



“Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship”

Meeting: Tuesday September 17, 2019 3:30pm – 5:30pm
451 Junction Road
Madison, WI
UW West Clinic Room 1287

Enter the clinic... turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

Group Information:

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Madison Multiple Myeloma Support Group website
madisonmultiplemyeloma.org

Mailing Address: Wisconsin Multiple Myeloma Support Group
3309 Chicago Avenue Madison, WI 53714-1815

Information Sources :

International Myeloma Foundation (IMF)
Phone: 800 - 452 - 2873
Email: TheIMF@myeloma.org
Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
Phone: 203 - 972 - 1250
Email: info@themmrf.org
Website: www.multiplemyeloma.org

Upcoming Meeting Speakers... Mark your calendars now!

Dr Natalie Callander will likely join us for the October meeting.

Dr Shannon O'Mahar will be our featured speaker for the December meeting. She may be presenting 2019 ASH conference highlights.

Mark your calendars for the 3rd Annual Myeloma Patient and Caregiver Symposium in Pewaukee, WI Saturday, September 28th. This is a great conference and you will not want to miss it. It is not too late to sign up!

Our Myeloma Support Group will be recognizing a milestone 20yrs at this September 17th meeting. No speaker is planned. Leaving the time open for us to celebrate! If you are group member but have not attended in a while, mark your calendar for this anniversary celebration and stop by to visit. See you all there!

Cancer Psychology overview.... Dr. Erin Costanzo spoke to our group at the June meeting. Here are some of the highlights of her presentation.

Common emotional responses- denial and disbelief, shock and numbness, overwhelmed and confused, fear, anger, grief, depression, fighting spirit and hope.

Common psychological concerns- telling friends, family, children and coping with their responses. Information gathering and treatment decision-making. “Why me?” Searching for cause and reasons. Adjusting roles and responsibilities. Lost sense of control, helplessness. Proactive coping, planning.

During treatment: Common psychological concerns- Coping with physical disability and side effects. Body image. Change in identity and roles. Communication with health care providers. Complementary therapies and self care. Sexuality. Work and finances. Concerns about family.

After treatment and no maintenance treatment phase: Common emotional responses- Joy, happiness, sense of lost orientation, purpose, fear, anxiety, recurrence worry, emotional distress around follow-up visits, emerging depression and survivor guilt.

No maintenance treatment phase: common psychological concerns- Unmet expectations about returning to “normal”. Loss of support from health care providers, friends and family. More time to focus on thoughts and emotions related to disease and treatment experiences. Loss of the “safety net”. Uncertainty regarding disease status and recurrence worry. Finding meaning. Change in priorities and identity. Developing a “new normal”. Relationship changes. Staying healthy / preventing recurrence.

This is very interesting information! Remember this disconnect when with your provider. Make sure your concerns are heard.

Myeloma provider's ratings of top patient concerns- Bone pain+ bone pain affecting functioning and mobility. Other pain and fatigue. Discouraged about illness.

Myeloma cancer survivor's top concerns- Uncertainty about future health. Concerns about sexual function. Weight gain and fatigue. Worry about symptoms. Difficulty planning for future. Fluctuation of emotions. Poor concentration.

Coping strategies- Prioritize physical activity and sleep! Use Social Support- family, friends, other cancer survivors, online support/social network, Psychologist or counselor, chaplain, minister or other spiritual counselor. (Your support group! My addition to the script.)

Take a proactive approach- talk about it, expressive writing, creative expression through art, music and movement.

Don't be afraid to seek professional help to get you moving in the right direction. It can really make all the difference in staying healthy, mentally strong and off to live your new normal in the best possible way.

Brand new booklet from the IMF Educational Series.... Understanding Peripheral Neuropathy in Myeloma. This can be viewed online and is very well written. Very comprehensive and will expand what you may already know about this subject. Bet you didn't know about “Pickle Juice”? See page 13.

Our group member, Georgia passes along this information about a class that she has joined.

I have just started a “Strong Bone” class and I love it! It meets at our village hall in McFarland. It really

works ALL of your muscles and is good for balance. The leader had a change in her bone density and started this class. It is actually fun and it is for men and women. There is music and laughter and so much easier to exercise with others. The hour goes by quickly and it's a good feeling mentally. I had tried it out before transplant with another instructor and loved it. After transplant, still love it! Highly recommend it to all.

IMF Info Line – If you or someone you care for has Myeloma, you have questions. Probably, lots of them. You can search the Internet all you want, but other than asking your doctor, there is no better way to get your questions answered than to call the IMF Info Line. Missy, Judy and Paul know their stuff and they want to share what they know with you. Just ask anyone who has called the IMF Info Line. Patients or caregivers are welcome to contact the Info Line staffed by trained specialists at 800-452-CURE (800-452-2873). The Info Line is staffed between 9am and 4pm Pacific Time, 11am to 6pm Central time or infoline@myeloma.org.

New information!

The Trillium Fund was established by our founding support group members to facilitate Multiple Myeloma research here in Madison at the Wisconsin Institute of Medical Research. If you or your family wish to donate or send a memorial to this program, checks can be made payable to the “UW Foundation – Trillium Fund” and sent to UW Carbone Cancer Center, University of Wisconsin Foundation, 1848 University Ave, Madison, WI 53726. Donations may also be made online at www.supportuw.org/give (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Daniel Rosen at (608) 264-5437 or email curecancer@supportuw.org.