A small book that provides big help in navigating your way through college!

CMTA
Charcot-Marie-Tooth Association

A GUIDE TO SURVIVING COLLEGE FOR CMTers
by Yohan Bouchard

Get the information you really need in a fun, quick & easy way
Entering college is a huge step.

The search for a college is not simple and it's not made any easier by having a physical disability. However, there are many resources to keep you on the right track. It is my hope that the hints and advice in this guide can help you find the resources you need to succeed in a college environment.

- Yohan Bouchard -
When I first started searching for a university in my senior year of high school, it seemed daunting. Leaving home and living with people I’d never met before was a scary thought. I knew the tight-knit network of my childhood would have to change and my supportive parents would not be right there. Finding a college where I felt at ease was difficult and the process that eventually led me to find Pitzer College was a long one. But after three years, it’s become apparent that I made the right choice. One size does not fit all, however: There are many different colleges and each is unique in structure, support and accessibility. This guide is to help would-be college students with CMT have the best experience possible. Choosing the right location and the right size to fit your capabilities is vital, and this all begins with the college search process.

When looking at potential colleges, it is important to do the following:

• **Profile colleges:** Make sure you apply to colleges that are a good fit for your personal, physical and academic interests and needs. Consider campus resources, tuition rates, housing options, population sizes, majors, faculty, student retention, graduation rates and job placement rates before applying. One website that can help is www.niche.com, formerly known as collegeprowler.com. In addition to general statistics on tuition, acceptance rates and SAT scores, this site allows you to see how schools are rated by graduating students.

• **Schedule a visit:** See just how accessible classrooms and campus resources are by scheduling tours with prospective colleges. This is typically arranged with the admissions office. Visit student services offices and buildings that correspond with your desired major, since you will likely spend a lot of time in these areas. An interview is also recommended: Speaking with admissions staff can help you get a better feel for the college and its representatives.

• **Meet with Student Services:** Many campuses have student services offices dedicated to serving individuals with disabilities. The staff members at these offices generally work with college administrators to ensure that the school follows disability laws. The student services are the primary place to go for any accommodations or questions.

• **Contact Student Housing Services:** If you plan to live on campus, check with residence hall administrators to learn about accessible dorms, dining halls and parking.

• **Seek Financial aid:** Financial aid is sometimes available for students with disabilities. www.Bestcolleges.com has more information on how to get help from various agencies.
In addition to medical records, ask your physician to provide: Current disability diagnoses; your doctors’ credentials; and medical and academic reports on the impact your disability has on your academic life.

Have up-to-date medical records ready before college. This is extremely important: Without current data, universities may not grant accommodations. Visiting a CMT Center of Excellence or a neurologist who has an understanding of CMT is advisable before applying for colleges. All this information can be found at www.cmtausa.org.

Know what services the university provides before choosing it, as well as the geography. If the campus has hills or inclines, be sure that there are alternate ways to get up them. This includes stairs or elevators. There is nothing worse than having to go up a large hill multiple times a day just to get to your dorm room to sleep. Be sure to have a firm understanding of the layout and geography of your university so that you can find the easiest and shortest routes between locations.
Many schools want to help accommodate you and your needs. Contact the accommodations office as quickly as possible in order to begin the process of creating a file. This will help expedite any needs that teachers may have for specific information in class.

Many schools provide a wide variety of accommodations. Some schools will provide note takers if typing or taking notes is difficult, as well as extra time on tests, or even free transportation services around the campus. Some colleges will have people help you with food services if your dorm is too far away from the dining areas. To get this help, proof in the form of doctors’ notes and records are required, which you should already have.

Also, schools will often help with finding a dorm room that meets your needs, be it a single room on the first floor or a room next to an elevator. This does not mean you are guaranteed an optimal room, but most colleges will try to work with you to find the best room available.
Your professors can be your best advocates—so long as they know what you need. Building a relationship with a teacher is vital to having the help you need to succeed. Teachers will often do the most they can to accommodate any need you may have, but sometimes there is a limit, which varies based on school policy. Therefore, speaking with each of your professors and understanding what options are available is extremely important. It may be difficult to approach a professor as a freshman or even a senior, as they can be intimidating, but know that teachers are there to help.

