School Tools Toolkit: Back to School with a Bleeding Disorder

This toolkit provides guidance for parents, caregivers, educators, school staff, and students on preparing for a safe and successful school year while managing a bleeding disorder. It offers tips, examples, and strategies tailored for every grade level.

Parents & Caregivers

Parents and caregivers play the most important role in preparing children with bleeding disorders for the school year. Before classes begin, gather necessary paperwork such as the IHP or 504 Plan, meet with the school nurse, and prepare an emergency kit with clotting factor, ice packs, and a letter from the hematologist. A small insulated bag labeled with the child's name and instructions is a simple but effective solution.

Safety is another priority. Children should wear a medical ID bracelet or necklace, and the nurse should be supplied with clotting factor and other medications, along with clear instructions. Teachers can be given a laminated Quick Reference Card listing signs of a bleed—such as joint pain, swelling, or headaches—and emergency contacts. For example, if a child suddenly limps or complains of knee pain, staff should immediately alert the nurse and parents.

It is also critical to work with the school to update or create an IHP or 504 Plan. These plans may allow unrestricted access to the nurse, elevator use, or modified physical education. A useful example is including a note that a student requires elevator access during a joint bleed. Communication should be proactive, ideally through a short care team meeting before the school year begins. In some cases, the school nurse can even demonstrate what different bleeds may look like. At home, parents can help children practice self-advocacy with role-play, such as learning to say, 'My elbow hurts, I need to see the nurse now.'

Teachers, Nurses, and Administrators

Educators and staff are often on the front lines of supporting students with bleeding disorders. A child may appear fine immediately after a bump or fall but later develop swelling or pain. For example, if a student avoids using an arm after recess, it could signal a bleed.

School staff should be alert to early signs such as unexplained bruises, swelling, persistent headaches, or unusual fatigue, and report concerns immediately. Reviewing the student's IHP or

504 Plan is essential, and substitute teachers should always have a summary sheet of accommodations. These may include elevator passes, the ability to carry water or snacks, or flexible seating arrangements.

Communication should remain discreet and respectful, with quick updates to families when needed. For instance, a brief email after recess noting that a child seemed more tired than usual can help parents monitor symptoms. Supporting independence is equally important. Students should be allowed to excuse themselves quietly to see the nurse, perhaps with a simple hand signal to minimize disruption or embarrassment.

Students Living with Bleeding Disorders

Students themselves are an important part of their care team. Children and teens should learn to describe their condition in age-appropriate ways—for example, 'I have hemophilia, so I need to be careful if I get hurt.' Wearing a medical ID is important at all ages, and older students should carry emergency contact information in their backpacks.

Students should also understand their accommodations. A child might know, for example, 'I can use the elevator instead of stairs when my joints hurt.' Communication is key: if pain or unusual symptoms occur, students should feel comfortable saying, 'I need to see the nurse; my head hurts.' As they grow older, students can also take responsibility for reminding adults if supplies run low or if they need to call home.

Early Childhood (Preschool)

Preschoolers require close monitoring since they cannot always explain their symptoms. Teachers should check for bruises during diaper changes or after playground time and avoid rough play by providing safe, padded equipment. Parents can place a laminated care card in the child's cubby with clear instructions, such as: 'If a nosebleed lasts more than 10 minutes, call 911 and contact the parent immediately.' Daily communication logs are helpful, with notes like 'fell on playground, no visible injury—monitoring.' Children can be taught simple words such as 'hurt' or 'boo-boo,' or use picture cards to point out pain.

Elementary (K–5)

Elementary students are active and may not always communicate pain. Teachers should watch for sudden changes, like a child withdrawing from recess activities. Safe alternatives should

replace high-risk games—walking relays or yoga instead of dodgeball. IHP or 504 Plans should include accommodations such as permission to keep water and snacks in the classroom to prevent fatigue. A back-to-school meeting with staff can reinforce awareness, and visual reminders, like posters in the lounge, can help teachers recognize signs of bleeds. Children at this age should be encouraged to practice simple advocacy, such as saying, 'My elbow hurts, I need a break.'

Middle School (6–8)

By middle school, students are more independent but still need guidance. They can begin logging symptoms using journals or smartphone apps and should be encouraged to choose safe electives, like art or music, over high-risk sports. Modified physical education options such as yoga, swimming, or walking are good alternatives. Accommodations may include lockers located near classrooms or extra time to move between classes. Teachers should check in discreetly, asking quietly, 'Do you need to see the nurse?' Self-advocacy becomes more important at this stage, and students can learn to email teachers directly if they miss class due to treatment or hospital visits.

High School (9–12)

High school students are preparing for adulthood and should take on more responsibility for their health. They can practice calling the treatment center themselves rather than relying on parents. Sports decisions become especially important: swimming or track may be safer alternatives to football or wrestling, and female students should receive support in managing heavy menstrual bleeding. High school 504 Plans may include flexible attendance for infusions, such as allowing up to two absences per month without penalty. Students should be encouraged to self-advocate by explaining their health needs to teachers at the start of the school year. Managing their own health records, carrying a wallet card with diagnosis and medications, and maintaining medication schedules prepares them for the transition to adulthood.