Giving a small community a big voice

Read a patient’s perspective on living with a rare, life-threatening blood cancer called myelofibrosis and why it’s important to rally the community.

By Tina F. | Sep 01, 2016

Many of us have experienced familiar symptoms – perhaps stomach pain, swelling, excessive fatigue – that can prompt a visit to the doctor’s office. For the lucky ones, the symptoms are a sign of something benign, maybe just a stomach bug, stress or a poor night’s sleep. But for some, these symptoms can indicate a more serious, chronic disease and open up a whole new world of complex medical terms, prognosis discussions and treatment options.

At age 43, I started having severe acute stomach pains, and once the pain became too much to bear, I headed to the hospital. After a series of scans, the doctors could see that my spleen was enlarged well beyond its normal size. In addition, it turned out I had thrombosis (clotting) in my portal vein. Both the enlarged spleen and clotting were clear signs of a blood disorder, and a bone marrow biopsy confirmed that I had myelofibrosis (MF).

Never heard of myelofibrosis? I hadn’t either. MF, along with polycythemia vera (PV), are part of a group of rare blood cancers called myeloproliferative neoplasms (MPNs).[1] MF occurs when the bone marrow cells that produce blood cells are gradually replaced by scar tissue.[2] Often, the spleen takes over blood cell production on the bone marrow’s behalf, which happened in my case and caused my spleen to enlarge significantly.[2] Other common and debilitating symptoms include fatigue, night sweats, itchy skin and bone/joint pain.[3] Many patients suffering from MF like me have to see a hematologist for frequent checkups and blood work.[2]

I was fortunate enough to be near a hub of qualified hematologists in Florence, Italy, and I received my diagnosis and comprehensive treatment plan early. Many patients are not as lucky as I am and go through weeks or months of testing before a diagnosis and possible symptom relief are reached.

Once my stomach pains subsided and the situation got more stable, I didn’t look like someone with cancer on the surface – but I felt like one. Knowing my condition was chronic, could be fatal, and could also decrease my quality of life took a toll on my anxiety levels and pushed me to realize and focus on what in life is really important. Although learning more about MF online, and through my hematologists, helped me come to terms with my condition, I still felt lost and alone. I found out quickly just how rare MPNs are; the community of those affected is small and dispersed across the world. There weren’t many people who really understood what I was going through and how it impacted my daily life.

I would like people to learn three key takeaways about living with a little-known, life-threatening disease like MF:

1. **Listen to your body**. No one knows your body better than you do. If something feels persistently wrong, get it checked out. Some of the signs, such as fatigue or bone/joint pain, can often be dismissed by people as something minor or as part of aging. Recognizing the signs of MF or PV is important so they can be addressed as early as possible.

2. **Education is key**. Because MF and PV are rare, often it takes a specialized hematologist to spot them. Medical education plays a key role in putting MPNs on the radar of general physicians during regular checkups.

3. **Looks can be deceiving**. While it may not be obvious externally, people suffering from rare cancers often feel isolated and alone, and live with symptoms that can significantly reduce their quality of life. Caring, understanding and compassion from others around them can go a long way.

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Hear from a patient who is working to help #MakePeopleNotice those affected by a group of rare blood cancers. #MPNs

References

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