

Living Successfully with Multiple Myeloma

by [Peter Tischler](#)

I'm not the smartest guy around and, to be honest, I'd guess that many people in our group are smarter than me. But I'm very good at one thing: I can absorb an enormous amount of data, condense it into a summary, and communicate the results of that data to other people in such a way that they will understand it. That's what I did in business and that's what I've been doing with information about myeloma. Mostly, I do this one-on-one when people ask for help. This editorial is an attempt to reach a larger audience of people with our disease.

When I was diagnosed with multiple myeloma (MM) and was led to believe that I would only be around for a few years, I thought about what I wanted from medical science. I decided that I wanted quality of life and a chance to survive until a cure was found, with a reasonable quality of life during that survival. I also wanted to avoid undue pain and suffering – I'm a bit of a wimp! As I learned about our disease and how to survive with it, I was often distressed that so many people with MM had not availed themselves of their best chances of survival and quality of life. In some cases, it was not their fault. They hadn't yet had time to learn how to optimize their chances. But in other cases, both the patient and caregiver had abdicated their care to someone who is overworked and cannot possibly devote enough time and resources to them – their doctor. As good as your doctor might be, he (or she) doesn't have the time to do everything for you.

So who's going to take care of you? Who will take that responsibility? It had better be either you or someone who loves you, because nobody else will have the time, energy, resources, and desire to take on the job.

The following is a list of things that you (patient, caregiver, family) must know and do in order to best ensure that you will survive with the quality of life you want.

1. Take care of your kidneys

- Drink at least three liters of non-carbonated, non-caffeinated, non-alcoholic liquid each day in order to flush your kidneys.
- Avoid ionized contrasts that are typically used for CT scans. Ask for alternative contrast or don't let them use contrast. Failing to do this could cause your kidneys to shut down and the only solution would be dialysis. Injections for MRI and PET/CT scans are okay.
- Read labels on medications and over-the-counter products. Especially avoid non-steroidal anti-inflammatory drugs (e.g. Ibuprofen)

2. Avoid infections

- Limit exposure to people who have colds. Be mindful around children, especially during the cold/flu season. In public places (restaurants, church, etc.) stay away from children and anyone else who is coughing and/or sneezing; ask to be seated elsewhere. When flying, consider wearing a mask. Don't be so vain as to think it's ok. Your life depends on being careful.
- Develop a habit of washing your hands frequently. Always carry anti-bacterial cleaner (e.g. Purell) and anti-bacterial wipes.
- Make sure your family members get a flu shot every year. The flu shot may work for you, but it will definitely work for your family and, thereby, protect you.
- Be proactive if you do get an infection. A "simple" bronchial infection can easily become a life-threatening pneumonia in your depressed immune system.
- Wound infections easily turn into a sepsis crisis in you. If a wound is not healing properly, seek medical attention quickly.
- With your immune system, any temperature over 101 (some say 100) is cause for medical attention.

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3. Form a survival team

- You (patient, caregiver, family member) have to be the head of the team. Nobody cares as much about the issues as you do. Make sure that your caregiver has as much knowledge about your condition as you do. At times of treatment with steroids and other chemo drugs you may become overwhelmed with all the information you need to keep straight. Your caregiver is your link with sanity and good judgment.
- We usually get a local oncologist by circumstance. If that oncologist doesn't meet your needs, change oncologists. Make sure it's somebody you can count on in a crisis (there usually will be crises, at some point).
- Find a myeloma specialist who can direct your treatment. That's somebody who researches and treats **only** myeloma. There aren't many, so don't be fooled into thinking that someone who has treated a few MM cases is a specialist.
- Have a good internal medicine physician. Hopefully, you will be in this for the long haul. You need to keep up your general health.
- If you have kidney problems, consult with a nephrologist and add him/her to your team.
- Add any other specialists for any other chronic conditions you might have.
- Don't forget nurses – they know much more about symptom control than doctors.
- Make sure that they all get copies of reports from each other. This is your team – make sure they can work together and remember that you're the team leader.

4. Don't be a "good" patient

- Make it clear, to each physician, what you (patient and caregiver) want and expect from your medical team members. They are often not all that concerned with issues (e.g. quality of life) that are important to you. You must make sure those other issues are considered by everyone.
- Get copies of your file records from all your doctors. By law, they cannot be withheld from you, and you need them in order to be team leader.
- Do not let your physicians "snow" you with medical jargon or condescend to you with overly simplistic explanations. Keep asking questions until they are communicated to your satisfaction.
- Acquire a small cassette recorder and, with the physician's permission, record all appointments. Explain that it's because you don't want to forget anything that is said. Also, take notes during the appointment.
- It's okay to say, "Let me think about that" when your oncologist tells you that "we're going to start treatment immediately," unless he means that he's going to take the drugs also. This is a very slow-growing cancer and you need to think, research, talk with others, and even get a second opinion.
- Ask for treatment options (that's plural) and the pros and cons of each one. Ask why he/she favors the one being recommended.
- When something is wrong, complain – loudly. When something hurts, complain – loudly.
- Question anything that you're not satisfied as being right, especially with technicians and office staff. But don't become a general pain in the butt. You have to pick your battles - fight and win the important ones.

