



College & JIA

Prepared by the PR-COIN
Patient Advocacy Team

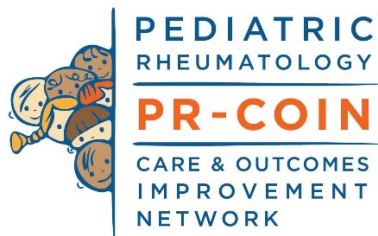


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This College & Juvenile Idiopathic Arthritis toolkit was created based on United States laws as of September 5, 2021.



About This Toolkit

For many, transitioning into college can be difficult and overwhelming, especially when you're dealing with juvenile idiopathic arthritis (JIA). This handbook, reviewed by patients, has resources that will make the process less stressful. Whether you're in high school, college, or just a family member, this handbook can help guide you through the transition process. We include information about preparing for classes, dorm life, and surviving college life with JIA.

This toolkit focuses on the college accommodations from the perspective of a JIA patient. If you need information on other accommodations or on accommodations for college/graduate level exams, please see the [JIA Accommodation Toolkit](#), which covers accommodations from kindergarten through to the workforce and was created by the PR-COIN Parent Working Group.

Please remember:

Accommodations exist to make aspects of your life accessible and less stressful. You should not feel guilty using accommodations, especially if it means you will be better able to manage your illness and take care of yourself. When you're sick, the last thing you need is extra stress - you should never have to sacrifice your health or well-being to succeed academically or in the workforce. Accommodations can help ensure you are adequately supported so you can improve your quality of life!

Finding a ‘Good Fit’

There are many factors to consider when deciding on a school. Some people may choose a school they know will be more accommodating while others will seek accommodations after choosing their school. Here are some things to consider when identifying colleges and questions to ask on college tours.

Things to consider

- Do you feel comfortable managing your own care away from home?
- Will you have easy access to medical care?
- Will you need supplemental health insurance?
- What services are offered at the student health center?
- Are there options for dorm/bathroom layouts that will suit your needs?
- Will the layout of campus pose a physical challenge for you?
- Does the school offer online classes, academic support, or tutoring services in case of flares?
- How responsive/efficient is the school’s disabilities center?
- If extreme hot or cold impact your arthritis, what is the climate/average temperatures where the school is located?

Questions to ask on college tours

- What types of rooms does the school have available?
- Can you choose which dorm you live in?
- Where’s the health center, and what services do they offer?
- How does scheduling work?
- How often are community bathrooms cleaned?
- Where is the disabilities services office located?
- How does roommate matching work?
- How far is it to walk across campus?
- Where are elevators located in buildings?
- Where are the offices for financial aid, cashier’s office, counseling, etc.?
- Where are easily accessible study areas located?
- Are there transportation services to take you around campus?
- Can medications be delivered to residence halls?

PAT TIP: Don’t choose your school around your disease. Choose your school based on your major, region, size, etc., and then seek out the school’s disability support services.

Preparing for College

Once you've decided what school you'll be attending, it's a good idea to start preparing for your first year ASAP—especially if you'll be moving away from home. If you need any accommodations (for academics, housing, transportation, or dining), it's a good idea to contact these departments before you arrive on campus in the fall. Use our checklists and template letters to make communicating with your college easier!



Healthcare Checklist

Regardless of whether you're staying local or moving:

- Meet with your school's disabilities support office to arrange for your accommodations.
- Contact your school's health center to find out what services they offer and if they can help coordinate care. Use our template letter!
(<https://docs.google.com/document/d/10jeLDNjijYTusmQmVZI14iMQPN-LB2xx/edit?usp=sharing&oid=115414671144100072123&rtpof=true&sd=true>)
- Contact the managers/nutritionists in Dining Services if you have specific dietary needs.
- Contact your rheumatologist/primary care physician to request a medical summary of your care to date for your files.

If you're moving away from home, you'll also want to:

- Find a rheumatologist in the area. Ask your rheumatologist if they have any colleagues near your college.
- Locate a pharmacy, treatment center, and ER nearby.
- Check with your doctor to see if there are any immunizations you should receive based on the location of the school or before living in a communal setting.
- Contact your insurance to find out if you need a supplemental plan. Your school may offer supplemental insurance, which you may opt out of if you already have sufficient coverage. If you don't know where to start, use this script.
(<https://docs.google.com/document/d/1K2zs4AnY9MYyw29daGoqHGnRh80RS9OTCIW7k0OLgds/edit?usp=sharing>)

Academic Accommodations

What accommodations are right for you will depend on whether you have limited stamina, frequent absences, need to leave class due to fatigue, location of your arthritis, etc. Use the sample accommodations and questions below to help guide you in the process.

