



# All Aboard! The DM1 Voyager

*By Diane Bade, RN*

The journey of one family through the life of Myotonic Muscular Dystrophy type 1

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I'd like to take you on a Journey today. It is the Journey that won't appear in most travel brochures, even though there are perhaps few journeys quite as mysterious and challenging and for the price, as short. It is the Journey most families with Myotonic Dystrophy have either taken, made reservations for, or are currently traveling.

I, at this point must tell you that I have yet to complete this Journey, so I can only personally speak to the road thus traveled.

I signed up for the dream of a lifetime when I met and married my best friend. He was tall, athletic, and the ideal family man. We immediately booked tickets on our Discovery Journey. We traveled; snow and water skied, golfed, bowled and partied.

Our discovery journey began with some episodes of things just getting stuck in the works. Food that didn't seem to want to go down all the way; "stuck" if you will. A construction work injury: a foot cut by a skill saw that "somehow" got "stuck" and didn't turn off. There were also a few auto accidents and some tickets; perhaps just a little "lapse" of judgment here and there. But all in all, this still seemed like the fun ship we were destined to be on. After several years and many episodes of "stuck" food a surgery called a fundoplication was completed. On this leg of the journey we encountered what was to become a native beast: pneumonia.

Now, I don't want you to think we were bored waiting for each port in our Journey; no we kept ourselves busy creating additional passengers who would soon accompany us; our three children.

Each port had its own climate, and attractions. For our children these were: hearing and speech delays. diets and therapies for Attention Deficit Disorder, Psychological Evaluations for Depression and finally, being told by a Pediatric Neurologist to be sure to have the children close their mouths so as not to appear "stupid". Unfortunately they continued to be mouth breathers and we soon left that port without any souvenirs. Educational and physical "delays in development" led us to many years of mystery; we were "lost at sea", if you will.

In the midst of raising our children, my husband had a fall from a second story construction site. He literally dove off the roof. Apparently he felt a loss of balance and went to correct himself, but his foot "stuck". This time he needed a craniotomy. This guy was beginning to be a problem patient so I quit seeing others for a while and became the full time tour director for our journey. Following the craniotomy, we again encountered the Pneumonia beast and some difficulty with mood regulation. We set out for another port, seeking a solution to his depression and his lack of will "get back" in the swing of things. This side trip permeated the next many years. He was given some pretty bleak psychological evaluations indicating he was "stuck" in some sort of depressive disorder. If only he would try harder to get back on board the fun ship, because we believed that's where we belonged!

Medical Doctor's had their ideas. It must be sleep apnea, that's it, just a little change in habits or maybe a little surgery (To some ENT's known as a "piece of cake") will fix it all. But with that journey, another unwanted passenger, an anesthesia complication boarded our ship. An overnight stay turned into our longest stay in the port of nightmares. Finally released with a trach and NG tube we try to rethink this discovery manifest. I'm trying real hard to figure how I missed seeing this passenger board our ship and why I didn't kick him off at the get go. I need to be more than Full time tour director, I've got to be "all time."

Our eldest son was becoming a man-child. He had just turned 15 and was the future Joe Namath, Arnold Palmer and any other sport hero. He decided he would play football (probably with USC for a while anyway). His coach called us into port for tickets on yet another maiden voyage. Seemed our sports

enthusiast was just not cutting it, he wasn't even growing or developing man-child muscles, though he did have all the desire of the greatest achievers! Perhaps another Cruise to the medical world was in order.

This (after a few calls in other ports) led us to hear the words. "Your son has a neuromuscular disease, it's called Myotonic Dystrophy. There is no cure, so it's best to just get back on ship and go about life as usual. Oh, and by the way Mr. Bade, you have it too." Okay, this is where I ask for a refund, this isn't the fun ship anymore. What do you mean my baby has MD? AND MY husband? How? It's not in my family! What about the other kids? Better test them too. Do I really want to know? (About now I'm booking tickets for the whole family on the Denial Ship) How could I be a nurse and not know about this? How could I not have seen? Must be that I just need to pay closer attention and head off unwanted passengers on our tour. I become the hypervigilant, what most medical professionals know as a "pain in the ass" (a very technical medical term) family member. I read all the journals, surf the net, and attempt to create a new manifest for our Voyage. That old one definitely needed modification.

What I perhaps failed to acknowledge is that while I was trying to direct the voyage, I was not the Captain. It took a complete cancellation of my passport for me to recognize that fact. Following an emotional mutiny, I decided that the cruise would be better if I were not onboard! I, fortunately, was rescued at sea and am alive to continue this journey. I am now allowed back onboard, but with a restricted passport. I cannot take the Journey that my husband or my children will take with DM1. I must be an observer. Now, I've never done well observing at a distance, I'm a 'hands on' learner. I begin to build my repertoire of life vests. Support Groups keep me centered yet focused. My Faith keeps me sane and on deck. My love for this crew keeps me fully ticketed for passage.

