Emotional Challenges: Handling Setbacks and Letting Go



Letting go is one of the hardest parts of parenting. As parents shift from caregiver to coach, it's natural to worry about stepping back, while teens may feel anxious about taking on more responsibility and making mistakes. These feelings are a normal part of the transition to independence.

Mistakes are not failures. They are opportunities to build problem-solving skills, confidence and resilience. If your teen misses an appointment or forgets to order medication, focus on what can be learned rather than taking over.

Tips for Staying Involved Without Taking Over



- Praise effort and progress rather than perfection.
- Talk through mistakes calmly and constructively.
- Keep emergency backup plans in place.
- Give your teen opportunities to practice new skills and learn from experience.

When challenges arise, ask "What can we do differently next time?"
This simple question encourages problem-solving, accountability, and teamwork. When young people are invited to participate in decisions about their care, they begin to see themselves as active partners in their health rather than passive recipients of treatment.

Transitioning: One Parent's Perspective

Today we're talking with Amber whose 18-year-old twins, Alex and Max, recently moved away from home to attend college and are learning to become independent young adults. Both teens have hemophilia A and are living on a campus 260 miles from home. As a parent, Amber shares the complex feelings of releasing responsibility and trusting the process of letting go.

Amber, can you tell us what it's like now that your kids are managing most of their own medical care while they're away at school?

It's scary and amazing all at once. You have to trust that you've given them the tools to rise up and handle it. There's pride in watching them step into that responsibility, and a bittersweet feeling knowing it marks a shift in how they need you.

-continued on back-

Cascade Hemophilia Consortium

Mission Statement

To provide a compassionate and connected care partnership for individuals with bleeding disorders – delivering accessible, affordable, high-quality care while equipping patients and their families with the knowledge and support needed to manage their health with confidence.

Transitioning: One Parent's Perspective -continued-

What are you and your husband's hopes, as parents, as your kids become more independent?

We hope they still check in, ask questions as needed and lean into us if something feels off. At the same time, the goal is for them to be increasingly self-sufficient and truly confident in managing their disorder as they grow.

What has been the most challenging part of releasing some of the responsibility and letting your teens take on a more active role?



The most challenging part is giving them the space to manage things on their own.

What helped ease your worries?

I love knowing Alex and Max reached out to their medical team independently, asking for guidance on hospitals in their new location. This is something I would have handled in the past and watching them rise to the moment has been incredibly reassuring.

Do you or your kids have any feelings about leaving the pediatric team one day?

Our boys have received excellent care during their years with our pediatric team. It will be sad when it is time to move on, but it also feels like the natural next step in their journey.

It's completely natural for young adults to have occasional reservations about taking on responsibility. At the same time, most teens crave independence. How have your kids handled the transition process up to this point?

Like most teens, Alex and Max want to take ownership of certain parts of their lives, but not all of them. This year we had them start making their own doctor appointments - something they didn't exactly want to do, but an important step in learning to manage their care, and they handled the transition better than we expected.

Thank you for sharing your experience, Amber. It sounds like you found a good balance between encouraging your teens to take ownership of their care and being there to support them when needed. It isn't always emotionally easy, but having your kids on-board and being aware of your goals helps to make the road a little easier to travel.

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Colleen Joiner, LMSW, CCM

Dear Readers,

As parents, we strive to teach our kids the skills they need to live successful, independent lives once they leave the nest. From doing laundry and cooking meals to driving a car, there are many life lessons that prepare them for adulthood. For parents of children with a bleeding disorder, there are additional responsibilities to help ensure health, safety, and independence.

You, your child, and your Hemophilia Treatment Center (HTC) team begin building these skills at a very early age, gradually adding responsibility as your child matures. By the teen years, the importance of mastering these skills often feels more pressing and the parent-child relationship begins to evolve. One analogy captures this journey well:

"Parenting a young adult is less like holding the handlebars and more like cheering from the sidewalk. The goal was never to keep them from wobbling it was to teach them how to recover when they do."

What a powerful perspective! As teenagers move toward adulthood, parents are navigating a transition of their own, from caregiver to coach. This shift often comes with a mix of pride, uncertainty and a bit of nervousness. But remember, practicing new skills, having open conversations and learning from mistakes are all part of the process. While the journey isn't always easy, watching your young adult gain confidence and spread their wings can be one of parenting's greatest rewards.

Colleen

Coming Soon!

In an effort to improve the patient experience
Cascade is excited to introduce **CHC Connect!**

CHC Connect is a new service that makes it easier and more convenient to receive, review, and sign documents electronically, such as delivery tickets, consent forms, and other Cascade documents. You can securely complete these documents from your phone, tablet, or computer via a link sent to your phone or email.

CHC Connect is expected to launch in November 2026. Most patients will begin receiving new forms to sign electronically in January 2027.

Keep an eye out for a **CHC Connect** flyer coming *in the mail*. The flyer will provide more information about the new service and how to get started.

