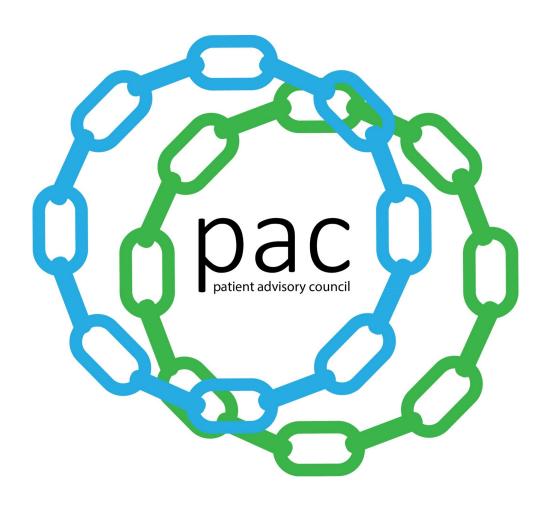
# Patient Advisory Council \*\*Commodations\*\* Toolkit\*\*











# Disclaimer

This document was created by members of the ImproveCareNow Community. Do not rely on the information in this document to diagnose or treat any health condition. This information does not constitute medical advice and is not intended to be a substitute for professional medical advice, diagnosis, or treatment.

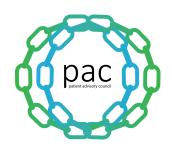
Disclaimers posted at

http://www.improvecarenow.org/icn tools disclaimer apply to this document.



## Please remember:

Accommodations exist to make aspects of your life accessible and less stressful. You shouldn't 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!



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# **Accommodations and ADA Laws**

## What are accommodations, and why are they important?

An accommodation is a modification or change that would allow an individual to do something they may not otherwise be able to do. Accommodations help remove barriers to provide equal access (i.e. help level the playing field). They don't lower the expectations that are asked of you, but instead will help you work around specific challenges you face. Accommodations exist to make things better accessible - you should never feel guilty using accommodations, especially if it means you will be more able to manage your illness and take care of yourself. When you're sick, the last thing you need is extra stress, and you shouldn't have to sacrifice your health or well-being for anything. Accommodations can help ensure you are adequately supported, so you can better manage your illness and life!

#### What is the ADA? *∂*

The Americans with Disabilities Act (ADA) is a civil rights law that was enacted in 1990 to promote social and economic equity by providing equal opportunities for all individuals with disabilities. The ADA prohibits discrimination against individuals with disabilities in any areas of 'public life' including jobs, schools, transportation, and private/public spaces. For more information, click the link above.

# How does the ADA protect the rights of IBD patients?

Many chronic illnesses qualify as disabilities under the ADA because the severity of symptoms impacts daily life and can limit an individual's ability to participate in daily activities. Individuals with any form of disability (including IBD) are entitled to the same rights, services, and opportunities as able-bodied/healthy individuals. The ADA helps ensure that individuals with IBD can access these rights, services, and opportunities.

There are five main areas ('titles') that the ADA provides coverage for: **employment**, **public services**, **public accommodations/services operated by private entities**, **telecommunications**, **and miscellaneous provisions**. Most of the accommodations that IBD patients utilize relate to either employment or public services (including education). This toolkit provides information about academic, workplace, and other 'public life' accommodations.



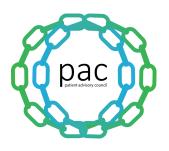
#### **Grade School (K-12)**

Individuals with IBD are protected under the Rehabilitation Act of 1973 under section 504. A **504 Plan** is developed by the legal guardian(s), student, and school staff to *provide accommodations to remove education barriers*. This does not apply to private/charter schools as these schools do not receive federal funding (please see 'Private Schools' section for more information). To help students complete homework and tests, patients can set up a 504 Plan to accommodate their needs. A 504 Plan can help ensure students are receiving the help they need to continue their education.

