

Preface

We all have our own stories and we come from many different places, Yet, we are one community because we are all affected by myotonic dystrophy, many of us living with it. You can help this global DM community by telling your story, showing others around the world that they are not alone and empowering yourself by making a difference.

Since the launch of our project and its announcement via Facebook on July 20th 2018, the news has spread around the world very quickly: Hundreds of DM-affected individuals, their family members and interested parties have visited our website; more than 120 of them from the United States alone.

So, how can you get started on writing your story? A number of famous, award winning authors have observed that a blank page of paper is the most fearful thing they have ever faced. What? People living with DM overcome challenges every day. A blank piece of paper is not a problem. Here are four steps to follow in writing your story, featuring the story of Bernhard.

Take care,



Erich
project leader

Writing your story . . . A Starting Point

Step One in developing your story is an opportunity to explore your personal experience living with DM, identifying important points that can help you reach, and possibly inspire, others. Meaningful stories are based on a set of your truths as you understand them, truths that express your values and your feelings. Ask yourself - What are the two or three points about your DM experience that affect your life the most? These are your truths. Now, what words best describe these truths? Is your truth a feeling? (“I am afraid, yet hopeful.”) Perhaps your truth is a thing. (“I cannot use a fork.”) One of your DM personal truths may be a person or people, (“I love him.”) Give Step One focused thought and write down key words that describe your personal DM-related truths. Connect these descriptive words together into a few sentences and, already, you have a story framework. (“I am afraid, yet hopeful. You see, I cannot use a fork any longer. But, my husband will help me. I love him and he loves me.”)

Step Two requires your imagination. First, create an image in your mind of the person or people to whom you are telling your story. Is it an adult living with DM? Perhaps it is a researcher at a university research center working on a DM cure. Your audience may be a doctor or caregiver. Maybe, it’s the parents of a teenager with juvenile-onset DM. With your audience in mind, recall specific details about the personal truths you identified in Step One. Be sure that these details are ones of interest to your audience. For example, what makes you fearful or hopeful? Is your inability to use a fork a recent development? How do you eat? Add these specific details to the paper where you wrote your personal DM truths.

Step Three is to read Bernhard’s story reprinted on the back of this page. What are his personal truths? Who is his audience and what details does he use to guide us in understanding his truths? Important point: Bernhard writes his touching and very human story in the first person. Often the most powerful and effective way to express a personal truth is to use the pronoun “I”.

Step Four is to commit to writing your story and then working on it for 30 minutes each day until you finish it. Using Bernhard’s story as a guide, blend together the information you developed in Steps One and Two to write your own story aimed at the audience to whom you want to speak.

Then, post it, along with a photograph if you choose, on the *Our Voices – Our Life* website. You could change a life, perhaps your own. Thanks!

Mike

The Story of Bernhard, Baden-Württemberg, Germany



When you stand on a peak in the Alps at sunrise, it does not matter how hard, arduous or dangerous the ascent was at night. You're up at sunrise and you realize: the effort was worth it! All that was not visible from below is now in front of you. You have reached your goal, you have arrived with all your senses. And ... right in front of you, the next summit is waiting for you.

This was my life until 2016, when PROMM turned my life completely upside down. I was 52 years old at this time. Much was not left from what it used to be. The simplest things, such as the daily shaving I could not do it anymore. Activities that are considered as normal for each healthy person, became impossible for me. I do not remember what was worse in the first time: knowing that I need a wheelchair to get out of the house by myself? Having my wife taking over my work in the house and the garden or having her helping me up and down the stairs? There were times when I was ashamed towards the people who are most important to me and I felt to be a burden because I could not cope with everyday life without them.

Then my mountain tours came back to my mind. The countless beautiful moments I was allowed to experience! The moments up there were not simply given to me! They were made by hard work, because I gradually developed myself as a climber, ice climber, ski walker and Para glider pilot and I learned again and again. It taught me how the rope team must be, which I will join. It had to be people whom I could trust to help myself if I could not go any further. Finding them was not easy. It took a lot of work and it took a long time, but it was worth it.

When I joined the DGM (=German Community Organization for individuals living with a neuromuscular disease) I came to realize that I am not alone with my illness. The tips I got from those affected helped me to get on with a better coping with the diagnosis. Thanks to my doctors, I got the right tools for my everyday life. My psychologist helped me to get along with the changes emotionally. The therapists in my rehab clinic sharpened my perception of my body, which no longer acts and reacts as it used to. My therapists at home were ready to work with me into a new world for us. We work hand in hand, learn new things every day and are curious what awaits us at the next summit. Working at the DGM German Society and on Facebook gives me the feeling that I can do something and that I'm needed. Keeping my wife and daughter laughing is still one of my favorite tasks.

Read more stories and submit your own at www.dm-voices.com => How to participate => The Stories

Next Steps

September 8th 2018

Presentation of the website in French language in Paris / France

September 14th 2018

Presentation of the project at the MDF-Conference in Nashville (flyer and documentation)

November 8th 2018 *Presentation of the website in German language in Hohenroda / Germany*

Next Story



Each of our quarterly newsletters will present a selected story of a DM-affected person or of a family member.

The story in our next newsletter could be yours! Write your own, following our suggestions and submit it on our website www.dm-voices.com

More information



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