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HOW TO ADVOCATE FOR YOURSELF IN COLLEGE: NAVIGATING THROUGH THE ACCOMMODATION PROCESS

This proposal was submitted to Dysautonomia International's administrative team and was approved for a Webinar! Thereby, at the end of the summer, I will host this webinar entitled "How to Advocate for Yourself in College: Navigating Through the Accommodation Process." In the webinar, I will relay the points outlined in this script/ proposal.

Background Information:

-In higher education, there is an office that provides support for students with disabilities. This "office" can take on a variety of names, such as "The Office of Accommodations Access and Disability Services," "University Disability Resources," "Office of Disability Services," etc. -These systems/ offices exist in accordance with policies outlined by ADA. The role of these offices is to enable students with disabilities to be able to access their programs and classes by requiring instructors to provide reasonable accommodations. These reasonable accommodations come in various forms, such as course materials in alternative formats, flexible attendance requirements and deadlines, and exam accommodations.

-While these systems are in place, it is up to **individual students** to request and **self-advocate** for the accommodations they need.

-No one understands the ways in which your disability affects you more than you do. Thereby, it's necessary for you to identify and then convey the ways in which your disability can interfere with your academic/ educational experience.

-Most of us are a part of the Dysautonomia International community because we have an autonomic nervous system disorder. These disorders are often considered to be invisible illnesses. That is, though one is suffering from the debilitating symptoms of dysautonomia the person appears healthy and lab tests seem normal. However, on the inside, our nervous system is raging war with our bodies. Most of us have dealt with another individual invalidating our debilitating symptoms since we appear to be "perfectly healthy." Unfortunately, the invisible nature of autonomic disorders places an additional burden on us to articulate the symptoms we experience and the effects of said symptoms in an academic setting.

-At first, I was upset that I had to do what felt like validating my symptoms. To combat feelings of discontent, I reframed this burden as a gift in that it allowed me to educate more people on dysautonomia. For many of your professors/ college administration it will be the first time they hear of dysautonomia and you have the power to help spread awareness about our community in an accurate manner.

-You may not feel comfortable engaging with self-advocacy to the extent in which I will outline and that is totally okay. But, self-advocacy is a skill that every disabled person should learn more about. You can implement parts of these tips or none, but you should carry these tips with you through different situations in your life. There may come a point in time in which you have no choice, but to self-advocate

-Advocating for yourself takes time and effort, but the benefits of self-advocating may help make your college experience more enjoyable.

Understand Yourself and Your Needs:

-The first step in self-advocacy is reflecting on the ways your disability affects your life. -Start by making a list of all the symptoms you can experience as a result of your disability. For example, fatigue, brain fog, dizziness, etc. Then identify the ways in which each symptom could potentially affect your academic performance.

-For example, I have Postural Tachycardia syndrome. When I am having a flare-up some of the symptoms I experience are tachycardia, brain fog, headaches, intolerance of exercise, insomnia, fatigue, and dizziness. In college, these symptoms all affected my academic performance. Specifically, intolerance of exercise and tachycardia made it virtually impossible to walk to class. Whereas, insomnia, brain fog, and fatigue (collectively) were a perfect stew of symptoms to severely affect my concentration levels.

-Additionally, for me, mornings are particularly challenging as I am often more symptomatic. I will then take my medicine and wait for it to kick in.

-More generally, my salt intake is important to maintain as well as my fluid intake in order to prevent lightheadedness and passing out.

-Given all the ways in which my POTS symptoms affect my life I began thinking of accommodations that I find necessary for my success in college.

-For example, scheduling my classes later on in the morning, having extra time to walk between class times, having alternative forms of transportation available to me when I am unable to walk to class or alternative modalities of attending class (zooming in), having permission to eat and drink in class, etc.

-It's powerful to reflect and understand the ways in which your disability affects your daily life. Importantly, this reflection step is necessary before you can explain the ways in which your disability can impact your academic performance to another person. After all, you must understand the ways your disability affects you before you can explain such to someone else.

Articulating Your Needs:

-After identifying the ways in which your disability could impact your academic experience you want to meet with your college's office that provides support for students with disabilities. At this meeting you want to clearly articulate the ways in which your symptoms can affect your academic performance and what accommodations are necessary to account for the ways in which you can be affected. If you are not sure what type of accommodations to ask for, your office advisor may have suggestions of accommodations used in the past for similar situations. -For example, in my first year of college, I expressed my concern with my schedule in that I needed to have my classes start later in the morning and to have significant time in between classes for walking purposes. My office advisor then suggested a class scheduling accommodation that gave me priority to schedule my classes without entering into the lottery that some classes tend to go to. This accommodation eliminated the stress of having a class schedule that would set me up for potential failure/ struggle due to not receiving a favorable lottery number for a class I needed in my schedule.

-You should also identify "what if" scenarios. Essentially, it's best to address the worst-case scenario before it happens. For example, what's the protocol for when you have a flare-up the day before or on an exam day. Discuss with your office advisor what the protocol would be in a

situation like this. It's helpful to relay details on how many days it typically takes for you to fully recover from symptoms during a flare up etc.

-Recap the meeting in writing for your own personal records and to make sure you understand your accommodations correctly.

Meet with Each of Your Professors:

-At most colleges, the office that provides support for students with disabilities will provide you with an accommodation letter that can then be distributed to your professors.

-Schedule a meeting to talk through your accommodation letter with each of your professors. Before the meeting consult the syllabus of the course and note any important deadlines. Discuss with them those "what if scenarios that I mentioned earlier."

Tips to have an effective meeting:

 Have a list written out of the ways in which your symptoms can affect your performance in their class. When discussing your disability you can choose to be specific or keep it vague.

Vague Example: I have a disability that causes these symptoms.....and if I am experiencing these symptoms then these are the accommodations I would need in your class....

More Specific Example: I have Postural Tachycardia Syndrome, which is an autonomic disorder that affects me in these ways....if I am experiencing these symptoms then these are the accommodations I would need in your class...

2. Go through each part of your accommodation letter and discuss how your accommodations can be applied in their specific classroom setting.

3. KISS: Keep it simple stupid! Keep it succinct and to the point.

Know Your Rights:

-Sometimes you might be met with unaccommodating professors. At these moments it's important to know your rights! You have rights as an adult with a disability. Therefore, you should familiarize yourself with the laws set out in the Americans with Disabilities Act (ADA), which ensures equal access and equal opportunities to individuals with disabilities that impact one's lifestyle. Under these laws you are provided with protection and private and public institutions are required to make certain reasonable accommodations for you. Essentially, ADA protects qualified persons with disabilities from discrimination in many areas of postsecondary education including admission, academics, and research.

-Become familiar with your school's medical withdrawal policies in advance so you know what that process entails if needed.

Benefits of Self-Advocacy:

-It helps you build confidence. With time, self-advocating gets easier. You are bound to be in another situation in which you will have to self-advocate and this is great practice.
-It improves your academic performance. When you self-advocate, you get to ask for whatever specific needs you require in order to succeed. It's important to remember that your accommodations are necessary and meant to level the playing field between you and another

student that is not contending with a disability. Without self-advocacy, you will not receive the specificity of the accommodations you need, which can negatively impact your academic performance.

-It enhances your communication skills. Being able to advocate for yourself is a powerful life skill and honing your communication skills will serve you in all areas of life.

Disclaimer:

-Not all 18-year-old students that just entered college are ready to self-advocate. It's a challenging process. It's also a major shift because your parents are no longer able to advocate on your behalf. While this transition is scary, through following these tips you can become a self-advocate.