UT Health San Antonio Mays Cancer Center
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MPN Quality of Life Study Group

A Quarterly Report for MPN Patients

What's in this Issue?

The MPN QoL Study Group is very excited to put forth the fourth issue of the *Quarterly Report for MPN Patients*. In this issue, we feature a great read on the "how's" and the "why's" of self-monitoring fatigue. Our group has shown that fatigue is one of the most prevalent symptoms among MPN patients, and self-monitoring is a useful and informative tool that can help patients take an active role in monitoring and managing their fatigue.

Additionally, we share in incredible patient story that outlines Shannon' Richmond's battle to re-discover her purpose and her happiness after being diagnosed with MPN. Through the process of re-discovering herself, she found ways to give back to the MPN patient community and help raise awareness for MPN and the advancement of MPN research.

Finally, we share some upcoming MPN patient events to consider attending and share the first, of many more, MPN QoL Study Team Member personal biographies.

How to Get Involved with Our Group

We are looking to share more patient stories in future issues. If you would like to share your story with us and others in the patient community, please email rmeckert@asu.edu. A story that shares an experience or journey with others can be immensely powerful and can help in letting others know that they are not alone in managing their MPN. Hearing of each person's unique story lets others in the MPN community know that we are all in it together as we strive to be the happiest and healthiest versions of ourselves that we possibly can be!

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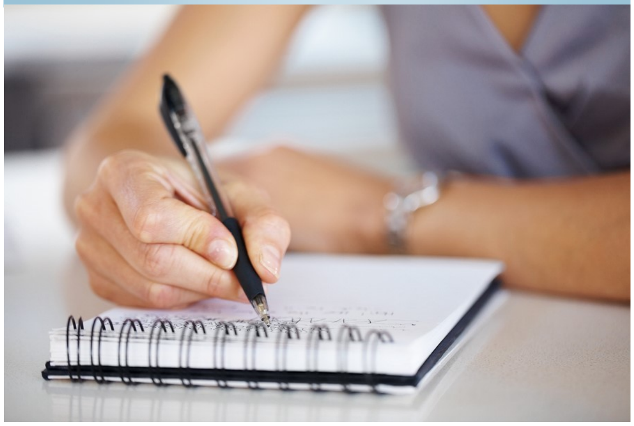
Special points of interest

- Learn the "how's" and the "why's" of self-monitoring fatigue
- Read an inspiring story of a patient that battles to re-discover her happiness post-diagnosis
- Learn of upcoming MPN patient events and conferences to attend
- Learn how to get involved by sharing your story with us

Self-Monitoring Fatigue: How and why?



Fatigue is one of the most commonly reported symptoms among MPN patients, being reported in upwards of 90% of patients or more in some studies. Fatigue also has a profound impact on MPN patients' overall quality of life and is cited as the symptom that patients would most like to resolve. There are many methods of managing fatigue that have been studied in other cancers, including pharmacologic and non-pharmacologic methods. The effectiveness of pharmacologic methods of managing fatigue is debated and there is the potential for side effects. Therefore, non-pharmacologic methods may be more appealing to both physicians and patients alike. One non-pharmacologic method that can be used to 1) manage your fatigue and 2) become more familiar with your own unique, varying levels of fatigue throughout the day involves self-monitoring. The following sections describe "the why" and "the how" of self-monitoring your fatigue.

Self-monitoring fatigue can help you become more aware of the ebbs and flows of your daily fatigue levels.

What Causes Fatigue?

There is no simple answer to this question as there can be many potential reasons why MPN patients are fatigued. However, the video in the link below does a great job at shedding some insight into the reasons MPN patients' experience fatigue:

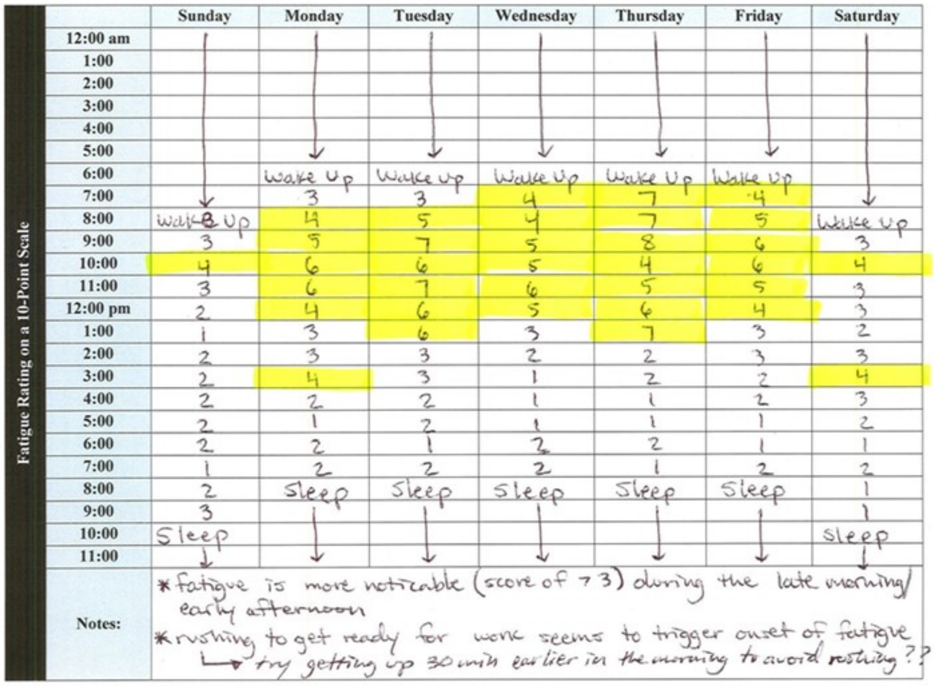
[Patient Power: What Causes Fatigue in MPN Patients?]

