

MM Fighters! Support Group Meeting
April 23, 2022
Virtual Meeting

Samantha Clark from Evergreen Health was our presenter this month. She provided a clear introduction to an often misunderstood topic...what the difference is between Palliative Care and Hospice. Her presentation generated a lot of questions and discussion, and provided some great direction for us along our Myeloma journey!

Thought For The Month

To the world you could be one person, but to one person you could be the world.

A great reminder that our group exists to help one another, and that you can never tell the impact of one kind gesture. Our members have done a wonderful job reaching out to those with questions, concerns and challenges, and I have heard numerous times how one phone call or email was able to be a tremendous assistance to one of our members. Keep up the good work...you will be surprised at the positive results!

Members have also been supporting the Defeat Myeloma fundraiser in good style! Nancy is now the individual leader in donations! Great going!

There are still 2 months left until the event, so plenty of time to donate, form a team, support the MM Fighters or a friend...simply go to www.defeatmyeloma.org and select "DONATE"! You will be supporting Myeloma research at the Fred Hutch, which benefits us all!

Speaker

Samantha Clark from **Evergreen Health** gave a thought provoking presentation on Palliative Care and Hospice. (For those of you who remember Bill and Mimi, they could not stop singing their praises for the services that Evergreen provided Bill.)

Sam started her presentation examining the difference between

- **Hospice**, which focuses on comfort, being at home and avoidance of hospitalization, usually goes hand-in-hand with prognosis of 6 months or less, and
- **Palliative Care**, which concentrates on alleviating symptoms and suffering.

For Palliative Care, Sam explained how they like to create a "bird's eye view of the patient, understanding their treatment goals, advanced care planning and symptom management, as this helps guide them in the delivery of services.

Care offered varies by location

- SCCA has a wonderful nurse – Kim Harlow
- Evergreen offers outpatient, tele-med and inpatient
- Providence and Hospice of Northwest are other strong providers

Go to www.getpalliativecare.org to get a fuller understanding of the various services offered.

There are a number of different types of Hospice, often offered by the same service, while some institutions focusing only on one type of care.

- Hospice care centered at the home
- Hospice care that is intertwined with hospital care

Although Hospice is usually considered a 6 month treatment, it can be extended after further review of progress, desires, etc.

To learn more about both services, Evergreen offers virtual Advance Care Planning workshops every month. Contact information regarding this program and Evergreen Health Palliative Care can be found in the last slides in Sam's presentation.

Samantha Clark's slides can be found attached to the email, along with a link to the video of the presentation.

Patient Roundtable

Bill, a new member who has run the whole spectrum of MM from MGUS through Smoldering to active Myeloma introduced himself and his wife Beki. Bill is preparing to undergo Car-T cell therapy at the SCCA in May. At the end of our session he asked about some lights and sparkles he was seeing in his right eye. A number of MM Fighters chimed in with their experiences, and Tony was pretty insistent that they go to the ER right away to get it checked out. Turns out that vision problems often need to be addressed right away or they can easily become permanent. A good thing for all procrastinators to remember!

Fortunately, after a long stay in the ER, the good news is that there does not seem to be any permanent problem, and that the Car-T therapy can proceed.

One member asked about the meaning of the FISH test results. It was suggested that a booklet from the IMF (under publications on their website) can help. You also need to corner your doctor in order to understand his interpretation of these results.

Jean has had severe neuropathy due to her Myeloma treatments, and has been very enthusiastic about the results of the Palliative Care she has been receiving to combat this side effect. The doctors and pain specialists at your cancer clinic can help in these areas, but do not overlook Palliative Care if other treatments are not working.

The MM Fighters have at least 3 members undergoing Stem Cell Transplants, with Bill receiving a Car-T cell therapy, so be sure to keep them in your thoughts!

David and Judy were visiting the Seattle area again from their comfortable abode in CA when they both were struck by the Novovirus. This is a highly contagious virus spread through food and water that is contaminated during preparation. It supposedly is hitting the Seattle area at this time, so please be careful! It hits the immune compromised especially hard.

Next MM Fighters! Meetings:

Caregivers Meeting – May 7th, 2022 – 10 – 11:30 AM Contact mmfighters.caregivers@gmail.com for more information – **Virtual Meeting**

NEW GROUP! Myeloma Families with Young Children! Contact Jen at erikson.jen@gmail.com for more information!

May 21st, 2022 – Mary Rasmussen – SCCA – Nutrition for Myeloma Patients – 10AM – 12:30 PM – Virtual Meeting