

Safe Spaces: Managing Alpha-1 Triggers in Hotels

Alpha-1 Antitrypsin Deficiency (A1AT) is a genetic disease that affects the liver and lungs. It is often misdiagnosed as COPD or liver disease. People with A1AT are particularly vulnerable to respiratory difficulties triggered by environmental factors like air quality, pollens, cleaners, fragrances, and smoke. In public, Alphas (as those with A1AT often call themselves) must be vigilant to maintain a safe environment to minimize illness and exacerbations.

Recently, Christy traveled to an Alpha-1 Foundation education day, where she experienced environmental triggers that led to respiratory distress.

"Even though I was diagnosed just over a year ago, I've spent that time researching Alpha-1 and understanding how it impacts my life. I attended the education day to gain more insight from local Alphas and medical professionals."

Did you have any concerns about traveling or hotel stays before attending?

"We live locally, so we didn't stay overnight. We're familiar with traveling for my son's soccer games and felt prepared. The brochure also requested that attendees avoid wearing perfumes or anything that might affect others' breathing."

What environmental factors in the hotel impacted your breathing?

Were there any unexpected triggers?

"Based on the brochure's guidelines, I didn't anticipate issues. However, after our 40-minute drive, I went to the restroom before dinner and was overwhelmed by a strong fragrance from an automatic air freshener. I warned others, and some mentioned they noticed a faint smell in the hallways. Those staying overnight reported that while their rooms were fine, the hallways had a persistent scent."



How did you address your symptoms once you noticed them?

"During dinner, I felt worse and had to use my inhaler and allergy medicine. Eventually, I had to take a blood pressure medicine. My oxygen dropped to the mid-eighties, and my blood pressure peaked at 210/134. I mentioned my reaction to the bathroom smells to Scott Santarella and Alexis from the Foundation, who were very concerned and offered assistance. I was fortunate to have the necessary medications to manage the reaction."

How responsive was the hotel staff to your needs or requests for accommodations?

"Scott and Alexis spoke with the hotel staff, who agreed to turn off the automatic fresheners. By Saturday morning, the smell was reduced. I also moved my seat in the dining room from the back to a more comfortable area, which helped, along with taking additional medication. The conference room, thankfully, was free of extra cleaners or deodorizers, so I was able to focus on the speakers without further issues."

In hindsight, is there anything you would have packed or prepared differently?

"While I'm not on oxygen, the episode made me consider bringing it if I were. I always travel with extra medicines, including emergency medications for my lungs, heart, and anaphylaxis. If I were staying overnight, I'd ensure I had all my emergency medications and medical equipment on hand."

What questions would you suggest other Alphas ask at the front desk? If you could create an ideal "safe room" environment, what would it include? Any tips for Alphas choosing a hotel?

"The Alpha-1 Foundation has guidelines to ensure Alpha safety, but this was the first education day in Birmingham, AL, so there was some uncertainty. My daughter works at a different hotel within the same chain and has access to hypoallergenic cleaners, so if you're sensitive to certain cleaners, you can always request hypoallergenic products for your room."



If you have A1AT Deficiency and your genotype is MZ, feel free to scan the QR code to access the *Alpha-1 Antitrypsin Deficiency MZ (rare breeds) Support Group* on Facebook. Just answer questions to join.



Christy is a dedicated advocate for the Alpha-1 community, sharing her journey with Alpha-1 Antitrypsin Deficiency to help others understand and manage this rare genetic condition. Diagnosed in 2023, Christi has quickly become an active member of the Alpha community, gaining insights into living with environmental sensitivities and protecting her health.