

Who I Needed When I was Younger

How growing up with health challenges has made Jenna Reed-Cote a better social worker

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I'm getting to relive my life in more ways than one and I couldn't feel luckier. So many people wish they had the chance to do it all over again and I get to be one of them.

Even better, I get to be who I needed when I was younger.

Now some of you may be surprised that I'm happy that I get to revisit my past—it wasn't exactly easy. I mean, it did start with the prediction by doctors that I may never be able to sit up independently, followed by a bunch of surgeries on my head, spine, colon, bladder, and feet (over and over again). There were many times that I thought bullying would do me in, especially in elementary school. Dealing with mental health issues by the age of ten was yet another thing my peers couldn't relate to—not many conversations on the playground comparing antidepressants and therapists.

Part of me felt at home among the staff at the hospital because they all knew about my health challenges, so there weren't too many questions asking "what's wrong with you?" But I did, more often than not, feel like a piece of meat as a patient, powerless to help myself and my team achieve my ultimate health—I was just a kid, right?

Once, on a routine visit with a specialist, all questions about my health were directed toward my parents. Even though I was the one experiencing the symptoms, the doctor thought my parents would know better. My mum and dad made every effort to empower me though, and this was no exception: they told the specialist I could respond on my own, thank you very much. With more time being spent in hospitals than playgrounds, I had become a professional patient and among the many things this influenced was my vocabulary. So, at six years old, I looked the doctor in the eye and articulated my physical experience using accurate medical terminology.

I knew that I was filled with untapped knowledge about my body and my potential, and doctors seemed to have tunnel vision, only focused on the presenting problem, rather than the whole body. Because of experiences like this one when I was six, I began to study these practitioners and analyze what made them good at their job and what didn't. I wanted to be one of the good ones. I wanted to be the practitioner I needed when I was a kid. Suddenly, what had been the worst part of my life—my health challenges—felt like a gift and the foundation for my life's work.

I decided on a future in social work, feeling most at home in healthcare settings—especially pediatrics. As a social worker, I've had so many opportunities to put my skills to the test with phenomenally resilient kids and their families—some of these skills learned in the classroom and some developed from personal experience.

My journey from patient to practitioner may seem like a natural progression, and it was for the most part; however, I did struggle fully embracing the potential of this new role. Instead of my past informing my present as a practitioner, making me feel more confident, it actually started filling me with serious doubt. Was I doing this for the right reasons? Was I using my future patients to try to exorcise my past demons? Would I be unable to empower my patients on their own journey because I'd try to liken their journey to mine? It was scary.

Some (or most) of you may think this shows my knack for overthinking, but I much preferred facing these questions early on and confronting them, rather

than being over-confident and believing that simply because I had been a professional patient I would become a formidable practitioner. So, I dedicated myself to figuring out how to marry what I learned in school about being a competent and effective practitioner with what I had learned from being a patient for so long.

What have I learned? In the patient-practitioner relationship, there are opportunities for both sides to learn and teach. The patient deserves to feel their power as the expert on their life—nobody knows more about what goes on inside them more than they do. The body isn't the only way to predict or understand a person's potential for success—you have to listen to the mind and spirit, too. We can't be afraid for things not to go the way we planned. If my life's any indication, medical mysteries are far more common than medical certainties, so we need to be open to brainstorming and thinking outside the box. A willingness to collaborate between patients and practitioners is so important.

I've also learned that kids are so much more capable of understanding the world around them than we give them credit for. We need to be taking every opportunity to stretch their understanding of ability vs. disability, strength of the body vs. strength of the spirit, practicing inclusivity and accessibility vs. putting up barriers to weed out the weak. We think they're not ready for such deep concepts but it really is just a matter of communicating with them in a way that makes sense and, in a way, they feel they can put this learning into action.

This has also been my greatest joy: teaching kids to see the potential in each other that may not be so obvious on the surface. As an ambassador with the Rick Hansen Foundation, I get to do presentations for kids as young as four. We talk about what some of the smartest people in society thought I was capable of achieving when I was born (probably not being able to sit up independently). We talk about how my life unfolded, how I was trained by world champions in martial arts and got my black belt (a month after brain and abdominal surgery). We talk about the two university degrees I earned despite learning challenges and constantly missing school to be with doctors. We talk about how I've done all these things that nobody guessed I would accomplish by looking at me, because it is so easy to focus on the surface of a person. Maybe we do this out of a kindness, worried that questions may offend—so we don't ask at all. But it creates a bigger problem: we end up isolated and miss out on seeing that we all can persevere in unique ways because we've had to veer from how it's always been done.

As much as adults struggle with the reality of creating accessibility in the world—especially the cost—I try to empower kids of all ages to make their environment accessible and inclusive of their peers. It's not just a job for adults and can be as easy as hanging up backpacks and coats so that someone like me (in a wheelchair) can get around. But even more simply than that, I tell them they could change a kid's life (a kid like I was), just by being a friend and including others—not because they feel bad, but because they see the potential that lives under the surface. And just like that, I see it click with them and their new resolve going forward. I leave my presentations thinking of them approaching a kid like me and looking to connect—maybe over a TV show or a pet—ultimately finding one thing (they didn't think) to connect on: all of a sudden there's a spark.

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