

Build with what you have



Building with LEGOs often results in an interesting quandary: the more one builds, the fewer pieces you have left in the collection, no matter how carefully they might be organized for easy retrieval.

Living with a chronic, progressive, debilitating disease like multiple sclerosis is a lot like that. It can be described as “the gift that keeps on taking.” One’s strength, cognitive resources, coordination and stamina are all taken away slowly but surely...sometimes even quite abruptly.

Yet, we are all called to “**build**” something meaningful with our lives. None of us have the same set of pieces, and although we may try to get more through education, hard work and creativity, there are always limits.

My life as a clinical neuropsychologist ended when I got a severe form of progressive MS. It was devastating. I’d worked very long and hard to create a life I thought was meaningful, and it was taken away. I was left to “pick up the pieces” and start over with “plan B.”

My “plan B” included moving from Miami, FL to Jackson, MS to be closer to family. It didn’t take long, however, to realize that I was needed here. You see, none of the buses in Jackson were wheelchair accessible. The lifts had been poorly maintained and none of them actually worked. The sidewalks and bus stops were either non-existent or inaccessible. To make a long story short, it became obvious that Mississippi hadn’t implemented the Americans with Disabilities Act, that was signed into law in 1990, and went into effect in 1992.

There’s a mantra in the disability community: **educate or litigate**. I much prefer the former,

and did my best to educate and encourage compliance. Unfortunately, it hasn't always been enough. In this instance, it took litigation in Federal Court to motivate system-wide transportation reform.

There's another important mantra in the disability community: **nothing about us without us**. So, people throughout Jackson's disability community formed an ADA Advisory Council that offers free advice and guidance as we work to remove barriers to full inclusion, and move closer to a city that welcomes everyone, including those with disabilities.

Lastly, I built an ideal city called "LEGO Jackson" which goes on display each year at the Arts Center of Mississippi. LEGO Jackson grows in size and popularity each year and inspires children and adults alike to take care of their neighbors, their homes, and their city. [This year's addition: LEGO Jackson Hospital complete with physical therapists, MRI machines, and scientists!](#)

I now have a lot fewer "pieces" than I had before. MS affects my cognition, although most people do not notice. Chronic exhaustion limits what I do despite my workaholic personality. Some days it is hard to get out of bed, and it is always a struggle to speak loud enough to be heard (my vocal cords are paralyzed).

There are very few things that I'm absolutely certain of, but one of them is that we are all tasked with creating something meaningful with what we have available. In order to make something happen, you have to be able to imagine it first. Part of it is to show people we can make this happen. We have to roll up our sleeves and try, but we can do this.

Remember, in life, we are asked to build something meaningful using fewer pieces than we wish we had.

Be creative. Keep building. Never stop.