Preparing for College WITH A RHEUMATIC CONDITION
PREPARING FOR COLLEGE
This guidebook touches on areas of college life that might be different or important to prepare for given your autoimmune condition. This is an exciting time and we hope you find this helpful as you get ready for this next step in your life. This guide doesn’t include everything. But that’s okay, since college is all about learning new things!
CONGRATULATIONS!
Welcome to a new and exciting step in your life.

Getting Organized ........ 5
Health & Wellness .......... 6
Self-Esteem ............... 9
Sexual Health ............ 10
Drugs & Alcohol .......... 13
Cheat Sheet ............... 14
KNOW YOUR HEALTH HISTORY AND CURRENT TREATMENTS

Your health history: It is very important to know your basic health history and which medications you’re taking. This will be helpful if you need healthcare while you are at school. Look up “health summary” online to find forms to print out. You can use them to clearly outline your basic medical needs.

Contact info: Make sure to have your rheumatologist’s contact information somewhere you can easily find it. Depending on where you go to school, it might be a good idea to find a rheumatologist close by your college. You may want to make a “Health Alert” in your phone in case you have a medical emergency.

Vaccines: Talk with your rheumatologist about which vaccines you should get. Many patients on immunosuppressive medications can still get meningitis vaccine before college. HPV vaccines are often important for both young men and young women who may be sexually active and are on immunosuppressive medications.

MEDICATIONS

List of medications: Keep an updated list of your medications and dosages. Carry the list with you in your wallet, notebook or smartphone in case of emergencies.

Refrigerator: Figure out whether any of your medications need to be kept cold in the refrigerator. If they do, check with your school to see about getting a refrigerator for your room or find out if there is a refrigerator in a secure place that you can use. Do not keep your medications in refrigerators that are shared with other people.

Injection: If you need injections or infusions, talk to your rheumatologist to figure out how and where you can get these at school. Your school’s health center can also recommend local infusion centers.

INSURANCE

Most college students are able to stay on their parents’ insurance until they are 26 years old. Some colleges offer health insurance for students. Look up college insurance plans before you leave for school, since they can affect your medications, blood work and any medical visits you may need.

SHARING HEALTH INFORMATION

You are not required to share your personal health information with your college. But it can be very helpful to do this. Most colleges have a Disability Office or Disability Officer. This person can help make sure that your medical rights are protected while you are at school.

Sharing your health information with your college can also help you get “health accommodations.” These can include priority registration for classes, choice of seating in class and/or excused medical absences.

If you have questions about health accommodations, talk to your advisor, health services office or Disability Officer.
What is wellness? It’s a holistic approach to your health that focuses on taking care of every part of you. This means taking into account mental and social factors, and not just the physical factors that affect your wellbeing. Keeping a healthy balance in your life helps to keep symptom flares down. And it’s really important to remember what sets off your flares.

**FOR YOUR BODY**

**Sleep:** Sleep is important for your health and your schoolwork. Set a sleep schedule that fits well with your classes and homework. Aim for at least 8 hours of sleep every night.

**Diet and exercise:** Stick to a healthful diet. Your body needs nutritious food to stay energized and strong. Exercise at least 3 times a week for 30 minutes at a time. For motivation, try using the buddy system. Find a friend who is up for joining you in health and wellness activities.

**Sunscreen:** Wear sunscreen outside. Do not stay out in the sun for long periods of time—even if you are not taking immunosuppressive medications. Sunlight can make your symptoms worse. Apply more sunscreen after a few hours outdoors or after going for a swim.

**Keep track of your health:** Download an app! There are many online apps for tracking your fitness, sleep, diet and even your mood. Do an online search to find apps that might work for you.

If you have a fever higher than 101.5°F (38.6°C), go to your college health center right away, especially if you are on immunosuppressive medications.

**Do not stay by yourself if you feel sick. Ask a friend, roommate or resident assistant (RA) to stay with you and go with you to the health center.**

**FOR YOUR MIND**

**Emotional health:** Take time each day for a check-in of how you’re feeling physically and emotionally. Stop and ask yourself, “How am I doing, right at this moment?” Be aware of stress, since it can raise pain levels and set off flares. You may want to look into daily meditation, deep breathing exercises and/or mindfulness apps.

**Socializing:** Friends are important for support and fun. But sometimes your symptoms or flares might keep you from social activities. Surround yourself with friends who are understanding about your needs and who can roll with unexpected changes in plans.

Find your own style. Part of the fun of college is figuring out who you are—and who you want to become. Your medical condition is just one part of your life, so spend some time exploring and enjoying other parts of your personality and yourself!
Preparing for College with a Rheumatic Condition

People with rheumatic conditions are more likely to have low self-esteem and a poor body image. They are also at higher risk for depression and anxiety. It’s important to be aware of how you are feeling and challenge any negative self-talk to avoid cycles of low self-esteem.

**TIPS FOR KEEPING UP YOUR SELF-ESTEEM**

Be caring with yourself. Sometimes you are your own toughest critic (even tougher than your Teaching Assistant!).

Many first-year college students struggle with mental health needs. Even experienced college students do, too.

College can make you feel alone and scared. Remember: You are not alone and there are people at your school who can help.

Most colleges offer free and confidential counseling services. Get in touch with your school health center or ask your college advisor.

It’s your choice whether or not, and with whom, you want to share information about your health.

**SOCIALIZING**

There are many people to meet at college. Try to surround yourself with people who you find supportive and interesting, even if it’s only a small group. Feeling like you’re stuck on your own can make negative feelings worse, so reach out to others if you’re feeling down.

Social media can connect and divide us. Use apps and platforms to connect with others—but ignore the haters. You have better things to do than worry about Internet trolls.

