

# WELCOME TO HOLLAND

by  
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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

## Amsterdam International

*To fully get this post, please read (or re-read) Welcome to Holland before starting. Thanks.*

In the special needs world, there is a poem (essay? whatever.) called "Welcome to Holland." It is supposed to explain what it's like to have a child with special needs. It's short and sweet.

It skips everything.

While "Welcome to Holland" has a place, I used to hate it. It skipped over all of the agony of having a child with special needs and went right to the happy ending.

The raw, painful, confusing entry into Holland was just glossed over. And considering the fact that this little poem is so often passed along to new-moms-of-kids-with-special-needs, it seems unfair to just hand them a little story about getting new guidebooks and windmills and tulips.

If I had written "Welcome to Holland", I would have included the terrible entry time. And it would sound like this:

### Amsterdam International

*Parents of "normal" kids who are friends with parents of kids with special needs often say things like "Wow! How do you do it? I wouldn't be able to handle everything---you guys are amazing!" (Well, thank you very much.) But there's no special manual, no magical positive attitude serum, no guide to embodying strength and serenity . . . people just do what they have to do. You rise to the occasion, and embrace your sense of humor (or grow a new one). You come to love your life, and it's hard to imagine it a different way (although when you try, it may sting a little). But things weren't always like this . . . at first, you ricocheted around the stages of grief, and it was hard to see the sun through the clouds. And forget the damn tulips or windmills. In the beginning you're stuck in Amsterdam International Airport. And no one ever talks about how much it sucks.*

You briskly walk off of the plane into the airport thinking "There-must-be-a-way-to-fix-this-please-please-don't-make-me-have-to-stay-here-THIS-ISN'T-WHAT-I-WANTED-please-just-take-it-back". The airport is covered with signs in Dutch that don't help, and several well-meaning airport professionals try to calm you into realizing that you are here (oh, and since they're shutting down the airport today, you can never leave. Never never. This is your new reality.). Their tone and smiles are reassuring, and for a moment you feel a little bit more calm . . . but the pit in your stomach doesn't leave and a new wave of panic isn't far off.

*(Although you don't know it yet, this will become a pattern. You will often come to a place of almost acceptance, only to quickly re-become devastated or infuriated about this goddamned unfair deviation to Holland. At first this will happen several times a day, but it will taper to several times a week, and then only occasionally.)*

A flash of realization---your family and friends are waiting. Some in Italy, some back home . . . all wanting to hear about your arrival in Rome. Now what is there to say? And how do you say it? You settle on leaving an outgoing voicemail that says "We've arrived, the flight was fine, more news to come" because really, what else can you say? You're not even sure what to tell yourself about Holland, let alone your loved ones.

*(Although you don't know it yet, this will become a pattern. How can you talk to people about Holland? If they sweetly offer reassurances, it's hard to find comfort in them . . . they've never been to Holland, after all.*

*And their attempts at sympathy? While genuine, you don't need their pity . . . their pity says "Wow, things must really suck for you" . . . and when you're just trying to hold yourself together, that doesn't help. When you hear someone else say that things are bad, it's hard to maintain your denial, to keep up your everything-is-just-fine-thank-you-very-much outer shell. Pity hits too close to home, and you can't admit to yourself how terrible it feels to be stuck in Holland, because then you will undoubtedly collapse into a pile of raw, wailing agony. So you have to deflect and hold yourself together . . . deflect and hold yourself together.)*

You sneak sideways glances at your travel companion, who also was ready for Italy. You have no idea how (s)he's handling this massive change in plans, and can't bring yourself to ask. You think "Please, please don't leave me here. Stay with me. We can find the right things to say to each other, I think.