#### What is a 504 Plan?

Section 504 of the Rehabilitation Act enables students with disabilities to receive accommodations to ensure academic success and flexibility in their learning environment. Students with 504 Plans do not necessarily require specialized instruction but do need the assurance that they will be granted equal access to public education. *How do I set up a 504 Plan?* 

- 1. Your parent/guardian will <u>contact the school</u> to set up a 504 Plan meeting. You'll usually meet with a guidance counselor or administration before the school year begins, to make sure your accommodations are in place.
- 2. During the meeting, you'll need to <u>bring a note from your GI team</u> (your MD, NP, or social worker) to confirm your IBD diagnosis and request accommodations. You'll discuss the accommodations that you'd like to set up, how the school can provide support, and what your responsibilities as a student are. (NOTE: schools are allowed to reject your requests if they are deemed unreasonable).
- 3. If your 504 Plan isn't providing enough support, your parent/guardian can request an updated plan. (NOTE: schools may have requirements that make students ineligible for specific accommodations).



## What are some common 504 Plan accommodations for IBD patients?

504 Accommodations include, but aren't limited to, the following:

- Unlimited restroom access
- Stop-the-clock testing
- Access to health center
- Exemption from physical education classes
- Flexible attendance for medical causes (arriving late, leaving early/during class, etc.)
- Options to make up missed class time for medical reasons without penalty
- Full participation in extracurricular activities despite classroom absences
- Tutoring following a period of absence due to complications of IBD

PAC TIP: Your needs are unique! The accommodations that work for another student may not be the best fit for you, so think about the specific difficulties you have when planning accommodations.

## What if the school doesn't agree to my proposed 504 Plan?

Assuming your requests are reasonable, the **school is legally required to grant your 504 Plan**. Parents/guardians can request a due process hearing if they disagree with the decision made regarding the school district's decision, and a complaint can be filed with the district's 504 Coordinator.

DO include the student when identifying his/her needs	DON'T assume the student is aware of their accommodations
DO include how/where/when/why accommodations will be implemented	DON'T assume the school is implementing the 504 plan
DO create a 504 Plan even if the student is healthy at the beginning of the year	DON'T assume every teacher, coach, and administrator is aware of the 504 Plan
DO make sure the plan is communicated well with the teachers, and check that the current plan is working well	DON'T make your child feel embarrassed about their 504 Plan-make sure they know it's okay to get help when they need it

Source: https://www.crohnscolitisfoundation.org/justlikeme/living-with-crohns-and-colitis/school/school-accommodations





## How do I get accommodations if I attend a private school?

Because private schools do not utilize government funding, they are not required to offer 504 Plans. However, there are still ways to receive accommodations. The process will likely vary depending on the private school, but generally you will need to:

- 1. Email the nurse, counselor, and/or teachers to let them know of your diagnosis.
- 2. Speak with your counselor and discuss the accommodations that you may need. Make sure to ask for any accommodations you may need later in the year.
- 3. The counselor should then notify your teachers of the accommodations you need.
- 4. Follow up with your counselor yearly to make sure your accommodations are still intact and updated to your needs.

#### Testing Accommodations: SAT, ACT, AP, GRE, LSAT, and MCAT

### What are some examples of testing accommodations I could request?

A separate exam room may reduce anxiety for students who need to frequently leave the testing room, have noisy medical/surgical equipment, or need to take food/medication breaks. Extended exam time/Stop the Clock breaks are useful accommodations for students who may need to take extra time, or need to take extra (no-penalty) bathroom breaks. Computer-Delivered Tests can help students with severe joint pain who may have trouble during essay portions of extended tests.

#### What if I haven't used these accommodations before?

It may be challenging to receive certain accommodations, such as extra testing time or stop-the-clock breaks, if you have not requested the similar accommodations at your school. Whenever you enter a new school or academic program, start the accommodations process early and always to maintain a record to support future requests. Even if you are feeling well, it is important to anticipate that your health may change in such a way to necessitate future accommodations.

## What kind of documentation of my disease do I need?

You may need documentation from a former school, exam administrator, or your gastroenterologist. Become familiar with the website pertaining to the exam that you will take, so you know what kind of documentation you will need - you should start your



investigation process months in advance of when you will need to submit your accommodations request.

