Sharing My Family’s MS Experience

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Comparto la experiencia de mi familia con la esclerosis múltiple

En 1968 mi padre estaba destacado en Nha Trang, Vietnam, donde era capitán de infantería, y muchas de las personas en esa base terminaron con el mismo diagnóstico: esclerosis múltiple. Cuando volvió y sus médicos le diagnosticaron lo mismo, mi madre no supo qué hacer.

Recuerdo aquel día perfectamente: mi madre salió a caminar tres o cuatro horas y luego me dijo que se la pasó pensando cómo iba a sacarnos adelante. Sabía que iba a tener que enfrentar sola la enfermedad de mi padre y, a la vez, criar a sus dos hijitas. Decidí ayudarla.

Cuando papá empezó a enfermarse gravemente, yo tenía 14 años. Era la única que podía cuidarlo después de que se iba la enfermera, a la que solo podíamos contratar hasta las 3 de la tarde. Tras volver a casa de la escuela, lo cuidaba a él y a mi hermana menor. Mientras tanto, mi madre, que tenía un doctorado de Cuba, trabajaba a tiempo completo y revalidaba sus credenciales de profesora, pues quería un trabajo mejor para ofrecer a su familia una mejor vida.

La situación era difícil para mí. Era muy joven, y mi padre no se daba cuenta de lo enfermo que estaba. Cuando intentaba levantarse de la silla, se caía. Medía 6 pies y 2 pulgadas (1.80 metros) y pesaba más de 200 libras (unos 50 kilos), así que tuve que aprender a levantarlo sola y ayudarlo con todo lo que necesitaba.

Ya que se sentía mal al respecto, yo hacía todo lo posible para que se sintiera bien, querido y atendido, pero era difícil. Por eso, en nombre de mi padre, el capitán José Manuel Fajardo, financio un programa dirigido a cuidadores en el Centro Lou Ruvo para la Salud Cerebral de Las Vegas. Tratamos de ayudar a las personas con lo que necesitan para su familia, ya sea trasporte a citas con sus seres queridos, que quizá tengan esclerosis múltiple, o fondos adicionales para acabar el mes.

Es maravilloso poder contribuir de alguna manera y, desde el diagnóstico de mi papá, hemos logrado mucho. Para él, no había tratamiento. Fue cuestión de lidiar con síntomas cada vez más intensos y la pérdida continua de todas sus facultades y sus habilidades hasta que, 14 años después de su diagnóstico, ocurrió lo inevitable.

No hay sino esperanza a la vista, y nos hemos unido para que las cosas mejoren. Todas las voces cuenten y, cuando hablamos en unísono, nuestra influencia aumenta.

Toda la vida he usado la música para inspirar a los demás. Todos ustedes me inspiran, porque sé que van a desempeñar un papel fundamental en la lucha por cambios. Juntos podemos hacer que la vida de las personas con esclerosis múltiple sea mejor y más fácil.

-Gloria Estefan

My father was stationed in Nha Trang, Vietnam in 1968. He was a captain in the infantry – a lot of the people that were with him in that base ended up with the same diagnosis – MS. Needless to say, when he came back and my mom heard the diagnosis from his doctors, she didn’t know what to do.

I remember that that day vividly; she went walking for three to four hours, later telling me that she was just thinking about how she was going to now get us through life alone when she knew that she was going to be facing my dad’s illness and raising two young girls. I stepped up to help her.

I was 14 years old when my dad started getting critically ill. I was the only one that could care for him after the nurse – that we could only afford to be there until 3 in the afternoon – and she left. I came home from school, and I was caring for him and my young sister as my mother was working full time and went back to school to revalidate her teaching credentials from the Ph.D. she had in Cuba. She wanted to be able to get a better job to better take care of us and my father.

It was a difficult situation for me. I was very young, and my father didn’t quite realize how ill he was. He would try to get up from his chair — he would fall. He was 6 feet, 2 inches and two hundred and some pounds, and I had to learn ways to be able to pick him up on my own and help him with all of the things he needed done.

He would feel bad about it, and I did my utmost to try to make him feel okay and loved and taken care of, but it was difficult. And for this reason, I fund a program at the Lou Ruvo Center for Brain Health in Vegas for caregivers in the name of my father, Captain Jose Manuel Fajardo. We try to be helpful to people when they need rides to and from appointments with their loved ones that may be suffering from MS, or perhaps need some extra funds to get them through the month or whatever they may need for their families.

It's wonderful to be able to be a part of it somehow, and we've come so far since my dad was diagnosed. There were no treatments available for him at all, so it was just a matter of dealing with the escalation of his symptoms and continued loss of all his faculties and his abilities until the inevitable happened 14 years after he was diagnosed.

There's only hope on the horizon, and we're coming together to make things better. Every single voice matters. And we are more powerful when we raise our voices together.

Throughout my life, I've used my music to try to inspire, and I'm inspired by all of you because I know that you are going to play a critical role in advocacy for change. And together, we can make lives better and easier for people with MS.

– Gloria Estefan

Editor's Note: This blog was edited from Gloria Estefan's story to MS Activists during Public Policy Conference. **Click here to watch her full video message.** Sign up to join Gloria as an **MS Activist.**