



Preparing for College with a Chronic Illness

Chronically ill young adults face many challenges as they plan their postsecondary education, and while these challenges are difficult, they are not insurmountable.

By Abbie Cornett

GRADUATING HIGH school can be one of the most exciting and scary times in young adults' lives. For most, completing secondary education represents having achieved their first milestone on the road to success as an adult. And, while this triumph culminates years of hard study for all students, it is a particularly impressive accomplishment for graduates who are battling chronic illness.

For those who choose to attend college, the battle to complete their education has just begun. Research has shown that, as a group, children with long-term illness are at very high risk of educational and vocational problems. Not only are they less likely to graduate high school, they are also less likely to attend or graduate college.¹ Failure to address the issues chronically ill young adults face can have long-term employment and financial repercussions. So, what can be done to prevent the college dream from becoming a nightmare?

Understanding the Law

It is likely high school graduates haven't given much thought to the laws that have protected them up to this point in their education. Access to education has been something their parents have managed. But, upon entering college, that changes. Expectations are that college students have reached a level of maturity to advocate for themselves. Unfortunately, this is frequently untrue due to lack of knowledge and experience. Therefore, the critical first step to success is to become familiar with the laws in place to protect their right to an education.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 protect the rights of persons with handicaps in programs and activities that receive federal financial assistance. Further, Section 504 protects the rights not only of individuals with visible disabilities but also

those with hidden disabilities (those that are not obvious), including chronic illnesses.² And, while the act does not list specific disabilities,³ its language specifies that individuals are protected if their physical or mental impairment results in a substantial limitation of one or more major life activities.

Understanding Civil Rights

Although college isn't an entitlement, all individuals do have a civil right to higher education. This means institutions have to provide access and opportunity to participate in college by providing reasonable accommodations. But, it doesn't mean institutions are obligated to guarantee an education if students don't meet the criteria for admission, nor are institutions required to guarantee success.

According to Liz Brown, disability services specialist at Bellevue University in Nebraska, educational institutions receiving federal funds cannot exclude otherwise qualified individuals with disabilities. This means those who meet all applicable qualifications cannot be prevented from pursuing postsecondary education based on their disability status. However, they must meet academic and technical standards for the program and/or institution just like any other student.

In addition, students with disabilities are allowed to request reasonable accommodations that create equitable opportunity in the postsecondary setting. But, reasonable accommodations cannot fundamentally alter academic standards or program objectives that are essential for every student. Common reasonable accommodations include attendance flexibility, extended time on exams, reduced-distraction testing environments, note-taking services, preferential seating, alternative format textbooks and use of assistive technology.⁴

It is important for students to understand the ADA defines disability broadly, so those who don't necessarily identify as having a disability may still qualify. If it is determined reasonable accommodations are warranted, it is then decided what accommodations are appropriate. Examples of accommodations a college might offer include:⁵

- Recording of lectures or having a note-taker with the student in class
- Extending the amount of time needed to take a test, or taking tests in smaller sections over a period of time
- Extending time on assignments
- Using adaptive technology such as a smart pen or screen reader for tests and assignments
- Special seating
- Accommodating absences

Registering for Accommodations

The first step in registering for reasonable accommodations is to contact disability services at the institution to which they are applying and directly disclose a documented disability. Once the disability has been disclosed, students are instructed to submit an intake form, release form and appropriate medical documentation such as the evidence of disability that includes:

- The disability's diagnosis;
- How the disability limits a major life activity;
- How the disability can affect academic performance; and
- Accommodations requested.

Based on the students' self-report and medical documentation, the disability services office will determine if reasonable accommodations are warranted and what accommodations are appropriate.

Before any information is sent to instructors, students will be asked to review the assigned accommodations and approve them. Instructors will then be notified of the approved accommodations. No disability-specific information is shared; instructors are only informed that students have been determined eligible for reasonable accommodations under the ADA. All disability/medical documentation is kept in a secure and confidential file that is available only to disability services staff.

The School Matters

When universities look at requests for accommodations, they must determine if the condition substantially limits a

major life activity such as learning, says Brown. Universities have come a long way and typically do a good job when it comes to accommodating visible disabilities such as hearing, visual or mobility impairments. Unfortunately, though, many still have room for improvement when it comes to dealing with chronic conditions, autoimmune diseases and rare diseases.⁶

Unlike students with visible disabilities, those with chronic invisible illnesses frequently encounter professors and university personnel who fail to understand the unpredictability of their illnesses. These individuals don't understand how the students can be well one day and sick the next, which subjects students to disbelief and claims of malingering.⁷

In addition, students with a chronic illness can face many other issues. Often, they are forced to miss class, sometimes for lengthy periods due to medical appointments, illness or hospital stays. They may also be required to take medication that has incapacitating side effects or may make them drowsy or fatigued during class.