Most organizations want documentation of:

- 1. Your disability, defined by you/your doctor (IBD is usually characterized as a "medical" or "physical" disability).
- 2. The degree to which your activities as a student are affected ("functional limitation").
- 3. How these functional limitations necessitate the specific accommodations requested. Your request will need to be specific and reasonable. It is helpful to research or ask your IBD center staff what other patients like you have received.

#### Does a 504 Plan cover college board tests (AP, SAT, ACT, etc.)?

Students with a 504 Plan are not automatically qualified for these testing accommodations. Applications for college board tests should be submitted in advance to ensure sufficient time to process the requests.

## **PSAT/SAT/AP/NMSQT** accommodations:

As of July 2018, if you plan to apply for SAT/PSAT/AP/NMSQT exams, start by reviewing the resources on this page . The process for receiving accommodations can take up to seven weeks, so start early. You can work with a teacher, school administrator, or guidance counselor to submit an accommodations request. Documentation guidelines for students with medical conditions are outlined here  ${\cal O}$ . START EARLY!

#### **ACT accommodations:**

As of July 2018, if you plan to apply for ACT exams, start by reviewing this link Q. You'll register for an exam date, and indicate that you need accommodations. After you receive a confirmation email, you will need to forward this (along with a 'release of information' form) to your school. A school official will need to submit your request for accommodations, outlined here **2**. Additionally, ACT's documentation of disability policy is outlined here  $\mathcal{A}$ .

## Is the process different for graduate-level exams?

Exams for graduate programs typically have more stringent standards when it comes to applying for accommodations. Start your research early so that you can be prepared when it comes time to register. Sometimes, you will not be able to choose a test date until your accommodations are approved.



PAC TIP: Talk with trusted mentors! If you are applying to an academic program, start conversations with trusted mentors about how you might disclose your illness. Do you want to share during the application process and highlight how your disability has led you to acquire valuable skills and perspectives, or disclose after acceptance when you can have an individual conversation with a disability services provider?

#### **GRE accommodations:**

Start by carefully reviewing this  $\varnothing$  and this  $\varnothing$ . The GRE requires that you apply for accommodations and receive approval before you can schedule a test date. This process may take up to three weeks, especially if they request additional documentation after your initial submission, so it is important to start planning at least three months in advance of when you wish to schedule the GRE. You and your doctor will be required to submit statements regarding your specific needs, in addition to other documentation specified on the website.

#### MCAT accommodations:

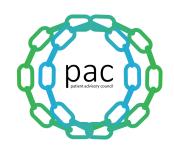
Start by carefully reviewing this link  $\mathcal{O}$ . Among other requirements, you will need to write a personal statement that describes your experiences navigating your academic career thus far with your disability. You should be specific about how your disability affects your abilities as a student. If you have navigated certain challenges without the need for formal accommodations at your school, consider how a strict testing environment may require accommodations

Sign In

that were not necessary in a casual classroom, and be prepared to justify your reasoning. The MCAT accommodations process also requires a detailed letter from your gastroenterologist. In order to submit these and other required paperwork, you will need to register with the MCAT's online accommodations system, MCAT Accommodations Online (MAO).



Start by carefully reviewing this link @ . You cannot apply for LSAT accommodations until you are already registered for the exam at a specific test center on a specific day. Be sure to choose an exam date as early as possible to ensure adequate time to submit your accommodations request and receive approval. Some test centers may not be able to accommodate your needs, so you may be required to change your testing day and/or location. Like the MCAT, you and your doctor will also be required to submit





statements regarding your specific needs, in addition to other documentation specified on the website.

## **College Accommodations**

#### How are college accommodations different from grade school?

The accommodations process in college has a few main distinctions. First, you'll be working primarily with your school's **Student Support Services or Disability Office** to set up accommodations. The other main difference is that the **student is responsible for self-advocating**. The disability office is able to set up accommodations and mediate if you have difficulties, but you also need to make sure you're expressing your needs and following through. Your professors are required to provide "reasonable accommodations" once you have submitted documentation of your disease.

