

# You never know what life will bring



**Jim Williams**

**“I wanted a perfect ending.** Now I’ve learned, the hard way, that some poems don’t rhyme, and some stories don’t have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next. Delicious ambiguity.” —Gilda Radner

It is impossible to know what life will bring. One day it seems that all is as it should be, and then something happens to a loved one and our whole world is turned upside down. Perhaps you lose all your savings for a reason beyond your control, and what you thought you knew is gone. That occurred in many lives during the Great Recession that began in

2008. Whatever the cause, events can change everything.

That happened to Lancaster, PA Branch 273 member Anne Rinier and her husband Mark. Anne carries mail and has done so for the last 28 years in central Pennsylvania. Mark and Anne enjoyed their life and loved to camp, go on walks and ride motorcycles. Their active life changed dramatically when Mark was diagnosed with hereditary spastic paraplegia.

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Events changed my family’s life when my mother was diagnosed with Huntington’s disease. Her sister had died from this disease as well as my grandmother and both of her brothers. Believe me, this disease changed everything.

The worst part, though, is the difficulty in getting answers about what to do and what the future holds. There are many questions that your doctor will be unable to respond to simply because the diseases are rare and few people have expertise.

That is where Anne and Mark are today. After years of asking questions, the diagnosis, while debilitating, at least gave them a place to start. I spoke to Anne a couple of times and understood where they are in their journey. My heart goes out to them and I decided to see if the Muscular Dystrophy Association could help them. Unfortunately, I

found that Mark and Anne are in the same boat I found myself in years ago. MDA does not cover that specific disease.

While MDA covers more than 43 neuromuscular diseases, there are limits to what it can help with. Its funds are finite. So people like Anne, Mark and myself have to look elsewhere for help.

**So why do I write about what could be a negative about MDA?** I write about Anne and Mark to show what a difference MDA can make for those who are covered. MDA has been a lifeline for those folks. I only wish that Anne and I had a group to help us like the Muscular Dystrophy Association.

After I broke the news to Anne, she was not distraught. I asked if I could tell her story. She said yes. I asked her if we could do fundraisers for her and Mark. She emphatically said no! It was her desire only to tell their story to send all our members a message of hope. I asked her what she would want me to share. Her message is this: Have patience and don’t give up when you are thrown for a loop by events.

Anne and Mark are working their way through this disease. They are depending on each other for the strength to face each day with hope. It is my goal to help them with any information I can give them. Sister, we will be praying for both of you.

## A reminder about the influenza season

**Influenza is a serious and contagious illness.** For those with neuromuscular diseases and other chronic illnesses, it is important to protect them from contracting it. This includes anyone who comes in contact with someone who has muscular disease. The best way to lessen the impact is to make sure you receive a flu shot. You should get it as soon as possible so that you are protected early in the season.

In addition to getting the flu vaccine, here are some other ways to lessen the chance of infection:

- Educate family members and those they come in contact with to understand the risk involved for those with neuromuscular disease and the importance of staying away from those with flu-like symptoms.
- Promote good hygiene at home, which includes washing hands with soap and water for at least 20 seconds, especially after coughing or sneezing. Alcohol-based hand cleansers also are effective if they have at least a 60 percent alcohol base.
- Encourage everyone in your home to practice respiratory etiquette by covering coughs or sneezes with tissues or with their arm. Dispose of tissues in a wastebasket.

Contact your physician if you have any symptoms of the flu. Remember that you are responsible for being careful to not infect someone else who could really be negatively affected by the flu.