



TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

January 2018

Newsletter # 122

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Hello Fellow Members and Friends,

If you are now receiving paper newsletters, and you have an email address where we could instead email you the newsletter (in colour) please contact Dave McMullen – see contact below. Thank you!

Next Meeting: Saturday, February 10, 2018 (note change of date)

Open to patients, family members, caregivers, and any other interested people.

Topic: Group discussion, including brief highlights of 2017 American Society of Hematology (ASH) conference, Myeloma Canada highlights, and myeloma patient experiences and success stories.

Meeting Time: 2:00 – 4:30 p.m.

Location: Jubilee United Church
40 Underhill Drive
North York, Ontario

The meeting starts at 2:00 p.m., but you are welcome to come any time after 1:30 p.m. to enjoy refreshments and socialize.

How to get there: Driving Directions:

Take the Don Valley Parkway, exit east on Lawrence Ave. Immediately turn left at the first intersection, Underhill Drive, and continue north two blocks to the church. There is plenty of available parking. Enter by the north door.

How to get there: Public Transportation:

1. Take the Lawrence Ave. East bus (Route#54) from the Yonge and Eglinton subway station. Exit the bus at Underhill Drive and walk two blocks north to the church.
2. Take the Woodbine 91C bus from the Woodbine Station on the Bloor-Danforth subway line. This bus goes up Underhill Drive past the church.

Google Maps Link: <https://goo.gl/maps/WkNhDr6kGVy>

Meeting Contacts:

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- Patrick Taylor 416-537-8538, pdmtaylor@rogers.com

Last Meeting: December 2, 2017

Guest Speaker: Leslie Brown, Certified Exercise Physiologist and Kinesiologist

Topic: Exercise and Physical Activity for Myeloma Patients

Leslie Brown has extensive experience in exercise physiology and kinesiology, in various organizations, including designing and leading exercise programs for cancer patients. We benefit in so many ways from exercise, appropriate for our individual condition. One of our long-term members improved her condition remarkably from Leslie's exercise programs and advice, at the East End Community Health Centre.

A summary of Leslie Brown's presentation can be found later in the Newsletter.

Members of the Toronto Myeloma Support Group celebrated the season at the December meeting, and took the opportunity to formally thank Barb Secord, the Building Manager of Jubilee United Church, for all her tremendous help to us in providing a regular and welcoming space for us to meet.

Announcements

1) Upcoming Guest Speakers

April 7, 2018: Dr. Anca Prica, Staff Hematologist, Myeloma Program, Princess Margaret Cancer Centre.
News in Myeloma Treatment and Research.

June 2, 2018: Dr. Shira Taylor, MD Psychotherapist
Mindfulness and Multiple Myeloma: Minding Your Inner Monkey

August 11: TBC

October 13: Dr. Jonathan Sussman, Radiation Oncologist, Director of the Supportive Care Research Unit, Juravanski Cancer Centre
Survivorship and Overview of Radiation Therapy for Myeloma Patients

December [Date TBC]: Dr. Ernie Mak, Palliative Care Physician, Princess Margaret Cancer Centre
Symptom Management in Myeloma

2) Myeloma Canada Oshawa Infoession



Guest Speaker: Dr Shaji Kumar
Professor of Medicine, Mayo Clinic College of Medicine
Consultant, Division of Hematology, Mayo Clinic, Rochester, MN

Dr. Kumar is becoming a world renowned researcher in myeloma treatments.

Date: Sunday, January 21, 2018
Time: 11:30 am - 4:00 pm

Location: Harmony Creek Community Centre
15 Harmony Road North, Oshawa, ON L1G 6K8

Information: Phone 1-888-798-5771
Email contact@myeloma.ca

Click [here](#) for registration.

