

Through the Stages

Tips for managing hemophilia
in every phase of life



sanofi

Life Stages

Navigating the transition between life stages can be challenging for anyone at any age. Living with a rare chronic condition can present even more complications.



Fortunately, with some helpful tips and future planning, individuals and families can feel more prepared for these transitional periods.



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Childhood to Teen



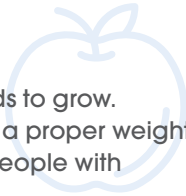
Building confidence on a strong foundation

As children with hemophilia transition to their teenage years, a strong foundation can be important as they begin to build their independence and become more socially aware.

Establishing healthy basics

Nutrition

Eating healthy can help the body get the nutrition it needs to grow. Nutrients build strong muscles & bones, and maintaining a proper weight helps to protect joints, which is especially important for people with bleeding disorders.

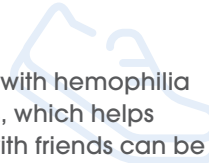


TIP

MyPlate.gov provides guidance on nutrition and adding more healthy meal options. Consult a doctor or nutritionist when adjusting eating habits.

Exercise

Physical activity can provide a host of benefits. People with hemophilia may benefit from exercises that strengthen the muscles, which helps protect joints. Engaging in age-appropriate activities with friends can be a fun way to exercise. Work with your doctor to evaluate the bleeding risk for any activity and modify as needed.



ASK

Hemophilia.org has resources and a list of appropriate sports and activities to help hemophilia patients play it safe.

Notes

Learning hemophilia fundamentals

Hemophilia education

Approaching hemophilia with a learning mind-set can help lead to a lifetime of seeking more education about the condition and treatment options. Age-appropriate camps, patient conferences, and Sanofi CoRe Programs can be engaging learning experiences.

Ask your CoRe about any upcoming educational opportunities.

ASK

Self-infusing

Learning to self-infuse can lead to greater independence in the future. Some first steps can include helping to assemble the materials and learning the importance of a sterile environment. Other things can be added as confidence increases, like mixing factor and tracking infusions, until most of the process can be performed individually.

Talk to your CoRe about resources to support self-infusion and tools to help keep you or your child on track.

ASK

Managing care

Taking an active role in managing the various aspects of hemophilia care can be beneficial to learn at a young age. Tasks such as learning the names of the medicines you take, knowing when to take medication, and keeping a treatment journal are all ways to begin.

Making others aware

While it's important to inform people like school nurses and teachers about a bleeding disorder, whether or not to tell friends and classmates is a personal decision that depends on the comfort of the individual. An example of telling a friend that you have hemophilia might sound like this:

CHAT

I have _____

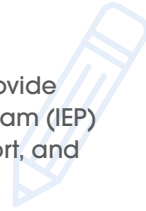
which means my blood doesn't act like most people's blood. If I get hurt, like a bump or bruise, it takes me longer to stop bleeding—on the inside and outside. I take medicine to help it stop.

Childhood to Teen



Starting at school

Schools and school districts often have programs in place to provide assistance for select students. An Individualized Education Program (IEP) is a plan that describes the special education instruction, support, and services that are provided.



TIP

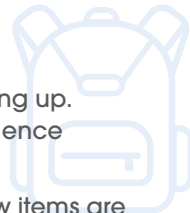
Check to see what programs are offered by the schools in your area. Guidance counselors and social workers can be great resources for learning more.

ASK

Talk to your CoRe about possible ways to work with school staff to help your child thrive.

Being away from home

Sleepovers and camps can be exciting events while growing up. Planning ahead can help ensure a more enjoyable experience and keep you prepared in the event of a bleed.



Along with informing parties responsible for care, the below items are important to have prepared.

- Factor, infusion supplies, medical identification, infusion log or app
- Important phone numbers in case of emergency

TIP

Make sure to keep your mobile phone's emergency medical ID information updated.

ASK

Ask your CoRe about the history and potential benefits of hemophilia camp to help decide whether your family is ready.

Care team questions

Here are some additional considerations that a care team might be able to help address:

- Whether on-demand treatment is recommended in order to participate in sports.
- How puberty might affect teens with hemophilia.
- Age-appropriate exercises for someone living with hemophilia.

