

GROWING UP WITH HEMOPHILIA B

A support guide for caregivers



Take this journey together

Caring for a growing child takes a lot of work—and hemophilia B adds another layer of complexity. Feeling confident about managing your child's care can be a process of constant learning and growth. This guide is designed to help you along the way.

We'll cover 4 major phases of childhood and key themes to consider for children with hemophilia B. At the end of the guide, you'll also find tips and guidance for looking after your own needs.

Life phases and key themes

Ages 0 to 2: Adjusting to a new experience — Page 3

Regardless of when you learned about your child's diagnosis, here's what you might expect during and after birth.

Ages 3 to 5: Fostering curiosity and initiative — Pages 4 & 5

At this age, your child is just starting to try new things. Encourage them to keep asking questions and be part of their care.

Ages 6 to 11: Building confidence — Pages 6 & 7

At this stage, your child wants to feel capable and competent. You can help improve your child's sense of self and confidence in treatment.

Ages 12 to 18: Transitioning to Independence — Pages 8 & 9

Supporting your teen in taking control of their treatment with IDELVION is a key step toward their independence.

Caring for yourself — Pages 10 & 11

As a caregiver, you deserve support in managing your own wellness. Learn about finding balance and asking for help when you need it.

AGES 0 to 2

Adjusting to a new experience



Whether you learned about your newborn's hemophilia B through a genetic test or after childbirth, the journey ahead can feel overwhelming at first. However, treatment is manageable, and there are healthcare providers who can help you.



Be an information sponge

Learn everything you can about your child's diagnosis. Scan the QR code to test your knowledge of hemophilia B.

The first 2 years

With the proper education and bleed management, your child's first 2 years can be filled with joy, discovery, and memorable moments. Many parents and healthcare providers have chosen IDELVION to help prevent bleeds in their young children.

Know the signs of different bleed types.*

- Joint/Muscle Bleeding: Pain, swelling, area is warm to the touch, or limited movement
- Head or Neck Bleeding: Mood changes, vomiting, or unusual sleepiness
- Abdominal Bleeding: Blood in urine or stool, stomach pain with no explained cause, or back pain

Infusion training

Your child's care team will likely train you on how to infuse factor replacement therapy with your child. Consider asking about giving an infusion during an appointment. If your child experiences a bleed, ask their care team when it's appropriate to infuse at home or when you should go to a hospital.

Know your child's factor

Work with your child's care team to learn which factor replacement therapy is the right fit. With IDELVION, the care team can measure your child's factor levels, which helps you know how well protected they are from bleeds.

*For informational purposes only. Always consult your healthcare provider(s) for medical advice, diagnosis, or treatment information.

Caregiver corner

Processing your child's hemophilia B can feel like a lot. Work with your healthcare team, and remember that resources are available to help you.



AGES 3 to 5

Fostering curiosity and initiative



Young children ages 3 to 5 are just starting to understand their world and themselves. Caregivers like you can start to help associate treatment with positivity and "me" time.

Making treatment a part of life

Managing your toddler's hemophilia B can be challenging. You can encourage exploration and guide them through their treatment during this phase.



Take small steps to establish healthy habits

Set consistent routines for things that could cause bleeding, like eating certain foods and brushing teeth. Talk to your child about why these habits are important and encourage them to ask questions.



Manage dental care

Children naturally lose their primary or "baby" teeth. Allow teeth to fall out on their own without wiggling them.



Talk with your child's daycare and preschool teachers

Schedule time to explain your child's diagnosis to the school's staff. Someone from your local Hemophilia Treatment Center (HTC) team may be available to help educate the staff about hemophilia B and what to do if a bleed occurs.

Communication tips

Young children may not have the ability to express their feelings or communicate their needs verbally. You can help them develop these skills by:

- Actively listening to your child's thoughts and feelings. Responding by repeating back what you've heard in your own words can make your child feel heard and supported
- Providing positive reinforcement by celebrating every achievement—even the small ones
- Letting your child know that it's OK to make mistakes. Reframe mistakes as opportunities for learning and encourage them to try again

Fostering initiative during infusions

Your child may need an infusion every 7 days with a treatment like IDELVION. While this may be new for you and your child, it will become a familiar habit over time.

1 Make it routine

Keeping things consistent around infusions can help you and your child feel confident and more comfortable.

 **Communicate** each step of the infusion process to your child so they can follow along

 **Set a reminder** for when it's time to infuse

 **Make it fun** by watching a video, playing a game, or listening to music

 **Encourage** your child with affirming words or a small toy or prize after treatment

2 Be a model

Children respond to your emotional state. If you're calm and encouraging, they can be too. When you feel overwhelmed, consider taking a moment to reset before interacting with your child.

