

Fact Sheet

College and Hydrocephalus

Living well with hydrocephalus is no longer an impossible dream. While many challenges remain, along with associated conditions that may affect quality of life, it is now reasonable to think that a lot of young people diagnosed in infancy with hydrocephalus can live full, productive, happy, and satisfying lives—lives that include a college education.

Whether you choose to stay close to home or travel far away, heading off to college is an exciting, intimidating, and emotionally charged event. For people like you, who have hydrocephalus, a few extra challenges are thrown into the mix. Not only do you have to decide which classes to take and how to furnish your dorm room, you also have to start figuring out how to be your own health care advocate, take charge of your own medical care, who to tell about your hydrocephalus, and how to assert your independence. To help ease your transition, we sought out some experts - young people with hydrocephalus who are now attending college (or who recently graduated), as well as their parents, who are coping with “letting go” while championing their children’s newfound independence. Their tips, guidance, and commentary are incorporated below.

A note to parents: This fact sheet was created primarily for high school students who are getting ready to head off to college. We know that you have many questions too, but it’s important that your child take the lead in discussing the following issues, implementing plans, and making decisions. Letting your child navigate this transition toward adulthood is an important part of the process of letting go.

Setting the Stage: Before You Go

When you begin considering your college options, several factors usually come immediately into play. The following are some issues you’ll want to consider before you get too far into the application process.

Location

For some, staying close to home for college feels like a safer, more comfortable option. One young woman, for example, told us that she felt her hydrocephalus limited her options, location-wise.

For her, keeping her parents close by was important when she considered what might happen if she got sick and had to go to the hospital. Luckily, she found a college that she really liked less than two hours from home.

For others, location is not an issue; some young people, in fact, see setting their sights on a distant college as an important step on the path toward independence. In this case, creating a balance between your desires and your parents’ worries is crucial. A lot of frank and open discussion may be necessary to reach a solution that supports you and validates your parents’ concerns.

Special Services

This fact sheet does not aim to address specific learning, social, or emotional issues: by this point, you've already made it quite a ways through the educational system and are probably well aware of your own strengths and your own needs. Still, if you have any learning disabilities, it's important to investigate the special services available when you're researching colleges. Understanding in advance the nature of the services available at each of your options should be a top priority, whether a college is local or far from home.

Medical Information

Wherever you choose to go to college, whether close to home or far away, it's important that you have all your key medical information close at hand, in a safe place - a file folder, a notebook, a binder, or in electronic form. The road to your independence starts here. This information should include:

- Contact information for all your doctors (phone numbers, addresses, email addresses)
- A copy of your most recent CT scan or MRI
- Operative notes, if relevant (these will often detail the kind of shunt you have and its settings, if its programmable or adjustable)
- Complete insurance information, including a photocopy of your insurance card, both front and back (the card itself can be carried in your wallet)
- Phone numbers of parents, family members, and friends to be called in an emergency
- A copy of your Durable Power of Attorney for Health Care (DPAHC)
- Any information about allergies to medications
- A list of medications (prescription and nonprescription) taken on a regular basis
- Map to the nearest hospital/emergency room

Most parents we talked to keep a second copy of all these items in a separate safe place - just in case.

Every young adult with hydrocephalus should also either wear a medical necklace or bracelet or carry a card, stating clearly that they have shunted hydrocephalus or hydrocephalus treated by an endoscopic third ventriculostomy.

If you decide to attend college far away, you also must put into place a plan for local care, in the event of a medical emergency. The first step is to ask your neurosurgeon to recommend a neurosurgeon near your college. Then, at the beginning of the school year, follow up with a personal visit to your new neurosurgeon, making sure that he or she receives a copy of your medical records. (For more tips on transitioning to a new doctor - especially if you're transitioning out of pediatric care - see our booklet "Health Care Transition Guide for Teens and Young Adults with Hydrocephalus," available for download at www.hydroassoc.org)

Finally, before you head off to school, you should make sure that all your vaccinations are up to date, including meningitis.

The Student Health Center

Parents emphasize, and students (sometimes reluctantly) agree, that one of the first things you should do at the start of the school year is visit your student health center, meet the nurse or doctor in charge, and give them information about hydrocephalus, including your parents' contact information. Because this is medical information, it is confidential, so you don't have to worry about an invasion of privacy. You should also indicate on the standard student health form that you have hydrocephalus; again, this information is confidential.


Who Else to Tell?

