

# Getting Through College: A Guide for People Living with CRPS

You deserve the same education as someone without CRPS. We want to make sure that happens

## Special Services You Should Know About

### Section 504

Section 504 of the Rehabilitation Act of 1973 is a civil rights law that prevents discrimination against individuals with disabilities studying at any institution that receives federal funds from the U.S. Department of Education. Some private schools that do not receive federal funding may be exempt from Section 504. A student qualifies for Section 504 protection if he or she "has a physical or mental impairment that substantially limits one or more major life activities."



### Americans with Disabilities Act (ADA)

ADA "prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities." Schools must provide reasonable accommodations to people with disabilities as well as "reasonable modifications of policies, practices, and procedures."

### Resources

#### US Department of Education, Office of Civil Rights

<http://www.ed.gov/about/offices/list/ocr/504faq.html>

#### ADA Disability Resources

<http://www.dol.gov/dol/top/disability/ada.htm>

#### Pacer Center Back to School Q&A

<http://www.pacer.org/publications/adaqu/school.asp>

*"Registering through the accessibility office [is helpful to the college process]. Then, talk to your professors early. You'd really be surprised how kind professors can be." - Anonymous*

Co-Written by Samantha Barrett and

Edward Kolek, Jr., Ph.D. of Nichols College

People of all ages can be affected by Complex Regional Pain Syndrome (CRPS, formerly known as Reflex Sympathetic Dystrophy (RSD). For the people living with CRPS every day, pain can be an additional challenge when it comes to continuing your education. While your pain is invisible, it is very real.

You can succeed in college regardless of your medical needs and issues. College can still be the time of your life, whether you are a young adult venturing out for the first time or a nontraditional college student who would like a chance for a better education.

We want to help you succeed in college. CRPS may simply require you to think of some additional factors than your peers may have to. Communication is a crucial part of your journey, as is self-advocacy. While your pain may vary day-to-day, the proper accommodations can help you get across that stage to get your degree!



How you can effectively communicate with your college and your peers to have a successful and fulfilling college experience

*"She said that it wasn't her fault that I was in pain, and that I should be able to come to class and get assignments done on time, just the same as a regular student" - Mackenzie B.*

## CRPS 101

CRPS is a chronic neuroinflammatory condition that causes extreme burning or icy pain through a region in the body. It is often the result of trauma to the body, such as a sprain, fracture, or surgery.

You may have swelling, abnormal hair and nail growth, temperature change, skin color change, limited range of motion, allodynia (pain from stimuli that is not normally painful— the touch of fabric or the wind blowing), and various other symptoms.

Stress, hormones, nutritional factors, and even weather changes may make pain worse. Ideally, you should keep your stress as low as possible.

## What To Look for in Colleges

Applying to and choosing colleges is an exciting, intense process. Having CRPS may require you to put a little more research into the colleges that you are applying for. To make your college experience easier in the future, there are a few things you should do ahead of time and a few items to consider.

- Are you going to be close to home or far away? If you decide to venture far away from home, you will want to find a medical professional near your school to be a part of your support system.
- Make sure the college has a disabilities office that will work with you. They will be your ally.
- Tour each of the schools you are considering. See how accessible it is for you. Consider what the campus will be like when the seasons change.

■ Schedule a meeting with all of the college's offices when you go in for your meeting. If you cannot meet with them all at once, see if you can schedule a meeting with each department separately. These include health services, public safety, admissions, student services, residence life, disability services, food services, and even the chair of the program you anticipate studying. This will help address your needs and gauge their expectations.

■ Consider online or hybrid (a mix of online and in person) course formats. See if the colleges you are interested in offer programs like these. This is a great back up plan to have in place.

## How To Explain CRPS

Explaining CRPS to new people can be challenging. We recommend:

- Use some of the technical terms (neuroinflammatory) and explain your pain sensations. Use metaphors to help give the person a point of reference.
- If you are sensitive to touch, let people know immediately.
- Explain how CRPS impacts you (exhaustion, brain fog/memory loss, anxiety, periodic pain flares etc.).

## Being Successful in College

Sometimes, people with CRPS have to take extra steps to make sure that they are successful in what they are doing. College is an example of where planning will help you succeed.

- Self-advocate and be sure to communicate. This is useful for everything from accommodation plans to discussing a plan of action with professors.
- Attend classes whenever possible.

■ Break up big projects into smaller, manageable tasks. Start them early!

■ Establish a routine for schoolwork, homework, and for extracurricular/social events.

■ Ask for help when needed. There may be tutors or fellow students who could help you. Professors also have office hours when you can meet with them.

## Accommodations That May Be Helpful

While you may not always need each element of your accommodation plan, you will want to have a plan in place in case of a bad pain flare. Here are some examples.

- Flexible attendance policy for pain flare days as well as a plan for cold weather.
- A seat in the room where you won't get bumped into that is also far away from anything that may cause excess noise or vibration.
- Classes on a first floor or in a building with an elevator.
- A handicap parking space if you are able to drive.
- If you are living on campus, you will need a room in a residence hall that is on the first floor by an exit.
- Special notetaking devices (laptop, iPad app, speech to text software, designated note takers) or for professors to provide a copy of the notes.



■ Alternate days to take tests and/or turn in assignments. There should also be other locations to take exams as well as alternative methods.

■ Special transportation in case of a pain flare, especially during bad weather.

■ Digital textbooks that can be brought to class instead of hardcopy books.

■ An online instruction forum, such as Moodle, in case of prolonged absence.

## Other Aspects to Consider

■ If you're feeling stressed out, or as though the change of living environment may impact you, consider making an appointment with someone in your college's mental health/counseling center.

■ Life is a mix of living, learning, and loving. While social elements are important, don't be afraid to stay in your residence hall instead of going out some nights.

■ Consider having a single room instead of one with roommates if that would benefit you.

■ Learn a relaxation technique that will work for you and set aside time to do that daily.

■ Practice your "pitch" about your CRPS and how each accommodation fits in with your disability and symptoms. It creates a connection.

*""I was always told that I wouldn't be able to graduate college. That was, until, I spoke with the disabilities advisor from my school. I graduated summa cum laude!" - Samantha B.*