



Stage 4:

The Teen Years (12–18 Years Old)



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Now that you're a teenager, the management of your hemophilia will be different than before. You may notice things about living with hemophilia that you never noticed before. For example, have you seen adults with hemophilia with stiff, arthritic joints who need a cane or a wheelchair to get around? They are living examples of what uncontrolled bleeding can do to your joints.

Moving into the teen years is a critical turning point for both you, as a teenager, and your parent(s)/caregiver(s). You will now be given some more freedom to make choices for yourself. You are now responsible for making the right choices to keep your body working for you in the many years to come. If you make good choices now, your body will function in tip-top shape when it comes time to give the same advice to your own children. While you take on this newfound freedom and responsibility, your parents will be going through a major change as well. They will begin passing some responsibility to you – responsibilities that they have been managing for you your entire life. You may have been feeling that your parents/caregivers have been bossy when they ask you to brush your teeth, eat your vegetables and take your factor. Bossy or not, they've been trying to get you into the habit of taking care of yourself.

This is a tough stage in your life when you are expected to act like a grownup, but some still see you as a kid. Teenagers face a lot of pressures, and having hemophilia can certainly make things more complicated. The goal of this section is to help guide you to a realistic approach to taking care of your body. You only have one body, so it's a good idea to take care of it.

Taking control of your treatment⁸

Have you heard the joke “How many teens with hemophilia does it take to change a light bulb?” The punch line is “None, their parents do it for them.” It's kind of funny, and it's also kind of true. As a teenager, it's important to know all about your treatment and how to administer it. Remember: It's your body and your hemophilia.

As a young adult with hemophilia, you should be able to answer these questions: Do you have hemophilia A or B? Is your hemophilia mild, moderate or severe? Do you know what kind of factor you use? Do you know if your factor is plasma-derived or recombinant? Do you know when and how many units to infuse? Do you have a target joint? Do you know what inhibitors are and do you have inhibitors?

Talk to your parents, your hematologist or medical staff to become familiar with this information. You can even start by paying closer attention to the box of factor you're opening and the pharmacy label on it. One day, sooner than you think, you'll be out in the world on your own. You'll be a step ahead by knowing this information.

Now that people can receive factor at home, treatment is much more convenient. But it's important to know how much factor you have at home. Paying attention to your factor and supply inventory will help avoid times when you run out and have to go to the emergency room for treatment, where you may have to wait a long time before you get treated and released. Your hematologist can help you decide how many doses of factor need to be kept at home.

You should talk to your parents and put together a plan to take a more active role in managing your factor and your hemophilia. It could be as simple as writing your parents a note that says, “I need more factor,” or picking up the phone and ordering from your pharmacy or pharmacy care provider.

As a teenager, you may want to start doing your own infusions. This means doing all the steps necessary for the infusion, including the needle stick. If you're not self-infusing already, let your parents and medical staff know when you feel ready to learn. Self-infusion is easy to learn and can be important for your independence. Once you're independently infusing your medication, you don't have to rely on other people and can go anywhere as long as you take your factor and supplies with you.

A lot of people complain about having to keep treatment logs, which record and document details about their bleeds, how much factor they used for each infusion and factor lot numbers and expiration dates. It is important to keep track of this information so you can see at a glance what types of bleeding episodes you are having, how often you treat and if there are any target joints developing. More and more insurance companies are making people keep treatment logs and turn them in as part of approving payment for the next shipment of factor. Treatment logs vary and can come from your hematologist, pharmacy, insurance company or factor manufacturer. Find a system that works for you, and stick with it.

General well-being

Dental care²³

It's important to take good care of your teeth so they, too, can last a lifetime. As you grow, you might need braces. Your wisdom teeth may need to be removed. Consult with your family dentist about this, and always make sure your dentist has the number of your hematologist. If you're on prophylaxis, schedule dental appointments on treatment days.

Immunizations

Even though you're finished with elementary school, your school may require additional vaccinations, immunizations or booster shots. Check with your school or its website to make sure that you are up to date.