Cascade... A Trusted Partner in Your Circle of Care

– October 2026 –

CASCADE

From Caregiver to Coach:
A Parent's Role in a Teen's Transition to Adult Care

Leading the Way



For teens with a bleeding disorder, the transition to adult care is more than changing healthcare providers. It's about developing the knowledge, confidence, and skills they need to manage their bleeding disorder independently.

Medical independence does not happen overnight. If every young adult instantly and perfectly managed their healthcare the day they turned 18, confetti would fall from the sky, and a mariachi band would appear. In reality, independence develops gradually through years of learning and practice involving parents, healthcare providers, and young adults. The transition is most successful when responsibility is transferred step by step, beginning in childhood and continuing into early adulthood.

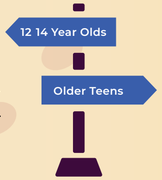
Parent-Led
- Parent schedules appointments
- Parent contacts providers
- Parent manages medications

Shared Responsibility
- Teen helps to schedule appointments
- Teen tracks treatments and bleeds
- Teen participates in clinic discussion

Teen-Led
- Teen communicates directly
- Teen orders supplies
- Teen manages treatment

Parents continue to serve as backup support

Keeping on Track: Transition Milestones



Transition recommendations developed by the National Bleeding Disorders Foundation and HTC teams around the country, help guide your child's path to independent healthcare management while allowing flexibility for individual growth.

Your medical team has additional age-based milestones they aim to teach your child. Ask your nurse or social worker for their recommendations and ways to support your child's progress and celebrate their growing independence along the way.

Here are a few examples of what your teen will learn:

12 14 Year Olds Should Begin To:
- Explain their diagnosis in their own words
- Understand their treatment plan and medications
- Recognize the signs and symptoms of a bleed
- Know when to contact their HTC team
- Spend part of their clinic visit meeting independently with members of their HTC team
- Self-infuse
- Understanding the importance of social support in the bleeding disorder community

Older Teens Should Begin To:
- Schedule medical appointments
- Communicate directly with healthcare providers
- Order their own specialty pharmacy medications
- Manage medications and treatment supplies
- Navigate insurance and healthcare systems
- Advocate for themselves at school, work, and in healthcare settings.

*Adapted by commonly used healthcare transition readiness concepts.

Providing Guidance While Encouraging Independence

Helping your teen transition to adult care is quite a balancing act. Too much parental involvement may prevent them from developing the skills they need while too much independence too soon can leave them feeling overwhelmed or unsupported. Encouraging independence doesn't mean stepping away completely. Teens often feel more confident when they know support is available.

Cascade's pharmacists are more than willing to help your child practice ordering their medication.

Just ask!

Questioning if your young adult is ready to handle medical care on their own is normal. If you're unsure what they can manage independently, make a list of tasks they can handle with support and those that still need practice. Then work together to set goals for the coming years.

Helpful questions to ask might be, "What is the one thing you can handle on your own this year?" or "You've listened to me calling your specialty pharmacy to order your medication. Why don't we call together this time? I'm right here if you need help."

Skill building is a dual effort between you and your young adult. Ask your teenager:

- ✓ "What parts of your care feel comfortable to manage at this point?"
- ✓ "What still feels challenging?
- ✓ "How can I support you without taking over?"
- ✓ "What skills would you like to learn next?"

If calling for appointments or medication, practice the conversation beforehand, if necessary.



HOW ARE WE DOING?

We would love your feedback!

We are conducting a brief anonymous survey to measure your satisfaction with our services and to find ways to better meet your needs. Your opinions and comments are very important to us!

Encourage Independent Communication

Confidence grows through practice. One important step toward independence is encouraging your young adult to take a more active role in their healthcare. During clinic visits, try giving them the opportunity to answer questions before stepping in. Your HTC team is an important partner in this process and is always willing to help foster these skills.

Before your comprehensive clinic appointment, consider asking what is on your child's mind and whether there is anything they would like to talk about with the healthcare team. When the nurse or physician asks how things have been going, a gentle prompt can go a long way: "Nathan, why don't you tell Dr. Smith how your bleeds have been lately?"



Encourage your young adult to:

- ✓ Ask questions during appointments
- ✓ Share concerns openly with their healthcare team
- ✓ Report bleeds and treatment challenges
- ✓ Take an active role in healthcare decisions

By gradually stepping back and allowing your young adult to step forward, you are helping build the confidence and self-advocacy skills they will need as an adulthood.

Remember, you don't have to have all the answers. Your HTC team is more than happy to help guide these discussions.

Gaining Problem-Solving Skills

Decision-making is an essential life skill for everyone, but it is especially important for individuals living with a bleeding disorder. One of the best ways to build your teen's confidence and ease your own concerns is to talk through real-life situations together. Turn these conversations into informal problem-solving exercises and encourage your child to think through the steps they would take.



For example:

1. What would you do if you missed a treatment?
2. What supplies would you pack when traveling? Where on the plane would you keep your factor?
3. If you experienced a bleed at school or work, how would handle it?