Agenda

- | | |
|------------------|--|
| 11:30 - 12:30 pm | Registration & Lunch |
| 12:30 - 1:00 pm | Who is Myeloma Canada? How do we Help?
Michelle Oana, Associate Director of Development
& Communications, Myeloma Canada
– Presentation + Question Period |
| 1:00 - 1:45 pm | About Myeloma & How Newly Diagnosed Patients Are Treated
– Presentation + Question Period |
| 1:45 - 3:00 pm | Treatment Approaches for Relapsed/Refractory Disease
Dr Shaji Kumar, Mayo Clinic, Rochester, MN
– Presentation + Question Period |
| 3:00 - 3:15 pm | Break |
| 3:15 - 3:45 pm | Myeloma Research in Canada
Gabriele Colasurdo, Manager, Patient Education &
Services, Myeloma Canada
– Presentation + Question Period |

3:45 - 4:00 pm The Patient Perspective
 Leslie Weatherby

4:00 pm Concluding Remarks & Adjournment
 Gabriele Colasurdo, Manager, Patient Education &
 Services, Myeloma Canada

3) Patient Education Session in Newmarket

This session is organized by the Leukemia and Lymphoma Society of Canada.

Topic: "Multiple Myeloma: Overview on Current and Emerging Treatment Options."

Presenter: Peter Anglin, MD, FRCPC, MBA, Physician Lead, Stronach Regional Cancer Centre and Central LHIN Regional Cancer Program

Date: March 5, 2018

Time: 11:00 am – 12:30pm

Location: DEF Cancer Centre Lobby, Stronach Regional Cancer Centre, Southlake Regional Health Centre, Newmarket , ON

Registration: Phone 1-877-668-8326 ext. 5546, or email Sarah.Khan@lls.org

4) Get on the Myeloma Canada Newsletter Mailing List

We recommend that anyone affected by myeloma consider joining the Myeloma Canada Newsletter mailing list. This way, you can keep up to date on any bulletins, notices, newsletters, and other information emailed from Myeloma Canada. You can sign-up for the newsletter through the Myeloma Canada website, on the "Join the Community" tab, at: <http://www.myeloma.ca>.

5) Videos from Previous Presentations

We have a selection of DVDs from previous presentations available for lending at our meetings. Some of our presentations are also on the Myeloma Canada website, on the "Resources/Myeloma Canada Educational Videos" page, at <http://www.myeloma.ca>. The page also contains a link to the Myeloma Canada You Tube channel, containing more videos of interest to those affected by Myeloma.

There is now a video of the excellent presentation at our October 14, 2017 meeting on "Pain Management in Multiple Myeloma", by Dr. Ernie Mak, on the Myeloma Canada website, linked here: <https://www.youtube.com/watch?v=0DynvNX8iLI>

6) Suggestions or Requests

If anyone has any topics or items you would like included in future meetings or newsletters, or other suggestions or requests, please contact Dave McMullen or anyone on the Executive.

Fundraising

If you are interested in making charitable contributions to organizations dedicated to Multiple Myeloma, the following are noteworthy.

Myeloma Canada

Myeloma Canada is the only Canadian national organization dedicated solely to the benefit of Canadians affected by myeloma, through education and support, research, promoting access to new therapies, and public awareness. Myeloma Canada has charitable status and donations will be deductible for tax purposes. Donations can be made online at www.myeloma.ca.

Myeloma Canada
1255 TransCanada, Suite 160
Dorval, QC H9P 2V4

Email: info@myeloma.ca
Website: <http://www.myeloma.ca>
Telephone: 1-888-798-5771

Princess Margaret Cancer Foundation – Myeloma Research Fund (Bloom Chair)

The Princess Margaret Cancer Foundation
610 University Avenue, Toronto, ON M5G 2M9
Telephone: 1-866-224-6560 Email: info@thepmcf.ca

Please make sure to specify the Myeloma Research Fund in the memo area of the cheque, as the funds will otherwise go into the hospital's general cancer research fund. The Princess Margaret Cancer Foundation, c/o Myeloma Research Fund, has charitable status for tax deduction purposes.

