

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group June 5, 2021

Business News

Thank you to **Nancy B.** who hosted the meeting, with approximately 40 people attending. Our topic of discussion was cancer survivorship planning and wellness.

Guest Speaker

Thank you to **Tara S. Roy** MS, NP, AOCNP, & Patient Advocacy Liaison for Takeda, who joined the meeting to discuss “Cancer Survivorship: Optimizing Your Wellness”. Tara has been in healthcare for over 32 years. She is an oncology nurse practitioner and just recently joined Takeda. The majority of her career has been taking care of patients with leukemia, lymphoma, and multiple myeloma (MM). She enjoys the patient advocacy liaison and educational part of her new role and interacting with patients.

The presentation was organized into four parts:

1. What is survivorship and why is it important?
2. What are the needs of people living with cancer diagnoses?
3. What are some potential strategies for establishing a survivorship care plan?
4. What are some additional components and considerations of survivorship care?

An individual is considered a survivor from the time of diagnosis through the duration of their lifetime. Tara asked the group about their MM survivorship timeline. The group’s MM journeys ranged from 3 months to decades. Survivorship is just as important to someone who is newly diagnosed as to someone who has lived with MM for a long time, and patients have different needs at different stages of their survivorship. The three stages of cancer survivorship and their definitions are:

- Stage 1: Acute survivorship - the time of diagnosis and initial treatment
- Stage 2: Extended survivorship – the effects of cancer and treatment are the focus

- Stage 3: Permanent survivorship – the long-term effects of cancer and treatment are the focus

It doesn't necessarily matter what stage you're in, the goal of survivorship is that your focus is on quality of life and maximizing your health. The goal of survivorship care is to assist patients through the various effects of treatment, with the focus on overall wellness, which is an active process through which people become aware of and make choices toward a better life. There are six dimensions of wellness: *physical, emotional, social, spiritual, intellectual, and occupational*.

Evolving therapies have led to improvements in patient survival. The number of cancer survivors is expected to increase by 25% over the next 8 years. Survivorship care is necessary for minimizing the impact of disease and treatment side effects on a patient's quality of life. Now we're fortunate to have longer survival, but we need to really focus on potential long-term and late effects because this affects survivors' overall health. This is especially important in MM which is considered a chronic illness, where a patient may undergo many different and varied therapies. The impact of disease and treatment involves all aspects of our lives. Healthcare providers are required to support survivorship care in order to maintain certain healthcare certifications.

Long-term effects are the medical problems that develop during active treatment and persist after treatment is completed. Some examples of long-term effects include fatigue, *hot flashes/sweats, sexual dysfunction, neuropathy, chemo brain, anemia, lymphedema, incontinence, pain, anxiety, and depression*. **Late effects** are the medical problems that develop or become apparent months or even years after treatment is completed. Some examples of late effects include cardiovascular *disease, metabolic syndrome, osteoporosis, lung problems, lymphedema, infertility, hypertension, menopause, hearing loss, sexual dysfunction, digestion problems, secondary cancers, acute leukemia or myelodysplasia, rheumatologic issues, neuropathy, and learning, memory, and attention difficulties*.

For example, there are certain therapies that patients receive today that may put them at higher risk for certain types of medical issues eight to ten years later. Now doctors must think in terms of preventive medicine today to prevent long-term, or late effects, later on.

When you're making any kind of changes to treatment, it is important to always ask your healthcare team, "What kind of late and long-term side effects might occur due to this new treatment?" When thinking about survivorship we need to consider late and long-term side effects, which may impact a patient's quality of life in the following categories:

- *Physical:* functional activities, strength/fatigue, sleep and rest, overall physical health, fertility, and pain
- *Psychological:* control, anxiety, depression, fear of recurrence, cognition, stress of diagnosis and treatment
- *Social:* family distress, affection/sexual function, roles and relationships, appearance, isolation, finances, and work
- *Spiritual:* meaning of illness, spirituality, hope, uncertainty, and inner strength

Many *physical* challenges may come with cancer and its treatment. Some are more prevalent than others and may require intervention. Frequent physical challenges include fatigue and pain.

Psychological effects are also common and the longer that a person lives with a disease, the greater the potential for psychological effects. It is important for you to discuss any psychological challenges you are experiencing with your healthcare team so that they can recommend additional support.