Nutrition^{9,13,14}

A report from the Centers for Disease Control and Prevention (CDC) showed that teens with hemophilia are almost twice as likely to be overweight as children the same age in the general population.²⁰ Keeping weight in best range for your body is especially important for people with bleeding disorders. Extra weight adds stress on joints (which can increase joint pain and frequency of joint bleeds), makes it harder to find veins for infusion and requires more factor per infusion since doses are based on weight.

While genetics can be part of the problem, personal choices also affect one's weight. Activity combined with healthy eating can help maintain appropriate weight.

Here are some helpful tips to get on the path to a healthy lifestyle:

- Eat with your family whenever possible.
- Don't eat meals or snacks in front of the TV.
- Read the nutritional label. Ingredients are listed in order of proportion. The label also shows calories and serving size.
- Avoid foods containing high percentages of sugar, fats, sodium and cholesterol.
- Eat from all food groups every day for a well-balanced diet, and eat more vegetables, fruits and lean meats. Limit sweets, pastries and other foods that are high in calories and low in nutrition.
- Avoid fried foods. Instead, bake or grill meats, and steam or grill vegetables.
- Replace vegetable oil with olive oil.
- Opt for nutritious snacks. Some examples include fresh and dried fruit, vegetables, pretzels and fat-free cookies.
- Drink plenty of water, milk or calorie-free beverages instead of soft drinks.
- Don't skip meals; instead, eat smaller meals and healthy snacks.



Exercise¹⁹

Exercise is also important for a person with hemophilia. Strong muscles mean healthy joints. Healthy joints usually mean fewer bleeding episodes. You can talk to your medical staff, including the physical therapist, to customize an exercise plan to help you get the exercise you need without aggravating a target joint or a bleeding episode. Regardless of which sport or activity you decide on, make sure you wear any recommended safety equipment.

As hemophilia care has advanced, kids with hemophilia can grow up living an active lifestyle. For many, this includes playing organized sports, such as soccer, swimming, basketball or even baseball. It's important to be comfortable with the level of competitiveness on your team and to make sure your coach is aware of your hemophilia. Most importantly, discuss your sports participation with your medical staff to determine whether you will treat hemophilia on a prophylactic (preventive) or an as-needed basis. Visit www.hemophilia.com to download a copy of the Coach and Educator's Guide to Bleeding Disorders.

School issues²²

Some teenagers make a conscious effort to blend in with other people at their school, while others get unusual haircuts or wear different clothes to stand out. Having hemophilia can make blending in a difficult task. Many teenagers try to avoid the subject by hiding or "forgetting" they have hemophilia and ignoring the symptoms of a bleed. This can lead to delayed treatment for a bleed or missed prophylaxis doses and result in more bleeding. Most people would agree that the cost of fitting in isn't worth the pain and joint

damage an untreated bleeding episode can cause. As hard as being different from your peers may seem, it is very important that key people at your school know about your hemophilia, such as your school nurse. Since you've lived with your condition all of your life, it is likely that you and your family know more about your hemophilia than your school nurse does. Take this opportunity to share information about your hemophilia and how it's treated with school personnel. Your hematologist or specialty pharmacy provider can help you. Telling some of your closest friends about your condition can also be a benefit. If you are injured and they know about your hemophilia, then they can help you get the medical assistance you need.

Although you may be shy about letting others know you have hemophilia, wearing medical identification jewelry (bracelet or necklace) alerts medical professionals to your condition in case of an emergency. It can save your life!

If you have trouble attending school, you may qualify for a Section 504 plan. The Rehabilitation Act of 1973 requires school districts to reasonably accommodate students whose health or disability limits one or more major life activities. These include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself and performing manual tasks. You may not think of having hemophilia as a disability, but hemophilia is recognized as one of the qualifying conditions covered by Section 504.

