



Travel Toolkit

A resource created by members of Patient Advisory Council of ImproveCareNow. The purpose of this toolkit is to share personal stories about traveling with Crohn's disease and ulcerative colitis, answer questions, and identify tips and techniques that can make travel easier, safer and more comfortable.

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About the PAC

The Patient Advisory Council (PAC), is a community of young (14+) patients with Inflammatory Bowel Disease (IBD) who come together to give and receive support, ask questions, share information, and network with each other. For more information, and to join the PAC, please visit: improvecarenow.org/patients



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 improvecarenow.org/icn_tools_disclaimer apply to this document.



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Meet Toolkit Creator - Nicki



Nicki Redmond

- ❖ I am 21 years old.
- ❖ I am a senior at the University of Cincinnati.
- ❖ I have had Crohn's disease since I was 16 years old, but was diagnosed with Indeterminate Colitis when I was 14 years old.
- ❖ I am currently in remission since 2015.
- ❖ I love animals, running, baking, spending time with family and friends, volunteering, and working with ImproveCareNow.
- ❖ I consider myself to be an IBD patient advocate.



Meet Toolkit Creator - Maddie



Maddie Huwe

- ❖ I am 16 years old.
- ❖ I am a sophomore at Veritas High School.
- ❖ I was diagnosed with Crohn's disease when I was 13.
- ❖ I have stayed in remission since 2015.
- ❖ I enjoy cooking, crafting, running, exploring the outdoors with my family, and spending time with my animals.
- ❖ I believe living in community with others who have IBD is an important part of staying healthy.

Meet the Toolkit Contributors

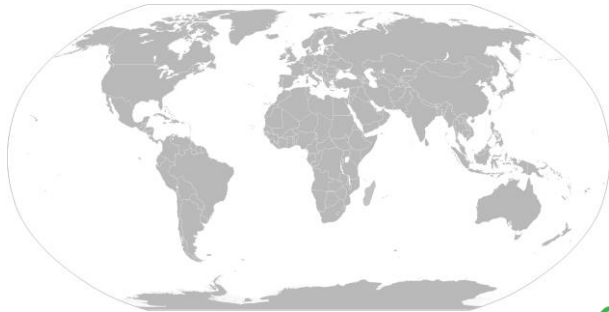
- Zehra Al-Timini
- Natalie Beck
- Catalina Berenblum
- Sarah Bivona
- Sydney Ford
- Taylor Heppner
- Maddie Huwe
- Emily Jones
- Rosa Kelekian
- Sami Kennedy
- Hindy Klein
- Randa Samaha
- Abigail Sandifer
- Chloe Sayers
- Rebecca Schinkel
- Bianca Siedlaczek
- Becky Woolf



Oh, The Places We've Been!

Some PACers travel destinations include:

- Various locations in the United States
- Paris
- Amsterdam
- United Kingdom
- Canada
- Argentina
- Grenada
- New Zealand



General Traveling Experiences

Brief travel stories from PAC members



Cat's Story

“Longest trip is the one I'm currently on (6 months). I've been on trips for 4 days to 3 weeks in the past, though. I try to go to places with good medical care in order to make sure I'm being as careful as possible, and contact my GI to make sure there's someone he knows at each destination. I watch what I eat, make sure to get enough rest, and not stress myself out too much. Planes usually make my IBD symptoms worse, so I try to travel by train if I can, or really take care the day after a plane journey. I also try to stay in nicer hostels or hotels because of my immunosuppression.”

Catalina Berenblum



Sydney's Story

"I was in Alaska for a week, and at the time I was still on a partial liquid diet, so I had to bring some Boost and Ensure with me. My bag was randomly checked for extra screening, so I wonder what the TSA agent thought when he looked in my bag and saw a trash bag of Boost/Ensure? I was in Canada for 4 days, and I had to bring Boost and Ensure with me on that trip as well. Somehow it got through customs... Some of the meals on this trip were pre-planned, so it was a little awkward when I couldn't eat something because it was a trigger food."