#### How do I obtain accommodations in college?

- 1. Contact your school's disability support services to set up a meeting at the beginning of the year.
- 2. Ask your Gastroenterology (GI) Team for documentation of your IBD. Next, discuss a list of "reasonable accommodations"- make sure you have an idea of what you want before the meeting (i.e. private bathroom, liberal bathroom access during class, etc.).
- 3. When you meet with the disability support office, a letter will be drafted to inform the appropriate departments (academics, housing, dining, etc.) of your accommodations. An example letter can be found here  $\mathscr{O}$ .
- 4. Once this letter is finalized and sent out, follow up with the departments involved to discuss your accommodations and support needs. If you have applied for academic accommodations, it is important to follow up with your professors. A sample letter can be found here  $\mathscr{O}$ .
- 5. Be ready to update your accommodations yearly, since your college experience/needs will change from year to year.

PAC TIP: Be proactive! Contact support services ASAP, and have documentation of your health condition in place before you need it in an emergency. Find out what academic resources are available if you have a flare-up or extended absences (tutoring, online work, office hours, email communication, note takers, etc.).

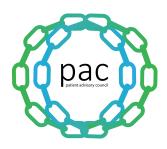




#### What academic accommodations are available to me?

Balancing the stress of college academics can be tricky with IBD, but accommodations can make the experience more manageable. If you're struggling to make it to class, needing to leave early for appointments, or having trouble getting work done while you're flaring, accommodations can help! There are many options for accommodations, whether you have limited stamina, frequent absences, or need to leave class to use the bathroom - here are some options to consider.

- A **Reduced Course Load** can help if you are feeling overwhelmed with the amount of work you are doing, and need to take fewer classes to stay healthy. Many schools have policies that require you take a certain number of credits each semester to qualify for financial aid or to remain a 'full-time student,' but accommodations may be able to nullify this requirement.
- **Priority Class Registration** will allow you to sign up for classes first, and fit your schedule around your needs. If you feel worse during certain times of day, or need to schedule appointments in the afternoon, you may be able to plan your classes accordingly.
- Note-Taker/Lecture Recordings can be useful if you have difficulty concentrating due to fatigue or extended/frequent absences. This can help ensure you don't miss important information during lectures, and can stay caught up even if you aren't able to physically be in class.
- **Test Accommodations** can be set up through the disability services office, including extra time, bathroom breaks ('stop the clock'), or taking exams in a private room.
- A **Nullified Attendance Policy** is important for students who have extended/frequent absences. Many professors only allow a certain number of absences each semester before you automatically fail their class. This accommodation means you won't need to force yourself to attend class when you're unwell.
- Assignment Extensions are helpful if you're not feeling well and need more time to finish
  an assignment. Stress can contribute to flare-ups, so communicate with your professors if
  you think you might need extra time to complete work.
- Modified Coursework in cases of extended absences, some professors may be willing to modify or excuse certain course requirements (ex: nightly reading responses, weekly discussions, etc.). Remember you also always have the option to take an 'incomplete' in a class if you're sick and are unable to complete everything by the end of the semester.



#### What do I do once my academic accommodations are in place?

Once the disability services office sends out your accommodations letter, make sure you discuss your accommodations and support needs with your professors. It is important to remember that regardless of accommodations, the best way to have continued success in college is continued, open communication with your professors. Inform them when you won't be in class and let them know if you are having trouble meeting deadlines. They will be much more receptive and helpful if kept in the loop - open communication will ensure them of your needs and keep away any doubts that you are abusing your accommodations.

PAC TIP: Be open with your professors! It might feel uncomfortable to talk with professors about your health, but you choose what information is relevant to disclose. Remember, the more aware they are of your situation, the more understanding they can be. If you're not sure how to start this discussion, try writing a list of 'things to know about me/my health conditions.' You can send this as a letter to your professors, or use it to help you prioritize any thoughts you have about your health and the types of support you need.

## What housing accommodations are available to me?

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. Since you'll be spending a decent amount of time in your dorm, you want to have an optimal living situation with the bathroom access, privacy, and amenities you need. A sample letter requesting these accommodations can be found here  $\mathfrak{S}$ .