Why Monitor Fatigue?

Self-monitoring your fatigue on a daily or weekly basis can help you become in tune with when your fatigue is most severe, when your fatigue is least severe, and what events may trigger your fatigue. Self-monitoring will help you become more familiar with the daily fluctuations in fatigue that you may experience, thereby allowing you to structure energy-demanding activities around when you are least fatigued and reserving less energy-sapping activities for when you may be most fatigued.

The most common MPN-specific tool used to assess fatigue levels is the MPN Symptom Assessment Form, which typically contains a few questions asking how fatigued you have felt in the past week or in the past 24 hours. While this is a very useful method of assessing overall fatigue levels, self-monitoring daily fatigue hour-by-hour or over the course of the morning, afternoon, evening, etc., allows you to get a more granular picture of your overall fatigue levels.

Understanding what times of the day and what activities may trigger your fatigue can help both you and your physician in determining which treatment strategies to take in order to manage your fatigue. As often is the case with many aspects of MPN, the more you know knowledge you have regarding your symptoms, the better able you are to manage them.

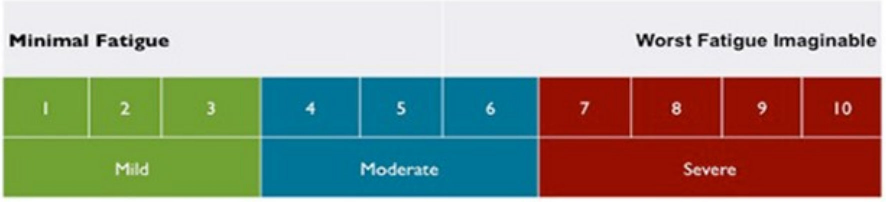


Fatigue Rating on a 10-Point Scale	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
12:00 am							
1:00							
2:00							
3:00							
4:00							
5:00							
6:00		Wake Up	Wake up	Wake Up	Wake Up	Wake Up	
7:00		3	3	4	7	4	
8:00	Wake Up	4	5	4	7	5	Wake up
9:00	3	5	7	5	8	6	3
10:00	4	6	6	5	4	6	4
11:00	3	6	7	6	5	5	3
12:00 pm	2	4	6	5	6	4	3
1:00	1	3	6	3	7	3	2
2:00	2	3	3	2	2	3	3
3:00	2	4	3	1	2	2	4
4:00	2	2	2	1	1	2	3
5:00	2	1	2	1	1	1	2
6:00	2	2	1	2	2	1	1
7:00	1	2	2	2	1	2	2
8:00	2	Sleep	Sleep	Sleep	Sleep	Sleep	1
9:00	3						1
10:00	Sleep						Sleep
11:00							
Notes:	*fatigue is more noticable (score of >3) during the late morning/ early afternoon *rushing to get ready for work seems to trigger onset of fatigue → try getting up 30 min earlier in the morning to avoid rushing??						

An example of a fatigue diary that was used to self-monitor fatigue over the course of one week. If you would like a blank version if this fatigue diary, email rmeckert@asu.edu.

How to Monitor Fatigue?

An example of monitoring fatigue over the course of a week can be seen in the image above. A simple method of tracking your fatigue levels is to track it hour-by-hour for one full week. Using the common 10-point Cancer-Related Fatigue Scale (see image below), you can assess your current fatigue level as each hour of the day passes.