Sydney Ford



Rebecca's Story

“When I travel, my IBD makes me quite tired, so the next day after my plane ride or long drive, I usually have to relax and sleep a lot. If I’m doing anything active or a lot of walking, I need to rest after the long day so I can continue to do things. Because my immune system is terrible, I often get sick after I go on a plane (cold/flu). Sometimes it ruins a trip. Other times I get sick on my way home so I have to take time off when I get home. Also I’ve had to cancel many big trips because I have a flare and my doctor won’t let me go out of the province. When I had my feeding tube, I went to Florida for a few weeks, I fed during the day so sometimes I had to plan around that or stop the feed for a while when I went swimming. I would also plan to do certain things when I could take my tube out. And right now I’m planning my first trip with an ostomy. I’ve done research as to what I need to pack, where the closest ostomy supply store is. My ET nurse even gave me an ostomy clinic number and location in the city I’m visiting.”

Rebecca Schinkel



Chloe's Story

“Before traveling with an ostomy, I had ups and downs. It was harder for me on planes/car rides because I would worry about finding a bathroom (in time). I was always prepared, though: I'd carry imodium with me! Traveling with my ostomy is easier for me, in the sense that I don't necessarily need to worry too much about getting to a bathroom in time. But, carrying extra supplies with you in your carry on or next to you during a long car ride is good for those 'just in case' moments.”

Chloe Sayers



Maddie's Story

"I was on Exclusive Enteral Nutrition through a N.G. Tube when I traveled. I learned to manage airport security while carrying my formula, and the basics of how to place a tube and pump formula in different environments (i.e. on an airplane, in the backseats of cars, or in hotels). I am now currently on the Specific Carbohydrate Diet (SCD), so traveling includes either packing my own food, or searching Google Maps ahead of time to find grocery stores that carry SCD legal products. My body does not do well with traveling, and my Crohn's will normally act up. This means finding places ahead of time that have nice restrooms and places I can take breaks in anticipation of this."

Maddie Huwe



Medications

Medication questions answered by PAC members



What was your experience using your medications when traveling?

"I always, always pack extra. You never know when there will be an unexpected travel delay. If you're going to be away long or have recently flared, consider asking your doctor if it would be a good idea to travel with a small emergency supply of "flare meds" (i.e., prednisone). Always have paper copies of a letter or letters from your doctor justifying you carrying your meds, even if you've gotten through security without even a glance at such letters before. TSA and foreign customs can be very specific (and variable from time to time depending on the national security climate and other factors) about what they want to see. Best to have it state specific medication names. Have your doctor intentionally not state your age in the letter (birthday ok), so you can use it for multiple years (until your meds change). Also be sure to carry your medications in their original bottles or boxes with the prescription labels intact, so that they are less likely to be mistaken for anything else by inspectors - and to avoid jet-lagged confusion on your part! I've more than once mixed up round white 6mp and round white prednisone while tired."

Sami Kennedy



What was your experience using your medications when traveling?

“Whenever I fly anywhere with it I make sure to get a letter from my doctor explaining that I'm medically dependent on it and I need to be allowed to travel with it. The only problem I ever experienced was by the Mexican customs, they were suspicious of my sharps container, which had some sharps in it. I learned to take an empty one in the future.”

Hindy Klein

“It's really difficult to get a 3 month humira waiver approved, so I would get started on that very early. Also, planes won't necessarily refrigerate medication for you, so it's important to make sure you have a cooler, that you're prepared to get a pat down at the airport, and that the place you're going to has a minifridge.”

Catalina Berenblum



What was your experience using your medications when traveling?

“Methotrexate makes me nauseous, so I did have to be sure to hydrate well and take my Ondansetron to help relieve my nausea, which was sometimes hard to do in the middle of traveling.”

Sydney Ford

“For the Humira I had to make sure I packed it with enough ice to make it to my destination, also to call the hotel ahead of time to confirm they had mini fridges. With my other medication I counted out enough for the amount of days I would be away and a week extra just in case something happened.”

Rebecca Schinkel



What was your experience using your medications when traveling?

“Imodium helped me in times of nervousness or if I was out and having a particularly bad day. It allowed me to have a small break from the bathroom and let me enjoy my vacation. Zofran was good as well because in the times where I would get car sick or sick due to being sick (you know what I’m talking about) I wouldn’t have to worry about having an embarrassing moment because I came prepared.”

Chloe Sayers

“Negative. These medications [6MP (Mercaptopurine), Vitamin Supplements, and Budesonide] did not provide me with the relief I needed for a very severe flare-up that consisted of a calprotectin exceeding 2000+ with no hospitalization, blood transfusion, or nutritional therapy.”