Donations may be made online through the Princess Margaret Cancer Foundation, at: <http://www.thepmcf.ca/Ways-to-Give/Donate-Now>. Select the "Myeloma Research Fund".

International Myeloma Foundation (IMF):

Dedicated to improving the quality of life of myeloma patients while working toward a cure.

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607, USA
Tel: 800-452-CURE

Donations may be made online at www.myeloma.org. Unfortunately, the IMF does not have Canada Revenue Agency recognition for tax deduction purposes.

SPECIAL THANKS TO MYELOMA CANADA FOR THEIR FINANCIAL SUPPORT OF THE TORONTO AND DISTRICT MULTIPLE MYELOMA SUPPORT GROUP

Summary of Presentation – December 2, 2017 Meeting

Exercise and Physical Activity for Myeloma Patients

**Leslie Brown, BSc.
Registered Kinesiologist and Certified Exercise Physiologist**

Note: Below is an abbreviated transcript of Leslie Brown's presentation.

A kinesiologist is someone who helps you get healthier through exercise. They're a little bit different than physiotherapists, who have extra training to be more hands on in manual treatment. Kinesiologists are specialized in the exercise part of a treatment plan. An exercise kinesiologist is someone who specializes in exercise for chronic conditions and makes sure people are progressing in their program.

Today, I'm going to talk about five things:

- define physical activity versus exercise,
- review exercise guidelines and recommendations,
- discuss the benefits of exercise for multiple myeloma patients,
- give special considerations to posture, core strength and balance, and
- discuss next steps to get started on an exercise program.

Every good presentation starts off with a true or false quiz, so here we go.

True or false: *Participation in physical activity and exercise is lower for people with multiple myeloma compared to other cancer types.* This is true. Despite promising benefits of exercise for people with multiple myeloma, there are some reasons why people are not being active. It could be from risks related to fractures, fatigue from myeloma or the treatments.

True or False: *I need to sweat to make it work.* False. Sweat is just the body's way of reducing heat, trying to cool itself down. The two true indicators of exercise intensity are heart rate and breathing frequency.

True or False: *No pain, no gain.* False. You should not experience pain during exercise. For people 55 and older, you should never feel pain in your joints or through the back. A little muscle discomfort is normal, but it should stop after the exercise stops.

True or False: *I'll feel better after just one session.* This is true. You just need one exercise session to feel better. It brings fresh blood throughout the body. To see measured outcomes, you need to exercise regularly, but to feel better, you just need one session.

There is a difference between physical activity and exercise. Physical activity is movement that expends energy such as routine activities, leisurely walks and chores around the home. Most research is pointing at limiting inactivity both during and post treatment for multiple myeloma.

Exercise is a subcategory of physical activity that is planned, structured and goal oriented. Put exercise dates on the calendar. Plan to go for a walk or to the gym several times a week. Exercise choices should be structured with a warm up, strength training and stretching or flexibility movement. You should have goals, such as the Canadian guidelines for exercise: 150 minutes of moderate aerobic activity, two days of muscle

and bone strengthening, and balance training (for those 65 and older) per week. Moderate aerobic activity is exercising while still being able to carry on a conversation.

A new study out of the UK for myeloma patients suggests that inactive myeloma survivors should begin one to three light 20 minutes sessions of moderate activity, progressing as they can tolerate. The study also found walking and stationary bike riding are safe for most survivors. However, it does suggest having a walking assessment done prior to beginning any exercise program.