- **Private Bathroom/Single Rooms** can be helpful if you have frequent bathroom visits or need to do surgical appliance changes. Sharing a room or bathroom with fewer people can help reduce any stress you may have around these issues. 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 TPN, 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.
- **In-Apartment Kitchens** may be offered at your campus this is especially useful for IBD patients with special diets or food sensitivities. If the meal plans do not offer sufficient options for you, consider requesting a room with access to a kitchen.



Air Conditioning is important if you (or your medications) are temperature sensitive. Certain
medical supplies/medication need to remain at room temperature (ex: ostomy bags can
melt if they are left in hot areas!), so make sure your space has sufficient heating/cooling.

#### What dining accommodations are available to me?

If your school has an on-campus nutritionist, arrange to meet with them to discuss meal accommodations. Otherwise, contact the 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  $\mathscr{P}$ .

- 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.

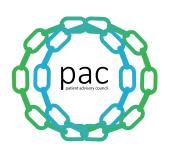
 Meal plan exemptions are possible if the Dining Hall is unable to accommodate a meal plan option that works for you. Talk to your on-campus nutritionist/dining staff about being

exempt from required meal plans.



#### What if I need to take off time from school because of IBD?

If you think you might need to take time off due to IBD, 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  $\infty$ .





# **Workplace Accommodations**

## What employment coverage does the ADA provide to IBD patients?

Individuals with IBD are covered under the ADA to ensure equal opportunity employment. The ADA protects IBD patients from being discriminated against during hiring, promotion, and pay raises - provided the individual is a 'qualified candidate' for the job. To be a 'qualifying candidate' for a position, they must still **meet the qualifications for the job and be capable of completing required tasks**. In most cases, the ADA also requires that employers provide reasonable accommodations (modifications to job or work environment) to qualified employees. For more information, click this link  $\mathcal{O}$ .

#### What coverage do I have if I need to take time off because of IBD?

The Family and Medical Leave Act (FMLA) provides individuals employed under a 'private sector employer' with protected leave to care for oneself or a family member with a medically-related illness. It is your responsibility to give notice of leave to your employer, including when/how long you anticipate being gone. Twelve weeks of protected leave (either consecutive or nonconsecutive) are granted in a twelve month calendar year - however, twelve months of employment with the employer must be completed prior to accessing FMLA benefits.

## What accommodations are available to IBD patients in the workplace?

Some reasonable accommodations for IBD patients include allowing enough time for restroom breaks, having an employee's workstation close to a bathroom, allowing time off or unpaid leave for doctors' appointments, flares, hospitalizations, etc, and having flexible work schedules.

- Access to a bathroom: If possible, move your desk to a location closer to the office bathroom. Consult your employer about finding a workspace that is suitable to your needs.
- Consider leaving a kit of essential items at the office.
- Time off/Medical Leave: Implement a plan with your employer for emergency situations and times of illness. Create a procedure for informing your employer if you are out of office and a strategy for managing your responsibilities while away.
- Schedules: This accommodation could be particularly helpful for individuals who are
  particularly ill at specific points of the day. Depending on when you feel your best, ask your
  employer if you can arrive at the office later/earlier. During a flare, consider the possibility
  of working from home.



# **Workplace Accommodations**

- Accessibility: For individuals struggling with fatigue, consider inquiring about accommodations like parking. A convenient parking space could reduce physical strain and ensure that the office is accessible to you and your needs.
- **Consideration for absences**: Ensure that your employer understands that there are times when you may be absent. Create a system for this that works for both your employer and you. Set up remote communication between you and the office, or an otherwise suitable solution.

#### How are these accommodations obtained?

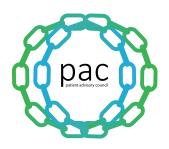
Talk to a supervisor about your company's policy for requesting accommodations. In most cases you can set up a time to discuss accommodations with a supervisor, and it may be beneficial to include Human Resources (HR) in the conversation as well. Have a letter from your doctor explaining what exactly your needs are, and be open and honest about what you need or may need. Most employers will be understanding and willing to work with you in formalizing these accommodations.