Dealing with a cancer diagnosis can change your relationships with your family, partners, work, and friends. Social support has been linked with better outcomes and a better ability to cope with cancer survivors. Here are some things to consider when navigating your network after a cancer diagnosis:

- Let others know what to expect as you heal
- Give yourself time to adjust to the changes
- Accept help (so that you can move forward and get healthy again)
- Address any problems that arise when you return to work
- Maintain contacts during recovery
- Plan what you will say about your cancer diagnosis

Your relationship with your partner changes when they are your primary caregiver. Your partner is a co-survivor as well, who may also experience physical, emotional, and financial impacts of a patient's cancer journey. When it is appropriate, remember to put the patient/caregiver relationship on the back burner and become partners again.

Spirituality is the relationship that a person has with a power beyond themselves that helps them feel connected and enriches their lives. A cancer diagnosis can increase a patient's spiritual needs. When self-esteem and spiritual faith are endangered, personal relationships can suffer, resulting in a spiritual crisis. It is very important to reestablish your spiritual well-being, especially as you continue along your survivorship path post-diagnosis. Paying attention to your spiritual needs is a necessary part of holistic care.

The ability to be able to snap back, move forward, and be resilient allows us to maintain quality of life. The first step in finding a new normal is to realize that physical, psychological, and social recovery takes time. Survivors can adapt to a new normal by:

- Being open to emotions – both positive and negative
- Understanding what you can and cannot control
- Coping with and reducing stress
- Finding resources to optimize wellness
- Establishing a survivorship care plan with their healthcare providers
- Learning relaxation techniques

A survivorship plan is an individualized guideline for monitoring and maintaining health that is continuously being updated as needed. It is also a roadmap of a patient's journey, including treatments, follow-up surveillance, and monitoring/testing for late effects. It is important to put a survivorship plan in place at the time of diagnosis in order to ensure that you receive the best treatment and support. As you build your plan, try to learn as much as possible about your treatments and follow-up care. Your medical team can help you create your plan and advocate for your needs. At the time of diagnosis, develop a journal to document your disease, and continue to do this when you have a change in treatment. *Ask your care team: Will you be able to provide a survivorship care plan? Will I have a survivorship visit and when?* Start with your cancer doctor at diagnosis, and then introduce your other doctors to the plan. Multiple providers play a key role in creating and maintaining your plan with you, including primary care providers, nurses and patient navigators, and social workers.

Communication is essential to implementing your plan and your role includes:

- Maintaining regular contact with your doctors
- Understanding the role of each member of your healthcare team and how they coordinate with each other
- Asking about emerging treatments and if they are recommended for you

- Asking about available resources
- Developing a referral network based upon your needs
- Reporting side effects to your medical team
- Maintaining follow up visits – stay organized, ask questions, keep your doctor informed about any health changes
- Being your own advocate

Your survivorship plan is not only about your MM journey, it is about your overall health. And so that means you have to think about everything from head to toe, that's both related to MM and not related to MM. Work with your healthcare team to schedule regular health assessments and screenings to monitor tumors, cardiovascular health, endocrine disorders, nutrition, bone health, hearing, vision, cognitive changes, depression, and fatigue. Three very important aspects of survivorship are sleep, exercise, and stress. Patients with good diet, exercise, sleep and stress management have the best outcomes overall. Follow a healthy lifestyle, maintain a healthy weight, establish a healthy diet high in vegetables, fruits, and whole grains, and get regular exercise. There are many different stresses in life. It's not so much about the stressor, as the need to have an outlet for that stress to manage it properly.

Survivorship resources include:

- ◆ **American Cancer Society** - <https://www.cancer.org/treatment.html>
 - Personal care manager, caregiver resources, insurance resources, survivorship care plan
- ◆ **National Coalition for Cancer Survivorship** <https://canceradvocacy.org>
 - Advocates for quality cancer care, resources and guides for survivors
- ◆ **Livestrong at the YMCA** - <https://www.livestrong.org/what-we-do/program/livestrong-at-the-ymca>
 - Promotes the importance of physical activity after a cancer diagnosis, provides free or low-cost customized exercise regimens for survivors

Some questions, answers, and recommendations from the zoom chat follow.

Q: How can we get a better understanding of our lab values?

A: Ask your health care team for help. Also, check the IMF site for materials on this topic.

Q: I provide each member of my care team with my survivorship care plan, but they tend to not look at it in depth. How do we get them to focus on it?

A: Sometimes we have to initiate it by asking them to review it with you. You are the captain of your ship (body), and you decide where you are going and navigate there with your care team's help and assistance.

