

THINGS TO THINK ABOUT WHEN APPLYING TO SCHOOLS/CHOOSING A SCHOOL

Students Say:

- When choosing a school, I found schools that were within close ranges of large hospitals that have a good hematology department. I think this is important because most college students don't have cars or the money for taxis to take them to appointments.

Moms Say:

- Make sure the school fits your child's personality! If your child has a smaller sense of community, a large state school may not be right for them. If they are big thinkers and independent, a large state school may work out beautifully.
- Be honest with yourself on what is best for your child – your dream of your child attending your alma mater or a Big 12 school may not be his/hers.
- Make sure to visit lots of different schools – and the one they think they want to go to needs to be towards the end of the list for visits. This will help them keep an open mind about possibilities.
- Parents also need to keep an open mind! The school my son decided upon was not at the top of my list. However, once we visited I had a completely different view and was able to see the benefits of why it was a great match for him.
- Some out-of-state school and private schools may have comparable tuition packages to in-state schools – be open to the possibilities.
- When choosing a college, accessibility was very important. Through campus tours, we were able to choose the flattest campus with the best wheelchair accessibility. Some of the colleges we visited were very hilly, which would have been a significant challenge for my son because he uses a manual wheelchair all of the time. The other consideration was whether the college was private or public. We found the public colleges were much more open to accommodations (they have to be – by law. Private colleges do not necessary have to provide accommodations). A third item to keep in mind is whether the school provides on-campus transportation for mobility-limited students, which can make larger campuses seem more attractive.

WHAT ACCOMMODATIONS HAVE YOU PUT INTO PLACE, EITHER ACADEMICALLY OR DAY-TO-DAY?

Moms Say:

- Medic Alert jewelry is a must!
- Have him explain his condition to his roommate.
- Meet with the school clinic's medical director. If they can make an introduction with the local hospital ER director, even better!
- Alert the campus police to your child's condition – if he/she needs factor, someone needs to know where to find it (say, in their college dorm). This way they aren't running around trying to get medication shipped in to the hospital.
- Check in with the school's Disabilities Office – have your child register even if they have never had accommodations before. This could be very important if they need to reschedule tests and assignments due to bleeds.
- Hold your child accountable for doing their infusions – ask them to use one of the infusion apps so that you are alerted (peace of mind) and so that if needed, they have a record of their last infusion at their fingertips in case of an emergency.
- My son registered with the Disabled Student Services as soon as he was accepted to the college. They worked with him to put in place accommodation plans (more time between classes, alternative assignments, handwriting assistance, and appropriate desks in the classroom). He also had special housing accommodation for dorm room placement. Instead of the freshmen dorms, he was placed in housing reserved for upperclassmen that had individual bedrooms and bathrooms that provided additional accommodations and privacy (for infusions). He also filed an Individual Health Plan to document what his healthcare needs are.
- California has the Department of Rehabilitation that provides assistance for disabled students, either through job placement or college assistance. They have helped provide additional assistance for tuition and books, and will help with job placement once he graduates.

IF YOU HAVE A ROOMMATE – WHAT DID YOU TELL YOUR ROOMMATE ABOUT YOUR DISORDER? DO YOU INFUSE IN FRONT OF THEM? WHERE DO YOU STORE YOUR SUPPLIES/MEDICATION? WHERE IS YOUR MEDICATION DELIVERED TO YOU ON CAMPUS?

Students Say:

- I have told my roommate in person about my disorder. I think this makes it much easier than trying to explain over the phone or Internet. Also I didn't want to scare her into thinking I was going to be bleeding everywhere all the time, I want to be treated the same as everybody else not as a fragile doll. She was very accepting and has been my biggest supporter when I'm sick.
- I don't live with traditional college roommates, and if I did, I certainly wouldn't run around flapping my gums about my bleeding disorder to the nearest roomy- I keep my cards close to my chest in regards to my condition.