Zehra Al-Timimi



Summary of Medication Tips

- Have a doctor's note ready to explain your need to carry certain medications on the plane
- Always pack more meds than you will need, as a precaution
- If transporting meds that need refrigeration, prepare a small cooler that you can transport them in on the plane
- Anti-nausea meds are a terrific option if that is something you struggle with when traveling
- If you have questions regarding medications and flying, please visit the TSA website: <https://www.tsa.gov/travel/special-procedures>



Nutrition



What are your experiences with your dietary restrictions when traveling?

“It’s challenging to find food in airports, otherwise not too bad.”

Sarah Bivona

“Traveling with dietary restrictions is pretty difficult for me - I have Celiac Disease in addition to IBD, so I have to be really cautious! I follow a very strict diet to help with some of my IBD symptoms, so finding food that works with my diet when traveling can be hard. This is definitely something that keeps me from traveling more.”

Rosa Kelekian



What are your experiences with your dietary restrictions when traveling?

“I usually avoid foods more than find alternatives for them. I sometimes need to store coconut milk, etc. in the fridge.”

Natalie Beck

“I have an allergy to tree nuts. I always carry a chef card like the one here:
<https://www.foodallergy.org/sites/default/files/migrated-files/file/chef-card-template.pdf> in the appropriate language to make my dietary restriction clear to restaurant staff and chefs.”

Sami Kennedy



What are your experiences with your dietary restrictions when traveling?

“I have to be careful to check all ingredients in food that I will be consuming to make sure that no beef, pork, or shellfish products are present.”

Abigail Sandifer

“I choose a hotel that has a fridge so I can take ensure etc. I usually look up menus of the restaurants nearby and then decide. If the menu isn’t online then I call in advance. I also pack snacks that I know I can eat and won’t bother my stomach.”

Rebecca Schinkel



What are your experiences with your dietary restrictions when traveling?

"I have to constantly check the amount of lactose in foods, since I'm severely lactose intolerant. I can have lactose, but it will make traveling feel awful. Also, I have a diverting LOOP ileostomy, so I can't have raw vegetables, hard food (i.e. pretzels, nuts), and lots of other stuff. It's hard enough being limited at home without having to worry about whether I can find food while I'm away from home."

Becky Woolf

"I am on the Specific Carbohydrate Diet. When I travel, I either have to bring my own food, or plan out ahead of time where I will purchase food at my destination."

Maddie Huwe



Describe strategies you have for transporting and purchasing food while traveling.

"I usually bring most of my food with me, or plan ahead of time where I can find safe food. I make a big batch of food before I leave, ideally things that don't need to stay cold (or if it does, I bring an icepack and eat it first!). I make sure to keep everything organized and packed securely in tupperware to avoid spills - if I'm traveling by plane, I don't bring anything liquid/paste/gel! I've invested in containers that stay cold for longer, an insulated lunch bag, and some reusable icepacks. I like to pack a lot of non-perishable snacks as well that I can eat throughout the trip, things like bars, dried fruit, chips, etc. When I get to my destination, I usually stop at a grocery store to pick up some 'safe' foods that I know are ok for me to eat."

Rosa Kelekian



Describe strategies you have for transporting and purchasing food while traveling.

"I try to carry as much as I can of my own safe snacks that can supplement or replace full meals when I'm away since I never know what my GI system will be able to handle if I'm flaring or if I'm restricted in what I can safely order because of my allergy. These are things like granola, snack bars, goldfish, non-refrigerated squeeze packs, and small microwavable meals. It's nice to have "safe" foods to fall back on from my backpack, especially in countries where there is a language barrier!"

Sami Kennedy

"I like to pack bags of snacks that I know I can eat. I'll pack Kale chips, soft fruits, and bagels."

Becky Woolf



Describe strategies you have for transporting and purchasing food while traveling.

"I take a thermos and lunch bag with cold packs. If I'm staying at a hotel I make sure they have a fridge available."

Rebecca Schinkel

"I am extra careful when purchasing food while traveling. Luckily, my dietary restrictions are not too harsh other than cutting out beef, pork, shellfish, and most foods high in carbohydrates. This means that I mostly stick to lightly-seasoned cooked vegetables and lean meats when traveling. Better safe than sorry!"

Abigail Sandifer



Describe strategies you have for transporting and purchasing food while traveling.