You might not be sure about your medical condition and the future, but you have already made it to college. You have the power to shape your future. Positivity goes a long way!

**QUICK STAT: 50 PERCENT**

50 percent of college students rate their mental health below average or poor according to a 2012 report by the National Alliance on Mental Health.
BOSTON CHILDREN’S HOSPITAL
Preparing for College with a Rheumatic Condition

Sexual Health

THE IMPORTANCE OF SAFER SEX

Immunosuppressing medication puts you at greater risk for infections, including sexually transmitted infections (STIs or STDs).

For everyone: It is very important to practice safer sex, including using birth control and barriers, like condoms or dental dams. You should use barriers for all forms of sexual contact—oral, anal and vaginal. Some STIs, like genital warts, can be passed between partners even when barriers like condoms are used.

There is always a risk of getting STIs though oral sex, especially if ejaculation happens or if there are any sores or wounds on either partner.

Lowering your number of sexual partners can lower your risk of infection.

Many immunosuppressant medications can cause serious birth defects, so it is important to get medical attention right away if you or your partner get pregnant.

For women: Some medications can change how well oral contraceptives (“the pill”) work. So it is important to use other forms of birth control (like condoms). Talk with your primary care doctor or gynecologist about other options, like an IUD.

You might not have regular menstrual cycles (periods) when on immunosuppressants, but you can still get pregnant even if you aren’t having a regular period. It is always important to use birth control.

Women on immunosuppressant medications are more likely to get urinary tract infections with intercourse. It is important to wash well after bowel movements and to wipe from the front to back. Urinating before and after intercourse and drinking a lot of water can also help to prevent urinary tract infections.

SUPPORTING YOUR SEXUALITY

Sexuality is all about your relationship with your partner, how you feel about yourself as a sexual person and how you find intimacy.

Sexual desire: Sometimes your medical condition or medications can affect your sexuality. You might feel changes in your: libido (sexual desire), mood, mobility, energy level, menstruation, ability to get or maintain an erection or ability to orgasm. All of these factors play into your sexual relationships.

You may feel unsure of yourself, worried about pain or worried that sexual encounters could worsen your condition.

You should be sure you feel comfortable with your own self-esteem and body image before getting intimate with someone else.

Being able to speak openly and honestly with your partner can help reduce worries about sexual experiences and intimacy.

Consent: Consent means making sure both partners agree to any activities they do together, from kissing to cuddling to intercourse. Always ask, “Is this okay?” Your partner should be getting your consent, too. No one should pressure you into intimacy or sexual activities.

Title IX: All colleges are protected by Title IX, a federal law that does not allow sex-based discrimination, harassment or violence. If you feel you have experienced sexual harassment or violence, tell your advisor or school health center right away.
There are plenty of ways to meet people, hang out and have fun at college without using drugs and/or alcohol. Your health is not worth the risk!

**ALCOHOL**

You should not drink alcohol while taking medications because of the danger of permanent damage to your liver.

Binge (very heavy, all at one time) drinking is one of the most dangerous things you can do while on immunosuppressive medication. It puts a very big strain on your liver. If you choose to drink, talk to your rheumatologist first and be open and honest about how often and how much alcohol you drink.

If you drink alcohol, limit yourself to no more than 2 drinks per week.

**DRUGS**

**Marijuana:** Marijuana can lead to greater feelings of worry and nervousness. The effectiveness of medical marijuana on rheumatologic conditions is not known. Smoking marijuana is not good for your lungs, so it’s best to not do it. If you are taking immunosuppressive medications, smoking marijuana could increase infections like bronchitis and should be avoided.

**Opioids:** People who have chronic pain are at a higher risk for abusing opioids, like painkillers, so take these medications only as prescribed. If a friend offers you pills, just say, “No, thanks!”

**Cocaine:** Cocaine and MDMA (ecstasy or “molly”) can affect your inflammatory system and will have serious effects on your health, including the strong risk of addiction.

**Smoking:** Cigarette smoking (including e-cigs) is dangerous for anyone. If you’re taking immunosuppressant medication, smoking cigarettes can raise your risk of cancer and heart disease. Cigarettes can also lead to flares of your disease. If you want help quitting, visit smokefree.gov or call 1-800-QUIT-NOW.

---

**QUICK STAT: 50 PERCENT**

Half of all college binge drinkers report having 5 or more alcohol-related problems during the school year according toInTheKnowZone.com. The CDC defines binge drinking as 5 or more drinks in 2 hours for men, or 4 or more drinks in 2 hours for women.
It is your right to get the accommodations you need (like help with walking or extensions on tests after a symptom flare) under the Americans with Disabilities Act. Start college off right by laying the foundation for your success.

RESOURCES

College Advisor: See your college advisor to make sure that you have all of the accommodations you need for classes and dormitories.

Health Services: Visit the college health services department to ask about how you can store medications/refills and to learn more about your college health plan (if applicable).

Local Hospitals: Get familiar with local hospitals and keep their contact information for your rheumatologist.

Transition: The Boston Children’s Hospital Teen Advisory Council developed a transition booklet called “One Step at A Time.” This booklet has other tips for staying on top of your medical condition.

Check out these websites for more support:

- us.reachout.com/facts/maintaining-good-health
- jatransition.org
- resources.lupus.org

24 HOUR HOTLINES

National Suicide Prevention Lifeline
1-800-273-8255

National Sexual Assault Hotline
800-656-HOPE
online.rainn.org

National Domestic Violence Hotline
1-800-799-7233

National Council on Alcoholism and Drug Dependence Hopeline
800-622-2255

Crisis Text Line (U.S. only)
Text HELLO to 741741 or message them at facebook.com/CrisisTextLine to chat with a Crisis Counselor.