Academic Accommodations Examples

- **Reduced Course Load** – If you need a reduced course load, the school may be able to waive or reduce the minimum number of credits required each semester to qualify for financial aid or to remain a ‘full-time student.’
- **Priority Class Registration** – This may allow you to avoid scheduling classes for times you feel your worst, around regular medical appointments, or in a way that limits walking.
- **Note-Taker/Lecture Recordings** – This is helpful if you have difficulty concentrating due to fatigue, have extended/frequent absences, or are unable to take extensive notes due to your arthritis.
- **Test Accommodations** – Set up accommodations through the disability services office to allow extra time, opportunities to stand up and stretch (‘stop the clock’), or take exams in a private room.
- **Nullified Attendance Policy** – This accommodation means you won’t need to force yourself to attend class when you’re unwell or get penalized for frequent appointments.
- **Assignment Extensions** – These are helpful if you’re not feeling well and need more time to finish an assignment. Be sure to communicate with your professors if you think you might need extra time to complete work.

Academic Accommodations Checklist

Before the school year starts:

- Contact your school’s Disability Support Services to set up a meeting.
- Get documentation of illness from your rheumatologist team and discuss options for accommodations.

The first week of school (or earlier, if possible):

- Meet with Support Services to determine a list of reasonable accommodations.
- Review the support office’s letter to your professors informing them of your accommodations.
- Meet with professors to discuss accommodations ASAP -you can use this template (<https://docs.google.com/document/d/14EInj06ik74geuU7HxPZFRXqCir9PuRh0RjT8FsGXog/edit?usp=sharing>) to get started!

Check out the [JIA Accommodations Toolkit](#) for more tips!

PAT TIP: Be open with your professors! Sharing your accommodations and touching base with your professors will ALWAYS be in your favor.

Housing Accommodations

College may be your first experience living away from home, and it's important to feel comfortable with your living situation, particularly since shared rooms/bathrooms are common in college dorms. It's also important that you are able to keep your medications safe and get the rest you need.



Housing Accommodations Examples

- **Private Bathroom/Single Rooms** can be helpful if you have frequent fatigue, need to do injections or infusions, or need to reduce your exposure to germs. When asking for housing accommodations, you can consider requesting a single bedroom, private bathroom, a double room with a private bathroom (for only you and your roommate), etc.
- **Fridge Rentals** are offered by some colleges so you can keep medication (like Enbrel, Humira, or Stelara) in your room. Having a personal fridge can also be useful if you are on a restricted diet and need to keep food in your room.
- **Air Conditioning** is important if you (or your medications) are temperature sensitive.

Housing Accommodations Checklist

As soon as you choose your college:

- Review dorm room options on your school's housing website.
- Decide if you'll need any housing accommodations, such as a single room, private bathroom, or fridge access.
- Contact the school's disabilities services center or housing department ASAP to set up accommodations. Your rheumatologist can adapt this template letter from GIKids.
<https://www.gikids.org/files/documents/resources/ibd/SAMPLE%20SINGLE%20OCCUPANCY%20DORM%20ROOM%20REQUEST%20LETTER.pdf>

PAT TIP: Be proactive. Even if you're not currently flaring, arrange for the accommodations you may need if you do flare so they're available should you need them. Let your professors and housing/dining know who you are and what your accommodations are so they are prepared should you need to use the accommodations.

Dining Accommodations

If your school has an on-campus nutritionist, arrange to meet with them to discuss meal accommodations. Otherwise, contact the Disabilities Services Center and/or Dining Department to come up with a plan. You may want to discuss to-go options, special meal options, or meal plan exemption. Don't be afraid to speak up and say that the meal plan does not meet your needs! A sample letter can be found [here](#).



Dining Accommodations Examples

- **To-go** dining options can be very helpful if you need to quickly catch a doctor's appointment or go to a lunchtime infusion. They can also be helpful if you are flaring and don't feel well enough to eat at the dining hall.
- **Special meal options** may be available if you're on a limited diet. Your on-campus nutritionist/dining staff can order meal options specifically for you, or the chef can prepare meals that fit your needs. Some colleges even have a private dining area for students with food restrictions, allergies, or special diets.
- **Meal plan exemptions** are possible if the Dining Hall is unable to accommodate a meal plan option that works for you. Talk to your on-campus nutritionist/dining staff about being exempt from required meal plans.