“I will plan ahead where I will purchase food before I travel, normally by using Google to find grocery stores that carry fresh fruit and veggies, along with raw nuts or dried fruit. While traveling, one of my main protein sources is cheese, so I also try to find a place that carries high quality cheeses. If traveling by car, I bring mostly all of my food with me in a large cooler. The week before I travel, I prepare simple meals and package them in pyrex containers or sealable plastic bags. If I'm traveling by plane, I bring bags of nuts, dried fruit, and seeds to get me through the flight until I can get to a store. I found it helpful to have a doctor's note that states that I need to carry food with me into facilities as well.”

Maddie Huwe



Describe challenges you have faced when traveling with enteral nutrition.

"I got a fold-able pole for my pump and packed it into my suitcase. My formula was put in a bag that kept it cool. This often led to having to pay for another bag to check, as it takes up so much space. I also got stopped by security EVERY TIME because of all the liquids I was carrying!"

Becky Woolf

"It was difficult to carry formula while traveling, especially if by plane. If I was traveling for even just over a week, that would mean needing to bring several good sized boxes of formula, which takes up quite a bit of space. Also, if I was traveling late into the night/evening, I would need to place my tube in the car, at the airport, or on the plane, since my pumping was scheduled for 8-10 hours during the night."

Maddie Huwe



Describe strategies for traveling with enteral nutrition.

“I use a fold-able pole to make it travel friendly.”

Becky Woolf

“Having a doctor's note stating that I needed to carry my pump and formula was very useful, especially while traveling by plane. While carrying supplies, I simply had to get used to explaining why it was necessary. There wasn't a perfect way of transporting lots of boxes of formula. If traveling by car, we just had to make extra space. If by plane, we would bring an extra suitcase to check on the plane with all my formula in it. I used a travel backpack made for enteral nutrition feedings for easy travel pumping.”

Maddie Huwe



Summary of Nutrition Tips

- Consider a chef's card that explains your dietary restrictions in necessary languages
- See the FARE's website for helpful information about a chef's card:
<https://www.foodallergy.org/life-food-allergies/managing-lifes-milestones/dining-out/food-allergy-chef-cards>
- Be vigilant about avoiding trigger foods
- Find a hotel with a fridge so you can store your own food
- Pack snacks
- If you follow a strict diet, consider pre-packing all your own meals for the trip
- Before your trip, look for stores that carry products you can eat or might need
- For enteral nutrition, find a foldable pump or backpack to make pumping easier
- Consider checking an extra suitcase on the plane to carry all your formula



Stress, General Traveling Tips & More!



Describe an experience where stress affected your IBD while traveling.

“My symptoms are often worse when I'm traveling, especially on bigger trips. I'm not sure if it's the different environment, or food, or a little bit of everything. Even if I'm enjoying the trip, it's still hard to be away from home when you aren't feeling great.”

Rosa Kelekian

“Stress tends to exacerbate my symptoms. This can make flying difficult. I always try to get an aisle seat so I can have easier access to the toilets.”

Randa Samaha



Describe an experience where
stress affected your IBD while traveling.

“I worry a lot about going through airport security with my ostomy bag. Sometimes i get stopped because of it, which is never a big deal, but I always stress about it while waiting in line.”

Bianca Siedlaczek

“Diarrhea while traveling to Europe because of nerves.”

Taylor Heppner

“I get anxiety around what I’m going to eat, bathroom access, if my medications will stay cold.”

Rebecca Schinkel



Describe an experience where
stress affected your IBD while traveling.

“I was stressed because I had lots of exams after I returned from a wedding in Nashville, and right as my family got to the hotel room, I began episodes of excreting bloody stool.”

Becky Woolf

“Most times I travel on an airplane or in a car for more that a couple hours I become exhausted and need rest. On several occasions when traveling to the east coast, I had to take the day following the plane ride really slowly and with lots of time to relax.”

Maddie Huwe



Describe some strategies for dealing with stress-related symptoms while traveling.

“I do as much research as possible before I go, like the restaurants in the area, the bathroom access around the place I’ll be travelling. I also have an app that will tell me where the nearest bathroom is wherever I am.”

Rebecca Schinkel

“I attempt to get as much done before I travel so I will stress less. It's not possible to do everything, but it does help.”