## How can I talk with my employer about accommodations?

When approaching an employer about accommodations it is important to set up a time to meet. Let them know that it is an important conversation and could take some time. Discussing accommodations in person is important so you can discuss specifically what support you need from them, what workplace modifications would help you better do your job, and what communication they need on your part. If you feel you do not need accommodations, but still would like to disclose your disease to your employer, that can be done by email or in person, whichever you feel most comfortable with. Most employers will be understanding and grateful you made them aware; however, you are not required to disclose this information if you are not requesting accommodations.

## What should I do if the employer is reluctant to provide accommodations?

If your employer is reluctant to provide you with reasonable accommodations, you should put your requests in writing and send it to your supervisor and Human Resources. This should include your reason for requesting accommodations, specific accommodations you may need, and information on the ADA laws. If after this your employer is still reluctant, and your accommodation requests are reasonable, a lawyer can help you take legal action to file a disability discrimination lawsuit.



# **Public Accommodations**

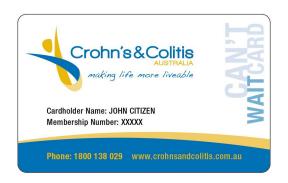
Ally's Law: Restroom Access Act

#### What is Ally's Law/'l Can't Wait'?

Ally's Law, which has been passed in 16 states\*, requires that stores/establishments with employee-only bathrooms allow customers with IBD to use these restrooms if needed. \* Colorado, Connecticut, Delaware, Illinois, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Ohio, Oregon, Tennessee, Texas, Washington, Wisconsin

#### How does this work?

Many people will be very accommodating of your needs. However, staff and other people can be reluctant to give you first priority. Multiple sources have Restroom Request cards. These cards can be used if someone is unwilling to comply with Ally's Law (provided the law is practiced by the state), if you urgently need a toilet but bathroom lines are long, and more. In these situations, you can show people your Restroom Request card to get priority usage of toilet facilities. It is important to use these cards respectfully and responsibly, as their fraudulent use is a misdemeanor crime.



#### Where can I obtain a Restroom Request card?

- Crohn's & Colitis Foundation  $\wp$ : To obtain the card, you must sign up to be a member. Membership fees range from \$30-\$1,000. The cards are included in your membership benefits and will arrive in the membership packet received upon becoming a member.
- Note from doctor: You can always ask your doctor if they have Restroom Request cards. If not, you can ask for a small note confirming the diagnosis and requirement for restroom access under Ally's Law.





# **Public Accommodations**

## **Early Boarding on Flights/Airline Accommodations**

#### What is early boarding?

Early boarding, frequently referred to as "pre-board," is an option IBD patients qualify for, but often are not aware of. Early boarding allows individuals to board the plane before other passengers. This can be useful to patients for several reasons - for instance, you may be having symptoms or be in the midst of a flare, and have difficulty waiting in line to board, or may be struggling with fatigue and need extra time/assistance getting to your seat.

#### What about airlines that don't have assigned seating?

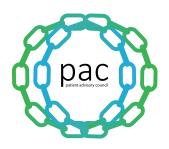
If you are flying with an airline that does not have assigned seating, you may need to be able to sit in the aisle and/or near the back or front of the plane for quick and easy bathroom access. Early boarding provides the opportunity to pick your seat before everyone else boards, ensuring you get a seat that fulfills this need. If you are ever injured or unable to walk onto the plane, you can be assisted down the jet bridge in a wheelchair, which is also part of early boarding.

## How do I get early boarding?

- 1. Go through security as normal.
- 2. Once you are through security, find the service desk associated with the airline you are flying. Be sure to locate the service desk nearest to your departure gate, as this one will be designated to help individuals on your flight.
- 3. You will need to talk to the airline employee working at that desk to receive early boarding. To do this: simply tell the employee, "I need pre-boarding for a medical disability." They may ask whether you need assistance down the jet bridge (this is for a wheelchair) or a special seat (i.e. needing a seat near the restroom)
- 4. If flying with an airline without seating assignments, say you require a special seat. If flying an airline with assigned seats, say you cannot stand for long periods due to medical complications.
- 5. The airline employee will print a boarding pass with 'early boarding' printed on it.

