

# Living Successfully with Multiple Myeloma

10+ Years

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## Disclaimer

- All facts used in **today's presentation** have been painstakingly researched. Shockingly, I even took a stab at giving you my personal experience and opinion. Attendees who are sticklers for less off-the-wall facts should sign up to do their own presentation.
- Persons employed by the International Myeloma Foundation are lucky to be working at all, let alone wasting valuable time expressing your opinions. Attendees who have read ***Living Successfully with Multiple Myeloma by Peter Tischler*** recently should sit on their hands and let someone else have a chance at hearing the facts for a change.
- All opinions expressed in **today's presentation** are well-reasoned and insightful. Needless to say they are not those of the International Myeloma Foundation, its member support groups or NTMSG. Anyone who says otherwise is itching for a fight.

Michael Feldman's Whad'Ya Know?

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## North Texas Myeloma Support Group

- Proud member of the North Texas Myeloma Support Group!!
- Joined the support group in November of 1996.
- <http://northtexas.myeloma.org>
- <http://northtexas.myeloma.org/newsletters.html>
  - User id password required
  - Send an email to [ybiru@aol.com](mailto:ybiru@aol.com) to get access to the secured area
- Affiliated with the International Myeloma Foundation
  - <http://myeloma.org>
  
- The next nine items are plagiarized from Peter Tischler's Living Successfully with Myeloma article that appeared on Myeloma Today

**Every support group should have a website presence**

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## Who am I?

- |                                       |  |
|---------------------------------------|--|
| □ Diagnosed at a young age of 25      | □ Able to fight the disease & treatment side effects |
| □ 2-3 years survival statistics       | □ Live 5 years & beat the odds                       |
| □ Stage III B                         | □ It can't get any worse                             |
| □ Multiple Lesions                    |  |
| □ 4+ M-Protein level                  |  |
| □ 90%+ plasma cell involvement        |  |
| □ Very anemic and prone to infections | □ Now I know the reason for my chronic cold/cough    |

**Better me than someone in my family**

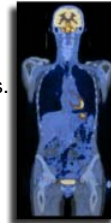
**I was more concerned with losing control of my "time" than having cancer**

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## Take Care of your kidneys

- Drink at least three liters of non-carbonated liquid each day.
  - non-caffeinated
  - non-alcoholic liquid
- 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 kidney shut down and put you on 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)



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## Avoid infections

- Limit exposure to people who have colds.
  - Children
  - public places
  - Flying
- 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.
  - Controversial for MM patient, but it will definitely work for your family 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 can easily turn into a sepsis crisis.
  - If a wound is not healing properly, seek medical attention quickly.



**Any temperature over 101 (some say 100) is cause for medical attention.**

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## Maintain your immune system

□ Our immune system is defective, but it isn't dead and can be optimized 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.

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**Reduce stress, exercise, eat right, take supplements**

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## Form a survival team

- We (patient, caregiver, family member) have to be the head of the team.
  - Nobody cares as much about the issues as you do.
- 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.
- Find a Myeloma specialist who can direct your treatment.
  - That's somebody who researches and treats **only** Myeloma.
- Have a good internal medicine physician.
  - You are in this for the long haul. You need to keep up your general health.
- Others to include as part of your team:
  - Internal medicine physician
  - Nephrologist
  - Nurses
  - Other chronic conditions



**This is your team – you're the manager**

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**Make sure the team members can work together**

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## Educate yourself

- 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 – our experience.
- Read the "Myeloma 101" written by Peter Tischler and provided by the NTMSG
- You have to have a computer and a reliable internet connection
  - The Web (The IMF website included) has an incredible amount of up-to-date information
- Subscribe to the IMF's online support group
  - 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.



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**This may be you, your spouse, or a family member**

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## Keep medical records

- Trends are important.
  - 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 you can easily access them when needed.
- Keep shorthand medical notes in your purse or wallet:
  - up-to-date medicine list with dosages
  - physicians with their phone numbers
  - testing schedule
- Fill out important forms for possible crisis times:
  - Living Will
  - Medical Power of Attorney
  - Do Not Resuscitate (DNR).
  - It's good to have them even if you don't choose to use them.



**Go to the NTMSG website and download an automated or static TESTING HISTORY TEMPLATE**

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"Somehow your medical records got faxed to a complete stranger. He has no idea what's wrong with you either."

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## Avoid Crisis

- Testing is used to track the disease and effectiveness of treatments.
- Continue to get tested while on plateau to get “early warning”
  - The most important early-warning test is the Freelite Test.
  - Establish a baseline (Whole-body MRI, quantitative immunoglobulin, and a bone density test, skeletal survey with x-rays).
- Consider having prophylactic medications available, especially if you are traveling.
  - a good antibiotic (ex. Levaquin),
  - an antiviral (ex acyclovir) and
  - something to use for flu (ex.Tamiflu).
- Avoid elective surgery
  - trauma of surgery might trigger an MM “flare.”



**Create an early warning system, react immediately, don't "tough it out"**

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## Don't be a “good” patient

- Let each physician know what you want and expect from your medical team members.
- 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 fall for medical jargon.
- Tape record all appointments and take notes during the appointment.
- Don't jump into treatment
  - 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 and the pros and cons of each one.
- When something is wrong or something hurts, complain – loudly.



**Pick your battles - fight and win the important ones.**

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**Follow Andy's advice on “how not to be a good patient”**

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## Know your doctors' limitations

- Doctors and nurses are, in most cases, are overworked and understaffed.
- Doctors make mistakes; so do nurses, technicians, and office staff. Including:
  - 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
- When do you change an Oncologist?
  - Oncologists have a "treatment philosophy"
  - Oncologists may be either too aggressive or too conservative to suit your needs.
  - Willingness to communicate with or take direction from Myeloma specialists.
  - Willingness to listen to or adhere the wishes of the patient and family.
  - Willingness to be educated with information from you or the IMF or other studies.
- Know your doctors' strengths and weaknesses.



**Nobody, your doctor included, knows everything.**

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- Q & A
  
- And more.....

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