



Tips for Studying Abroad with a Chronic Illness

Written by Taylor Hein '21

In January of 2018, my systemic lupus erythematosus (SLE) diagnosis arrived at once as a flagrant insult. It was personal, sharp, and penetrating. Mortality didn't merely come politely and gently knocking, but it instead immediately broke down my door with a swift ferocity, completely unapologetic and unyielding. To be told in your first year of college at eighteen years-old that you have a chronic illness is crushing, regardless of what kind of disease it is. Your spirit of youth—your sense of invincibility—is irrevocably altered. Your body, once a vessel for accessing the unending possibilities of life, becomes a constricting and aching cage. To add insult to injury, lupus is an autoimmune disorder, meaning that my body was literally attacking itself.

Returning to school in the spring was jarring and alienating. I knew I had the support of my friends and family, but it was incredibly difficult to manage this new disease and manage my relationships. In my case (and most others), my chronic disease is not visible. I do not have a physical indicator that I am unwell. It was very hard for those close to me who did not have a chronic illness to understand the new parameters of my body. This was perhaps the most disheartening and discouraging part of my age of becoming with lupus: trying to help people understand that just because you cannot see it, does not mean it is not there. As a college student, you are, by default to society, healthy and in your prime. There is nothing quite like someone taking a single glance at you and denying the truth of your body, the truth of such an integral part of your identity. However, you do not have to be an adult to have a chronic disease; you do not have to be in a wheelchair to be disabled.

In the summer of that same year, I was diagnosed with fibromyalgia, another autoimmune disorder. Instead of targeting my joints and internal organs, fibro attacked my muscular system and affected my cognitive abilities. I have always been an incredibly independent person, but these diseases were ceaselessly trying to impede upon my spirit of autonomy and sense of adventure and spontaneity. As I grew to learn about my body, it became increasingly important for me to continue to live my life as best as I could in my new normal. I learned that I had to say no to some things in order to preserve the mental energy and physical capability to do others. As a young person learning to limit oneself, it is incredibly frustrating,

One would think that living with two autoimmune diseases which cause me chronic pain would make my decision to study abroad extremely difficult, or even that I would never actually consider going in the first place given its potential risks and certain obstacles. For some, it may be. For me, my diseases became even more reason why I should go. I would like to encourage others to consider it, as well. If you have a chronic illness and are doubtful as to whether you can go, or even if you are a parent/guardian concerned about a loved one, I would like to share some important advice and wisdom I obtained throughout a yearlong journey in my study abroad experience that I wish someone had shared with me. I hope to help others understand that it is very possible for someone with a chronic illness to study abroad and have an incredible time while they are there.

I. Planning

Firstly, I would highly recommend visiting either with a personal therapist or one of the counsellors in student psychological counselling services at Chapman. You do not have to be in a crisis or deep in a depressive episode to utilize the university's free student mental health resources. It is just as important to be proactive and lay the groundwork for a successful semester by discussing your plans, concerns/fears, and excitement with a professional equipped to guide and support you beyond just your network of family and friends. Similarly, if you have a specialist doctor (I have a rheumatologist, for example), make sure that you have met with them to discuss your desire to study or abroad and share the plans for your upcoming travels. Personally, my doctor was incredibly helpful in asking necessary questions before I went abroad. For example, he asked how I planned to manage my flare-ups, if I felt comfortable not having regular appointments with him, what we would do if I had a medical emergency or difficulty with my diseases, etc.

In my particular experience in Ireland (which would be similar to England, Scotland, or other rainy regions), there was the issue of barometric pressure that my doctor helped me to understand and prepare for. Many chronic diseases, especially autoimmune disorders like lupus and fibromyalgia, have an adverse reaction to changes in atmospheric pressure. I can tell days in advance when it will rain in Orange because my body gets into a flare-up. During my flare-ups, I experience increased widespread muscle and joint pain, extreme fatigue, and often cognitive challenges where my memory and concentration are incredibly impeded. Someone else's flare-up might be entirely different from mine, but this is important to consider, nonetheless. If you have a disease effected by changes in barometric



pressure, you must know the climate of your intended region and plan accordingly, especially in your mental preparation with a therapist or counsellor. Naturally, Ireland is an incredibly rainy island. I was fully aware that going to Ireland would mean that I would likely be in consistent pain to some extent. This is something I needed months to mentally and physically prepare myself for. Make sure that you are well before you go, both in body and mind with a counsellor and your doctor.

