

Live discussion: mobility, exercise, adaptations

In March, physical therapist John Bargas and occupational therapist Diane Johnson, both of Banner Good Samaritan Medical Center in Phoenix, were the hosts of one of TMA's live discussions. Bargas has worked in physical therapy for 20 years, 14 of them in neurological physical therapy, and the last nine at Banner.



needs and concerns? Did he or she educate you as to why one option is better than the other? Do you feel any pressure to choose one over the other? Are you given the opportunity to try the different options?

Here in Phoenix, I work closely with the different wheelchair vendors. If requested,

our wheelchair vendors will bring a scooter or a power chair out to your home to make sure that it fits your needs in your home environment. Is the PT able to arrange that for you? If not, does the vendor have a showroom where you could go look at the equipment? Since these are generally expensive pieces of equipment, I prefer that my patients have a chance to try out the equipment before we submit an order. These are all things I would ask the PT to arrange for you.

Another area that I discuss with the patient during a seating evaluation is transportation of the powered mobility. Depending on the equipment you get, there may be a lift for the back of your vehicle, or you may need a handicapped van for transport. Does your PT know of any businesses in your area that could help with that?

Again, it takes a bit of coordination, but your PT will probably be able to help you with this. This is a bit of a "puzzle," and you need to have all the pieces explained to you, so that

you can make an informed decision. I have found in my experience that I need to really listen to my patients so I can make sure that they are making the decision that best suits their needs. If not, then the powered mobility won't be used. One caveat: make sure you understand what your insurance will pay for, if you have a co-pay, and how much it is. This is something that our wheelchair vendors work closely with the patient on. No one wants a "surprise."

I have IBM and find that ongoing medium level exercise seems to be all I can do; so far progression of the condition seems to be very slow, much slower (and not affecting my quadriceps at all), than other IBMers I know who do not exercise. It seems to be surprising my specialists who now wonder if I don't have IBM but some other condition. I have trouble walking, but find long bike rides easy and freeing! Any comment?

John Bargas: Keep working with your doctors on differential diagnosis. Due to your slow progression and your positive response to exercise, you should continue with it, as long as it does not negatively effect your quality of life.

I have IBM and have lost a lot of grip strength. What physical therapy can I do to improve or maintain what strength I have?

Diane Johnson: First, I would recommend an occupational therapy evalua-

Johnson works for Banner in its multi-disciplinary clinics that include both neurodegenerative diseases and movement disorders, and is the primary OT on the clinic team. She also has a specialty in wheelchair seating.

Following are edited excerpts from the questions and answers. For the full transcript, go to www.myositis.org, and look under "Community/Live Discussion."

My physical therapist recommends power mobility for me. How can I find out what scooter or chair is right for me? Also, how will I get it in and out of and on my vehicle so that I can go out by myself?

Diane Johnson: Is your PT a seating specialist or an assistive technology practitioner? How long has he or she been doing seating and mobility evaluations? If you have had a seating evaluation, did he or she go over the pros and cons of a scooter vs. a power chair? Did he or she listen to your

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Published by: TMA, Inc.

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Do you believe in magic?

By Marianne Moyer, TMA Board of Directors Chair

Google "magic" in songs, and you'll get hundreds of hits. In keeping with the Annual Patient Conference theme, "It's not magic, it is science," I believe that magic is something wonderful AND believable. Remember the Lovin' Spoonful song, "Do you believe in magic?"? I believe there is something magical happening in the world of myositis. Here's why.

Each year we say this Conference will be better than the last one, and 2012 will be no exception. TMA staffer Aisha Morrow found a wonderful venue, with first-rate hotel and Conference rooms at a competitive price. Aisha performed magic for us! The sessions will be some we know and love, like "Get Acquainted," "Myositis 101," and "Coping with Prednisone." Since many attendees are always first timers, it's critical to provide the basics, but you'll also see an emphasis on caregiver issues, support groups, and new developments like tendon transfer surgery, autoimmune antibodies and ongoing research. That's the "science" part. Theresa Curry is like a magician, pulling all kinds of good information like a rabbit out of her hat.