Like all other areas of life,
success in college is
dependent on how well
students communicate.

Recognizing the many challenges of chronic illness, a number of schools are committed to working directly with students with disabilities to help ensure access to higher education. One such school is Bellevue University, a member of the Association on Higher Education and Disability (AHEAD), an organization of professional members who are involved in the development of policy, as well as the provision of services that meet the needs of people with disabilities, and who are involved in every area of higher education. Formed in 1977, AHEAD began delivering training to personnel who provide higher education via conferences, publications, workshops and consultation. Its members are a diverse network of professionals who actively pursue disability issues on

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*Ig=immunoglobulin

Important Safety Information

WARNING: Thrombosis (blood clots) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

If you are at high risk of blood clots, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor for signs of clotting events and hyperviscosity. Always drink sufficient fluids before infusing Hizentra.

See your doctor for a full explanation, and the full prescribing information for complete boxed warning.

Hizentra is a prescription medicine used to treat:

- Primary immune deficiency (PI) in patients 2 years and older
- Chronic inflammatory demyelinating polyneuropathy (CIPD) in adults

Treatment with Hizentra might not be possible if your doctor determines you have hyperprolinemia (too much proline in the blood), or are

IgA-deficient with antibodies to IgA and a history of hypersensitivity. Tell your doctor if you have previously had a severe allergic reaction (including anaphylaxis) to the administration of human immune globulin. Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

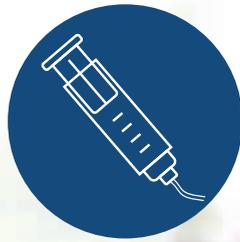
Infuse Hizentra under your skin *only*; do not inject into a blood vessel. Self-administer Hizentra only after having been taught to do so by your doctor or other healthcare professional, and having received dosing instructions for treating your condition.

Why Choose Hizentra?



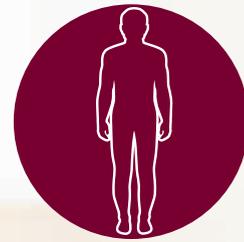
Choose where you infuse

Self-administration with Hizentra means you and your doctor can decide where you can infuse. Convenient dosing routines mean you won't have to adjust or cancel your plans due to IV infusion appointments.



No IV infusions

IV infusions can be challenging for people who have hard-to-find or damaged veins. Hizentra allows you to infuse just under the skin, not into a vein, after training from your doctor.



Proven safety

Hizentra has an established safety profile and demonstrated tolerability. In clinical trials, the most common side effects were redness, swelling, itching, and/or bruising at the infusion site; headache, chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible.



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Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:

- Reduced urination, sudden weight gain, or swelling in your legs (possible signs of a kidney problem).
- Pain and/or swelling or discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).
- Bad headache with nausea; vomiting; stiff neck; fever; and sensitivity to light (possible signs of meningitis).
- Brown or red urine; rapid heart rate; yellowing of the skin or eyes; chest pains or breathing trouble; fever over 100°F (possible symptoms of other conditions that require prompt treatment).

Hizentra is made from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common side effects in the clinical trials for Hizentra include redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible. Tell your doctor about any side effect that bothers you or does not go away.

Before receiving any vaccine, tell immunizing physician if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Please see brief summary of full prescribing information for Hizentra on adjacent page. For full prescribing information, including boxed warning and patient product information, please visit Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use HIZENTRA safely and effectively. See full prescribing information for HIZENTRA.

WARNING: THROMBOSIS

See full prescribing information for complete boxed warning.

- **Thrombosis may occur with immune globulin products, including HIZENTRA. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer HIZENTRA at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

INDICATIONS AND USAGE

HIZENTRA is indicated for:

*Treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years and older.

* Maintenance therapy in adults with chronic inflammatory demyelinating polyneuropathy (CIDP) to prevent relapse of neuromuscular disability and impairment.

-Limitation of Use: Maintenance therapy in CIDP has been systematically studied for 6 months and for a further 12 months in a follow-up study. Continued maintenance beyond these periods should be individualized based on patient response and need for continued therapy.

For subcutaneous infusion only.

DOSAGE FORMS AND STRENGTHS

0.2 g per mL (20%) protein solution for subcutaneous injection

CONTRAINDICATIONS

- Anaphylactic or severe systemic reaction to human immune globulin or components of HIZENTRA, such as polysorbate 80
- Hyperprolinemia (type I or II) (HIZENTRA contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including HIZENTRA.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC, including HIZENTRA treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI])
- HIZENTRA is made from human plasma and may contain infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

ADVERSE REACTIONS

The most common adverse reactions observed in ≥5% of study subjects were local infusion site reactions, headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, upper respiratory tract infection, rash, pruritus, vomiting, abdominal pain (upper), migraine, arthralgia, pain, fall and nasopharyngitis.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS

The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.