Section 504 plans are given to students who require some accommodations to place them on the same level as other students. For some people with hemophilia, certain activities in a physical education class can be too strenuous. You may be able to participate in alternative activities or take a different class in order to meet that educational requirement. It may be as simple as the teacher knowing you have hemophilia and being familiar with signs and symptoms of a bleeding episode.

Please note that each state or school district will have specific procedures for implementing a Section 504 plan.



Psychosocial issues

Dating and intimacy are subjects few teenagers like to discuss, but they are important for every young person. Many teenagers struggle with telling a boyfriend or girlfriend about their hemophilia. Talk about it with your closest friends, parents or other people whose advice you trust. In any relationship, honesty and open communication are essential. Treat the people you date with respect, and expect the same from them. If you choose to be intimate, choose to prevent pregnancy and sexually transmitted diseases. For more advice on this topic, speak with your parents or your hematologist.

A teenager's desire to fit in can sometimes have negative effects. Some teens choose to experiment with alcohol and/or drugs. In addition to being illegal, drugs and alcohol impair judgment and can cause you to engage in risky behavior. Think about where you stand on issues such as drug use, underage alcohol use or other behaviors that may have negative consequences. Make your decision and stand firm, despite what your friends may say. If they are your friends, they will respect your decision. If they do not respect your decision, then perhaps you should reevaluate some of your friendships.

As you approach 18, you will want to become more independent and do things by yourself or with your friends. You may still want to spend time with your

parents, and you may want to have nothing to do with them, all at the same time! This is a natural part of growing up and testing your independence. Even though your parents may embarrass you, it's important to treat them with respect and to try not to criticize them. It's good to keep lines of communication open with your parents.

Driving skills

Some people can't wait to drive. Others are scared to death. As a teenager, you'll get to be in the driver's seat and step on the gas! It's important to get as much supervised behind-the-wheel training as possible so your driving experience is a positive one. Always wear your seat belt. It not only keeps you safe, it's the law. If your hemophilia limits your mobility in any way, you may want to discuss accommodations that can be made in order for you to drive safely. Refer to your state laws and regulations for teen driving.

It is important to understand that taking pain medications, whether over-the-counter or prescribed, may cause drowsiness, and driving while taking them may be considered "driving under the influence." This can cause fatal or life-threatening accidents. Do not drive while taking pain medications.



Developmental Guide

As you grow into a young adult, your body will change. Puberty will continue, and you will have to deal with issues like body hair, getting a deeper voice, acne, body odor and further development of your reproductive organs. Your testosterone level will increase, and you may find yourself getting angry more easily or getting more competitive on the sports field.

Teenagers typically experience a rapid rate of growth. Some teens grow so fast that activities they once did with ease become awkward to them, and they may notice their coordination isn't the same. Sometimes they trip over their own feet or lose their balance easily. The majority of the time, these issues can be chalked up to growing too fast for your other senses to catch up.

As a result, you may find that your long bones (legs and arms) sometimes ache, seemingly for no reason. These are often called “growing pains.” Growing pains generally occur in different parts of the thighs, calves and feet. The pains can be severe enough to wake you from sleep. A key symptom of growing pains is that they occur only when you are at rest, usually at night and rarely during activity. This distinguishes growing pains from pains caused by diseases or abnormalities, which are typically worse when you are active.⁸

During your teen years, you may experience growth spurts. As a result, your factor dose may increase since factor is dosed by weight. Update your weight regularly with your medical team to ensure you have the right dose of factor. You should let your hematologist and pharmacy know if you gain or lose more than 10 pounds.

Pain management¹⁰

As a teen with a bleeding disorder, you may experience pain as a result of the condition and its treatment. You can significantly impact how pain affects you by understanding what pain is, and how to deal with and avoid it.

What is pain?

Pain is how your body reacts to an injury or an illness. It is a sign that something is wrong. Pain can be protective — it's the body's way of saying, “Pay attention to where you hurt.”

How can you tell you are in pain?