For me, the most magical treat of all is reflected in my current effort we're calling "Marianne's Meanderings." I'm visiting a handful of KITs (support groups) around the country with two goals in mind. The first is to let them know that the support group is an extremely powerful way that patients and their caregivers can learn more about coping with myositis. It breaks my heart that I continue to talk with people at these meetings who say "I've had myositis for 12 years and this is the first time I've spoken to another patient." The magic here is that these people now have someone with whom they can "Keep in Touch." My second goal is to engage in dialog with other KIT leaders so we can create synergies to connect our groups, help other KIT leaders, and ensure that TMA is doing whatever is needed to help them. That's magic and it's science.

I'm very excited that once again we will offer a few of the Conference sessions to those unable to travel to Orlando. Streaming video is a science that delivers the magic of speakers who are outstanding in their field right to your computer. We'll let you know which sessions will be available and when, but remember that even if you miss seeing them live, these sessions (like the three from 2011) will be available on TMA's website, shortly after the Conference concludes.

Here's to magic and science!
Marianne

Myositis Information Cards

TMA now has personalized cards to help you spread the word about myositis. These business cards display your name, phone number and email along with contact information for TMA, and a brief, plain language description of DM, PM, or IBM. You select which disease description you want on the back of your card. Use these cards to inform people about myositis and direct them to additional resources about the disease. It's also a great way to spread awareness and save you the trouble of explaining what myositis is.

For \$20.00 you will receive 100 personalized cards, and the UPS Store offering these cards will donate \$5 to TMA for each order. The price includes taxes, shipping and handling for U.S. destinations. To order your cards, contact the UPS Store at 770-297-9944.

Live Discussion, from cover.

tion with either an outpatient OT or an outpatient certified hand therapist. They will assess your hand strength and help you learn what would be best for you to maintain or improve your grip strength. It may be gentle range-of-motion exercises, it may be a home exercise program with soft thera-putty, it may be tendon glide exercises.

In addition, the OT should work with you on compensatory strategies to improve function. For example, would built-up handles on utensils help you? Using a button hook for buttons, or elastic laces on your shoes? The therapist could do an "Activities of Daily Living" assessment with you during which you go over your day from the time you get up until the time you go to bed to help you address any issues you have.

I have PM, diagnosed in 1999. My age is 70. Is there any way to increase my muscle strength, rather than just trying to maintain what I have left?

John Bargas: If what you have left allows you to live a life that is functional and independent, then I would say that maintaining is good and you've found a good balance. If you feel that you have higher goals and activities you'd like to do but cannot currently, I would advise seeing a local physical therapist who can help you toward your goals. If you're finding the workload to be excessive and leaves you fatigued, losing ability or in pain, then I would say that building muscle strength may not be the best approach for you, and a maintenance program will work best and may need to be adapted periodically if further weakness occurs.

Is a vibration machine good for people with myositis and osteoporosis? If so, which would be better, the up and down motion

of the "power plate" or the oscillating motion of the nobrex K1?

John Bargas: Vibration machines activate muscles. Your body has to counter the perturbations the machine gives you and therefore reacting to the movement is healthy. All motions have benefits. Be careful though. Vibration can also inhibit or fatigue muscles. If you find yourself fatigued, you may want to decrease the frequency and duration of the exercise session.

What is the ideal type of exercise for patients with myositis? Is Pilates one of them?

John Bargas: There's no ideal type of exercise. The ideal program should be client-specific to meet the needs of that client. A physical therapist working with a person with myositis should identify weak muscles and stronger compensatory muscles. He or she should find exercises that work all muscle groups without the excessive fatigue that leads to diminished functional mobility or increases fall risk due to post exercise fatigue and further balance impairment. The therapist should focus on range of motion and protection of weaker muscle groups and may decide to use resistive, anti-gravity exercise to strengthen muscle groups not affected by the disease and can help improve function, and therefore quality of life.

How can a myositis patient realize the optimum level of exercise: that is not to do too much and then feel exhausted, and not to do too little and not exercise sufficiently?