When my family enters the hospital, my nice Volunteer Director, Nurse and socially respectable observing passenger all seem to take lifeboats. I am now the "wife" the "Mother" and sometimes I'm still known as "the bitch". I've learned to expect the unexpected yet I am still quivering when it arrives. I've learned that to be complacent usually means that others will suffer from complications. I watch helplessly at times as my family takes their discovery tour and docks on a special island where multitudes of "the way it used to be's" and "If only's" clutter the shore. My heart literally drops a deck or two as I watch my husband cough and struggle for breath at some of our ports. I agonize silently as my kids take repeat cruises through gastric reflux, abdominal pains, and isolation from other "normal" kids. I wonder what ship will be built that will take them beyond the realm of what we have already encountered or are yet to discover.

I've watched others travel the road of chronic disease. Too often I've watched them struggle to go it alone, their support systems rusted and fatigued. I will be forever grateful to the MDA and our support group for the wind they have put in our sails. From humble beginnings and the birth of MDF, we are assured we are not alone, we are united and we have a common hope. You may encounter us at different stages of our Journeys and wonder why we stay on board; to this I can only speak for myself:

I have never sailed with a more spectacular, a braver, and a more non-stop entertaining crew.

I hope one day that our ship does change destinations, that it gets around to the other side of the island and we can look back to a place and time that "used to be" where the battle for a cure was fought.

- ❖ In July of 2005 my dear first mate ended his voyage. He lives on in my heart and in the dedication of so many friends and families that have joined us over the years. He is at rest in the Master who continually provides the wind for our sails and life vests for each storm in our seas. I miss him, love him and know that I and our children are better travelers for having him pave the way for all of us.

*Diane Bade, RN*

~~Wife~~ Widow, Mother and yes, still an occasional bitch.

Diane Bade, RN  
Arcadia, California

Diane is a registered nurse, by training and a care giver by avocation. Diane works as the Director of Volunteers for Methodist Hospital of Southern California. She has been associated with Methodist Hospital since the age of 15 when her parents were involved in a fatal car accident. Spending months at the bedside provided a view of healthcare and the impact it made on not only her but her family and career choices. She is energized and inspired by the efforts of over 600 volunteers who help to create the compassionate patient experience that she believes in. Caring for the whole person, physically, emotionally and spiritually, Diane incorporates her values in assisting patients and families. She has traveled her own course as caregiver, professionally and personally.

She is the widow of Christopher Bade having journeyed with him for over 30 years with (DM1). Three adult children; Scott, Nicholas and Christine, all with the Myotonic Dystrophy mutation, are a daily support for Diane in the loss of Chris. Diane is also blessed to have her husband's family; Pat Bade, Susan Bade Hull and Judy Morrison as an extension of Chris with her.

Diane copes with the challenges of life by faith and humor. She has been involved with the MDA Myotonic Dystrophy support group network since its second meeting and hosts the Los Angeles Area Support Group meetings in her home in Arcadia. Raising funds for research and assisting families dealing with the constraints of chronic illness has been enhanced by the formation of the Patricia A. Bade foundation of which Diane is a trustee. The annual Bade Memorial golf tournament has raised thousands of dollars for Duchene and Myotonic Dystrophy research. She is proud of the traditions and relationships that have grown through the years in her efforts to reach families, caregivers and medical personnel caring for the multitude of issues and complications arising with Myotonic Muscular Dystrophy.



## Caregivers Emotional First Aid Kit

1. Smile, it's not funny how often we forget to do this simple act and how well it lifts our spirits
2. Call someone who makes you feel good, especially if you haven't spoken with them in a long time
3. Have a bite of something sinfully delicious, while being conscious your own dietary limitations. When was the last time you treated yourself to a snack?
4. Take a bubble bath, once you make sure that your loved one is safe and secure, nothing expresses caregiver self-care better than a leisurely bubble bath
5. Read, pick up that novel or re-read that motivating poem. When was the last time you turned off the television, turned down the phone and read something nice? (P.S. this tip goes very well with tip number 3.)
6. Get a massage. It's like taking a mini vacation. It will relax you and take care of all the tension you build up every day.
7. Buy yourself some flowers. You deserve it and the sight and smell of something beautiful and fragrant will give you a reason to smile (see number 1).
8. Take a walk at a pace that allows you to feel the energy of the wind washing over you.
9. Go shopping buy something "just for you", something that makes you feel special.
10. Go online. You can explore different places, find new friends and learn new things. Make the Internet your getaway even when you can't get out of the house.



## Today's Caregiver Family Checklist

The most loving gift a person can give to one's family is to put your affairs in order before a disaster or medical emergency. To assist in providing that gift, Today's Caregiver has compiled the following list. The information and documents you should have prepared:

- All bank accounts, account numbers and types of accounts and the location of banks.
- Insurance Company, policy number, beneficiary as stated on the policies and type of insurance (health, life, long term care, automobile, etc.).
- Deed and titles to ALL property.
- Loan/lien information, who holds them and if there are any death provisions.
- Social Security and Medicare numbers.
- Military history, affiliations and papers (including discharge papers).
- Up-to-date will in a safe place (inform family where the Will is located).
- Living Will or other Advanced Directive appropriate to your state of residence.
- Durable Power of Attorney.
- Instructions for funeral services and burial (if arrangements have been secured, name and location of funeral home.)