
N L M S F E- BULLETIN
September 21, 2016

HEADLINES:

1. Who is on your Care Team and who you should be able to count on for help
2. How to Manage Fatigue -a common side effect from treatment
3. Peripheral Neuropathy and Massage Therapy
4. GOFUNDME, SMILE.AMAZON.com

1. Who is on your medical care team / Who can you count on for help?

This is a **list of medical professionals that are available and likely to be on your healthcare team** once you are diagnosed - so you know who they are, what support they provide, and how they can help you. This information can help you be aware of **who you can reach out to for help at various stages of your treatment.**

Diagnostic Radiologist - the trained physician who diagnoses cancer using imaging tests such as mammograms, ultrasound, X-rays, CT scans, MRI scans, PET/CT scans.

Note: in the next E- Bulletin I will define each type of scan and what the imaging results offer.

Interventional Radiologist - using imaging scans, to obtain biopsies or to guide treatment delivery directly to tumors, including those that use heat, cold, or radioactive beads to kill malignant cells or hinder blood supply to a tumor.

Note: Stereotactic deliver of treatment is starting to be used according to Dana Farber Cancer Institute . . .more on this subject on the next E- Bulletin.

Pathologist - reviews tumor tissue stains/samples to classify different types of cancer by studying the cells and tissues under the microscope, using special tests to study proteins and genes on the cells. The pathologist's diagnosis is key to the official diagnosis and ultimate treatment plan to be pursued by a the medical oncologist.

Medical Oncologist - Reviews the pathologist's diagnosis, and sets the treatment plan in motion - i.e. chemotherapy, radiation prior to chemotherapy if deemed appropriate, targeted drug therapies.

Note: You want to make sure you select a medical oncologist that specializes in SARCOMA and especially one who has extensive experience in treating Leiomyosarcoma (LMS).

Surgical Oncologist - the surgical oncologist and the medial oncologist coordinate the treatment plan based on the case they are dealing with. Surgical procedures to remove tumors, with wide margin resection is the usual first line treatment component for LMS depending on the case of course.

Gynecologic Oncologist - may be a specialist in treatment of cancer found in the reproductive organs, and usually trained in surgery and treatment (chemotherapy) administration.

Oncology Nurses, Infusion Nurses, Nurse Practitioners - provide hands- on care for patients and may seen independently from the medical oncologist. Collaboration is of course key.

Genetic Counselors - help patients understand their genetic risk for a disease, their options for genetic testing and treatment choices, and preventative

measures. There should be coordination/collaboration with the medical oncologist / surgical oncologist.

Other Essential team members:

Patient Navigators - help guide patients and families through the treatment process. They also provide information on best facilities for patient rehabilitation after a hospital stay if needed and home health care professional services.

Oncology Clinical Pharmacists - dispense oral anticancer treatments and medications to reduce treatment side effects, and provide patient education regarding the medications as well.

Physician Assistants - conduct routine tests and certain routine procedures.

Dietitians - help manage the nutritional aspects related to cancer care.

Note: **The Integrative Medicine Dept.** - all cancer hospital/treatment centers should have this resource, where patients can learn more about the best diet strategy/plan that fits their needs during and after treatment (maintenance). This is an important area for patients and dietitians/integrative medicine physicians to be in partnership and provide the necessary guidance.

Financial Social Workers - provide counseling, advocacy, and referrals for financial, insurance, and mental health needs. Finding the right resource for the questions and guidance you need is imperative and the social worker should provide the best resources available to provide the necessary support for questions to be answered.

Home health Aides- provide care and medications in patients' homes after a hospital or rehabilitation stay.

Occupational and Physical Therapy - therapists evaluating a patient's physical capabilities, and history of treatment, can establish an appropriate exercise and therapy plan to help patients be restored to a quality of life that involves improved strength, mobility, and function.

Palliative Care Specialist - alleviates pain and other symptoms, and can help manage quality of life at any stage of cancer.