Try a calming breathing exercise

Breathe in for 4 seconds, hold that breath for 4 seconds, then breathe out for 8 seconds, paying attention to how your body feels.

3 Involve your child

Infusion time is a great opportunity for teamwork. You can encourage your child to play a bigger role in their care by involving your child in the following tactics:

- Prepare for their injection by opening alcohol wipes
- Hold the gauze and apply pressure to the injection site afterward
- Draw a check mark on the calendar when their treatment is complete
- Learn about factor levels and why they are important

Caregiver corner

As you are starting to build routines around your child's care, schedule time for yourself, too. Pages 10 & 11 highlight how you can care for yourself along the way.



AGES 6 to 11

Building confidence



Children ages 6 to 11 are learning how to accomplish increasingly difficult tasks. This is the time to build confidence and get them engaged with their treatment.

Involving your child in treatment



At the doctor's office

As you attend regular appointments with your child's hematologist and primary care physician, involve your child by asking if they have questions for the doctor.



At school

For situations that may arise at school, ensure your child understands when to reach out to you, teachers, or a school nurse. Ask your school about a 504 School Plan that supports the educational needs of students with medical conditions.



At camp

Consider having your child join a camp for kids with bleeding disorders, where they can learn about their hemophilia B and how to infuse, all while building lifelong friendships.



At play

As your child tries new things, talk to them about taking precautions to prevent bleeds. For example, when they're learning to ride a bike, make sure they're wearing pads and a helmet.

Communication tips

Your child may be getting more questions from friends or teachers about having hemophilia B. Regular discussions with your child can help them feel more confident talking about their hemophilia B with others.

Here are a few important topics to cover:

- What is hemophilia B?
- How many people have what I have?
- What is IDELVION?
- When do I receive my infusion of IDELVION?



Scan the code to visit
IDELVION.com for
caregiver-specific
resources

Strategies for building a sense of self

Celebrate the small wins. Positive reinforcement from you can help your child develop a sense of competence. Continue to be their biggest fan supporting their school experience and other areas of interest, like their hobbies.

Reinforce efforts over outcomes. Offer emotional support even when your child is struggling. Show them it's OK to face challenges and that it's the effort that matters.

Be an active listener. Encourage your child to share their opinions, and be respectful when they express them. Inviting your child to share shows that you care.

On treatment day

1 Help them take an active role in infusions

You can help your child feel more involved in the process by having them:

- Help you prepare the infusion
- Set a timer and remind you when it's time for treatment
- Take out and put away treatment supplies properly



2 Make infusion time bonding time

Adding fun activities and providing encouragement during infusions can help your child feel more confident and ready for their next treatment. Inspire them to incorporate activities they enjoy into the infusion.

3 Congratulate your child after infusions

Finding a way to celebrate treatment time can help your child develop a feeling of competence in handling their treatment. Being involved can also provide a solid understanding of hemophilia B for them and a sense of ownership of their treatment management overall.

Caregiver corner

Managing hemophilia B during childhood can be an emotional time for both of you. Take time to process your own feelings regularly. Is there a family member or close friend with whom you can have a conversation?



AGES 12 to 18

Transitioning to independence



Supporting your teen in taking control of their IDELVION treatment is a key step toward their independence. Getting your teen comfortable with their treatment early can help them feel less overwhelmed during this transition.

Communication tips

Developing strong methods of communication can help your teen feel prepared for taking ownership in their treatment. Consider the following methods to help you understand your teen's motivation, so you can work together to help them manage their treatment on their own.

"I felt empowered that I could protect my son and keep him safe."

~ Milinda, a caregiver of a child with hemophilia B



Scan the code to watch a video about her journey or go to idelvion.com/real-lifestories



- 1 Active listening:** Pay attention to what your teen says and *how* they say it. What might be under the surface, motivating them to speak or behave the way they do?
- 2 Setting goals together:** Work with your teen to set realistic treatment and lifestyle goals using the activities suggested on the next page.
- 3 Role-playing scenarios:** Practicing conversations with healthcare providers, teachers, coaches, or mentors can build your teen's confidence and encourage resilience as they become more independent in managing their care.
- 4 Try journaling:** If your teen is struggling to communicate, encourage them to write down their thoughts in a journal or on their phone.