Moms Say:

- It is important for the roommate and the RA to know what is going on.
- I think that infusing in front of others is a preference – your child will know what is best.
- My son stores his factor in a fridge in his room. Supplies are stored in his room as well.
- We are still working on the factor delivery issue. Our problem is that we get a 90 day supply at one time and he does not have the space to store all of it. See if your homecare company can divide up the order – half to the dorm and half to the home address. Or, plan to take factor to them when visiting.
- Many universities have limitations on the size/ number of dorm fridges due to fire concerns. It may be worthwhile checking with the school before move-in to see if this can be waived for a resident. Possibly best to work through the on-campus clinic to start the dialogue with the Residence Hall department, since they'll carry more weight than a random student.

 Alternately, the campus clinic/ pharmacy *might* be willing and able to accept shipments and store the product in their facilities
- My son had 3 roommates his freshman year. He told them about his disorder. He had his own bedroom and kept his factor and supplies in his bedroom. I think he usually infused in his bedroom, but they knew he was doing it. Medication was delivered to our home and he would pick up when he needed more. (His dorm was only about 20 minutes from our house). He moved back home after freshman year as he figured out it was really too hard on him to be in the dorm.

DID YOU HAVE AN INDIVIDUALIZED EDUCATION PLAN (IEP) IN HIGH SCHOOL? HOW HAS IT HELPED YOU AT COLLEGE?

Moms Say:

- We did not.
- Yes. It has helped give him extra time for assignments if he was experiencing a bleed or hospitalization. It has also helped him receive alternative assignments if the class was doing an activity that he couldn't participate in. For example, his biology class did a field trip to the beach. He was allowed to do an alternative assignment.

HAVE YOU HAD A BLEED WHILE ON-CAMPUS OR DURING THE SCHOOL YEAR? HOW HAVE YOU DEALT WITH THAT? WERE YOU ABLE TO ATTEND CLASS?

Students Say:

- During high school and into college, I have often bled in public. My frequent nosebleeds are the most common cause for me to need to tell others about my disorder. While I am sometimes embarrassed about bleeding in public, I have realized that it is just going to happen and there's not much I can do to stop it; I can only change how I react to it. I try not to show that I'm embarrassed, so that others who may be going through similar issues can see that it is not something to be ashamed of.

Moms Say:

- No data yet – but fingers crossed on this one – this keeps me up at night but ultimately it is his responsibility now and I've had to pass the baton. I have confidence that he will handle this well – but I still worry!
- Oh yeah – many. Usually he would just power through and go with a bleed (or multiple bleeds). Occasionally has missed a day or two. When he was in the dorm his freshman year, he had a bad situation (throat, arm and thigh bleed). He was trying to power through but it became critical. He texted me and said he was hurting and sick – I knew that was bad because he never told me anything was bothering him. I went to the dorm and found him with vomit everywhere and not able to move. I loaded him up in my car and took him to the ER. Needless to say, he got admitted to hospital. He never asked his roommates for help.

HAVE YOU TOLD YOUR PROFESSORS ABOUT YOUR CONDITION? HOW UNDERSTANDING HAVE THEY BEEN?

Students Say:

- I have told my professors about my disease, but I made sure to do it properly. I didn't take up their time after class when most of them start preparing for other lectures; instead I went to them during office hours. I had a quick little note I had typed up to further explain my disease, so that if I forgot anything the professors would have all the information to keep. This is so important because you don't want to be lumped in with the group of students who just skip class; the professor needs to know that there will be times you will miss class and that it's for a good reason. Most of the professors worked out a way for me to turn in late work, which was great.
- I often tell professors in college classes so they know that if I leave class suddenly, it isn't because I'm trying to be rude. I have never had a professor be anything less than very adaptable and kind.

Moms Say:

- He just stated school last week but I know he will not have a problem communicating this if necessary.
- Yes, some. I don't think he talks a lot about his condition unless he has too, but he has had a couple of math professors that wouldn't accommodate him at first (writing was really hard for him – elbow bleeds) so he had to approach them. Some understood, some didn't. He had to drop one math class his sophomore year because the teacher wouldn't accommodate.

HAS YOUR PEER GROUP ACCEPTED YOUR DIAGNOSIS? HOW MUCH HAVE YOU SHARED WITH THEM?

