“There are a few things you should know about me, before we begin.”

I was on the phone with a new member of my care team. While the doctor I was seeing was someone I’d seen before as a member of my transplant team, I was now being referred to gastroenterology, which meant his clinic nurse would be joining my team. A few days before a bumbling receptionist had called to confirm a procedure I’d be having the beginning of next year, and the entire call had gone less than smoothly. I left a note for his clinic nurse to call me, hoping to gain both clarity on what was being asked of me and to provide them some understanding of who I was. After all, I am the boss of my medical care, and every doctor, nurse, dietician, pharmacist, or therapist is someone I employ to help me.

The first thing I do in meeting with a new person on my care team, or on our introductory phone call, is **tell them a bit about myself and ask about them**. A lot of times this question catches people off guard, as the interaction that exists between patient and provider has long since been transactional versus any kind of meaningful relationship. Yet I’m supposed to trust these people with my life, willingly submit to any intervention they desire and not question too much.

I have met many, many amazing healthcare providers who I genuinely believe are doing their best to respect patient’s autonomy and healing journey, but I’ve also met many who act in opposition. It’s important to me my team is composed of people I can trust.

The next thing I request is that **important information be shared with me either with or by someone I trust**. I have a few designated care providers on my team that I trust completely and allow to deliver the hard truths to me. If they aren’t available to share the news, for whatever reason, I ask that whoever is sharing the news with me waits until I can have one of my support people with me, such as a friend or family member. This allows me to feel safer, less bombarded with information, and I can practice co-regulation as a way of calming myself down rather than immediately shifting into a nervous system stress response because I’m in a situation I don’t feel completely safe in. While this is often respected, sometimes someone won’t look at my file, or someone will be filling in, in which case I will state on the phone to have either one of my trusted providers call me directly or for the call to be returned when I know someone can be with me.

I **ask for options**, and a lot of them. The only way I can make an informed decision about my care is if I know my options. In the scenario of my upcoming procedure, I began by saying I don’t feel comfortable with the traditional course of action outlined here so what else is available to me? When I’m making these decisions, I’m taking into account my physical, mental and emotional well-being. Sometimes I’ll consult a friend, or another provider before making a decision. This also applies to more emergent situations, and I let everyone on my team know beforehand in case we run into a situation that is more time sensitive. If I am uncomfortable for whatever reason, we will pause and regroup. If I am not able to make decisions for myself, my support people have been made aware of my wishes and can act on my behalf. If I know beforehand what the possibilities are, I can have time to sense how each one feels in my body and make a decision from a better nervous system state.

I explain to every provider that no amount of study is worth more than my lived experience in my body, and I’ve been living in my body for a very long time. I often come up with new ideas, theories and suggestions, which can be unsettling for people who aren’t aware of the fact that I don’t take things at face value. I say “no” often. I say “but what about this” often. I find the sooner my team knows, the easier it is to have collaborative discussions and come up with solutions that actually work.

“So, what do you think?” I said after I made my non-negotiables clear, “can we work together here?”

“I think we can,” the nurse replied.