Bob recommended the book, "Receiving Care with Grace and Gratitude".
Gail recommended GA Core, a local web resource: <https://www.georgiacancerinfo.org/cancer-news/georgia/new-survivorship-materials-available/783>

Submitted by Wendy R

Meeting Minutes
Southside Virtual MM Support Group
June 26, 2021

Business News

Southside group's next meeting is July 24, 2021. **Understanding Lab Values.** Tara S. Roy, MS, NP, AOCNP, Patient Advocacy Liaison from Takeda Pharmaceutical Limited. *Meeting Prep:* Please look at your lab reports, comparing outcomes from the last three visits (3 months, three years, etc.). What are the important labs and what is your target value for each? What questions do you have?

General Meeting

Doris welcomed all present and opened our June meeting with a moment of silence. We welcomed one new member **Anderson F. Chuck and Susan** from the Northside group also joined us for this meeting. We acknowledged many of the different health issues that are observed in June: Men's Health Awareness, Alzheimer's and Brain Awareness, and National Cancer Awareness.

Anderson shared that he was still in the midst of defining what are possible myeloma signals in his body and what might be normal aging, like the aches

and pains. He was diagnosed months ago with smoldering myeloma and recently had a bone marrow biopsy. He is being treated at Piedmont Hospital but has scheduled an appointment with myeloma specialists at Emory Winship. He is attending this meeting to listen and learn from others. **Chuck** was diagnosed with myeloma in October 2020, and after eight rounds of chemotherapy RVD, a bone marrow biopsy showed no detectable myeloma. He is not a candidate for a stem cell transplant (SCT) due to previous cardiac issues. Chuck has had two open-heart surgeries. He is now on maintenance therapy of Rev, Dex, and monthly Zometa. Gail recommended that he monitor the amount of time he remains on Zometa (Very important bone strengthener) due to potential long-term side effect of osteonecrosis of the jaw (ONJ). Susan said they had been advised and would move to quarterly Zometa at some future date.

Discussion on Muscle cramps. Many members in the group have experienced muscle cramps and shared their solutions. **Marcia** was advised to take Tums which work for her. **Glenda** was prescribed two capsules of potassium (K+) until May. Gail will send a list of foods that are high in potassium. White potatoes have a high level of K+. **Carolyn E.** drinks tonic water and other members drink quinine water. **Sheryl B.** shared it is important to drink lots of water to stay hydrated. **Yvonne** shared there is a foam spray for muscle cramps and spasms that she will share with us.

Overall, muscle cramps may come from dehydration or from depletion of minerals, especially calcium, magnesium, and potassium. It can also come from muscle overuse, especially in athletes. Most frequently, the cramps present in the calf, hamstring, or quadriceps muscles. *Some myeloma medications may contribute to these deficiencies.* Eat a nutrient dense diet and drink lots of water with medications, not just sips to get the meds down. Nighttime cramps may occur from the way we position our legs at night – legs extended away from the rest of your body (called plantar flexion), or from being inactive during the day. Avoid having your feet and legs in the same position for an extended period of time. Regular exercise and stretching leg and calf muscles are helpful. Cramps can last for less than 10 minutes but can be very painful. Immediate relief for the cramps includes gentle stretching and

massage of the muscles, applying heat (warm cloths). Gail's quick solution is a calcium tablet under the tongue. Gail has asked pharmacists and doctors and they say it will do no harm.

Guest Speaker

Our scheduled speaker, **Karen B Stevenson, M.D., M.Div.**, could not join us at the last minute due to a family emergency. Deborah was able to reach out to her friends, and we welcomed two speakers who graciously agreed to join us on short notice. We were joined by **Jacqueline Hall**, retired Master's Clinical Nurse Specialist and by **Rev. Kathy Flowers** of Elizabeth Baptist Church. Each had several pearls of wisdom on grief to share with us from their considerable experience. We were extremely grateful to them both for altering their plans to join us. Our topic was "The Gift of Grieving".

J. Hall: Grief is that feeling we carry through life's losses – it diminishes our feelings of happiness and well-being. Grief is not just tied to death, but rain and storms, serious diagnosis, or even the anticipation of uneasiness or pain. We cope by crying, isolation, turning inward, and by riding an emotional roller coaster. So many of the bad things we anticipate never happen. We focus on the "what ifs" and should know that "This too shall pass". You have to forgive yourself – give yourself permission to change. Know that God is loving...is caring. Continue to talk to friends, relatives, counselors... work to decrease feelings of guilt.

Rev. K. Flowers: Know that grieving is a natural part of life, and that you can lean on Him, Trust in Him, and that you are not alone. You question yourself, "What should I do, what should I have done, what difference could I have made?" For resources on grief, Rev. Flowers suggested just googling for affirmations to fit your needs – grief, loss, acceptance. The Bible is always a resource, as well.

