

IBM Warriors Best Practices

for Living with Inclusion Body Myositis

These best practices were put together by patients in our closed Facebook support group, Inclusion Body Myositis Support and Understanding.

SELF HELP

- Join the MSU/TMA web sites and learn as much as you can about Inclusion Body Myositis.
- Listen and learn from the “world wide professional Myositis experts” and fellow Warriors.
- Attend TMA annual patient conference.
- Wear your myositis wristband every day. People will see it and may ask what Myositis is. It’s a great tool for making more people aware of Myositis.
- Take charge of your own health; don’t be afraid to get a 2nd opinion, or even a 3rd
- “Take care” of your **caregiver** so they can take care of you. Remember, they make your life easier so don’t make their life harder.
- NEVER give up!
- Discover what energy-saving devices are available and are of most use, your need for these will change.
- Take the IBM-Functional Rating Scale Evaluation

HELPFUL DEVICES

- Using a cane or walker/rollator make you safer when walking and gives you more freedom. Safety First. Don’t be afraid to use the aids that are available to you.
- Spring loaded Fiscar scissors make cutting easier.
- Assistive steering devices & push button auto ignitions on the car.
- A LONG shoehorn to help put your shoes on.
- Long handled kitchen tongs for picking things up.
- Use a pillow or foam pad to elevate the seat on your wheelchair, rollator, and on your house furniture, bringing them to a comfortable height to make standing easier.
- Take a thick foam pad to doctor offices to sit on and give you extra height when trying to stand.
- Purchase a bottle/jar opener

PHYSICAL HEALTH

Learn to listen to what your body is telling you each morning. Listening to your body will help you get thru your day better and keep you safer.

- If you suffer from Chronic Fatigue, take/schedule naps.
- If you have foot drop and trip often, invest in an Ankle-foot orthosis (AFO), also known as a “foot drop brace.” Find the lighter more flexible fiberglass types that are not as rigid or hot, if possible.
- If you have trouble standing from a seated position invest in a lift chair.
- Invest in a chair stair lift if climbing steps is difficult.
- Prepare for possible falls. Cover sharp corners, remove all trip hazards like area rugs, install grab bars and anchor heavy objects that might fall when you bump into them. Have someone else check your home for anything you might have missed.
- With your doctor’s permission, find ways to keep moving. Laughing, brushing your hair, opening and closing your hands, turning your head right and left are some safe ways for most of us to move.
- Invest in a Medical Alert Button
- Focus on things you do and do them with intent. Walk with intent so you don’t trip. Grip with intent so things don’t drop things.
- Replace heavy dishes with lighter, smaller, plastic dishes and silverware too.
- Keep items you use the most near the area you use the most and at a level you can easily reach.
- Have your cell phone with you and turned on at all times. Charge it daily.
- Exercise every day or every other day, but only as much as you are comfortable with.
- Not all muscles are affected by IBM. Use the ones not affected to try and compensate for the ones that are.
- Keep your focus on what you are doing. Concentrate when walking and trying to turn while walking. Go slow and take your time.
- Be aware of what your feet are stepping on. Even a slight irregularity on the ground can trip you up.
- Team up with your caregiver and create or update a “Bucket List” you can enjoy doing together.

MENTAL HEALTH

- Count your blessings. Start your day with positive thoughts.
- Finding purpose for the talents you possess will keep your self-worth strong and may help reduce or prevent depression. It may slow or prevent cognitive decline.
- Don’t be afraid to ask for help. True friends will be there for you.
- Do what you can while you can. Travel
- Plan things to look forward to and then reward yourself. Make the best of every day so we keep making our Book of Memories.

- Try to reduce your stress. Chronic worry will only depress you. Find ways to relax. (Meditation, deep breathing)
- Keep Depression under control as best as possible. If necessary, take medication and/or get therapy.
- Be appreciative, say “Thank You”. Do something to let your support group know you appreciate them.
- Go outside everyday, even for a few minutes. Enjoy the fresh air, breathe it in but do it safely.
- Find a spiritual program or people who share your beliefs.
- Write your prayers in a journal and when discouraged go back and read them. You’ll be amazed how many were answered but you forgot. Pray and give thanks.
- Find ways not to be alone. If necessary, get a pet. Dogs and cats make great companions.
- Find ways to interact with other people. Set a goal for interaction each day.
- Play brain-stimulating games like Word-Find, Sudoku, and Crossword Puzzles to keep your brain active.
- Play “Brain Games” on Lumosity.com or games like Word Chums and Words with Friends.
- Learn a new skill, start a blog, write a book or volunteer in your community. It keeps you younger and prevents depression.
- Laughter is the best medicine. Read joke books or watch funny movies.

DIET AND NUTRITION

- Eat healthy foods like lean meats, fish, veggies and fruits.
- Limit/reduce sugar, salt, fat and empty calories
- Try a Paleo-type diet. Find ways to reduce toxins in your body.
- Replace soda and other high calorie drinks with water. Water will help you deal with your IBM, reduce calorie intake and help regulate/maintain your body temperature. Water helps remove waste products and toxins and aids digestion. It keeps your skin smooth.

Thank you to the Warriors of Inclusion Body Myositis Support and Understanding for all your suggestions.