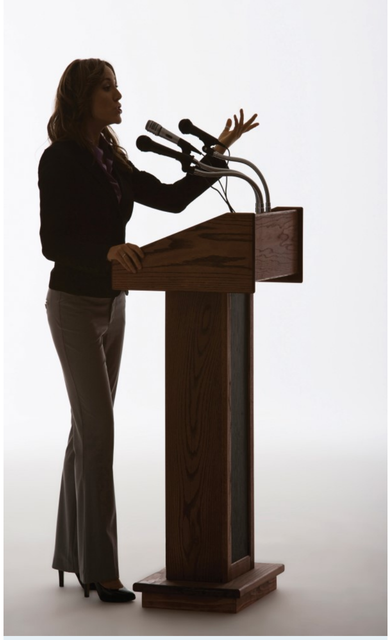
Minimal Fatigue									Worst Fatigue Imaginable
1	2	3	4	5	6	7	8	9	10
Mild			Moderate			Severe			

After you finish tracking your daily fatigue levels for one full week, you may begin to notice a pattern. In the example above, this person found that the morning is typically when their fatigue is most severe, and that rushing to get ready for work triggers worse fatigue. This person may try to wake up a little earlier in the morning to avoid rushing. It might help to reduce feelings of fatigue, or it might not. The important point is that this person is now more informed of their fatigue levels than they were previously, which can ultimately lead to a solution for managing fatigue. You too can monitor your fatigue and learn more about how it fluctuates than you previously knew.

Now What?

Now that you have information on your daily fatigue levels, what do you do with it? Here are a few examples of things to consider:

1. Schedule your most energy-demanding tasks during the times that you notice you are least fatigued.
2. Incorporate physical activity or yoga into your daily routine. Physical activity and yoga has been shown to improve fatigue symptoms in cancer patients. Our group's prior work has also shown some early evidence that yoga may also benefit MPN patient fatigue.
3. Incorporate short (10-15-minute) naps during the times that you feel most tired.
4. Try meditating. Our group's prior work has shown some preliminary evidence that meditation may help reduce fatigue in MPN patients. Additionally, meditation may help improve your sleep, which could help fatigue levels.
5. Discuss your fatigue diary with your physician to see if there is anything that they recommend for managing your fatigue.



Why Attend an Event?

Attending MPN events that are focused on the patient (as opposed to an academic research conference) can be great for many reasons, including:

- connecting and sharing goals and experiences with other MPN patients
- learning more about your MPN from experts in the field in an easy-to-understand and concise format, and
- understanding ways to be active in the management of your MPN

Voices of MPN: In-Person and Live Webinar Events

Voices of MPN put on Patient Education Sessions around the United States each month with the goal of bringing together patients and experts in the field. These events are unique opportunities to learn more about your MPN from experts, meet with other MPN patients, and learn of ways to take an active approach in managing your condition. These events are a few hours in length and include snacks and refreshments.

Upcoming events for August include:

- August 7th—Salt Lake City, UT—7:00-9:00 pm
- August 9th—Augusta, GA—7:00-9:00 pm
- August 14th—Ann Arbor, MI—7:00-9:00 pm
- August 30th—Sioux Falls, SD—7:00-9:00 pm

Upcoming events for September include:

- September 11th—Rochester, MN—7:00-9:00 pm
- September 13th—Troy, MI—7:00-9:00 pm
- September 25th—San Diego, CA—7:00-9:00 pm
- September 27th—Oklahoma City, OK—7:00-9:00 pm

To learn more about these events, how to register, and about other upcoming events and locations later in the year, please visit the website below:

Voices of MPN Patient Education Sessions: Upcoming Events

If you are interested in attending an event, but do not live close to any of the upcoming events remaining in 2018, there are webinars that you can attend. These events are great alternatives to in-person events as you will hear from an Oncology Nurse Educator about MPNs, learn of ways to actively manage your MPN, and be able to ask questions using the interactive chat feature.

Upcoming live webinar events include:

- August 22nd—7:00 pm EST
- October 3rd—8:00 pm EST
- November 12th—7:00 pm EST

Live webinars have a limited number of spots available. Visit the website below to learn more about the live webinar series:

Voices of MPN: Live Webinar Events

Shannon Richmond — Re-Discovering Her Purpose and Raising Awareness for Research

I think my MPN story started in 2015 during my deployment to Afghanistan. Halfway into my deployment, I began feeling incredibly tired and found myself unable to finish workouts, which was really unusual for me. I tried to push myself through thinking it was likely depression because of my surroundings. When I finally got home, things seemed to improve for a short period of time, but then the fatigue crept back in and I was sick almost weekly. Eventually, blinding headaches led me to ask a physician friend of mine to draw some blood and make sure things were okay. Sadly, things weren't okay and I was sent immediately to an oncologist.

On January 20th, 2016, I was diagnosed with Polycythemia Vera. For several weeks I was defiant and likely in denial. I continued to stay active and train hard for endurance sport despite weakness, fatigue, and continued detriments to my health. I had always identified as an endurance athlete and was not about to let go of that identity; although, a lot of this proved to be too much. I started on a downward spiral - I no longer considered myself an athlete, I felt lost, I became deeply depressed, and even worse, I made the decision not to share my diagnosis with anyone. I didn't even share it with my family. I thought that if I could keep the diagnosis a secret it wouldn't affect me. It would be as if it didn't exist.