II. Accommodations with Disability Services

If you do not already have accommodations through Disability Services, I would highly recommend emailing them at DS@chapman.edu to set up an intake appointment. It is important to remember that the civil rights laws established by the ADA (Americans with Disabilities Act) are exclusive to the legal system in the United States. Consequently, you must research the disability rights laws in your prospective country to prepare for your travels and classes ahead of time because the laws will be different. The country's social perception of disability might also be drastically different, so educate yourself on both fronts. Some might be incredibly progressive and have better laws and social perceptions of those with disabilities, and some might be further behind legally and socially. Regardless, bringing with you a letter from Chapman's Office of Disability Services might still be helpful to ensuring that you get some type of similar accommodation at your foreign university.

I contacted the International Office at the University of Limerick to notify them of my disability. Just like at Chapman, they advised me to notify each of my professors via email prior to classes starting in order to communicate any accommodations I might need. Thankfully, all of my professors were incredibly understanding. I had to miss a class one day because of a flare-up and it was not an issue at all. You just have to reach out to them ahead of time and communicate your needs. Keep in mind that you must do the intake appointment with Disability Services in person at their Chapman office, so be sure to make the appointment with plenty of time before you leave. Starting this process early also gives your doctor(s) time to write a letter describing their proof of diagnoses for Disability Services, which you will require for your intake appointment. In general, the international/global education office at your foreign university will be your main point of contact for questions about accommodations and medication needs (such as requesting a refrigerator for any refrigerated prescriptions you might have for your dorm/apartment).

III. Medication



In this process of preparation, I would highly recommend starting the process of getting a full semester supply of all of your medications (or ensure you have a full month if you are doing a travel course) an entire semester before you actually leave. I spent two months relentlessly fighting my insurance company for my supply of medication. You will usually begin this process by contacting your doctor to request a special prior authorization (PA) for an extended supply, often referred to as a “vacation length” supply. Your doctor will then send this form to the insurance company. Give them seven business days to process it and if you do not hear back from them after one week, call them and ask for a status update. It is integral that you are persistent with the insurance company because they will be reluctant to authorize an extended supply. They might even suggest that you get the medications while abroad, but I strongly recommend against this. Especially if you take birth control, take into consideration how conservative a country like Ireland might be and how this would affect your ability to obtain the medication.

My insurance company tried to tell me to purchase one of my medications while I was in Ireland even though my policy did not cover international refills. Essentially, they suggested that I pay \$3,400 a month instead of bothering them for a vacation supply. Do not let them bully you into doing this. You never know what might happen when you are actually abroad, and you cannot rely on the possibility of getting them in another country. Medical care and pharmacies are incredibly different from the United States. Your prescription(s) might not even exist in some countries or they might be listed under an entirely different name. This is why research ahead of time is so important. If you have to visit a hospital, this knowledge will be essential when you inform them of your current medications. You need to ensure that your medications are even legal in your prospective country. I simply searched “database of legal prescriptions in Ireland” and I found a search engine to enter my medications (all of which were legal). If you find for some reason that one or more are illegal, you need to contact your doctor immediately to devise another strategy.

When you do finally get the authorization for the refill of an extended supply, I would also ask your pharmacy to print two bottles of each of your medications. One will be empty and the other will contain the entire supply. When you travel outside of the country you are studying in, it is good to leave your larger supply in your housing and take a smaller amount with you for whatever duration you are traveling. If your bag is lost or your backpack pick-pocketed, you will still have your primary, extended supply at home. This would prevent you from having to pay full price for a refill of the lost prescription at a foreign pharmacy.

IV. Self-Advocacy and Transportation of Special Medications

Fourth, it is clear that throughout this research and the interactions with your insurance provider, doctors, and pharmacy, you must learn how to be a self-advocate. I learned this lesson when the insurance company tried to bully me out of getting a 5-month supply. You have to be firm. You cannot allow them to make you feel like your medical needs are an inconvenience to them. Do not apologize for your illness or your needs. It is their job to help you, that is why you or your parent/guardian pays for the insurance in the first place. This skill of self-advocacy will be important when you are travelling, as well.

Personally, I have a medication that needs to be refrigerated which presented an entirely new set of unique challenges of self-advocacy. I always got more trouble from TSA about my medication than I ever received across any airport in Western or Eastern Europe. One TSA officer tried to tell me that I needed to throw the ice packs away because they were technically a “liquid.” Do not let them bully you into this, either. You can get more ice on the plane as supplementary means of keeping the medication cold. If you have special chemical ice packs designed for the cooled shipment of your medication for extended periods, reinforce that it is a medical necessity and you will need to speak to a supervisor. I once threatened to forward my hospital bills personally to the TSA agent if they took away my specialized ice packs and let my medication go bad during my ten-hour flight. Although not everyone might be comfortable with such a confrontational methodology, the agent did quickly let the packs and my medication through.