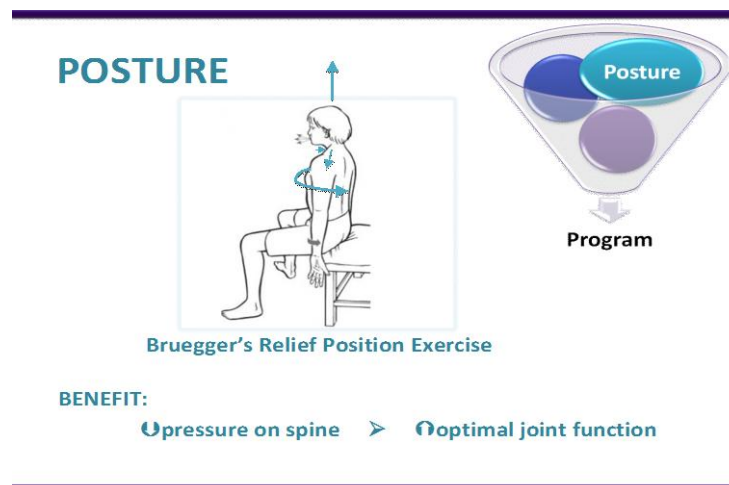
So, what are the benefits of exercise? On the positive side, it improves your quality of life, increases your energy levels, improves your activities of daily living, reduces body weight, increases endurance, improves your mood, eases depression, improves your balance, improves treatment outcomes, provides opportunities for socialization, reduces health risks and co-morbidities such as cardio disease, reduces arthritis stiffness, improves posture and reduces fatigue.

Some tips to get started are to discuss potential exercise programs with your doctor, nurses, physiotherapists, kinesiologists, Wellspring or community health centres. A pre-exercise assessment will look at your medical history and side effects, your exercise history before diagnosis, any previous fractures and current fracture risk, risk of falls, arthritis and joint injuries, medication effect on exercise, posture, gain balance, musculoskeletal tests, overall level of functioning, your current goals and your exercise preferences.

Remember that two ten-minute blocks of exercise are just as effective as one 20 minute block. Aqua exercises are perfect as they do not put any weight on the bones yet still exercise all the muscles. If you are undergoing radiation, you should definitely check with your doctor before beginning aqua fit.

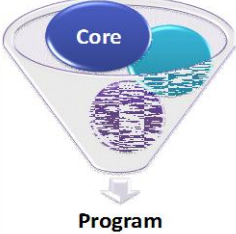
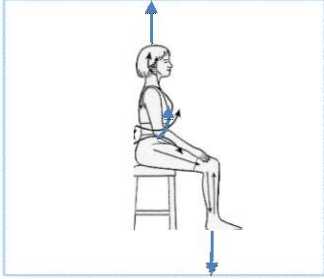
Individualized programs will assess your posture, core strength and balance. The benefit of improving your posture is to lower the pressure on the spine while increasing optimal joint function.

We're going to do an exercise for posture. While seated on the edge of a chair, bring your feet a little wider than your hips. This creates a strong centre of support and pulls your pelvis forward. Now, adjust so your shoulders are right over your hips. Reach your arms to the back, roll the shoulders back and reach the fingers to the floor. Then relax. You should feel a stretch through the chest, as the shoulders come together and strengthen the mid back. Repeat several times. (see diagram)



Core and posture are close in their relationship. If we can increase our core strength, we can help reinforce good posture and optimal joint function. For this exercise, sit back in a chair, again with the feet a little bit wider than the hips. Shoulders are over the hips. Press the top of your head up to the ceiling then relax. Breathe out as you press your head up, breathe in as you relax. You can make it bit more challenging by pushing the feet into the floor at the same time as you press your head up. Repeat several times.

CORE



BENEFIT:

- core stability
- reinforce good posture & optimal joint function

We're going to try a balance exercise. When we're thinking balance, we're thinking about more than trying to stand on one foot. We need to pick exercises that challenge how we respond to weight transfer. Shift the weight from your toes rocking onto your heels. You may hold onto a chair to do this. As you progress, you can advance to the diagram below. Remember to keep your shoulders stacked over your hips. The benefits of balance are reduced risk of falling, thus reduced risk of fractures.