## What if I need to use the bathroom while the seatbelt sign is on?

As you board the airplane, show the flight attendants your 'I Can't Wait' card. Let them know you may need to get up to use the restroom in a hurry, even if the seatbelt sign has been turned on.



# **Public Accommodations**

## What if the airline employee asks me more questions about my disability?

It is important to note that it is illegal for the airline employee to ask you for more information, to ask for proof, or to ask for any information regarding your disability aside from requiring assistance or a special seat. Asking anything more than that qualifies as discrimination and is illegal. Although you should not have problems, remember these rights in case any issues arise.

## Are there any accommodations for airline security?

For more information about going through airline security/TSA, click here  $\mathscr{O}$ . You may want to download the TSA's 'disability notification card' using this link  $\mathscr{O}$ .

# **Hardship/Disability Parking**

## Who will allow for Hardship Parking?

Although patients with Inflammatory Bowel Disease usually don't qualify for handicapped parking per the Department of Motor Vehicles in most states, <u>some universities</u>, <u>schools and workplaces may offer "Hardship Parking" to patients flaring with IBD.</u>

## What would I use Hardship Parking passes for?

Hardship parking passes can be very useful if you:

- Need a car on campus to get to doctor's appointments
- Need to go to a grocery store off campus to purchase food for a specific dietary need
- Are severely anemic or in pain, live off campus, and don't have enough energy to walk long distances to class because of a flare -- often the university can offer you a spot as close to your classroom building as possible.

## **How do I apply for Hardship Parking?**

In order to apply for hardship parking, contact the Disability or Accessibility Office at your University. They may have information regarding Medical Non-Mobility Parking passes, or they may refer you to the Parking and Transportation Department. Keep in mind that both of these offices generally have deadlines by which students and employees must apply for parking, so make sure you look up information with ample time allotted for approval.

## Will I need justification? Do I have to pay?

Justification and a letter are usually required by the patient's gastroenterologist, and most of the time, patients will need to pay the full price of the parking pass.



# **PAC Perspectives**

## What accommodations have been helpful to you?

"The main accommodations that helped me (from middle school through college) were nullified attendance policies, extensions on assignments/tests, bathroom access, and (during severe flares) modified coursework. Not worrying that my inability to attend class would impact my grade **reduced a lot of stress**, because I didn't feel like I had to force myself to be at school when I felt awful. Extensions on assignments also helped me enormously (both when I was flaring and not). Without these accommodations, I might not have graduated high school, let alone college - and now I'm applying to graduate school!" -Contributor 1

"I have requested the accommodation of stop-the-clock breaks on every standardized exam since my diagnosis. While I have only once needed to use this accommodation and "stop the [exam screen] clock" for a bathroom break, I have always benefited from the peace of mind of knowing that I will not be penalized if I feel an urgent need to go. Having IBD, I can't know how my health will be six months ahead of time while registering for a standardized exam, so I appreciate the security my accommodations provide." -Contributor 2

"The I can't wait bathroom laws have helped me when using public bathrooms."
-Contributor 3

"My accommodations have helped me get access to bathrooms when I have been in dire need. One time at the airport I was in security and I had to go so bad and the TSA agent was actually kind and put me through the pre-check line and let me use the restroom without losing my spot. Having my "I can't wait" card was so helpful."

-Contributor 4



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## What do you wish you had known about IBD accommodations?

