

To Stay in the Game, Maintain Your Frame



MET-1055866

Living with Multiple Myeloma



Cheryl Boyce is a patient advocate who is living with multiple myeloma, a blood cancer of the plasma cells found in the bone. She shares her story below and talks about the importance of disease education. By sharing her personal experiences, Cheryl hopes to support others in the multiple myeloma and cancer community.

Please visit www.MaintainYourFrame.com or www.naltblackchurch.com for additional information on multiple myeloma. This content is for informational purposes only and is not intended to be a substitute for professional medical advice, diagnosis, or treatment.

Tell us about yourself.

My name is Cheryl Boyce. I live in Columbus, Ohio. For 25 years, I served as Executive Director of the Ohio Commission on Minority Health. The Commission was the first state agency in the United States exclusively devoted to eliminating health disparities among minorities (including African American, Latino/Hispanic, Asian and Native American communities). I retired in October 2010. I now do public health consulting. I also volunteer with a nonprofit group committed to providing community education and raising funds for multiple myeloma research.

Diagnosis.

I was diagnosed with multiple myeloma in 1998. I went to my primary care physician to refill a prescription. During the visit, I mentioned that I was always exhausted. I believed this was due to my extensive work travel schedule. My doctor ordered routine blood tests. The tests revealed a high protein level in my blood and then I was referred to an oncologist. While this visit confirmed I had multiple myeloma, it also convinced me that I needed to become an advocate for myself. The initial oncologist I saw was extremely negative and stated that there was nothing he could do for me.

On the way to work each morning, I listened to a gospel radio station. One day my attention was captured as the visiting minister of the day on the radio gave a mini sermon, 2 Kings 7. He preached about the lepers outside of the city, ending with, "the point is He wants you to go forth and live." I listened to this message and it was an epiphany for me. I then did my own research on the National Cancer Institute website and referred myself to an oncologist who was known, trusted and respected in the African American community in Columbus, Ohio. This decision was a major turning point in my life. Establishing a relationship with my oncologist based on trust and mutual respect was extremely important as I felt imminent security. God speaks to us in many ways, this day He used the radio as a catalyst to move me from a feeling of hopelessness and despair to using the many resources He made available to me to fight this disease.

To Stay in the Game, Maintain Your Frame



MET-1055866

First thoughts.

I knew what multiple myeloma was so at first I was in shock. I pulled as much information to read as possible. I eventually got past the feelings of despair and decided to be strategic and deliberate in my approach. I wanted to read and evaluate information without being totally consumed by my disease. With the modest numbers of advances noted in 1998, I looked for information on available treatment options, clinical trials, etc., to quell the fears of those first thoughts.

I have always hated the long, dark nights of winter. After being diagnosed, nights seemed even longer and darker. My husband was sensitive to my inability to sleep and he would often hold me. As sleep overcame him, I mercifully felt the presence of the Holy Spirit. I felt comforted. During those nights I also found tremendous comfort in the songs of Zion.

I also shared my diagnosis with my church family. I needed their prayers. I know that people often share the good news at church but not the bad news. Since multiple myeloma is supposed to be rare, I was stunned by the number of members of our church or family members who were diagnosed with multiple myeloma and had not shared it. Today, my church has served as the site for an annual multiple myeloma symposium.

Open communications.

Open discussions with my physician and other healthcare professionals have been essential to my treatment plan. I would not have a physician with whom clear channels of mutual communication did not exist. I make notes of concerns and questions I have when I have them. This has proven to be important for me. Something that seems pressing today might get lost in time. By writing in real time something of importance, that is not urgent, it's maintained for discussion at my next doctor visit. I also make notes between visits about information I read or hear from my wide network of multiple myeloma friends (these are people I have met who have multiple myeloma or are caregivers).

Prior to a physician's appointment, I review my notes so I can make the most of my time with my doctor. I also believe that it's critical, especially during treatment, to take someone with me to my doctor visits and debrief with them afterwards. When I was going through treatment, I was not sure that I was accurately hearing everything the doctor was saying to me, so I felt the check and balance with my husband's (or friend's) notes were extremely helpful. Additionally, actively engaging a loved one in this process helped with further discussions and decision making. I have kept all these notes and my physician's responses in a home file containing my medical information, as potential reference points for subsequent doctor visits.

Maintaining bone health.

This word infrastructure took on a new significance for me living with multiple myeloma. Multiple myeloma can lead to bone complications such as weakened bones and fractures, so protecting my bones became a priority. I have taken several steps to maintain bone health including but not limited to: being very conscientious of my calcium and vitamin D intake (dietary and through supplements); increased exercise, and weight resistance training.

Message to others.

There is hope! There have been tremendous advances in multiple myeloma treatment and research. This disease can seem overwhelming, but it helps to take one day at a time. Having information and being educated about multiple myeloma is very important for both patients living with the disease and their spouses/family/friends. Having a physician you trust and can relate to is especially important as you explore treatment options. It was important for me to feel that the best decisions were being made for me. That meant full engagement by me, my family and my doctor.