John Bargas: Remember, each person diagnosed with myositis has a different distribution of strength and weaknesses. Therefore, I strongly recommend that you see a movement specialist (like a physical therapist) who can help you find the ideal program for you and address your specific issues. Think about keeping a log of your activity and exercise with a

fatigue/effort rating like the Borg scale (a way to measure perceived exertion).

Try to make connections between exercise completed and how it relates to function for you. Exercises that lead to improved function should be duplicated two to three times a week, and if some lead to exhaustion and dysfunction, you may want to adapt. How to adapt? Find a local therapist who specializes in chronic degenerative neurological conditions. They'll know how to help you. They'll just need to make sure not to exercise you during a flare-up.

I have had PM since April 2004. I am 44 years old. I am currently off all myositis medications since August 2011, at the advice of my rheumatologist because my CPK levels have been normal for over a year. However, my body still feels like it has weights tied to it. I am unable to follow any exercise program for more than 10 minutes, then I am exhausted. I need to do some sort of activity. Any advice?

John Bargas: Have you tried aquatic shallow-water physical therapy followed by a community-based shallow water program? It is less exhausting and you can duplicate functional activities in the water that you cannot on land. If your body feels like it has weights tied to it, gravity reduced activity/exercise should work well for you.

I have newly-diagnosed DM with interstitial lung disease. I have had an EMG and I'm told the weakness is mild and there are no neurological concerns. My calves are stiff after standing or walking much at all, is this the pain associated with inflammation? Are my muscles being destroyed and broken down when this happens?

John Bargas: Please ask your physician this question as well. It's not uncommon to have stiffness and some

See Live Discussion, page 7.

Bill Simeral: Recovery is possible

My name is Bill Simeral and this is the story of my life with polymyositis and lupus. It begins as a story of horror but ultimately is one of hope.

I am married and have four grown sons and eight grandchildren. I led a physically active lifestyle until getting sick at age 62.

As a young adult I learned alpine skiing and discovered what would become my lifetime passion. Life in our house revolved around skiing. My wife gave me a cherished sign many years ago that read: "We interrupt this marriage to bring you the ski season." Although I stopped teaching and coaching years ago, I continued to ski 30-40 days a year or more and worked out year round to stay in shape.

My real vocation was in agribusiness and I owned a brokerage business that I sold in the late 80s, when I entered the emerging technology business. Today I still do computer and network consulting to keep busy.

In 2004 I was as fit and healthy as I had ever been and was still enjoying golf, skiing, hiking and mountain climbing. That September, my annual blood tests showed a low platelet count and anemia, although I had no symptoms. After nine months with no diagnosis, it was thought that I had lupus. The disease had probably been lurking for 15 years because I had a history of low platelets and mild anemia but no other symptoms until my platelet count dropped.

After symptoms appeared, lupus was quickly diagnosed. My rheumatologist suspected I had mixed connective tissue disease which also can include polymyositis and scleroderma. My condition gradually worsened and short-course treatments only worked for a few days. I was admitted twice

to the hospital for further tests and put on 60 mg of prednisone.

After Thanksgiving 2005, polymyositis hit me like a freight train. I lost 40 pounds of muscle in a week, could not swallow, and was soon fighting for my life. I entered the hospital and would not get out for two months. In a few days I was quadriplegic and had autoimmune induced hepatitis with a failing liver. Prednisone did not work nor did IV meds. Just in time, I was given a five-day treatment of IVIG that worked, but the muscle damage was done. I had limited use of my hands and could wiggle my feet but nothing else worked. It appeared I had no muscles left.

In January 2006 I was transferred to Marianjoy Rehabilitation Hospital, unable to move or swallow and with a feeding tube. During my initial evaluation, I was asked to set my end goals and, predictably, they were to ski, play golf, and hike and climb again. My rehab doctor counseled me that would not be possible. He thought I was in total denial about my condition and prospects.

I had my wife prepare a sign for my hospital room with these short-term goals: STAND, REACH, and SWALLOW. When the doctor saw my sign, he realized that I was not nuts, just determined to see if recovery was possible. I was the eternal optimist facing a forest fire with a bucket of water.