Telling your new roommate(s) about your hydrocephalus is extremely important because you'll probably be around them more than anyone else while you're away at school. Try to tell them about your condition within a few days of the beginning of school so that they know what to expect and how best to help you should you need their assistance. It's also a good idea to tell your dorm's resident advisor or counselor that you have hydrocephalus. He or she may be able to offer support or guidance as you decide who else to tell about your hydrocephalus. Make sure that your roommate(s) and/or RA/counselor know the signs and symptoms of a shunt malfunction and a shunt infection so that they can easily assess your condition if you are unable to do so yourself. Help your roommate(s) understand the seriousness of your condition and be sure to answer any questions that they may have as honestly as possible. Also, tell your roommate(s) where your emergency folder is so that they can get to it quickly if the need arises. Finally, ask your roommates and/or RA if they would be comfortable with accompanying you to the emergency room in the event of a problem so that they can make sure that your family is contacted and that you get the care you need as soon as possible. One young woman, now in graduate school, said, "When I told my RA about my hydrocephalus and explained the warning signs of a shunt malfunction, I kind of acted as if it wasn't a big scary deal, but at the same time said that if it were to happen, it was really critical to take me to a hospital."

One of our student experts told us that after the first week of school, she felt comfortable telling a new friend that she had hydrocephalus, that she had several surgeries, and what the friend should do if she didn't see her for a few days (come and check her room). Sharing this information, she said, brought them closer. While you might feel like telling someone about something as personal as your hydrocephalus is either asking for sympathy or simply being too revealing, it can also play a key role in bringing a friendship to a new level.

Another young woman told us that at first she worried about who to tell and what their response would be - but then realized that worrying was pointless. After getting to know her roommate better and establishing some common ground, she explained that, for her, a really bad headache and lethargy could be signs of a shunt malfunction. A malfunction was unlikely, she told her roommate, but if one seemed possible, it was extremely important that her parents be notified, as well as her doctor. She also told her roommate where she keeps her medical info file, just in case she got sick and wasn't able to grab it herself.

One young woman remarked that she's sure that a lot of her college friends (especially her sorority sisters) know about her hydrocephalus, but that for the most part no one treats her differently. "If they didn't understand," she said, "then they're not worth talking to." Another student commented, "If you act as if you are different . . . I believe others will see you that way. Just be yourself." Some students move beyond simply telling chosen individuals about their hydrocephalus, seizing the college environment as an opportunity to educate others about various disabilities - not just hydrocephalus - by participating in awareness and advocacy projects.



Whether or not to tell your professors about your hydrocephalus is a decision that you will have to make once you start your new classes. Even if you register with your school's disability resource center, your professors will not be aware of your condition, so it is up to you to tell each of them yourself if you so choose.

Whatever your comfort level, it is critically important that you take charge, that you have a plan in place in the event of a shunt problem. Your preparation and initiative will go a long way toward gaining your parents' acceptance of your ability to make your way in the world as a responsible, independent young adult.

Tips and Advice

When we asked college students with hydrocephalus if they had any tips for those thinking about college, they all concurred that the most important thing you can do is be yourself, no matter what. "Don't worry," one said. "It just stresses you out!" "Have confidence in yourself," said another, "and others will too."

They also offered advice on more specific concerns that might come up for college students with hydrocephalus. The following are some of their suggestions.

Communicating with Your Parents


Most first-year students - whether or not they have hydrocephalus - say their parents want them to check in way too often. While parents' demands can seem pressing, especially among all the other demands of college life, parents' support is important - and so is their comfort with your safety. So do your parents a favor, and work out a schedule for communication. Email and cell phones can make things easier - it's not hard to shoot your parents an email every few days, or leave them a phone message letting them know what's going on.

While hydrocephalus can make parents overprotective, striking a balance between their concerns and yours is crucial. Open communication is not just a good idea: it's crucial for your parents' sanity - and for yours. So let your parents know about the steps you're taking to ensure your safety. Let them know when you meet with the head of the Student Health Center, let them know how your appointment with your new neurologist goes, let them know when you tell your roommate where your medical emergency folder is - you get the picture. If your parents are confident that you've put an emergency plan into place - and if they know the details of that plan - they will be more comfortable letting go.

Communicating with Your Peers

While classes are obviously an important part of your education, your social life is equally important - not just partying, but meeting different people, participating in challenging and exhilarating conversations, and being exposed to new ideas. One of the biggest challenges for all college students is making good friends and finding a social group that encourages you to be yourself, challenges you to grow, and allows you to enjoy new experiences. It might take several semesters, or even a few years, to meet like-minded people. Expand your boundaries beyond your dorm: try out different student clubs or associations; volunteer for causes that are meaningful to you; check out student groups like the disability council, the women's center, or intramural sports.

