



Live, laugh and love

“Live, laugh and love.” Perhaps you have seen this motto in a friend’s home, or in your own. To many people, these are merely words, a cliché. But in some families, the words resonate with power and meaning.

Recently I had the pleasure of speaking with the Murphy family, whose members have adopted “live, laugh and love” as their motto. They chose those words as an anchor of hope, at a time when their family had been stricken by a tidal wave of suffering.

Little Derek Murphy is now 6 years old. When he was 2½, Derek was diagnosed with Duchenne’s muscular dystrophy, or DMD. DMD is a muscle-wasting disease that first affects the hips, shoulders and thighs, and later the heart and breathing muscles. Survival beyond the early 30s is rare.

Derek’s parents, John and Sue Ellen, remember well the day the doctor told them their son was ill. John says, “As parents, we had all the dreams and hopes any normal parent has. We had plans for Derek’s future. In a flash, everything changed.” Sue Ellen said the couple felt “lost,” and asked, “What are we going to do?” They came home and tried to explain it to their two older boys, John and Sean. It was tough.

As a parent, I can remember hoping and praying that each of my three children would be healthy. I was lucky. The Murphys, and other families like them, have not been so fortunate. What does a family faced with this kind of diagnosis go through? To whom do they turn? This article and the next one attempt to tell the story of one family and how people in NALC’s Northeastern New York Branch 358 reached out to them.

Like many others who have experienced loss or tragedy in their lives, John and Sue Ellen speak of the five stages of grief. At the time of the diagnosis and even after, they lived through denial, anger, bargaining, sadness and acceptance. Denial because they felt “numb” with emotional disbelief upon hearing the terrible news. **Anger** because of feelings of helplessness or guilt often turned outward.

Some resort to **bargaining**—trying to barter for the child’s health. Parents may try to bargain with their god, or hope their own suffering can somehow be traded for the child’s health. But all the parents can accomplish, in the end, is to

love and care for the child the best they can.

Feelings of **sadness** are normal, but can be debilitating. John and Sue Ellen rely on each other to battle sadness. When one of them is down, the other finds the strength to get the couple moving again.

The final stage of grieving is called **acceptance**. People who reach this stage are able to give up impossible dreams, set disabling emotions aside, and deal with reality. The Murphys believe they reached acceptance quickly, after they decided to be proactive by working for MDA. They felt they were fighting back and getting a handle on their situation with Derek.

John and Sue Ellen told me they do not want people to feel sorry for them. In many ways, they say, Derek’s diagnosis has led to good things. Despite the trauma to their family, John and Sue Ellen have beaten the statistics by preserving their marriage of more than 12 years. Each calls the other the best friend possible, and both say they are stronger together now than ever before. They emphasize that they are normal people doing the best they can in a difficult situation.

Next month, I will continue the story of the Murphys and their family. John and Sue Ellen have taken important steps to cope with Derek’s illness and to grow through their experience. Their struggles provide a glimpse into the lives of many families who live with muscular dystrophy. I’ll also tell about Derek’s uncle, a letter carrier who stepped forward to be the branch’s MDA coordinator just six months before Derek was diagnosed.

In the face of their grief, the Murphys have committed themselves to “live, laugh and love.” We can learn from their lives. ✉