Becky Woolf

“Planning a rest day really after travel helps me. By setting that time away ahead of time, it helps me feel less guilty about it. Proper hydration also helps me recover much faster.”

Maddie Huwe



Describe some strategies for dealing with stress-related symptoms while traveling.

"I have breathing techniques that I have learned in years of counseling to deal with stress. I also have prescribed medication for extreme situations."

Abigail Sandifer

"I make sure I always have extra ostomy supplies on hand and always know where the closest bathroom is."

Bianca Siedlaczek

"I eat healthy and listen to music to help my stress."

Taylor Heppner



Describe some strategies for dealing with stress-related symptoms while traveling.

"I'm still trying to figure this out - I'm definitely not able to travel as much as I'd like to! One thing I've found helps me is to stay really organized and plan ahead of time. That way I'm less anxious about being stuck in a situation where I run out of meds or don't have something I need."

Rosa Kelekian

"Deep breathing and preparing as early as I can for prescriptions."

Natalie Beck

"Deep breaths and relaxation techniques. I try not to eat much on the plane or before the flight."

Randa Samaha



Describe some items you bring to make traveling with IBD easier.

"Food, wipes, extra clothing."

Sarah Bivona

"I make sure I have (more than) enough medication, supplements, and food. I get bad joint pain, so I make sure to pack comfortable shoes and my braces. I'm a light sleeper (and need lots of rest) so I always pack my earplugs and a sleep mask!"

Rosa Kelekian

"I put all my pills in weekly organizerr to ensure I have enough."

Natalie Beck



Describe some items you bring to make traveling with IBD easier.

"I always bring a coat, sweater, or scarf. My symptoms are worse when I am cold, so I try to stay warm."

Randa Samaha

"In addition to my pill case filled up for the appropriate amount of days, always bring an extra bottle of each of my IBD meds just in case I get stuck somewhere unexpectedly!"

Sami Kennedy

"I bring my phone and phone charger pre-loaded with simple puzzle games that help keep me calm in stressful situations. I also make sure to always have all of my medication handy and organized in its own bag to allow quick retrieval when necessary."

Abigail Sandifer



Describe some items you bring
to make traveling with IBD easier.

“Antidiarrheals, my meds, bathroom card for restaurants and stores.”

Taylor Heppner

“Snacks that I can eat, extra ostomy supplies, phone numbers of doctors/hospitals/medical supply stores.”

Rebecca Schinkel

“Pain meds, lots of water, stress balls, homework/laptop, agenda”

Becky Woolf

“Anti nausea medication, plenty of water and SCD snacks, earplugs, and a travel pillow.”

Maddie Huwe



Describe your best experience
traveling with IBD, and why it was the best.

“Going to a convention where hosts accommodated IBD related needs and safe food was readily available”

Sarah Bivona

“Any one where I remember all of my meds and don't get too sick!”

Natalie Beck

“I think my best experiences are when I plan ahead and ensure I don't eat certain foods that will make my symptoms worse. That can be hard to do, but I have learned to listen to my body.”

Randa Samaha



Describe your best experience traveling with IBD, and why it was the best.

"I went to New Zealand this past year, and it was amazing! I kayaked down rapids, hiked up mountains, and literally ran around Auckland all without issue! IBD doesn't have to stop you from taking far-away trips - just try to be as healthy as you can, and be prepared for emergencies!"

Sami Kennedy

"My BEST travel experience with IBD would have to be the trip to the ICN Conference in Chicago in September. I had only been diagnosed for a few months and was still not in remission. This caused a great deal of stress when having to fly by myself for the first time. Somehow, I prepped well in advance, and it was all smooth-sailing through the travel experience. Also, meeting other IBD-ers who understood my point of view allowed me to experience much less stress and anxiety on the return travel."

Abigail Sandifer



Describe your best experience traveling with IBD, and why it was the best.

“My best travel experience was when I went to Massachusetts with my brother. I was fairly healthy so I didn’t have to worry much about not feeling well throughout the trip. My ostomy bag had not leaked once during the trip and traveling through security/on the plane was without issues.”

Bianca Siedlaczek

“My trip to Europe was the best because I was expecting the stress to affect me but it didn’t.”

Taylor Heppner



Describe your best experience traveling with IBD, and why it was the best.

