

# To Tell or Not To Tell, That is The Question

[Neeva Stephen, Saturday, June 4, 2016](#)

Today I am feeling so much better than I did 2 days ago. The pain is manageable - only took my 'usual' pain meds this morning, not the kick arse ones provided by the hospital - and I am able to move around quite comfortably, without the stabbing pain making me stop moving completely or making me prop myself somehow in order to get up, sit down or change position on the couch. I am so very happy to be feeling better, but I will still be taking it easy the next couple of days, to make sure I don't crash and burn.

Now, the actual reason I am writing this particular 'note', is to share the situation I found myself in on Thursday morning, when I had decided I was going to Joondalup Health Campus (JHC). That is, as a Lymie, I had to make the decision whether to tell the treating Dr(s) who my Lyme Specialist is. Sadly, for many Lymies, just deciding whether to reveal they have been diagnosed with and are being treated for Lyme Disease is an absolute quandary. That particular decision wasn't difficult for me, though, because, when I started this journey 2 years and 11 months ago, I promised myself that I WOULD NOT lie to anyone about my diagnosis or the treatment I am receiving. This is very much a personal decision for each and every Lymie in each situation they find themselves, and I do not for one second judge those who choose not to reveal their diagnosis. I'm just a really bad liar and, quite frankly, being in so much pain I was struggling to tell them all of the facts I felt they needed to know, let alone trying to make up a sequence of untruths.

Anyhoo, getting back to the reason for this post, I did decide on the way to the hospital, after consulting a couple of Lymie friends, that I would not reveal the name of my Lyme Dr. Making that decision immediately 'upped' the stress levels and the scenarios of being badgered and refused treatment until I coughed up a name started running through my head. When the triage nurse asked if I had any preexisting health issues my answer of "Lyme Disease" went unchallenged, so one little "phew" was expelled. The next question, regarding whether I was on any regular medication and my answer of "Yes, I have a schedule if you want to see it", was also met with just as little interest and a "No, that's OK, just show the Nurse who attends to you". Another sigh of relief.

I was called through quite quickly, so once again the anxiety level started rising and I remember thinking "Here we go". I was very close to tears, but not due to the pain. I was absolutely terrified that, like many other Lymies who have had the courage to present to ED's around this country, I was going to be ridiculed and made to feel like a fool for believing I have a disease that "doesn't exist in this country". I already had my prepared response of asking if they believe Lyme Disease exists in places like Germany and the US and, if their answer was yes, then why did THEY assume I believed I had contracted it here, yada, yada, yada.

Instead of getting to test the waters with the nurse, the attending Junior Doctor saw me - I hadn't even had obs done - so I had to face my fear almost immediately. The convo went something like this:

Dr - Do you have any pre-existing conditions I need to know about?

Me - Yes, Lyme Disease.

Dr - Oh. Really?

Me - Yes, and I don't give a crap what you think about Lyme Disease, I'm here for a pain that may or may not be related.

Dr - OK, so are you receiving treatment for it?

Me - Yes, for 2 and a half years now. I have a schedule of my medications for you <grabs copy of schedule>.

Dr - Wow, is this everything you have to take?

Me - Yes, it is. Dr - I don't know a lot about Lyme Disease, but I thought it was easy to treat. Me - It is if it's treated soon after infection.

Dr - How long have you had it?

Me - Since I was 16 and I'm now 48. I was only diagnosed nearly 3 yrs ago. Dr - I had no idea you had to take all of this. Me - If I had been infected 6 weeks ago and put on antibiotics immediately I would just be coming to the end of my treatment, but due to the infections being in my body for 3 decades my immune system is shot, along with other complications. You will notice more than half of what's on that sheet are supplements, etc.

Dr - So are you being treated by your GP?

Me - No, I see a Lyme literate specialist.

Dr - Oh OK, so who do you see?

Me - Not telling you.

Dr - Sorry?

Me - I'm not telling you, as the handful of Lyme Drs in this country have been targeted by AHPRA and I'm not taking a chance that mine will be too.

Dr - <After a couple more questions and some more answers> No, that's OK, I really just need to know what you're currently taking.

By now I have realised he's not about to have me burned at the stake, so I take a chance and ask him his opinion on Lyme Disease. He tells me he hasn't seen much of it here - he's English, by the way - but that he does know it exists. Massive sigh of relief from me. His next question is "So what brings you here today?" I almost couldn't believe it. From then on all of the staff attending to me, which included another 3 different nurses over the day plus a Senior Doctor considered my Lyme Diagnosis and treatment protocol as a side issue they needed to design a solution around, not something they needed to alter.

I can't begin to explain how much of a difference receiving compassion, consideration and NOT being judged by those who are trained to help you can make. I have been mulling over and dissecting all of my decisions from Thursday and the responses I received and have come to some conclusions that I hope will serve me - and other Lymies - well in the future, as follows:

1. Each of us needs to listen to our gut instinct and say/tell 'our' story in a way that best supports us. For me, I really didn't want to waste my time or the hospital's and, more importantly, I did not want to take a chance of being given some medication that is contraindicated to my Lyme meds. So I took a chance on telling the truth, which I believe lead to a much quicker diagnosis of what was actually happening at that moment.
2. Not every pain, discomfort and/or other strange/different symptom IS Lyme Disease related. Us Lymies can also have normal-type people medical issues that require investigation, diagnosis and treatment. In this case, I do think the two things are connected; I'm just not sure how, and won't find out until I do some more research and eventually speak to my Lyme Dr about it.
3. Sometimes a leap of faith is worth taking, especially if you are confident that YOUR opinion and resolve about the decisions you have previously made, regarding your health, were the right ones. That is, I am very sure that Lyme Disease is the correct diagnosis, that the treatment is working - slowly, but that is good enough for me - and that I have absolutely NOTHING to be ashamed of in revealing my diagnosis.
4. Each and every opportunity to talk about Lyme Disease is a chance to educate people and should be used accordingly. Self-advocating is so incredibly empowering and hearing a Nurse say "I am very open minded and going to go look into this, so I know more about it next time" means that the advocacy baton has been passed on, as it should be.

All in all, the experiences of the past few days have been worth the pain I think, as the next time I require emergency medical attention - and it is highly likely there will be a next time - I won't need to stress about revealing my diagnosis. And that, my friends, is exactly how it should be, for all of us.