I had to be winched into the thera-

py pool, and that was the only way I could work my remaining muscles. The rehab hospital was like a Marine boot camp with two objectives: get me mobile and swallowing again. This was by far the most difficult

thing I have ever done, either physically or emotionally. I was totally fatigued all the time but I parsed my tasks by the hour. If I could get through the next hour I would then face the next one, and the next one. If I had envisioned the whole mountain I had to climb instead of concentrating on each step, I would have been quickly over-

whelmed and probably given up.

My therapists taught me to celebrate every small gain and ignore the repeated setbacks. I could never have done it without the help of my dedicated and creative therapists and doctors. When I began to be able to use my arms again, I asked my wife to buy some dumbbells so I could do extra work in my room. Before getting sick I could curl 50-60 - pound dumbbells but now could barely use my arms. She bought a two-pound dumbbell for me. I said, "But it's PINK!" She said the pink dumbbell was my incentive to get to the 3-pound purple one. At first, I could barely curl it, but within a few days moved on to the purple one.

Miraculously, I was able to stand (barely and with help) in ten days, and was able to walk and go up stairs within five weeks. I looked like a scarecrow, a shadow of my former self, but I was vertical and somewhat functional. I was finally going home.



Going home. Oh no! I was no longer in the safety cocoon of the rehab hospital and it was one of the most stressful days in my life. My poor wife was even more stressed than me, if that was possible, but I was determined to do all the things I knew I could do and do them safely as I had been taught. I continued to go to out-patient physical, occupational, and speech therapies, and gradually improved. The most difficult obstacle was swallowing but I finally got my G tube pulled and could eat and drink again. Everyone thought, given my athletic background, being quadriplegic would be the biggest obstacle but swallowing was. I was ecstatic when I could eat real food again and drink a cup of good coffee and a glass of wine.

The rest of the story, as the late Paul Harvey would say, was my own effort to recover. My "job" became to recover but also to enjoy each and every day. I had come within a few days of not making it so I was living in "bonus time" and determined to make the most of it. When formal therapy ended I went back to my health club to see how far I could recover my strength and stamina. The first day I spent several hours trying to figure out simple things like how to get on and off various machines safely. My first attempt to get on the Lat pull-down machine was a disaster. Normally I would set it at a heavy weight and used it as a counter balance to sit down slowly. Of course, I had to set it at very low weight and did not consider that it would not counter balance my body weight. I crashed to the floor and several people rushed to help. It took quite a while to get off the floor but the only thing hurt was my pride. And so, my own efforts began.

Five times a week I worked out and soon developed an effective strategy that balanced the need for exercise and rest which I called the "less is more strategy." My routine involved

stretching, light weights, range of motion, tai chi, moderate cardio (that's all I could do) by walking or elliptical, theraband, and swiss ball exercises. As I progressed I was able to return to my old workouts with free weights, machines, calisthenics, and walking, but at lower weight/resistance/intensity than before getting sick. I kept a log in Excel and recorded slow but steady progress.

My lower body came back faster and stronger than my upper body, and that is still true today. None of these workouts were easy since I was tired most of the time and had muscle and soft tissue pains after losing so much muscle tissue. Pain was my constant companion. The key was to keep doing it but also to know when I had done enough and take a break. Less is more, but do it again.

On December 17, 2007 I made my return to alpine skiing. I was nervous and not sure what would happen, particularly if I fell. One of my sons went with me to our small local hill and I skied a few shaky runs on the bunny hill and then on the "big" hill. I survived and called my wife from the hill to tell her I would not be going to the hospital that night. I did it. That winter I skied many times and continued to improve and gain confidence. By the 2009 winter season I was traveling with my grandson, a skilled ski racer, to his race, and coaching and demonstrating turns and technique to him and others on the hill just like nothing had ever happened. Even I was amazed and thrilled. I made sure to tell my doctors and therapists and thank them for giving me this part of my life back. I had dreamed the impossible and it had happened but I could not have done it without their help and dedication. And my wife's patience.

Until July 2011 I continued to take both prednisone and azathioprine to control my diseases. I have not experienced any flares since January 2006. I hope it continues, but I will not

waste a single day just in case. I hike with the help of hiking poles for safety on steep trails.