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5. Educate yourself (This may be you, your spouse, or a family member)

- Attend at least one IMF Patient & Family Seminar and participate in it. Go to the breakout sessions and ask questions. Spend time with other MMers there and learn how they're surviving.
- Attend a local support group as regularly as you can. There are things to learn and you need to feel "part of" a group of survivors. Even physicians can't give you what other survivors can – their experience.
- Read the "Myeloma 101" written by Peter Tischler and provided by the North Texas Myeloma Support Group. It will explain your disease in lay terms.
- You'll need a computer and connection to the Internet. The IMF website has an incredible amount of up-to-date information that is essential to the family with myeloma.
- Subscribe to the IMF's online support group of over 1,400 myeloma members worldwide. The daily experiential information is essential for anyone who wants to be proactive in his/her quest for quality survival. You might not understand much at first, but you will quickly become knowledgeable.

6. Maintain your immune system

- Your immune system is defective, but it isn't dead. Optimize it with healthy habits:
 - Reduce stress. This is important, as stress can further depress the immune system. Find ways to chill out and relax (in spite of it all).
 - Exercise. Also important both physically and emotionally. Find ways to exercise within your limitations. Low impact is best.
 - Good diet. Don't go crazy, but try to avoid stressing your systems with "bad" food choices.
 - Use multi-vitamins to ensure that your systems are not deprived of any essential nutrients. You might consider a nutritionist or dietician. Those taking steroids must be especially careful.
 - In some cases, an endocrinologist might be added to your team in order to ensure that you're staying in balance.

7. Keep medical records

- Trends are important. As you collect your test results, track the important markers (good and bad) so that you will see any trends developing. Learn which markers are significant and use a spreadsheet to visualize trends.
- Keep all your records in chronological sequence in one or more binders so that you can easily access them when needed.
- Keep shorthand medical notes in your purse or wallet: e.g. up-to-date medicine list with dosages, physicians with their phone numbers, testing schedule (even doctors will forget or get them wrong, sometimes).
- Fill out important forms for possible crisis times: Living Will, Medical Power of Attorney, and Do Not Resuscitate (DNR). It's good to have them even if you don't choose to use them.

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8. Know your doctors' limitations

- Doctors and nurses are, in most cases, overworked and understaffed. That's the managed care system and you have to learn how to best work with it and get what you need.
- Doctors make mistakes; so do nurses, technicians, and office staff. That's a fact of 21st century life and your job is to catch the mistakes. Mistakes that have happened to me include:
 - Not ordering tests that should be ordered (that's why you have to keep those records)
 - Wrong or inadequate instructions for imaging studies
 - Not recognizing a trend (those records again)
 - Miscommunication between doctor and staff
 - Over-medicating and under-medicating
- Oncologists have a "treatment philosophy" they've adopted through success and failure with other patients. You may not even hear about a treatment from an oncologist because of that physician's experience with it. You may, on the other hand, be urged to take a drug or dosage that's no longer considered cutting edge or even out of common use because of that physician's past experience. You must work through that with your oncologist.
- Oncologists may be either too aggressive or too conservative to suit your needs. You must deal with that or get another oncologist.
- Some oncologists are unwilling to communicate with or take direction from other oncologists, especially myeloma specialists. Deal with that or change oncologists.
- Some oncologists are unwilling to listen to or accede to the wishes of the patient and family. Deal with that or change oncologists.
- Some oncologists are unwilling to be educated with information from you or the IMF or published studies. Definitely change oncologists.
- Know your doctors' strengths and weaknesses. Nobody, your doctor included, knows everything.

9. Early Warning System – Avoiding Crises

- Testing is used to track the disease and for tracking the success (or failure) of treatments. It's also important to you to test when on plateau so that you will get an early warning when the disease reappears.
 - The most important early-warning test is the Freelite Test. This test will show disease progression before any damage occurs.
 - Some tests should be run early in your journey with myeloma, even though they're not yet needed for tracking, in order to establish baseline results for tests that will be needed later in your journey. Whole-body MRI, quantitative immunoglobulins, and a bone density test could be run in addition to the usual skeletal survey with x-rays.
- Consider having prophylactic medications available, especially if you are going to travel. Consider a good antibiotic (I have Levaquin), an antiviral (I have acyclovir) and something to use for flu (I have Tamiflu).
- Avoid unnecessary surgery, as the trauma of surgery might trigger an MM "flare." If surgery is necessary, have your oncologist keep close tabs on your markers after the surgery.
- Above all, react immediately when something is not right. The caregiver must make sure that the person with MM does not "tough it out." Once in a crisis, it could be too late to stop a cascade of system failures in an immune compromised person. "Toughing it out" when it comes to pain is ridiculous. Your oncologist should prescribe a pain medication that will keep you comfortable.