Beyond campus, another group of people can also be valuable sources of information, support, and camaraderie: other college students and recent graduates with hydrocephalus, who know what you're going through and can offer tips on how to cope with various issues. Contact the Hydrocephalus Association for



more information about a casual email list we have set up to help college students get in touch with each other.

Headaches

Headaches are a fact of life for a lot of young people, whether or not they have hydrocephalus. While the stress of deadlines and finals, irregular sleep patterns, too much junk food, and dorm life in general can sometimes cause headaches, when you have hydrocephalus, as you know, headaches can be more worrisome and potentially more serious.

It can be hard to tell the difference at first between a regular headache and a “shunt” headache. If a headache disappears or lessens after you take some Tylenol and lie down for a nap, chances are it’s not shunt-related. However, if a headache persists, or if you have doubts or a gut feeling that something’s not right, call home or call your doctor right away. As the saying goes, it’s better to be safe than sorry.

During crunch time at college, when stress levels are high, some young people with hydrocephalus report more frequent headaches and difficulty focusing and concentrating. Again, the Tylenol-and-nap route can be helpful. So can finding a quiet place to study or just relax. Beginning to understand what your body is telling you - that you need more sleep, more healthy food, even some fresh air and exercise - can help you ward off stress-related headaches.

Alcohol

It’s a fact of life that many college students experiment with alcohol. According to a number of neurosurgeons we talked to, there’s no medical evidence that a shunt directly affects your reaction to alcohol. However, as you already know, drinking in excess is not good for anyone, whatever their health status.

Still, even people who know better sometimes have too much to drink and find themselves rewarded with that nasty side effect, the hangover. In some ways, hangover symptoms can resemble those of a shunt malfunction: headache, lethargy, nausea or vomiting. However, a hangover should clear up within a few hours, or a day at most; if symptoms persist, you may be experiencing a shunt malfunction. Again, if you have any doubt, call home or call your doctor right away.

You should also be aware that many medications - prescription and nonprescription - are adversely affected by alcohol. Some simply lose their effectiveness, while others lead to extreme drowsiness or dangerous, even deadly, side effects. If you’re taking any medications, you really should not be drinking alcohol.

One student told us that in her first few months at college, she got caught up in the party atmosphere at her school and overindulged a few too many times. After suffering through several hangovers that she at first feared were shunt malfunctions, she realized that she didn’t need the added stress. Plus, she said, she realized that she could have just as much fun at a party without getting drunk. Now, she either nurses one beer throughout the evening or drinks clear-colored sodas with lime that look like mixed drinks. That way, she told us, she doesn’t have to keep saying “No, thanks” when she’s offered an alcoholic drink.

Other students simply opt not to drink at all. One student said that the alcohol-party culture at his school doesn’t appeal to him. Instead, he hangs out on weekends with a number of kindred spirits in his dorm who also aren’t interested in frat parties and the like.

Academics

While there isn't room here to cover all the academic aspects of college (entire books exist for that!), you should consider a few things. First, as we already mentioned, it's important, when you're researching schools, to find out what services are available for students with learning disabilities. (If you've had an IEP in place during high school, your team should be meeting to help you negotiate this transition.)

Second, we'd like to remind you (and your parents) that this might be a good time to schedule another neuropsychological evaluation. A neuropsychological evaluation can help pinpoint your learning strengths and weaknesses, and even help you choose which sorts of classes or departments might be a good fit for you.

Contact your new school's disability resource center and let them know that you have hydrocephalus. The people who work in this office can help you get any accommodations you may need, from extra time on exams to tutoring services and beyond. Some schools even allow students with disabilities to register for classes earlier than everyone else, which is a great advantage to have these days.

Conclusion

Congratulations! Having made it through all this, you're practically an expert on college yourself - and your knowledge is about to increase exponentially. We'd love to hear from you about your own college experiences, both good and bad. As more and more young people with hydrocephalus come of age and start to live independently, more and more resources and information will become available to them. You can be part of this process: your feedback - your willingness to share your hard-won knowledge with us and with those coming after you - will help us provide more resources like this one and help future students, just like yourself, take their first vital steps toward independence.

A Note to Parents

All children have the right to independence. They have the right, as they mature, to find out who they are, to explore the world, and to establish a life separate from their parents'. However, as a parent, you will always worry about your children, whether or not they have hydrocephalus. It's important, however, that you not let your natural instincts overwhelm your kids. As one mother said, "If you do freak out at the thought of your child going away, do it in private."

Helping our children reach independence is an ongoing process, and chances are that most of us won't get it 100% right. But we can support our children and give them tools that will enable them to take responsibility for themselves. We can then stand back, keep our mouths shut, and let them have a go at it.

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For additional resources about hydrocephalus and information about the services of the Hydrocephalus Association, please contact:



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