Over the past 5 years I have returned to physical therapy several times to treat some particularly difficult areas and have made progress with them. My own workouts, whether just normal ones or therapy guided, will never end. The massive loss of muscle means I do not have the reserves I once did and I want to make sure that as I age I remain as strong and functional as I can.

Why was I able to recover so well from such a severe case? First, I had great support from my wife and family and friends and really great doctors and therapists who bought into my delusion about recovering. Second, I am an eternal optimist and believed, although I had no idea how, that I would recover somehow. Third, I am incredibly stubborn (my Scotch heritage) and was determined to give it a go despite the advice of experts. Fourth, I immediately accepted what happened to me and defined a new normal for myself with the hope of improving it. Although I was not happy about it, I was not angry at what had happened and was able to focus my energy on first surviving and then recovering, one step at a time. And lastly, my doctors started my recovery even before getting the diseases under control. Early and aggressive physical therapy made a difference.

In the course of recovering I learned to reach out to others for help more than I had ever done. I participate in two support groups, co-lead a TMA support group, and also work with disabled patients at Marianjoy Rehab Hospital.

My advice to those with polymyositis or dermatomyositis is to persist and believe you will get better. Be an optimist who sees the glass half full. Manage your healthcare actively.

See Meet Our Members, page 8.

Surgeon explains IBM tendon transfer

Johns Hopkins surgeon Dr. Thomas Brushart has used tendon transfer successfully in IBM patients who have lost hand function. Dr. Brushart will be at the TMA Annual Patient Conference in September to talk about this procedure. He answers some common questions, below:

What is a tendon transfer?

The term “tendon transfer” refers to a surgical procedure in which a normally functioning muscle and tendon unit is disconnected from its attachment to bone and reconnected to a new bone or tendon to restore a function that was previously lacking. Several criteria must be met before a muscle and tendon unit can be sacrificed for this purpose, the most critical of which is that loss of its original function will not compromise the hand to extend the wrist, so one may be transferred without sacrificing significant wrist function.

Why is tendon transfer surgery potentially useful in IBM?

Tendon transfer surgery is potentially useful whenever there is an asymmetrical neurologic deficit in the upper extremity (if all muscles are equally weak, transferring one of them will make no difference). In the case of IBM, the most common early finding is weakness of what are termed the “long flexor muscles,” those that originate in the forearm and send their tendons through the palm to the fingers, where they bend the last (closest to the nail) joint of the thumb and the last two joints of the fingers. If other muscles in the arm and hand are still strong, there are enough that can be spared in order to restore finger and thumb flexion.

Is tendon transfer useful in all patients with IBM?

Tendon transfer is most helpful when the long flexors are very weak and other muscles are still strong. Based on

my experience with IBM patients I have formulated a tentative classification system to help treatment planning.

■ Stage 1: Long flexor weakness is mild to moderate, but patients can still make a full or nearly full fist and have independent finger function. At this point surgery is not helpful.

■ Stage 2. Long flexors are very weak or non-functional (the fingers can still be flexed, but only at the joint closest to the palm), yet the strength of wrist and finger extensor muscles is maintained. These patients are ideal candidates for tendon transfer to restore both thumb and finger flexion.

■ Stage 3. Both long flexors and extensors are weak, leaving only the small muscles in the hand with normal function. In this case, the last thumb joint can be fused (permanently stiffened in a position of slight flexion) so that the muscles at the base of the thumb can still flex the thumb as a unit. We are working on splinting systems to immobilize the last two joints of the fingers so that the power of flexion that remains at the base of the finger can be transmitted to the fingertips for light activities such as typing.

What happens after surgery?

Tendon transfer surgery is performed as an outpatient surgery, so an overnight hospital stay is not necessary. Most often the surgery is performed under regional anesthetic (the entire arm and hand are numbed). At the completion of surgery the hand and forearm are bandaged and splinted in a position that relaxes the tendon transfers to minimize the risk of damaging the new tendon attachment during the early stages of healing. This is usually removed one week after surgery, at which time a custom plastic splint is fabricated to immobilize the hand and wrist in the same position for an additional two weeks. Three weeks after

surgery the patient begins to mobilize the wrist and fingers under the care of a hand therapist, a process that may extend for an additional 2-3 months.