Dining Accommodations Checklist

As soon as you choose your college:

- Research the dining options on/around campus.
- If you're on a restricted diet, consider your dining needs, such as to go meals, special meal options, allergies, food restrictions, etc.
- Contact the dining manager to discuss meal plans and dining accommodations using our template letter!
(https://docs.google.com/document/d/1xtJGq_rJL8QnYs-9IsNjJRrcB6x6B_Kq3d54ZiCRms/edit?usp=sharing)
- If you run into any issues, your school's Student Support team or health center staff may be able to help advocate for your needs.

Tips for Surviving College

The beginning of college can be an exciting and challenging time. You may be dealing with new experiences, new friends, a new city, and harder classes, all of which may take some getting used to. Here are some tips for managing school, dorms, and the dining hall with JIA.

Tips for Balancing College & JIA

- If you feel worse during certain times of day, try to **plan your class schedule** accordingly. Check with the school's disability services to see if you qualify for priority class registration.
- Consider how many classes you are taking, how rigorous each class is, and what the workload will be. You can email professors before registering for their classes to ask about the workload. It's better to focus on doing well in a few classes and having energy left for life outside academics.
- **Don't overcommit** yourself right away. As tempting as it is to sign up for every extracurricular, take it slow and decide what you have time/energy for. Remember to leave time to rest and recuperate!
- If you find yourself struggling, don't be afraid to ask for help! Most schools provide free/low-cost counseling services to students.

Tips for School & Classes

- **Meet with your professors** ASAP to explain a bit about your JIA; for example, how it might impact you in class, what help you may need during a flare, etc. Let them know if you're not feeling well or won't be in class. If you've discussed this in advance, professors are often more understanding.
- If you're struggling with schoolwork or are unable to make it to class, take advantage of the resources your school offers: tutoring, study groups, office hours, or online courses can make a difference!
- Make at least one friend in each class. Not only do you make new connections, but you will have someone to keep you updated if you're in a flare or miss class due to an appointment.
- It's OKAY to skip class if you are having a flare! Don't feel guilty for putting yourself first over your education. We all have bad days, just talk with your professor and get notes from them or a classmate to catch up.
- **Accommodations can be helpful!** Disability support services can help arrange a note taker, request lecture recordings, excuse absences, provide assignment extensions, and more. Remember: accommodations exist to help you succeed!

Study Tips

- **Divide big assignments** into smaller sections so they're less overwhelming. If you're not feeling well, try to get through one small section at a time.
- Try to start assignments ASAP so you can **spread out the workload**. Whenever possible, don't leave things until the last minute!

- **Learn to prioritize** and conserve your energy for important things. Decide what has to get done in detail and what can be skimmed. If you're struggling to finish all your work, talk with your professors about modifying coursework but understand that it may not be possible due to degree requirements.
- **Organize your schedule.** Plan out your study sessions! It sounds silly, but it's helpful to have a schedule to stick by.
- Study with a friend occasionally or change scenery. You'd be surprised at how much this can help ease the stress of college and make things a little bit more enjoyable.
- For more study tips, take a look at these links:
<https://thehealthsessions.com/study-guide-for-chronically-ill-23-proven-strategies/>
<http://chroniccurve.org/post/31746427300/college-and-chronic-illness-19-tips-to-study>

Dorm & Shared Bathroom Tips

- If you feel comfortable, talk with your RA and/or roommates about JIA. You don't need to tell them everything, but it's good to give them a sense of what to expect. If they see you give yourself an injection, it's good to **provide a little context!**
- If you have a private bathroom, great! If not, scope out the bathroom situation around your dorms/campus, and find the least crowded/cleanest. If the academic buildings or dining hall stay unlocked after hours, they're often empty and more private.
- Living in the dorms can be a pain if you're immunosuppressed. Make sure to get an annual flu shot, wash your hands, and **wear shower sandals** if you're sharing a shower/bathroom!
- You may want to buy a medication lock box if you do not have a private room.

Dining Tips

- Many schools post their menus online or near dining facilities so you can scope out if there are safe options for you.
- Keep some easy, safe food options on hand for when you're flaring or unable to go to the dining hall. Some schools may be able to supply a small fridge/microwave if you need to prepare food.
- If you're struggling to find options, or are unable to eat in the dining hall due to a flare, student support services or the health center may be able to coordinate accommodations allowing you to take food to go, have special meals made for you, or exempt you from required meal plans.

Things to Remember...

