can help joint health as people age with hemophilia.

Osteoporosis (bone thinning) is another problem for aging people with hemophilia. With osteoporosis, a fall can cause fractures (breaks). HCV and HIV can also increase your risk of osteoporosis.

What You Can Do

1. **Manage pain.** Treatment can reduce pain and keep you active. Some examples of therapy for managing pain include physical therapy, topical medicine, and nerve stimulation to block pain. Prescription and OTC pain relievers can help, too. Check with your doctor before you start any new medicine. There are also some surgical options. Work with your hemophilia treatment team to find the therapy that works best for you.
2. **Be as active as possible.** Physical therapy can help with your joint function and quality of life. It may also lower your risk of falls. Even with joint damage, you can still do gentle movements to help improve flexibility, strength and balance. Work with your physical therapist to make a plan that fits your needs. Start slowly.
3. **Prevent falls.** Think about using a wireless medical alert device so you can call for help.
4. **Talk with your doctor about preventing or managing osteoporosis.** You may need to take vitamin D. Guidelines from the National Osteoporosis Foundation advise that men aged 70 and older get routine bone mineral density checks.



Other Aging Challenges with Hemophilia

Self Treatment

If you self-infuse with factor, you may have some challenges as you grow older:

- **Dexterity:** you may feel clumsy or not as skillful with self-infusing as before
- **Reduced vision:** it may be harder to see what you're doing
- **Scar tissue:** repeat injections in the same vein may make it harder to get access

If you have any of these issues, check with your hemophilia treatment team. Your team can give you advice and provide resources to help.

Mindset and Mental Health

Greg's Story

Meet Greg, a husband, father, practicing attorney, and avid swimmer. Greg was diagnosed with hemophilia soon after he began to crawl. His parents noticed a lot of bruising and took him to the doctor. Screening tests showed that Greg's blood wasn't clotting the right way. A factor assay test revealed hemophilia type A. This was a surprise to Greg's parents because there was no history of hemophilia in the family.



Today, at age 52, Greg usually feels great about how well he manages his health challenges. But he still has bad days. High blood pressure has affected his kidneys, and now he's worried about his heart health. Some of the medicines used to treat high blood pressure can affect clotting. So Greg has to rely on healthy habits to manage his blood pressure. On some days, his knee pain is bad. Prophylaxis with factor seems to help, but the pain can still be severe. It can really bring him down.

A few years ago, Greg found swimming. When he's in the pool, the stress seems to melt away. It keeps him active. And it's easy on his joints. When Greg's family members notice his typical stress symptoms, they remind him to "go jump in." With swimming, Greg found a way to help manage his mindset, and the benefits have made a big impact on his overall health.

Are You Like Greg?

You already know about the challenges of managing hemophilia. You may have had frequent health problems, hospital visits, and chronic pain. Having feelings of fear, anger, frustration, grief, or depression is common. Now add the challenges of aging. No one could blame you for getting down from time to time. Just don't stay there. Here are some tips to remember for a healthy mindset:

- **Control your stress.** It can have a negative effect on your blood pressure and immune system.
- **Know your condition.** Learn all you can so that you can make the best choices for you.
- **Keep a list of your questions.** Take it with you to visits with your hemophilia treatment team.
- **Be positive.** Treat problems as challenges that you can solve.
- **Surround yourself with people and things you love.** Laugh often and do what you enjoy.
- **Work with your health care team.** Take an active role in your health. Your team can help with other strategies for a healthy mindset. With their help, you can look forward to better emotional health, family stability, work-life balance, and feeling empowered.
- **Take medicine if you need it.** Chronic pain can affect your mindset. In surveys of people with severe hemophilia and joint pain, about 8 of 10 people reported bad moods as a result of pain. Talk with your doctor about taking an anti-depressant. It may help you feel better. If you are down or depressed, it might be the result of pain. But some types of pain medicine can also make depression worse. So work with your doctor until you feel better.

TIP

Health challenges can get you down. Always ask your hemophilia treatment team for help when you need it.



You Are a Trailblazer

Right now, there isn't enough research on aging with hemophilia. You may even understand more about your condition than many health care providers. They need treatment guidelines and recommendations, which are slow to develop. As part of the growing generation of people with hemophilia to reach this age, you need to become your own advocate. Face your challenges with help from your team and do everything you can to stay healthy. By doing so, you're adding to the hemophilia knowledge base. This can help many other people facing the same health challenges that come with both hemophilia and aging.

TIP

Be the person who leads your care.

More Information

Check these sources for more information about managing the challenges of aging with hemophilia:

- **CVS Specialty Hemophilia Care Program:** 1-866-RxCare-1 (1-866-792-2731)
- **World Federation of Hemophilia:** www.wfh.org
- **National Hemophilia Foundation:** www.hemophilia.org
- **HEMAWARE, The Bleeding Disorders Magazine:** www.hemaware.org
- **Hemophilia Federation of America:** www.hemophiliafed.org