How soon can I use my hand after a tendon transfer?

The hand must be protected for at least six weeks after the transfer(s). If too much stress is placed on the hand too soon, such as trying to help push up from a chair, the tendon transfer can pull apart and be useless. In my experience, the surgery and therapy are the easiest part. Patients and their families are most troubled by the inability to use the immobilized hand, especially if the patient is barely able to rise from a chair with the help of both hands. Planning for the post-operative period is critical, and outside help for 4-6 weeks is often necessary for patients in whom IBM has significantly compromised leg function.

Who should do tendon transfer surgery?

Although most experienced hand surgeons have performed tendon transfers for traumatic nerve injuries, few have treated systemic neurologic diseases such as IBM. My team and I are still learning from each patient that we evaluate, and have initiated a prospective study of the role of tendon transfer in IBM. Once we have gained sufficient experience with the outcomes of various treatment options ourselves, we can produce a treatment algorithm that insures that other surgeons and their patients will benefit from our experience.

Dr. Brushart is a professor of the Hand and Peripheral Nerve at Johns Hopkins. He can be reached at 410-955-9663; email tbrusha@jhmi.edu.

TMA Board Member Danielle Haines had tendon transfer surgery in November. See her firsthand account, next page.

A patient's experience with tendon transfer surgery

I am aware that I have had IBM for 22 years. Until four years ago, I had full use of my hands. Then I began to notice weakness and inability to make a tight fist in my right hand. I am left handed. The entire right side of my body is always two years ahead of the left in the progression of muscle weakness and functional losses. Six to eight months before my surgery at Johns Hopkins, my right hand was virtually useless. I could not hold a cup in that hand and dropped anything I tried to hold, even small objects. None of the fingers on the right hand flexed on command. Each day, I passively moved all the joints to prevent those joints from becoming stiff or immovable.

Surgery:

- Outpatient
- My surgery took two hours, fifteen minutes
- One incision on the back of the hand, measures 1 ½ inches
- One incision on the inner surface of the forearm, mine is 2 ½ inches
- The third one is on the under surface of the forearm, 3 inches in length
- Incisions were more tender than painful, especially the longest one
- I took a pill for discomfort only four times

Recovery

After five weeks, the incisions were barely visible thin lines (I had used cocoa butter on them as soon as the dressing was removed). Two fingers, index and middle fingers, moved as they had not in three years the first time I had therapy.

The thumb took longer, six weeks, but now bends.

I had physical therapy with a certified hand therapist for ten sessions over five weeks. With the exercises and techniques I learned, I was amazed at all the things I could do. Simple things like lamp switches, turning knobs, opening packages are now easy! My old useless hand is now my strong hand. Objective testing with metered devices and timed tasks shows near normal function of the surgical hand.

The difficulty for me was the weeks of not being able to use the hand or arm when getting up from a chair, out of bed or a car, etc. My husband had to "get me up," wash my hair and assist with all the activities of daily living.

Logistics: The nights before and after surgery, we stayed at a local hotel, six minutes from the Hospital. The first return visit is at one week for the removal of the bulky dressing and fitting of the splint. The second week after the surgery is the return visit for removal of the stitches.

As a retired orthopedic nurse, I found this surgery fascinating. It is to my knowledge, the first time people with IBM have had the opportunity to reverse the progressive decline in functional ability. Other muscle group losses are significant and frustrating. Losing the use of one's hands profoundly affects a person's dignity.

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discomfort with DM. Calf stiffness from standing and walking is more indicative of stretching and most likely not breaking down of muscle, especially with normal activity like walking.

After a year of very little or no exercise, I have been given permission to "restart" my physical routine, but now my CPK levels are again climbing. I feel so wonderful to be hiking and biking again, but am worried I may be told to again back off. As a DM patient, do I need to carefully tailor my exercise to a minimum for life to keep my body from running into trouble?

John Bargas: Good news is that you have a positive response to exercise like hiking and biking. Exercise itself does not cause disease progression, but exercising during periods of CPK elevation and during muscle inflammatory periods may not be ideal. At that time, muscle is already under stress, so additional stress may not be ideal. You should consult with your physician and follow his or her guidance on this topic.