“I went to Disney World and they went above and beyond to make sure I had access to everything I need. They let me send down my ostomy supplies 2 weeks early so I didn’t have to pack them, I had access to special private washrooms, all the restaurants accommodated my dietary needs without batting an eye. They even gave the number of the medical team and doctor on site which they don’t usually give guests. It was great and let me enjoy the experience more!”

Rebecca Schinkel



Describe your best experience traveling with IBD, and why it was the best.

“The first time I traveled after my surgery was to the 2017 Fall CC for ICN. I was really scared to go, as traveling ALWAYS causes a flare-up for me, and I had been in remission ever since the surgery and did not want to ruin it. But I ended up not having any new symptoms at all, which was a first!”

Becky Woolf

“We took a family vacation over the summer. I was able to sleep on the car ride along with taking anti nausea meds and staying super hydrated. When we arrived, I took the rest of the day really slowly, eating mild foods and resting. This really helped me avoid symptoms!”

Maddie Huwe



Describe your worst experience traveling with IBD, and why it was the worst.

“Getting stranded at a connecting airport while in a flare - stress was not helpful, and I almost ran out of prednisone.”

Sarah Bivona

“Food poisoning or dehydration or getting sick from the plane!”

Natalie Beck

“My worst travel experience with IBD was when I spent 10 minutes in the airplane bathroom, and when I came out, there was a huge line waiting. This experience was not only painful and traumatizing without the social pressure to finish up fast in the bathroom, but it was also completely and utterly embarrassing.”

Emily Jones



Describe your worst experience traveling with IBD, and why it was the worst.

“My worst experience was when I was traveling in France and I needed to use the toilet asap. I was with a school group and couldn't make it to the bathroom in time. I didn't know the area and therefore didn't know where the nearest bathroom was. I luckily had a close friend with me that helped me out.”

Randa Samaha



Describe your worst experience traveling with IBD, and why it was the worst.

“When I was 15, I had a flare over spring break when I was going to visit colleges for the first time on a long road trip with my mom - several hours of driving per day! I remember ordering a burger from some fast food place and basically taking everything off until it was just the bread and little else! Plus sitting knees up in the car and hoping I would make it to the next tour site...and then survive the walking tour...eughhh! Sometimes you can plan to have what you need, but your IBD just will not agree with the nature of your trip! That said, I still found my dream college that week.”

Sami Kennedy



Describe your worst experience traveling with IBD, and why it was the worst.

“My WORST experience would have to be when trying to travel to a conference in Indiana last summer. My plans had to be completely canceled due to a Crohn’s flare, and my medication had no effect on the symptoms. I ended up having to email my doctor to try to get in with him ASAP to determine the cause of the flare.”

Abigail Sandifer

“My worst travel experience with IBD is when one of the times I went to California. I was having a lot of difficulty with my ostomy at the time and it leaked a couple times at the airport/on the plane. It was very stressful because I would be out doing fun things with my family and we would all have to stop for a bit and find me a bathroom so I could change my bag.”

Bianca Siedlaczek



Describe your worst experience traveling with IBD, and why it was the worst.

“I went camping and I trusted my friend to make sure the campsite had everything I needed. It did not, there was only one bathroom for ten sites to share. I was anxious the whole time and ended up leaving early because of the bathroom situation.”

Rebecca Schinkel

“I went to a wedding in Nashville, and the 10-hour car ride must have done a number on me, because I had multiple episodes of excreting bloody stool, fatigue, nausea, and cramps the whole weekend!”

Becky Woolf



Describe your worst experience traveling with IBD, and why it was the worst.

“I went off to an outdoor summer camp while I was on night time N.G. tube feedings. In the middle of the first night, I woke up with unusually bad stomach cramping, and nausea. Most likely I caught a stomach bug, and with the combination of being slightly anxious, not having any rest time during the first day, and some dehydration, I got pretty sick and had to go home early.”

Maddie Huwe



Summary of Stress, Tips & More

- Plan way ahead of time to reduce last minute panic before your trip
- Get plenty of rest
- Hydrate and eat well
- Find an aisle seat for easy restroom access on planes
- If you are feeling stressed, find simple ways to calm down, such as music, small games, or deep breaths
- Listen to your body! If you need to take a rest day, change your agenda, or simply sit down to take a break while on your trip, do it
- Research the area you will be staying in to get an idea of where nice restrooms are, or grocery stores that carry products you need



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