Patient Updates

Doris (14 years with myeloma) nor **Carolyn H.** (17 years with myeloma) have had a SCT. Doris started with thalidomide, but is now on maintenance therapy

with Rev. She is stable and gets labs and sees her doctor every two months. Carolyn H. has been on several different clinical trials. She is starting to have heart problems, which is a long-term effect of Daratumumab. She has been on Dara for 6½ years. Carolyn H. is now being closely followed by a cardiologist and her oncologist. **Gloria** has been on Rev since 2015. As of Jan 2021, she is on Dara only as part of a clinical trial (CT). She started with Dara only. **Gail** shared that she is in Pomalyst-3 mg for maintenance and sees her doctors every other month. **Glenda** is back in remission and is taking Pomalyst-2 mg. She has noted muscle cramps in feet and legs. **Alma** shared that at the first of the year, she spent 33 days in the hospital. Because of COVID, family members could not visit. Due to her low Oxygen uptake, she did not have the energy to talk for extended periods of time. She could not read. She was grieving being in isolation. She had panic attacks... in ICU for 2 weeks. She was ultimately diagnosed with *Pneumocystis pneumonia* (PCP). This is a serious infection caused by the fungus *Pneumocystis jirovecii*. Most people who get PCP have a medical condition that weakens their immune system that lowers the body's ability to fight germs and sickness. She used positive affirmations to keep her spirits up. **Sheryl B.** shared that when she lost her husband 3 years ago, she was his caregiver around the clock. She knew she had done all that she could do and had no regrets in that area.

Open discussion

Sheryl asked whether anyone knew of the current use of Empliciti (Elotuzumab), approved in 2016. Her husband participated early in clinical trials for the drug. Gail shared that Empliciti is in the class of drugs known as monoclonal antibodies and includes Dara (Darzalex) and the newer drug Sarclisa (Isatuximab). It did not seem to keep up with the preferred Dara in terms of “progression-free survival”, and Dara has also moved to front-line therapy. Carolyn H. was on Emplicit for 4 1/2 years, starting in a Phase 1 trial. She developed a cataract in 2015 and was on the steroid prednisone for two months. This was changed back to Dex. Sheryl asked if other drugs had been approved with major side effects. Blenrep is approved and the patient must meet with the ophthalmologist at each visit. We all ask why anyone would take that risk. The response: The problem with the eyes appears to be reversible and generally those who might accept this treatment have few options for care.

Newer Myeloma Drug Classes

Oral Proteasome Inhibitor - Nintedanib	Peptide Drug Conjugate - Pepaxto
Oral – Selective Inhibitor of Nuclear Export (SINE) - XPOVIO	Monoclonal Antibodies – Darzalex, Empliciti, Sarclisa (Isatuximab)
Antibody Drug Conjugate (ADC) - Blenrep	CAR-T cell therapy

There are a number of new drugs and clinical trials (CT) – Phases 1, 2, and 3. **Do not get intimidated** by all these new names. Learn at your own pace through webinars and articles. Some examples include Ide-cel, BB2121, BCMA-directed CAR-T. Therapies are for smoldering high-risk, for RRMM (Relapsed and Refractory Multiple Myeloma). *Know your risks and potential side effects for any CT you might consider.* Here are some current CTs

- **Abecma.** First BCMA (B-cell Maturation Antigen) directed CAR-T – personalized immune therapy. *B cell maturation antigen (BCMA) is a novel treatment target for multiple myeloma (MM) due to its highly selective expression in malignant myeloma.*
- **DREAMM-2, DREAMM – 6** – studies of belantamab mafodotin (also called Bela or Blenrep), an anti-BCMA antibody-drug conjugate or ADC... corneal or eye toxicities that appear to be reversible.
- **STOMP Clinical Trials** – Phase 1 and 2 trials with multiple triplets – with Carfilzomib, Pomalyst – Dex.
- **HORIZON Trial**-promising drug in combination FDA Approval. **Pepaxto or Melphalan Flufenamide.** First in class drug. At least four prior therapies.

Issues to Consider through your journey

- **CURE Today-Patient Voices** [Advances in Second opinions for Cancer Treatment Decisions](#) Apr
- Should older patients limit steroids in treatment plan?
- **Patient Power. Is my vision getting worse?** Prolonged Dex can cause fluid retention and cataracts.

Respectfully submitted, Gail