Share this list with you family, caregiver, friends who are supporting you in your treatment journey.

Hopefully this information helps everyone at any stage - from initial diagnosis to end of treatment.

2. A summary of a good article by Barbara Sadick of Cure Magazine -

Fatigue is a common side effect of cancer treatment, with varying degrees from patient to patient. It can be sporadic or constant, with varying degrees of intensity as well. It can't be relieved by sleep and can be "paralyzing" at times. It affects physical, emotional, social quality of life. It is experienced by up to 90% of cancer patients, experiencing this side affect during treatments or the cancer itself.

Management tips:

30 -50% of survivors experience persistent fatigue for months after treatment. It is important to continue to discuss ongoing fatigue with your oncologist for more help.

Medications - if there is a medication that your oncologist would approve to help with fatigue, exploring options may be helpful.

Diet and Nutrition - small, well-balanced, high protein meals can provide energy. Ample fluid and limited caffeine and alcohol intake may prevent dehydration.

Note: there are articles about coffee drinking that may have antioxidant benefits . . .but studies have not yet linked exact research results pointing to this as yet.

Exercise - regular exercise routines can increase energy levels, lower blood pressure, improve the ability of the heart to pump blood and increase endurance (if

you are up to it). Evidence indicates that walking, cycling, swimming can help alleviate fatigue.

Sleep and Relaxation: sleep quality can be improved by practicing relaxation techniques, yoga, meditation, before sleep. Avoid long afternoon naps if possible. Set and keep a regular sleep schedule.

Complementary therapies: acupuncture can reduce pain and nausea by increasing the body's blood flow and natural painkillers. Practicing mind and body exercises - yoga, palates, tai chi, may help as well.

Talk to your medical oncology team about a consultation to help find a balance for you to be able to best manage fatigue.

3. An article on Massage Therapy - and chemo-induced peripheral neuropathy - by Jason Hoffman, PharmD. RPh (Sept. 19, 2016) -

Massage therapy may reduce peripheral neuropathy symptoms among patients receiving neurotoxic chemotherapy, according to a study presented at the 2016 Palliative Care in Oncology Symposium.

Chemotherapy-induced peripheral neuropathy (CIPN) is known to negatively affect quality of life and can necessitate dose reductions of anticancer drugs. There is no consensus of an effective strategy to improve CIPN. Researchers have evaluated massage therapy and feel that this is the primary prevention treatment option for CIPN.

A study was done with 62 patients receiving chemotherapy. All participants in the study underwent two massage therapy sessions; CIPN was measured using a validated survey instrument at baseline, after the first session and after the second session. Nearly all patients reported at least two CIPN -related symptoms, the most common being numbness and tingling of feet, feeling weak all over, trouble walking, and joint pain or muscle cramps.

After the first massage session, between 52% and 100% of patients reported improvement in CIPN-related symptom categories. Improvement in CIPN -related symptoms continued from the first session to the second session of massage therapy.

The findings suggest that clinicians should consider incorporating massage therapy as an approach to improving CIPN.

Talk to your medical care team if you feel that you could benefit from massage therapy to mitigate peripheral neuropathy symptoms.

4. A wonderful college student volunteer has posted a GOFUNDME on behalf of the NLMSF's efforts to raise money for the LMS research projects currently being focused on. Please join in the support for LMS Research funding by going to <https://www.gofundme.com/nlsfm>,

Our student supporter is very special to us and we appreciate her initiative to make a difference for a cause that she believes in. . . .she wants to make a difference too

SMILE.AMAZON.COM - Be an OnLine "PURPLE POWER SHOPPER" for an effortless way to help the Foundation raise money for research. 0.05% of a total purchase through Smile.Amazon.com comes to the Foundation for LMS Research.

All one has to do is select the National Leiomyosarcoma Foundation as the "Charity of Choice" – a one time selection is then automatically saved for future purchasing.

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