Practical skills for daily management

Identify your teen's comfort level

First, ask how your teen feels about taking ownership of their treatment. Then, identify tasks you and your teen can do together. Finally, ask what they feel comfortable doing on their own from now on. This collaborative approach can ease them into taking responsibility.

Assigning tasks

Once you've determined which tasks your teen can start to do independently and which will still need your involvement, gradually increase their responsibilities over time.

- **Example (12 to 14 years):** Encourage them to ask at least 1 question during an appointment
- **Example (15 to 18 years):** Under your or a doctor's supervision, allow them to practice self-administration of IDELVION if they have not learned how to already



Sample questions for your teen to ask their care team

- What are my Factor IX levels and how are they measured?
- What should I know about Factor IX peak and trough levels?
- How can bleeds cause long-term joint damage?

Preparing for major milestones

Help your teen prepare for the transitions ahead, such as starting their first year of college or a new job.

- Before your teen moves out, plan how to schedule and attend appointments
- Encourage your teen to set achievable goals, like contacting their care team
- Think through any special arrangements, such as packing a sharps disposal bin
- Role-play scenarios where they may need to explain hemophilia B to others

Is it time for extended dosing?

High Factor IX levels offer powerful bleed protection. After turning 12, patients may be able to work with their care team to extend dosing and receive infusions less often—**only IDELVION is FDA approved for 14-day dosing in adolescents and adults.**

Caregiver corner

Letting go is never easy. If your child eventually leaves home, remind yourself that you've prepared them for independence—and you're always a phone call away.



Caring for yourself

Wellness for caregivers



When you are caring for someone else, it can be easy to forget about your own wellness. Give yourself permission to pause and take time to care for yourself.

Make space for your own needs

Self-care can't wait

Wellness means a lot of things: eating nutritious food, getting exercise and plenty of sleep, and maintaining emotional health. Your child needs all these things—and so do you.

Give yourself a break

Things may not always go as planned, and that's OK. Be kind to yourself and ask for help when you need it. Remember, you don't have to do it all. Asking for help can give you space to practice self-care, like getting enough sleep or preparing a healthy meal.

Self-care strategies

Cactus or houseplant?

Imagine a cactus and a houseplant. The cactus can go a while without needing care, while the houseplant needs regular attention. Now think about your family, household, career, and personal goals. Which goals are like a cactus and which are like a houseplant? Prioritize your "houseplant goals," and give yourself a break on the "cactus goals."

Get out there

Set aside 10 to 15 minutes each day to go outside for a short walk. While you're there, take some deep breaths and let yourself enjoy the moment.



Helpful resources



Prepare for appointments

The Next Visit Discussion Guide can help prepare you and your child for their next care team appointment.

Download at idelvion.com/powerful-bleed-protection#dosing-guide.



Navigate daily challenges

Get guidance for common situations you may encounter with the IDELVION Problem-Solving Tool.

Download at idelvion.com/kickstart/problem-solving.



Support delivered to your inbox

Get information, tips, and resources about IDELVION and hemophilia B.

Sign up at idelvion.com/sign-up.



Connect with the community

Many organizations offer support for people with hemophilia B and their families. Start with these:

- National Bleeding Disorders Foundation (NBDF) – bleeding.org
- World Federation of Hemophilia (WFH) – wfh.org
- The Coalition for Hemophilia B (CfHB) – hemob.org



IDELVION ConnectSM

Sign up for IDELVION ConnectSM for copay support, insurance navigation, and more. Call 1-800-676-4266 or download the CSL Behring copay form at idelvion.com/savings-support/co-pay.

Remember, you are not alone

We hope this guide has helped you prepare for your important role as a caregiver with a child living with hemophilia B. If you ever feel alone on this journey, remember others are here to help. You can connect with people from the hemophilia B community by joining the IDELVION Advocate Program. Call 1-866-705-9661 or sign up at idelvion.com/advocate-program to learn more.

As always, If you have questions or need extra help caring for your own needs, give your care team a call.



IMPORTANT SAFETY INFORMATION

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in children and adults with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. IDELVION can reduce the number of bleeding episodes when used regularly as prophylaxis.

IDELVION is administered by intravenous injection into the bloodstream and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

The most common side effects of IDELVION are headache and dizziness. These are not the only side effects possible. Tell your healthcare provider about any side effect that you experience, and contact provider immediately if bleeding does not stop after taking IDELVION.

Please see accompanying full prescribing information for IDELVION, including patient information.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call **1-800-FDA-1088**. You can also report side effects to CSL Behring's Pharmacovigilance Department at **1-866-915-6958**.



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