Students Say:

- Yes, I shared the entirety of what the disorder is, what I have to do to treat, and how it affects me daily.
- Many of my close friends have health problems as well, and understand that it is their job to support me and my job is to tell them when I need additional help.
- I am more open than others about my bleeding disorder, particularly because I realize that it doesn't make me weaker than anyone else, it just is.
- When I share my diagnoses with others, I never feel bad; I feel strengthened that I am helping others become more aware about what I go through.
- Short of keeping a medic alert tag inconspicuously attached to my car keys, I don't really tell anybody about my having hemophilia, I see it as "brandishing my Achilles heel". Besides, I have enough life experience and personality to fill the voids of innate peer curiosity. Surely, being born a bleeder has had a profound impact on my lifestyle and personality, but I only tell people of the details of my condition if we are very seriously romantically involved, or if there is a predictably dangerous situation coming around in which I would benefit from having an auxiliary infusion tech trained up. (For instance, when I worked as a wildland firefighter for the state of Utah, I was forced to divulge the nature of my condition to my colleagues, much to my dismay and discomfort. That being said, if an incident occurred in the boonies, I would have at least had a fighting chance to get to an E.R. before complications arose from any serious bleeds, and I always carried factor with me, in addition to regular prophylactic dosages.

Moms Say:

- Not sure how much he has shared with his peers. It is pretty obvious there is something wrong with him (wheelchair, ace wraps, huge bruises), but I don't know how much he really discusses it. He is still friends with his roommates that he had freshman year, and he talks with people he meets in class, but he doesn't socialize much with anyone from school outside of school.

HAS YOUR BLEEDING DISORDER AFFECTED YOUR SOCIAL LIFE?

Students Say:

- Not at all.
- I've only told close friends, and kept it on a need to know basis. So acquaintances know that if I hit my head or start bleeding it's a bigger deal than it is for other people and I might need help, whereas my friends know who to call and what to do when I'm bleeding.

WHAT ACTIVITIES OR EXTRA-CURRICULAR ARE YOU INVOLVED IN?

Students Say:

- I'm currently involved with my University's Quidditch team.
- In school obviously sports were a problem. So I've kept myself involved in extracurriculars like theater, acapella groups, and cultural groups. Not being in sports isn't going to ruin your college experience, and there is so much more groups and clubs in college, and that makes it easier to make friends than high school.
- I participate in my university's Student Senate, am a leader for Alternative Breaks, a member of an honor society, and an intern at a political campaign. I fill my days with extracurriculars and staying busy, and that often comes bloody noses and other bleeding issues.

WHAT DO YOU WISH SOMEONE HAD TOLD YOU/WARNED YOU ABOUT?

Students Say:

- Other advice I have for students with bleeding disorders is to think about what's best for themselves. I know sometimes doctors and parents seem to control your life, but college is the start of your adult career. I know my mother was worried about me getting sick more often if I had a roommate, and suggested asking for a single room. I stood up for myself and told her (politely) that this was my college experience and I wanted a roommate. It hasn't been an issue since.
- Something I wish people had told me when going to college is that it's going to be easier than high school. I went to a small school where everybody knew all about my disease and me. College is not going to be like that, you can tell everyone or no one. It's up to you.
- I truly wish I had known that my bleeding disorder is not something to apologize for. Whether or not it seems like I'm inconveniencing my professors or grossing out my friends, this is a medical condition that others can adapt around.
- College has been an amazing experience thus far and I wouldn't change anything for the world. From the health services at my university to the adaptability of my professors, peers and friends, I have felt welcomed and loved during my time here.

Moms Say:

- I think he would say he wished someone had warned him that advanced math classes required a lot of writing and that Biology required a lot of field trips. He ended up changing his major after freshman year (started out as a Biology major) switched to Computer Science. He found out he couldn't keep up with labs and requirements for Biology major. He still has a lot of advanced math with computer science, but most of his assignments are on the computer, much better for him. He enjoys college now.
- I would also say don't necessarily push your kid (especially with an inhibitor to live in the dorm). It really is a lot to put on them. I wanted him to go to the dorm to be independent, but it was really, really hard on his health. He is much better being back home where I can keep an eye on him. I think he wasn't really mature enough to handle all of his health demands at 18 years old. Now that he is 20, he is more mature and he is thinking about moving into an apartment near campus. I would still be a little nervous about that, but think he would handle it better this time around.