

Hydrocephalus and College



Your education dreams should not be limited by your Hydrocephalus. 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 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 digs, you also have to start figuring out how to take charge of your own medical care, who to tell about your Hydrocephalus, and how to assert your independence. Information contained in this document was sourced from 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.

A note to parents: This information was created primarily for secondary 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. 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, said 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. She found a college that she really liked less than an hour from home.

For others, location is not an issue; some young people, in fact, see setting their sights on a college further away from home as an important step on the path toward independence.



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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 information does not aim to address specific learning, social, or emotional issues: by this point, you've already made it quite a way through the educational system and are probably well aware of your own strengths and your own needs. Still, if you have specific learning requirements, it's important to investigate the 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 baseline scan can be done prior to you starting college, contact your Neurosurgeon
- Your medical card/GP card and or Primary Medical Certificate should be taken with you. It is always a good idea to have photocopies of these done in case of loss
- Phone numbers of extended family members and friends to be called in an emergency
- A copy of the Shunt Complications Chart (see shunt complications in the Hydrocephalus section of our website)
- Any information about allergies to medications
- A copy of the Shunt Management Chart (see shunt management in the Hydrocephalus section of our website)
- Your Shunt Alert Card which you should carry with you at all times. Contact SBHI or your Family Support Worker to order yours.

If you decide to attend college far away, you must also put into place a plan for local care, in the event of a medical emergency. Contact a GP and pass on any information about Hydrocephalus to them that they may need to assist you with the management of your Hydrocephalus. Information is available on our website or through your Family Support Worker.

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The Student Health Centre

Parents emphasise, 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 centre, meet the nurse or doctor in charge, and give them information about Hydrocephalus, including your parents' contact information and shunt complications information including shunt complication protocols. 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?

It's a good idea to tell your residence officer if you are staying on campus or college counsellor 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. Also, alerting your counsellor to the signs of a shunt malfunction could be helpful. One young woman said "When I told my student counsellor 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."

Who else should you tell? While the parents we talked to insisted that their child's roommate should know, they also realised that young people themselves need to take the lead here, according to their individual comfort level. 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'd had several surgeries. 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 said that at first she worried about who to tell and what their response would be—but then realised 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 she followed the suspected shunt complication protocol on the shunt complications

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information sheet. 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 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.

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 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. 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 mobile 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

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Centre, let them know how your appointment went and let them know if or 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: 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 centre, or intramural sports.



Beyond campus, another group of people can also be valuable sources of information, support, and friendship: 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 SBHI or your SBHI Family Support Worker for more information.

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 exams, irregular sleep patterns, too much junk food, and digs 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 your GP recommended headache medication 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 follow the shunt complications protocol. As the saying goes, it's better to be safe than sorry.

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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 medication-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, there's no medical evidence that a shunt directly affects your reaction to alcohol. However any prescribed medications can and will affect your body's reaction to alcohol in ways which you may not be aware or ready for. 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, follow the shunt complications protocol.

You should also be aware that many medications—prescription and non-prescription—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 should not be drinking alcohol.

One student said 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 realised that she didn't need the added stress. Plus, she said, she realised 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-coloured sodas with lime that look like mixed drinks. That way, 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 like minded friends who also aren't interested in parties and the like and other students choose to return home for weekends.



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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 specific learning requirements.

Second, we'd like to remind you (and your parents) that this might be a good time to schedule a neuropsychological evaluation. A neuropsych 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 SBHI or your SBHI Family Support Worker for more information.



Conclusion

Congratulations! Having made it through all this, you're practically an expert on college yourself—and your knowledge is about to increase exponentially. 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.