Glimpse into socialising with chronic illness

I had an invitation to join a not to be missed, important and happy family celebration in the form of a high tea at a hotel on Sunday. This posed many problems for my body…preparation to get ready for a fancy tea, a long train trip to get to the hotel, an unknown in terms of the food, and hours spent away from my rest inducing couch. I was however, determined and optimistic to make it to this special do.

I managed getting ready, and had energy to spare for the train trip. I was feeling excited, and was enjoying the rare opportunity to go out since I have been unwell. We met up with the first arrivals of the group, and I enjoyed chatting, and even sipping a glass of wine. I thought that we would eat soon, and I was managing well.
However, we moved into the dining room only to find that the hotel had not received the message about my never ending list of food intolerances. They were keen to help and apologetic, however it was over an hour and half before I had food arrive to the table, long after everyone else had finished eating.
Normally I would not mind this at all, however with my chronic health issues, this posed a problem. I had started out feeling fairly well and chatty, but quickly plummeted into fatigue, my heart started skipping beats, my head began to spin, and I felt like I wasn't "there" anymore. I always bring emergency food with me, for this very reason, so in this classy establishment, I was there trying to subtlety eat crackers and nuts from my handbag! I started to look pale and vague, and people started asking if I was ok. I realised I wasn't talking, and I was probably just staring blankly. Aware that I was becoming the weirdo at the table, I attempted to join in, but when you are having heart palpitations, and nausea and dizziness is consuming you, it is more than a tad difficult! I

was guzzling water, and probably appeared to be rudely and selfishly diminishing the table's water supplies.
Fresh air outside helped a little despite nearly fainting on the way out, and there were frequent requests to the waiters to bring my food.
When the food finally arrived, it was very dry gluten free bread, with fillings full of fructose! So I increased my weirdo status by picking at the sandwich fillings, and raiding my handbag snacks. I then left the event early, and wearily and begrudgingly boarded the train for the trip home.
I felt so disappointed and upset that this lovely event had been ruined for me by my dodgy body. I had been so looking forward to an outing, and instead I felt very unwell, assumed the position of the token antisocial strange guest, was bitterly disappointed, embarrassed and frustrated, and began to have stomach upset issues due to the incorrect food that I had had to eat to have something in my belly.

How do we avoid this situation arising, when our bodies are determined to not play ball? I summon the courage to get out there and give these things a go despite my weak body, only to be knocked back and discouraged. I prepared myself as much I thought I could, resting the day before, eating and drinking well the morning of, and bringing food with me for snacks. I am not sure how else I can prepare my body for an outing! And it was not even a high energy event; just sitting and eating!! It brings back that ongoing question of what else is going on in my body, as plummeting that quickly and severely because of a lack of food is just not right. It also makes me feel concerned about returning to work; when is my body going to be able to tolerate a twelve hour, fast paced nursing shift if it can't survive a relaxed and charming high tea?! It also makes me feel so despondent, worried and frustrated about my ability to have a social life, which is important to a twenty nine year old!

I hope sharing my story of this event might help some people

not feel alone in this struggle, and maybe we can help each other with tips and ideas. Ultimately, we have to get out there and keep trying. Regularly going to the doctor and having tests, and living as healthily as possible is obviously extremely important when our bodies are not working properly, but we also have to try to keep living too. Make the most of the support from family and friends; you can rely on them to help you to keep trying. And if not, I am here for you!