Notes

Teen to Adult




Feeling empowered with independence


It is important that teens with hemophilia continue learning about their condition so that they feel empowered to begin taking charge of their life into adulthood—with the support of their family and care network.

Maintaining healthy habits


Taking ownership of health care may include a greater involvement in decisions and transitioning from pediatric to adult care providers. Some steps that can be taken towards maintaining a healthy lifestyle with hemophilia include:



Scheduling regular physical exams and checkups



Sticking to the recommended dosing schedule provided by your doctor



Maintaining a sound body and mind with healthy habits and exercise

Moving away from home

As teens transition out of the household, making sure that they are prepared for everyday living, as well as laying out emergency action plans, are smart things to consider. Some important steps can include:



Locating the nearest HTC



Researching where to get bleeding disorder supplies



Finding any new care providers

Community involvement

Moving away from home can sometimes feel like an isolating experience. Getting involved in community organizations and volunteering may present new opportunities to meet people, find hobbies, and establish a support network.

TIP Ask your CoRe or HTC to help you find any nearby hemophilia chapters in the area.

Disability rights

Transitioning from school to a career, it's important to know the protected rights for people with hemophilia. Worker.gov provides information about workers' rights and common workplace concerns.

Needing insurance

To ease the transition of moving off of parents' insurance, it is important to look ahead at when this might occur and begin researching options. Ask your CoRe about our Demystifying Insurance program to learn more about insurance basics.

Making others aware

When living with roommates for the first time, starting a relationship, or communicating to coworkers, it may be important for them to be made aware of your hemophilia and know what to do in the case of an emergency. An example of telling a friend that you have hemophilia might sound like this:

CHAT

I have _____

That means that my blood doesn't clot the same as other people's, which can lead to prolonged bleeds above and below my skin. It's a genetic condition that is manageable with treatment.

Care team questions

Here are some additional considerations that a care team might be able to help address:

- Finding oral care professionals that are familiar with bleeding disorders.
- Sexual and reproductive health and safety.

Aging with Hemophilia



Protecting your health

As adults living with hemophilia continue to age, it is important to take steps towards protecting your health in order to live as comfortably as possible.

Planning a family

DNA is responsible for passing on hereditary traits from one generation to the next. During the process of family planning, individuals with a family history of hemophilia may consider genetic testing to see whether they might carry or pass on the hemophilia gene.

Keeping your body in motion

Regular exercise can help to keep muscles and joints healthy as you age. Maintaining joint stability, muscle strength, coordination, and flexibility can help you retain your balance and help prevent falls. Opt for low-impact exercises that can also help improve balance and mobility.

TIP

Check out The Joint Movement at HemJointMovement.com. Created by Sanofi to empower people living with hemophilia who aspire to be more active, this site includes resources, workshops, and PT videos focused on joint health and overall well-being.

Managing joint pain

As people age, their joints age as well. For people living with hemophilia, joint pain can be associated with a bleed. Work with your care team to find the best way to manage your pain.

TIP

RICE is a steadfast method for alleviating joint pain and helping prevent further injury. It stands for Rest, Ice, Compress, and Elevate, and, in consultation with a care team, can be beneficial to the healing process.



Screening for age-related conditions

People with bleeding disorders are susceptible to the same age-related conditions as people without bleeding disorders. Scheduling regular screenings can help identify emerging health concerns. Coordinate with your primary care physician, hematologist, and HTC to help ensure that you are getting appropriate tests and screenings.

Care team questions

Here are some additional considerations that a care team might be able to help address:

- Physical limitations that may occur as a part of aging or as a result of complications from a bleeding disorder.
- Age-appropriate activities to help adults with hemophilia to stay active.

Notes

More programs from Sanofi

Talk to your CoRe about some of
our other helpful programs:

From Clinic to Kitchen Table: Step Up to Home Infusions

Teens and tweens will explore the logistical, social, and emotional aspects of managing home infusions in this interactive program.

Deciding If You're Camp Ready

Discuss common fears and get an in-depth look at the camp environment, including socialization, and support resources.

Cracking the Code

Cover the basics of DNA, including how it can affect your health and the relationship between DNA and hemophilia.



For additional resources on navigating life with a bleeding disorder, reach out to your Sanofi CoRe Manager.