- Activity level decreases
- Eating less, sleeping more
- Limping or avoiding use of the injured area
- Protecting where it hurts
- Being unable to sleep

How to manage your pain

You may try to hide your pain from your friends and family members, but don't let peer pressure interfere with your need to have pain evaluated promptly. You can be an active participant in your pain management plan by following these tips:

- Discuss factor treatment options with your hematologist if you participate in sports.
- If pain medication is ordered, take it exactly as prescribed, and observe how well it works.
 - How long are you comfortable after the medication?
 - Does it make you sleepy? How many times did you take the medication?
 - Does your pain seem better or worse?
 - Never take more pain medication than your physician prescribed.
- Follow up with your hematologist if the pain doesn't go away.
- Apply cool packs to bruises.
- Apply RICE (rest, ice, compression, and elevation) to an injury (see page 13).

- When factor is needed, treat immediately to prevent ongoing bleeding.
- Delayed treatment can result in chronic or ongoing pain in your teens and later years which may require surgery and/or narcotic prescriptions. Narcotic use can easily become habit-forming or addictive and is a very serious problem in the U.S. affecting individuals with hemophilia as well.

How to avoid pain

- Prevent pain by avoiding injuries. Use protective devices, such as helmets, knee and elbow pads or shin guards.
- Avoid pain associated with the infusion process by using a topical anesthetic cream before needle sticks, if advised by your hematologist.

Remember, do not take any medication containing aspirin or nonsteroidal anti-inflammatory drugs (NSAID), such as ibuprofen, as it can cause bleeding. Be sure to check with your pharmacist and read the ingredients list on any medication to see if aspirin is included. It can also be listed as “acetylsalicylic acid” or “ASA.”¹¹



Transitional tools

Once you turn 18, you are legally considered an adult. You’ll be given all sorts of responsibilities, whether you want them or not. At 18, you will need to become the primary contact for your medical needs. You will have to give permission for others to have access to your medical information, even your parents. You may want to start making your own medical appointments and calling your specialty pharmacy to order your factor. It’s important to start preparing yourself now so the responsibilities don’t come as a surprise to you.

For a person with hemophilia, health insurance coverage is a key concern when you become an adult. If you have a social worker, he or she can help you and your family navigate the path from being on your parents’ insurance to being on your own employer-provided insurance.

Currently, the Affordable Care Act allows young adults to stay on their parents’ healthcare plan until age 26. Plans and issuers that offer dependent coverage must offer coverage to enrollees’ adult children until age 26, even if the young adult no longer lives with his or her parents, is not a dependent on a parent’s tax return or is no longer a student.²⁴ Talk with your family about how long you qualify to be on your parent’s insurance.

Use this opportunity to get a good education. This can translate into a well-paying job with health insurance benefits.



Choosing a career

Your teen years are not too early to think about a career choice. Once you graduate from high school, some of the options you have may include:

- Attending a 4-year college
- Finding a job
- Attending a community college
- Attending a trade school
- Attending school part-time and working part-time

There are several scholarships available to people with hemophilia to pursue their higher education. Online research can easily provide more information about available options. Reliable organizations to start with are the National Hemophilia Foundation (NHF) and Hemophilia Federation of America (HFA). Don't forget to look for scholarships for individuals with your job interests and from service organizations in which you or your parents may be members.

Regardless of the path you choose, you will need to have a plan.

This is a time to explore which careers are attractive to you. Your school guidance counselor can tell you about different careers and the training they require. He or she can help you find a career matching your abilities and interests.

Having a career is an important step, as it can offer financial independence and give you a positive self-image.

When considering a career, it's important to consider if a job offers flexibility in case you do have a bleed. Other considerations include salary, hours, ease of commute, activity level and benefits package. Remember, eventually you will need to get your own insurance coverage.

By age 18, hopefully you'll be an independent person who can make medical decisions for yourself. That includes ordering your own factor, infusing your factor, following your hematologist's orders, filling out treatment logs and taking care of your body. Remember, it's your body and your hemophilia. As you continue to mature, you can find additional information later in this guide.