TMA's website at www.myositis.org has many resources for those with questions about physical therapy. Find out more about physical therapy and aquatherapy at "About Myositis" under "Treatment."

John Scandura, the physical therapy director of the elite National Training Center -- a Florida physical training facility that works on rehabilitation of world-class athletes as well as people with chronic disease -- will be a speaker at TMA's Annual Patient Conference in Orlando, Sept. 13-16. Scandura has a special interest in teaching patients how to work with their physical therapist toward the program that's best for them.



A defining moment

By Andrea Taylor Langworthy

Andrea Taylor Langworthy writes a periodic column for "The OutLook" about her experiences and observations as a patient. Andrea is a freelance writer who lives in Minnesota, where she leads the myositis support group. She writes a weekly column for the Rosemount "Town Pages" newspaper. She has IBM.

When I was first diagnosed with inclusion-body myositis, I prayed it would go away.

Twelve years later, I'm not cured. In fact, I'm worse. But healthier. The illness forced me to let go of a life I often compared to a treadmill: get on each morning and go-go-go until you fall off at bedtime.

There are things I miss about that old life, such as the ability to climb stairs or take a brisk walk, but now, I am doing things I never would have considered before. With people the old Andrea never would have met.

It took awhile but with my doctor's help, I finally figured it out: Being diagnosed with a chronic illness means the loss of the person you were, but it doesn't mean there isn't a new and improved version waiting right around the corner.

"Do you think I'm depressed?" I had asked the rheumatologist. "You're in mourning," she said. "Mourning the old you."

Elisabeth Kübler-Ross's theory of the five stages of grief came to mind: denial, anger, bargaining, depression and acceptance. I had been stuck in the denial stage and needed to go through the remaining ones in order to move on. I would need to bury the old me so the new version could emerge.

I took out my journal. For the first time, I stopped sugar-coating my feelings. Page after page, I vented at whoever had targeted me for this disease; whatever made my body turn on itself. Unlike the two women whose funerals I had recently attended, whose friends talked about them in saintly terms and said they never asked, "Why me?" I asked the question over and over.

Next, I promised to stop looking skyward, bargaining with false promises to give up sugar, movies, coffee, anything that would bring back my good health. I found a large box and lined it with tissue paper. Because I would never run, walk, or hobble 26.2 miles again, I placed my four marathon medals inside.

Next were my business cards: New and Used Vehicle Sales and Leasing. Selling cars required a lot of walking and hustle-bustle. Unable to hoist myself into a pickup truck, kick tires with a customer, or even lift the hood of a sedan, those days were gone.

I wrote perfectionism on a piece of paper and placed it in the box. I couldn't hold myself to the same standards as before. A high-heeled shoe followed; no more heels or flippy sandals for me. Sturdy shoes with flat soles to keep me steady and upright are required now. (But please, God — can't someone design some that are stylish enough for a wedding?)

When my husband and I sold the house we built when we were married, I kept a souvenir key. Every time I came across it, it brought memories of the three-season porch, the woods behind us, the deer and birds that made our lovely back yard theirs. The fourteen steps to the second floor had become impossible and dangerous for



me, so we moved. I dropped the key to the old place into the box alongside the journal I had just filled.

It was time to bury my denial, anger and bargaining and move forward to acceptance. I put the cover on the box, tied it with a big black ribbon, and asked my husband to bury it in the furthest point of the storage area.

"Amen," he said.

"It is what it is," I said. I looked out the living room window to our empty new deck and made a mental note to buy bird feeders and seed.

"It is what it is."



Meet our member, from page 5.

Stay as active as you can even when your labs are high. It can be the mildest of activity but use your body any way you can safely do it. I credit my doctors for ordering PT even when my CPK numbers were 13,000 or higher. It is always best to seek professional help when beginning. Reach out to others. I could not have succeeded without the support of my family, friends, and healthcare professionals. Don't forget to laugh.

It is my hope that my story will help others to find a way to cope with myositis and reshape their lives in a positive way. Recovery is possible.

Time for me to plan my next adventure trip.