All-nighters, cramming for finals, downing energy drinks—the 'work until you drop' attitude in college can make it difficult to take care of yourself. You should never feel like you need to sacrifice your health or well-being to pass a class. Just because your peers are up until 4 AM working on papers doesn't mean you're a less dedicated student if you need to prioritize rest. **It's ok if not every day is 'productive.'** There will be days that you don't feel well or can't focus

on your schoolwork as much as you'd like to. We have more 'off' days (or months) than most, which can be frustrating. It's nothing to be ashamed of. Your worth as a student isn't determined by how much you get done. If your body needs to rest, let it.

Taking Time off

If you think you might need to take time off due to JIA, check with your school about their tuition reimbursement policy - they may be able to refund tuition for any time you miss due to illness. However, be aware that the policy for medical leave of absence is different at each college. The dean of students, your academic advisor, or the disability services office should be able to provide you with information about the specific process/rules for your school. More information can be found [here](#).

PAT Perspectives

I go to the University of Missouri, and I have had an AMAZING experience with my school's disabilities office. My contact in the office has been wonderful in helping me get the accommodations that I need. I brought in my high school 504 plan and my doctor's note with the accommodations that would benefit me. My best piece of advice is to know what will help you and include any accommodations that you may or may not need. Be prepared for the worst-case scenario! You don't have to use every single accommodation, but you'll regret not having them when you really need them. I have always sent a letter of my accommodations to my teachers and set up a meeting with them to explain that I won't need every accommodation, but I will let them know if I will be needing them or not. ~ Kasey

I go to the University of Wisconsin- Madison and have found a great system for managing college and arthritis! I create my schedule so that my classes are later in the day. My school is on a hill which obviously is not always ideal with arthritis, but I've learned to use the bus as a way around that. My roommates have been super accepting of my arthritis, so I'm never afraid to talk about it. College is what you make of it, and there's definitely ways to have a "normal" college experience despite arthritis. ~ Kelsey

I have had only phenomenal experiences with my school's Access and Disability Resources! They, along with my doctors, have helped me figure out what accommodations work best for me. Even when I am doing relatively well, I always make sure my accommodations are established for the upcoming semester so that I have them just in case. When you have arthritis, there are many things that are out of your control. Setting up accommodations has allowed me to take control of my education and play an active role in making sure that I can stay on track despite health setbacks. ~ Makenzie

I have accommodations through the disability services office. The director is really helpful and sends out a list of my accommodations to my professors every semester, I then let the prof know what accommodations I plan on using. It is important to let your teachers know who you are and

what you need, especially for testing accommodations which may need prior planning. I usually meet or email a professor at the beginning of the semester to let them know what I need for the semester and then follow up two weeks before my first exam to make sure everything is set up. The best advice I could give anyone who gets accommodations is to be proactive and let your professors or housing/dining know who you are and what you need so they are prepared when you need to use an accommodation. ~ Andrew

Contact Information

Toolkit Creators

A portion of this toolkit was originally authored Rosa Kelekian, with contributions by members of ImproveCareNow Patient Advisory Council and was adapted for use for juvenile idiopathic arthritis patients by members of PR-COIN Patient Advocacy Team. To learn more about the PAC, view the original toolkit, or share your feedback, visit ibdpatient.org or contact them at pac@improvecarenow.org. **To contact the PR-COIN PAT, email us at prcoinpatientgroup@gmail.com!**

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Sources

Accommodations Network

<https://askjan.org/>

Get Educated

Withdrawing from college:

<https://www.geteducated.com/elearning-education-blog/when-life-goes-bonkers-withdrawing-from-college-with-a-full-refund-and-a-healthy-gpa/>

Sample Letters

Dining Hall Diet Request:

https://docs.google.com/document/d/1xtJGq_rJL8QnYs-9IsNjJRrcB6x6B_Kq3d54ZiCRms/edit

Professor Letter:

<https://docs.google.com/document/d/14Elnj06ik74qeuU7HxPZFRXqCir9PuRh0RjT8FsGXog/edit>

Single Occupancy Dorm Room Request:

<https://www.gikids.org/files/documents/resources/ibd/SAMPLE%20SINGLE%20OCCUPANCY%20DORM%20ROOM%20REQUEST%20LETTER.pdf>



PR-COIN Mission

The mission of PR-COIN is to build a thriving and inclusive community of patients, families, clinical teams and researchers that uses quality improvement science to deliver exceptional and equitable health care to children with rheumatic diseases and to bring research discovery to patients faster.

About the Patient Advocacy Team

The Patient Advocacy Team (PAT), is a community of young (14-24) patients with Juvenile Idiopathic Arthritis (JIA) who come together to give and receive support, ask questions, share information, and network with each other. For more information visit linktr.ee/prcoinpatients.