



## **Fact Sheet: Durable Power of Attorney for Health Care**

A Durable Power of Attorney for Health Care (DPAHC) gives the person, or persons, you designate as your agent(s) the power to make health care decisions for you in the event you are unable to do so. The person (agent) you designate must act consistently with your wishes as stated in your DPAHC. This notarized document gives your agent the power to access your medical records, to give consent for providing specific treatment or not providing specific treatment, and to give consent for stopping treatment necessary to keep you alive.

Whether or not you have a DPAHC, you have the right to make medical and other health care decisions for yourself, so long as you are able to give informed consent with respect to a particular decision. In addition, no treatment may be given to you over your objection at the time, and health care necessary to keep you alive may not be stopped or withheld if you object at the time.

For people over age 18 with hydrocephalus, a DPAHC is a critical tool. Remember: if you are over 18, you are legally considered an adult. Thus, members of your family—including your parents and your spouse—have no legal right to your medical records and no legal right to make health care decisions for you should you become ill. A DPAHC can help you manage this reality, strengthening your ability to live independently and ensuring the continuation of appropriate medical care.

Consider the following scenario: You end up in the emergency room of a strange hospital with a possible shunt malfunction. A friend calls your dad, who lives in another state. Your dad gets on the phone to the hospital, asking for information about your status, and bingo—sorry, the patient (you) is an adult, and the hospital can't release any information about you, even to your father. Even worse, your dad does not have access to your medical records, and your primary caregiver or neurosurgeon can't legally release this vital information to him. It turns out that shunt replacement is indeed necessary—this is a medical emergency—and your dad is not legally allowed to make medical decisions for you. Surgery is thus performed by a neurosurgeon you've never met, who perhaps has only limited experience with shunts.

This situation can be avoided with a DPAHC. Once your DPAHC has been completed and notarized, give copies of it to (1) those who are personally closest to you (parents, spouse, relatives, roommate, close friend, etc.); and (2) all of your doctors, asking that it be placed in your medical records. Also carry a copy with you in your wallet. In the event of an emergency, the individual(s) you have designated as your agent(s) will have access to your medical records and the power to make medical decisions for you, consistent with your wishes. In the example cited above, your dad (designated as your agent in your DPAHC), fully aware of your wishes, may consult with the emergency room team and then authorize that you be moved for surgery to a different hospital where the doctors are more experienced in shunting techniques.

The attached sample DPAHC is valid in the state of California, but each state has its own specific requirements for this document. There are several ways to find out about your state's requirements:

- Ask your primary care physician or neurosurgeon if he or she has a list of your state's requirements and a sample DPAHC form that you can copy.
- Contact your state's Medical Association (or Society), usually listed in the White Pages as (Name of State) Medical Association (Society). Ask for the state guidelines and a sample DPAHC. There may be a small charge for this.
- If you have access to the computer program Quicken, look under "Family Lawyer" for a list detailing the guidelines for a DPAHC in each state.

Creating a Durable Power of Attorney for Health Care is a smart, sensible move for anyone with a chronic medical condition that may require emergency intervention. It helps to ensure that:

1. Your wishes will be carried out should you be unable to make medical decisions for yourself.
2. You will have access to the best possible treatment in an emergency situation.
3. You and your family will enjoy peace of mind, making independent living a more safe and comfortable reality.

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Sample: State of California



**Durable Power of Attorney for Health Care**

By this document, I intent to create a durable power of attorney by appointing the person designated below to make health care decisions for me as allowed by Section 2410 to 2443, inclusive, of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity. Health care decision means any consent, refusal of consent, or withdrawal of consent to health care.

I, \_\_\_\_\_, residing at \_\_\_\_\_, hereby designate and appoint \_\_\_\_\_, residing at \_\_\_\_\_ telephone \_\_\_\_\_, as my attorney in fact to make health care decisions for me as authorized in this document. If for any reason (person designated above) \_\_\_\_\_ shall fail to qualify or cease to act as my attorney, I appoint \_\_\_\_\_, residing at \_\_\_\_\_ telephone \_\_\_\_\_, as my attorney in fact to make health care decisions for me as authorized in this document. In the event (2nd person designated above) <LINE> is not available then I appoint \_\_\_\_\_, residing at \_\_\_\_\_ telephone \_\_\_\_\_, as my attorney in fact to make health care decisions for me as authorized in this document.

If I become incapable of giving informed consent to health care decision, I hereby grant to my agent full power and authority to make health care decisions for me including the right to consent, refuse consent, or withdraw consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition, and to receive and to consent to the release of medical information regarding my physical or mental condition, including, but not limited to, medical and hospital records.

My agent has the power and authority to execute on my behalf documents entitled or purporting to be "Refusal to Permit Treatment," "Leaving Hospital against Medical Advice," as well as any necessary waiver or release from liability required by a hospital or physician.

I sign my name to this durable power of attorney for health care on \_\_\_\_\_ (date) at \_\_\_\_\_ (location).

\_\_\_\_\_  
\_\_\_\_\_  
(Signature)  
(Type name)

Notary Seal

## **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 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 info 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 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.

### **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 provided by the Hydrocephalus Association, please contact:

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