In terms of its actual transportation, I would highly recommend Trader Joe’s cooler bags (you can also just buy a regular smaller cooler depending on the size of your medication) lined with some shipping insulation, which you can usually find on Amazon or another retailer. Use frozen chemical ice packs in conjunction with supplementary bags of ice throughout your flights. I would recommend buying the chemical ice packs intended for shipping and not bodily use because they will last much longer (avoid the instant cold packs as a primary cooling method because they don’t last very long). It is ideal if you can add a new couple of bags of ice every 2-3 hours. You can ask your flight attendant for these bags of ice. Be sure to inform them at the beginning of the flight what your medical needs are. Again, advocate for yourself. During the flight, they might forget to bring you the ice and it is up to you to get their attention. I set timers/alarms on my phone throughout the flight to make sure I did not forget. In the event that you forget to bring extra plastic bags for the ice and they say they do not have anything



to put the ice in, use the airsickness bags in the back of the seats to keep the ice from leaking too much in the cooler.

V. Medical and Emergency Information

This leads me to the importance of always having your medical and emergency information with you, whether you are just going to class or travelling to another country. Especially in terms of TSA, I carried with me copies of all of my prescription orders that my doctor had written for me. I was immediately able to give TSA my written prescription needs when they tried to take away the ice packs. When you arrive at school, some universities will also give you convenient cards during orientation week that you can keep in your wallet where you can list your name, any medical conditions you might have, and an emergency contact. However, I would recommend writing out a more comprehensive document to keep on you at all times. List your name, any chronic diseases or medical conditions you have with brief descriptions of each of the diseases/conditions, a comprehensive list of your medications with brief descriptions, list any allergies you might have (especially to medications which might be administered in an emergency room/ICU, such as latex, anesthesia, etc.), at least three emergency contacts with your relationship to them, their international numbers and email addresses, and lastly the contact information of your foreign university.

VI. Communicating Abroad

In terms of effective and reliant means of communication, especially in case of an emergency, I would recommend using WhatsApp to contact your friends and family (it's free to download) in addition to purchasing a Vodafone plan if you're in Europe. This plan will include a sim card that gives you an international number and roaming data and you can usually get a student discount if you bring your foreign university ID. You can "top up" as you go and there are no contracts; I usually just purchased 15 Euros a month. You simply add money as you run out of data and you can put your old sim card back in your phone when you return home. Vodafone cellular data also works in almost every European country. This is essential to making sure that you can make calls without Wi-Fi in case of an emergency. If you have a smartphone, I would also recommend making sure that these emergency contacts have your live location. I added my parents and a couple of friends I made in Ireland to FindMyFriends so that they would have my location if there was an emergency where I had to be taken to the hospital and my phone wasn't working for some reason.

VII. The Spoon Theory

Lastly, and perhaps most importantly when you are studying abroad with a chronic illness, you must consider the Spoon Theory. In her 2003 essay “The Spoon Theory,” Christine Miserandino perfectly explains what it is like to live with a chronic disease, consequently coining the term, “Spoonie” for those with chronic illnesses. In essence, living with a chronic illness means that you only have a certain amount of finite physical and mental energy you can use in a given day. This energy is represented by “spoons” and can be spent on regular living activities, such as showering, going to lunch with a friend, etc. If you use all of your spoons by the afternoon, for example, you either have to borrow spoons from the next day or rest/limit your spoons for productive tasks for the rest of the day. This metaphor for disability is incredibly helpful when understanding what it is like to be a student living with a chronic illness and it can be especially pertinent to your study abroad experience.

Ultimately, just be kind to yourself. Some days, you might have to tell your friends that you cannot go out or you cannot go with them on a trip, and that is completely okay. Do not feel guilty about your medical condition or needs. Sometimes you might want to actually explain to them what the Spoon Theory is. You will find that some people will be incredibly understanding and accommodating, and some people will not be able to understand it. Distance yourself from the latter. Be proud of yourself for even being abroad. Be proud of yourself now for even reading this and considering studying abroad and/or being curious about it. You will have great days and you will have days that you struggle, but I assure that with the proper preparation and support, this experience will change your life, just as it has changed mine. Even if you do not feel comfortable spending an entire semester abroad, I would encourage you to participate in one of the countless fantastic Travel Courses that the Center for Global Education offers. These courses typically last no longer than a month and would be a fantastic way to globalize your education with your chronic diseases in mind.

For further preparation and support in your study abroad experience beyond the Center for Global Education, you can contact The Chapman Spoonies via the Chapman Student Organization Engage Portal or email myself, the Club President at thein@chapman.edu. You can also find us on Instagram @thechapmanspoonies. We are a student-led organization dedicated to educating our campus about chronic illness and providing a community for students living with it, including (but not limited to) diabetes, lupus, fibromyalgia, rheumatoid arthritis, endometriosis, Crohn’s disease, multiple sclerosis, epilepsy, and complex regionalized pain syndrome.