This downward spiral continued as I desperately searched for something in my life to give me a sense of meaning and purpose. I was empty and felt like a shell of former, pre-diagnosis self. In desperation, I searched for something, anything to bring me back to life. Sadly, that led me into a truly toxic relationship with someone who claimed to love and support me but was verbally and emotionally abusive, ultimately leading me into a deeper depression and a further loss of self. Eventually, realized the harm that this relationship was to me, and left them. However, soon after leaving, my oncologist informed me that my condition had progressed faster than expected. I now had Myelofibrosis. This was the most difficult, painful period of my entire life.

Slowly, with the support of the wonderful people in my life, I began to fight my way back towards reclaiming myself. I began training again for triathlon and other endurance races. I allowed my friends and family to comfort and support me and I started to open up about cancer. I also started to take a hard look at what I wanted out of life. I'm still working through things, but I have gotten so much closer to the life I want for myself. I have regained my positivity. I still struggle at times, my training is not like it once was, and there are still days when getting out of bed is almost too much; however, I have a much bigger purpose for myself.

My races and goals are now not just in pursuit of my own personal achievement, but are for everyone who fears that their life may be over because of this diagnosis. I would love to be someone that others can look to and know that they too can continue on with their dreams and passions. Cancer is no longer the end of life, it's something that may slow you down a little or cause you to alter plans, but you can continue to achieve your goals.

Last November my best friend (and athletic hero) Kelly and I raised money for the Leukemia Lymphoma Society (LLS) when we ran the NYC Marathon as a part of Team in Training. It was inspiring to be doing something so big for someone other than myself. In March of 2019, I will hike to Everest Base Camp (EBC) to, once again, raise money for the LLS as part of Team in Training. Perhaps this is the meaning that I can find in my cancer diagnosis? I can help change things for the better, either by raising money for research or by helping to inspire the next person. Ultimately, this would mean that everything over the past 2 years has been worth it!

If you would like to donate and help me reach my goal of $30,000, my Team in Training fundraising page can be found at: http://pages.teamintraining.org/vtnt/ebc030219/SRichmond

MPN QoL Study Team Bio — Ryan Eckert

My name is Ryan Eckert, and I am a Research Coordinator for the Mays Cancer Center at UT Health San Antonio MD Anderson. I have had the great pleasure of developing this Quarterly Report with the input and assistance of other members of the MPN QoL Study Team. I am fortunate to have the position that I do today and grateful to be a part of research that is making a difference in the lives of MPN patients across the country! I was offered a Research Coordinator position with the Mays Cancer Center after graduating with my Masters degree and after working with Dr. Ruben Mesa (UT Health San Antonio) and Dr. Jennifer Huberty (Arizona State University) throughout my Thesis project. My Thesis was a 12-week online yoga study for MPN patients and was conducted back in 2016/2017, which some of you reading this report may be familiar with as prior study participants.

I received both my Bachelors and Masters degrees from Arizona State University in Exercise and Wellness. I have always been fascinated with he science or exercise, which was what led me to originally pursue an Exercise and Wellness degree. I always thought I'd end up as a Strength and Conditioning Coach for some professional or collegiate athletic team, but after getting deeper into my undergraduate and graduate studies, I began to develop an interest in research. After graduating with my Masters and having successfully defended my Thesis, I knew I wanted to look for a position that would allow me to remain in the research realm to some capacity. After a few months of unsuccessful job hunting, Dr. Mesa informed me that he had a position for me. I have now been working as a Research Coordinator for the Mays Cancer Center for over six months now. I also never gave up on my early dream of being a Strength and Conditioning Coach and have a part-time business, Peak Endurance Solutions, LLC, which I founded back in January 2017. In my business, I focus on strength and conditioning for endurance athletes. I am also a very dedicated endurance athlete myself, focusing primarily on triathlon. Outside of work, I am usually found outdoors swimming, cycling, or running. I am incredibly grateful for the sport of triathlon as it has taught me a lot about myself and has been a way for me to grow and develop as a person.

Contact Us

Please feel free to contact us with questions or comments you may have. We are always looking to improve the content and topics that are covered in this report, so please let us know if there is anything you would like to see in future issues. We are also looking to share patient stories in future issues (250-350 words)

Please contact Ryan Eckert at rmeckert@asu.edu with your questions/comments or personal story.

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University of Texas Health

UT Health San Antonio Mays Cancer Center
7979 Wurzbach Rd.
San Antonio, TX 78229-3900

Arizona State University

School of Nutrition and Health Promotion
500 North 3rd St.
Phoenix AZ, 85004

Mayo Clinic

5777 East Mayo Blvd.
Phoenix, AZ 85054