There are several ways to approach a professor about special accommodations and general aid. The simplest way is to ask right after class ends. If you’re uncomfortable with the idea of other students overhearing your conversation, most professors have several hours a week where students can go to their office and talk to them about school-related manners. This allows you to have a one-on-one discussion without having to worry about others overhearing.

When speaking to a professor, especially one you may not know or just met, remain respectful, but be assertive. Don’t be afraid to voice your needs. They want to help, and as long as you show them the proper respect and act genuine, they should listen to you.
Don’t be afraid or shy to go to the accommodation office of your college to talk to a staff member about anything that you might need. They are there to help and make college an equal experience for every student.

If you encounter any problems, counseling services are usually available. These trained therapists are a valuable source of aid and can get you through tough patches during college. They can act as another support net, but only if you are willing to go to them.
You may be hesitant to wear AFOs, but it is not a big deal. In my experience, people don’t view me any differently for wearing them. If you want to meet others who are going through experiences similar to yours, check to see if your school has a club or organization for students with disabilities. While the other members may have different disabilities, you’re likely to find your differences outweighed by your similarities—and joining will help you feel less alone.

Just remember not to let your CMT stop you from enjoying college. There are services to help make it an enjoyable experience, and lessen any difficulties that you may encounter. College is an important time to grow and gain experience as well as to learn how to be an independent adult. Ultimately, it is your responsibility to seek out the help that is available. Try to not put off seeking special accommodations until it is too late. The sooner the school knows what you need, the more enjoyable college will be.
Friends are the best support you have away from home. Because the majority of your free time will be spent either studying or hanging out with them, it’s a good idea to give them a basic explanation of CMT and how it affects you. While CMT is complicated, your explanation doesn’t have to be—just tell your friends that you have it, what you have difficulty doing and how it affects you. If they want to know more, send them to the CMTA website.

When trying to get my friends to understand what CMT is and how it affects me, I start by listing my basic physical symptoms. I tell them that I have a problem with my nerves, and it makes it more difficult to keep up. The description can be just a few words: If questions come up and you feel comfortable answering them, you can go into more depth. When I explained CMT to my friends, some of them wanted to know more, while others were satisfied with the basic explanation. Explaining CMT helped my friends understand why I may not be able to do certain activities. If they are truly your friends, they should be able to understand and accept your differences. Every person has something; it just comes in different forms, so having CMT does not mean you are the only one dealing with a condition.
Recent technological advancements are a big help for students who have physical disabilities. For example, CMT can make it hard to take notes or write papers. Two products are particularly helpful with this issue: Nuance’s Dragon Naturally Speaking is a voice-activated dictation program. After a short training period, the program can accurately interpret your voice and translate it into text in most Microsoft programs, such as Word, making writing a paper a hands-free process. Also, another company called Livescribe has developed pens that record audio as you write notes, lessening the stress on the hand.

Other aids worth asking for include:

- Sound amplification aids
- Speech-to-text software
- Accessible testing locations
- Note-taking services
- Priority class registration
- Course substitutions
Although it may seem scary at first, college can be one of the best times of your life, and having CMT does not change that. Adapting to college life isn’t easy, but there are lots of support systems available to help you succeed. You just need to find them. As you have your own experiences, you may find more things that could help others, so please help make this guide better with feedback and any additional information.

If you have suggestions to add to this guide, please send them to info@cmtausa.org.

Resource Guide:

www.niche.com
www.Bestcolleges.com
www2.ed.gov/about/offices/list/ocr/transition.html
www.affordablecollegesonline.org/college-resource-center/resources-for-students-with-disabilities
www.nuance.com/dragon/index.htm
www.livescribe.com/en-us
About the Author

Yohan Bouchard is currently a Senior at Pitzer College, pursuing a Bachelor’s degree in Psychology, with a minor in History. Yohan was diagnosed with CMT1A at the age of 7 and has been involved with the CMTA since his diagnosis. Yohan has found that his college experience was both rewarding and challenging due to his CMT and felt that sharing his personal experiences would help others to make their transition into college a little easier.