BALANCE EXERCISES



Pick exercises that challenge balance and weight transfer.

BENEFIT:

- balance
- risk of fall
- risk of fracture

There are some types of exercises to avoid: spinal twisting, spinal turning, spinal extensions, fast or high impact movements and movements at end range of joint flexibility. Monitor your yoga movements for twisting and turning of the spine. Always stop if there is pain.

At East End Community Centre, we run a program called Gentle Fit which is composed of a light cardio warm up, posture and balance exercises, gentle body weight strengthening exercises, resistance training using therabands and a modified flexibility cool down. It provides an opportunity to connect to the community, learn about other services at the health centre such as cooking and better nutrition, and engage in supervised safe group exercise. The class runs for approximately 60 minutes twice a week. It is geared for people 55 and older.

There are other exercise programs similar to Gentle Fit at many community health centres. It's best to check the Internet for your closest centre.

Many people are familiar with Wellspring, and it's good to note they offer a cancer exercise program conducted by physiotherapists, kinesiologists and exercise physiologists trained in cancer rehab. They conduct an individual assessment of each participant and then develop a personalized 30 week exercise program. The first twenty weeks are held twice a week at the centre and the last ten are held once a week. The latter is a transition for you to continue the exercises at home.

Wellspring also released an exercise study on how their patients did on the program. They found significant improvements in the participants with cancer related fatigue, increased performance in the six minute walking test, improved social well being, improved systolic blood pressure, improved balance and improved health related quality of life. If you are interested, you should contact the Wellspring Centres at kate@wellspring.ca.

Q. At what point are you good to do weight training? Is there an indicator?

A. You should have an assessment from your doctor or your team. They would know whether you are ready to begin exercises and what type of exercise would be best for you.

Q. It's been my experience that structured exercise programs usually want you to have your doctor's permission before you begin, has that been your experience too?

A. Definitely. There's a tool called Get Fit which asks specific questions about exercise modifications for cancer. That should be given to your health team to provide information on what should be limited.

Q. Should you do exercises if you are on steroids?

A. Absolutely. Often what that protocol would look like is starting with non-weight bearing exercise, such as pilates, and slowly building up from there.

Q. Will exercise increase or decrease my overall fatigue?

A. In the short term, you will feel more exhausted, but in the long term, it will decrease your fatigue.

Q. What about elliptical machines?

A. Typically, I recommend a bike or walking over elliptical machines. If you can use it without any pain, it's good for you.

Q. What about treadmills?

A. No problem.

Q. What should your heart rate be for light to moderate aerobic exercise?

A. It varies. One equation is 220 minus your age is equal to your maximum heart rate. So, for light aerobics, you would want to get to 60 per cent of that number, and for moderate aerobics, you would want to reach 75 to 80 per cent. However, if you are taking beta-blockers, you may not be able to get your heart rate up to the max. The simplest test is the talking test. If you can talk while you're exercising, you are in a safe zone.

Q. I used to play a lot of tennis before my diagnosis. How do you rate it in terms of twisting?

A. If you are going to return to those sports, limit the swing and speed of your stroke. Your body may be used to that movement, so check to see what your risk is.

Q. What about badminton?

A. With badminton, there are hard, fast movements which are very difficult on the multiple myeloma body, so I would not recommend it.

Q. Is there a charge for the Gentle Fit program?

A. All our programs are free, all through internal funding. East End is a charity and we have made it a core initiative. We also offer a chronic pain program, falls prevention, and hope to begin a COPD and asthma program in spring.

Q. Can people outside of the GTA take part in the program?

A. For a class like Gentle Fit, it's a drop-in program so you can come when you can. You should check your local community health centre to see if they offer a similar program.

Q. My mother is big fan of Wellspring threabands but hers broke. Is that common?

A. They don't last forever, usually about a year with regular use. Also, if it got wet, it could affect the longevity. Even sweaty hands could shorten their lifespan.