Based on March 2018 revision

campuses they are involved with, as well as in the field of higher education. The association is active in all aspects of promoting equal and full participation by people who experience forms of disabilities in higher education. And, it supports the institutions, systems, professionals and professions that are important for attaining their mission.⁸

But, not all higher-education institutions are members of AHEAD. And, while that doesn't mean those institutions can't meet students' needs, it is important for students to perform due diligence to ensure the school they are considering recognizes the impact of chronic illness on students' success. To do this, students can start by contacting the school's disability services office to ask the following questions:³

- What services are typically available for students with disabilities?
- Where is the disability office located, and what are its hours of operation?
- Is there a document that describes available services?
- Are there other students enrolled with similar disabilities?

Don't Be Afraid of the Word "Disability"

When preparing for college, students need to decide early on if they are going to disclose their disability. While the decision to disclose is a personal choice, it is important to keep in mind that disclosure is a requirement for receiving accommodations. Unfortunately, many times students with a chronic illness shy away from the word "disability" or don't think disability services are relevant to their condition. According to a U.S. Department of Education study, about half of those with disabilities enrolled in postsecondary coursework did not define themselves as disabled, and 40 percent of students in their study did not inform their schools of their disability.⁹

Unlike the K-12 school system, postsecondary schools aren't obligated to identify students who need accommodations. And, if students fail to register as disabled before their illness requires the need for accommodations, they can face devastating economic and educational consequences such as the loss of scholarships, automatic withdrawal from classes or failing grades. At the postsecondary level, it is the students' responsibility to make their disability known and to request academic adjustments.²

Like all other areas of life, success in college is dependent on how well students communicate. Brown's first recommendation to students is to be willing to ask for help. This

Additional Resources

- Disabilities, Opportunities, Internetworking and Technology (DO-IT) — www.washington.edu/doit
- Going to College: A Resource for Teens with Disabilities — www.going-to-college.org
- The Chronic Illness Initiative: Supporting College Students with Chronic Illness Needs at DePaul University — files.eric.ed.gov/fulltext/EJ825778.pdf
- The Civil Rights of Students with Hidden Disabilities Under Section 504 of the Rehabilitation Act of 1973 — www2.ed.gov/about/offices/list/ocr/docs/hq5269.html
- We Connect Now — weconnectnow.wordpress.com

could be from anyone with whom students feel more comfortable, including disability services, an academic advisor or an instructor.

Fulfilling the College Dream

College life can be a struggle for anyone with or without a chronic illness. And, for those with a chronic illness, certain rights and laws are in place to help them succeed. But, it's the students' responsibility to communicate their disability to the school at the postsecondary level. In addition, students need to be proactive to ensure the schools they are considering are both committed to and have programs in place to assist them. Only then can they have the best chance of fulfilling their college dream. ■

ABBIE CORNETT is the patient advocate for *IG Living* magazine.

References

1. Health Behavior News Service. Childhood Chronic Illness Affects Future Income, Education, Career. *Science Daily*, Feb. 7, 2011. Accessed at www.sciencedaily.com/releases/2011/02/110205162504.htm.
2. U.S. Department of Education. The Civil Rights of Students with Hidden Disabilities Under Section 504 of the Rehabilitation Act of 1973. Accessed at www2.ed.gov/about/offices/list/ocr/docs/hq5269.html.
3. Winahead's World. Transitions to College for Students with Disabilities. Accessed at winahead.wordpress.com.
4. The American Psychology Association. Reasonable Accommodations Explained. Accessed at www.apa.org/pi/disability/dart/toolkit-three.aspx.
5. Kels Invisible-Warrior. A College Student's Guide to Disability Accommodations. *The Mighty*, July 30, 2017. Accessed at themighty.com/2017/07/college-students-guide-to-disability-accommodations.
6. Edwards, L. When It Comes to Chronic Illness, College Campuses Have a Lot to Learn. *Cognoscenti*, March 5, 2014. Accessed at www.wbur.org/cognoscenti/2014/03/05/school-and-health-laurie-edwards.
7. Royster, L, and Marshall, O. The Chronic Illness Initiative: Supporting College Students with Chronic Illness Needs at DePaul University. *Journal of Postsecondary Education and Disability*, Vol. 20, No. 2, 2008. Accessed at files.eric.ed.gov/fulltext/EJ825778.pdf.
8. Association on Higher Education and Disability (AHEAD). Accessed at www.disabled-world.com/disability/education/ahead.php.
9. Morasso, L. Many Disabled, Chronically Ill Students Entering College Lack Support. *Center for Health Journalism*, March 11, 2014. Accessed at www.centerforhealthjournalism.org/2014/03/10/many-disabled-chronically-ill-students-entering-college-lack-support.