


Tools and Tips for Enjoying Disney with Cystic Fibrosis

by Lisa C. Greene

I remember the first time I went to Disney World. I was eleven years old and had just moved to Tampa, FL. I was so excited I couldn't sleep. My brother and I had spent the day making decorative "ticket holders" for our ride tickets. Back then, rides required individual tickets and the best rides (at the time) were E tickets. I'm really dating myself here since Disney has not been on the ticket system since 1982! My high school Grad Night was spent at Disney and my Girl Scout troop camped at Disney's campground. I remember the excitement at the news of a new Disney park- Epcot Center - and was thrilled to be able to visit when it just opened back in 1982.

So, I'm a long-time Disney fan. And, now I get to see Disney through the eyes of my two children which is magical. Even though I now live in the Seattle area, we get to visit Disney almost every year when we go to visit Grandma who still lives in Tampa.

I do have to say that visiting Disney, in the summer, with two kids with cystic fibrosis is a different experience than the days of my youth. So, here are some "CF tips" about visiting Disney that I've learned along the way:

1. Get a Guest Assistance Card: Immediately upon entering the park on the first day of your visit, stop at the **Guest Relations** center. It is marked on the maps with a big blue and white i that looks like this: 

Tell the guest services assistant that you need a Guest Assistance Card because your child has CF and that you are concerned about overheating (in the summer) and fatigue due to decreased lung function.

According to Disney's new disability policy: Starting October 9, 2013, guests with a new disability access card will be issued a ticket with a time to enter an attraction, based on the current wait time, so they don't have to stay in line.

In the past, we were able to get a stamp that allowed us to wait in a shaded area, like for some of the shows. I don't know how they are handling this now since the new changes but it doesn't hurt to ask.

2. Bring your own water bottles: Drinks and water bottles are very expensive at Disney so we always bring our own. We bring one for each person, write names on them with sharpies, and freeze them the night before. I leave mine unfrozen to use right away if needed. There are water fountains everywhere to refill or you can get ice water at the restaurants. Never go into a line without your water bottle. The wait is longer than you think and if you leave it in your parked stroller, you'll be sorry (spoken from experience). I use a water bottle holder with a strap to keep mine with me at all times so the kids don't have to carry theirs on the ride. I also bring Gatorade Powder Sticks (the ones you just add to a water bottle).

3. Bring your own salty snacks: I bring ziplock baggies of pretzel sticks-the super salty ones from Cost Plus. You are technically not supposed to bring food into the park but I explain we have special dietary needs and have never had a problem. I also give my kids salt tablets in the morning but check with your docs on this.

4. Be sure to bring enough enzymes: You'll be surprised at how fast you go through them with ice cream, snacks, etc. Also bring your other pills especially if you think you'll be out late. I bring a tiny cooler that fits in my backpack to keep things cool.

5. Bring a small towel or washcloth or two: You'll need this to wipe sweat, dry yourself off from water rides, and lots of other uses including recovering from the drenching Florida thundershowers that are typical in summer. We bring lightweight rain jackets rolled up tight in the bottom of our backpacks. They come in handy to sit on and cover up on the water rides that will drench you. I know it sounds crazy but we carry extra underwear and socks (it's so uncomfortable walking around in soaked socks and undies!!).

6. Have a plan: Do not go to Disney without taking some time upfront to plan your visit. You won't see everything unless you spend two days at each park. It's just too big. Have a list of your "Must Sees" then list your second and third choices. Look at the map ahead of time and make a plan to conquer in a methodical circle. You do NOT want to be zigzagging back and forth across the park. They are wayyyyy too big. You'll run out of time and foot power.

There are copies of park maps on my website. Also, if it's your first visit to Disney World (in FL), I suggest you spend one day at a park rather than "park hop." You lose at least an hour and a half of time just leaving one park and getting to another. They are far apart, very big, and transportation is slow. Remember, time is money at Disney!

7. Keeping those calories up: It's amazing how quickly time can slip away and all of the sudden you are starving, kids are melting down, and you can't find a restaurant (does it sound like I've been there, done that?!). When you walk past a food cart or restaurant, take a look at your watch. It might be good to stop now rather than wait. If your kids say they aren't hungry (cause they want to keep going on rides), you might have to say, "It's time to eat now. You're free to go on more rides *after* we eat."

Try to plan for food in the off peak times. Restaurants get very crowded so it takes a long time to get through the lines plus you're lucky to find a table. We try to eat lunch around 11 AM and dinner around 4 with snacks as needed in between. Also, we don't do fancy sit-down meals (except for the character meals which are very fun). Your children won't remember the fancy meal but will remember that they didn't get to go on Space Mountain if you run out of time. For us, the name of the game is eat and run. With kids, it's all about the rides!

If you decide to do a character meal, be sure to make reservations wayyyy in advance. Then, plan your day around that. We've found breakfast to be the easiest one to plan for because you just don't know where you'll be (in the park) for lunch or dinner and it could be a long walk to the restaurant. The character meals are so magical with young children; priceless memories.

8. Stay cool: Summertime in FL (and CA for that matter) is hot, hot, hot. Dress lightly, bring sunscreen, and carry water at all times. We also bring small handheld fans and a water squirt bottle to cool off. They sell them at Disney but they are big (in size) and expensive. There are several rides that are air-conditioned, especially the shows. You can always go stand in a lobby of a theater, a shop, or a restaurant for a few minutes to cool off if the heat is getting to you. Ice cream helps as do cups of ice. I bring a tiny folding umbrella to use for shade and in the rainstorms.

Avoid the heat of the day by taking a nap, then return and stay late at night. And, mentioning rainstorms, that might be the best time of the day if you are prepared. The crowds clear out and it cools down. The negatives are that some rides close plus you might get wet. Of course if you *want* to get wet, there are water rides that will do the trick!

9. Pace yourself: Disney is wonderful, magical and can be overwhelming. The parks are bigger than you might think, covering acres of ground. Make sure you get plenty of sleep the night before (even though it's hard cause everyone is so excited!). What has worked well for us, especially with younger kids, is to start out early, go until about 1 or 2, go to the hotel for a nap, breathing treatments, maybe a quick swim (or soak your aching feet!), grab dinner (order pizza), and then go back to close the park out at night. Night time is truly magical: the parades and fireworks phenomenal, it's cooler, and less crowded. Plus, we are refreshed.

More than anything, bring your sense of humor and patience. Disney can be a little crazy with big crowds, pushy people, tantruming toddlers, and the summer heat that brings out the worst in some- including our own kids! Come prepared with a plan, a well-packed back pack (remember that you'll have to carry it for miles so pack smartly), a big wallet, and your child-like sense of joy and wonder, and you will have the time of your lives!

Lisa C. Greene is the mother of two children with cystic fibrosis, a certified parent coach and public speaker. She is also the co-author with Foster Cline MD of the award-winning Love and Logic book "Parenting Children with Health Issues." For more information, see www.ParentingChildrenWithHealthIssues.com.

For more *Tips for CF Parents*, visit Lisa's website at www.TipsForCFParents.com.