Living with Polio as an Adult in the Philippines

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I am in my mid-30s, single without a family of my own yet and living with polio. My focus is on working and living a purposeful life. The things that get me through living with polio are acceptance and my ability to let things go, along with a good support system, medical team, sense of humor, faith and love.

Family and Work

My family helps with most of the household chores. My only tasks are to cook twice a week and do the dishes after dinner because most of the day I'm gone working my day job. From Monday to Friday, I work as an HR representative at our community hospital. On Sundays, I teach piano. Most of my students are children. I feel blessed because this job sort of just landed on my lap. The music school is only three blocks from my home, and it lets me express my passion for music.

I only have Saturdays off for now, but I am planning on slowing things down and working only half-days on Sundays. I feel slowing down might be best due to the polio. I feel I'm running on a battery that can't be recharged.

My Hospital Care Staff

Since contracting polio at 4, I've been going to the same rehab center in University of Santo Tomas (UST) Hospital. The head of the Apolinario Rehab Center, Dr. Ophelia Reyes, retired to the US when I was 23 years old. But my ortho family have been the same people until just two years ago. It's so important to have the same team and not constantly have to change doctors. They come to know you and can, for instance, customize a fitted leg brace for me for a lower cost and in less time than other places. They are my angels.

Challenges

A big challenge now is that the orthotists resigned (or were laid off) from the hospital where I've gotten my braces since the time I was four. I don't want to transfer to a new hospital because my entire support team is there at "my hospital." The new guys haven't been able to make my new brace work even after many fittings. I compare it to having a good seamstress—the one you've been with a long time will know all the tricks to make it fit right the first time. Hospitals sometimes seem to favor "innovative" new braces rather than relying on traditional approaches and experienced technicians.

The fitting and adjustments are elixirs for us polio survivors wearing KAFO/AFOs. Adjusting it twice a year or having a "tune-up" every three months works best for me. When I follow this schedule, my leg is less fatigued after walking. However, it is costly. In the Philippines, it is next to impossible to find help to pay for a brace. Many with disabilities that are in need of braces end up in wheelchairs even though they could walk if they had a KAFO. I wish there was more funding for braces so these people could live a more purposeful life.

Psychological support is almost nonexistent here. There are very few support groups around even though I know many people who would like to share their experiences in a group setting.

Getting around is also difficult. Transportation is costly for people with a disability. Use of accessible private vehicles is expensive. Public transport is not very friendly to people with disabilities and using it to commute is difficult.

Acceptance and Letting Go

I think it's important that I learn to accept that things should slow down for me, that keeping up the normal hustle and bustle of my life might lead to regret. There is so much beauty in taking it slow and appreciating all the in-between time now that I'm an adult. Before, I use to put so much importance on belonging and competing. But fulfilling dreams is not just about reaching milestones and racking up "accomplishments." I've learned there are advantages to taking things more slowly. It makes me listen to my body and heart more closely. It helps me know what I was put in this world for—fulfilling my mission and being a good human being. Because having that, even with polio, makes living a great joy. ■