"Don't feel reluctant to get/use accommodations. A lot of students feel uncomfortable using accommodations, because they feel like they're getting 'special treatment,' which isn't the case! Accommodations exist to level the playing field, and provide us with access to rights like education. Don't let anyone make you feel bad for taking care of yourself or your needs – you have the right to support! Don't be afraid to talk with your school counselor, a social worker, or the disability services office if your teachers (or other students) are giving you a hard time about using accommodations. It's also important to remember that accommodations aren't just for when you're flaring; they can help you maintain remission, by avoiding unnecessary stress/exertion. If it's something that will help you feel better and stay healthy, it's worth asking for." – Contributor 1

"It is important to recognize that you need to apply for all accommodations you might need for a standardized exam, even if you are feeling well currently. I find it helpful to imagine in advance the worst possible scenario I could be experiencing at the time of the exam, where I would be sick enough to require accommodations but well enough to take the exam. The reason this is important is that all accommodations requests for standardized exams take into account the accommodations you have requested and been approved for currently. It can be more challenging to receive a new accommodation that you have never requested previously requiring you to jump through extra hoops to definitively prove that your needs have changed. Additionally, most accommodations must be arranged months in advance of your test date, preventing you from being able to accurately predict what the state of your health will be on exam day." - Contributor 2

"It's better to have more accommodations than not enough just in case. IBD is unpredictable." -Contributor 3

"They are very useful and worth looking in to. I didn't have the 504 plan when I was younger and I got penalized a lot in school for absences, etc. I wasn't aware that I had these accommodations in college as well as was forced to be in a dorm with a bathroom that 8 people used. I got a pretty bad infection my freshmen year due to this situation and if I would've known about these accommodations, I would have been much healthier!" -Contributor 4



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## What kinds of additional support would be helpful?

"It's hard in pediatric care, since much of the accommodations process goes through the parents, but I think it's important to **include the student in the process** as well. I think it's important for providers to talk with patients about the quality of life difficulties they are having, and have suggestions for improvement!" -Contributor 1

"Patients should be aware of who at their center is most knowledgeable about accommodations - a social worker? A psychologist? One of the doctors? A parent liaison? I have found that it differs center-to-center."-Contributor 2

"I would have loved if my care center informed me sooner of the various accommodations available." -Contributor 3





# **Contact Information**

# **Toolkit Creators**

Rosa Kelekian, UCSF Benioff Children's Hospital Becky Woolf, Pediatric Specialists of Virginia Contact us <u>here!</u>

# **Contributors**

Megan Drovetta/LMSW Children's Mercy
Hospital
MaiKu Moua/LMSW Levine Children's Hospital
Sami Kennedy/Patient Advisory Council
Sydney Ford/Patient Advisory Council
Tyler Moon/Patient Advisory Council
Missy Neihart/Patient Advisory Council
Bianca Siedlaczek/Patient Advisory Council
Maddie Huwe/Patient Advisory Council
Chloe Sayers/Patient Advisory Council
Maddie Ferguson/Patient Advisory Council
Grady Stewart/Patient Advisory Council
Natalie Beck/Patient Advisory Council



# Sources

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https://www.act.org/content/act/en/products-and-services/the-act/registration/accommodations/policy-for-accommodations-documentation.html

#### **ADA National Network:**

ADA information: https://adata.org/factsheet/ADA-overview

#### **Association of American Medical Colleges**

#### **MCAT Accommodations:**

https://students-residents.aamc.org/applying-medical-school/taking-mcat-exam/mcat-exam-accommodations

#### **Crohn's & Colitis Foundation**

<u>504 Plans</u>: http://www.crohnscolitisfoundation.org/assets/pdfs/504factsheet0816.pdf <u>ADA information</u>:

https://www.crohnscolitisfoundation.org/managing-the-cost-of-ibd/employee-employer-resources

<u>Travel Information:</u> https://www.crohnscolitisfoundation.org/what-is-ibd/traveling-with-ibd

#### **Educational Testing Service**

GRE Accommodations: https://www.ets.org/gre/revised\_general/register/disabilities

#### **Healthline Media**

Ally's Law/I Can't Wait:

https://www.healthline.com/health/crohns-disease/restroom-legislation#outlook

#### **Law School Admission Council, Inc.**

LSAT Accommodations: https://www.lsac.org/jd/lsat/accommodated-testing

#### The College Board

<u>SAT/PSAT Accommodations</u>: https://www.collegeboard.org/students-with-disabilities 22