



TORONTO & DISTRICT MULTIPLE MYELOMA SUPPORT GROUP NEWSLETTER

Website: www.myelomatoronto.ca

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Newsletter # 162

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Hello Fellow Members and Friends,

Next In-Person Meeting: Saturday, October 5, 2024

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

Topic: *Kyphoplasty and Related Treatments*

Speaker: Dr Roger Smith, MB ChB, FRCSE, Neuroradiologist, Departments of Medical Imaging and Neurosurgery, Co-Director Multidisciplinary Metastatic Spine Clinic, University Health Network



Dr. Smith has performed in excess of 1500 vertebral augmentation procedures, 96% for metastatic cancer including multiple myeloma. He also performs image-guided needle procedures for pain. His interventions have relieved pain and significantly improved the quality of life of myeloma patients.

Meeting Time: 2:00 – 4:00 p.m.

Location: Jubilee United Church
40 Underhill Drive
Toronto, Ontario (see directions below)

PLEASE NOTE: The meeting starts at 2:00 p.m., but you are welcome to arrive any time after 1:30 p.m. to meet others and help with setup. There will be no Zoom access. However, the presentation will be recorded and a summary will be in the next newsletter. Since many in-person attendees will have weakened immune systems, participants are welcome to wear masks.

How to Get There: Driving Directions:

Take the Don Valley Parkway, exit east on Lawrence Avenue, and then immediately turn left at the first intersection, Underhill Drive, continuing north two blocks to the church. Because traffic is often heavy on the Don Valley Parkway, some drivers prefer to use Leslie Street or Don Mills, exiting east at Lawrence. 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>

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Peter Scherer, 647-460-5005, peter.scherer@ymail.com

Last In-Person Meeting: August 10, 2024

Topic: *Being a VIP – a Very Informed Patient: How to Advocate for Yourself*

Speaker: Chantel Wicks, Ontario Regional Community Engagement and Development Manager for Ontario, Myeloma Canada

A detailed summary of Chantel Wicks's engaging presentation can be found at the end of this newsletter.

Announcements

1) Upcoming In-Person Meetings with Guest Speakers

December 7, 2024: *Caregivers and Caregiving (followed by Seasonal Celebration)*

February 1, 2025: *Share and Care*

April 5, 2025: TBA

2) Upcoming Virtual Share and Care Meeting

Thursday, November 7, 2024, 7:00-8:30 p.m., Virtual Zoom Meeting

Share and Care Zoom meetings are normally held on the first Thursday of every second month. The login link to Zoom is sent by email prior to meetings. The meetings provide a great opportunity to welcome new participants, meet fellow myeloma patients and caregivers, and raise questions and learn from each other in a caring and supportive environment.

3) In Tribute to Dave McMullen



Dave and Erika McMullen

Dave McMullen, until recently the Chair of the steering committee of our support group, passed away peacefully on Saturday, August 30, 2024 at Juravinsky Cancer Centre in Hamilton. A private funeral service was held on Saturday, September 7, 2024 at the St. John's Anglican Church in his hometown of Ancaster, Ontario.

Tributes

[John David McMullen Obituary](#) (Globe & Mail)

[Passing of Patient Representative David McMullen](#) (Canadian Cancer Trials Group)

[A Peek at the PAC](#) (Myeloma Canada Patient Advisory Council)

Messages of condolence and tributes may be left online here:

<https://www.circleoflifecbc.com/obituaries/John-Mcmullen-7/> - [!/TributeWall](#).

Donations in memory of Dave McMullen may be made here: [Myeloma Canada Donations – Dave McMullen](#)

Munira Premji's Remarks on Behalf of Our Support Group

Erika McMullen graciously asked Munira Premji to deliver a eulogy at Dave's funeral service on behalf of our support group. Below are her remarks:

The day I met Dave was a turning point in my life. In 2012, I was diagnosed with two blood cancers at the same time – Non-Hodgkin Lymphoma and Multiple Myeloma. Later that year, just before my first stem-cell transplant, my husband Nagib and I attended a meeting of the Toronto & District Multiple Myeloma Support Group. When we walked into the Jubilee United Church, we were met with a booming "Hello!" and a big smile from this tall, handsome man. Dave McMullen was at the door welcoming us. You see, Dave was also diagnosed with Multiple Myeloma the same time as me and had become an enthusiastic member of the support group. He took the time to talk to Nagib and me, to understand our hopes & fears, and to answer all the questions we had about my upcoming stem cell transplant. We felt incredibly supported.

That was the start of our long and cherished friendship with Dave and Erika. But it was not just us. Dave supported everyone who reached out to him with compassion and humanity. Through his example, he taught us to do the same.

Subsequently, Dave became the Chair of the Steering Committee for the Toronto & District Multiple Myeloma support group and co-founded the Halton-Peel support group. His mantra was "knowledge is power." And since his cancer diagnosis twelve years ago, Dave went to great lengths to study the disease, attending conferences and seminars across North America, working closely with Myeloma Canada and seeking knowledge wherever he could. He made it his mission to understand the ever-changing pesky world of myeloma from the perspective of a patient, and to disseminate this information to the people who needed to hear it.

For me, every time I went through a new treatment, Dave was the first person I reached out to - he was my 1-800-CALL DAVE. His insights and up-to-date knowledge of myeloma provided valuable information to myeloma patients across Canada and beyond, so they could make the right decisions for themselves.

Winston Churchill said, "We make a living by what we get, but we make a life by what we give." Well, Dave made a life for all that he gave. For his service, Dave received many awards. This included being presented with Ontario's distinguished June Callwood Outstanding Achievement Award for Voluntarism in 2022. And in 2023, being honoured with the CCRA's illustrious award for "[Exceptional leadership in patient involvement in cancer research.](#)"

But he never did this work for the recognition. It was never about him; it was about helping people, being in service to others. I know that each one of us in this room has witnessed this gift of giving from Dave that was part of his DNA.

A quality that Dave brought to the Steering Committee and Support Group was his vision of providing the best possible care to myeloma patients and their caregivers. And he succeeded in doing this. This past Thursday, we had our regular Care and Share meeting of myeloma patients and their caregivers, and there were many tears as members talked about the impact Dave had on them, how grateful they were to know him, and how his legacy will forever live on.

He transformed our Steering Committee, pushing us to new heights and inspired us to dream bigger, work harder, and be better. And he pushed himself every day. Five weeks before he passed away, he was rappelling down the side of a building in downtown Toronto to raise money for Myeloma Canada. Who does that?!



Dave McMullen rappelling down the side of the Hilton Hotel, July 6, 2024

I think the quality that I will remember most about Dave was his attitude toward life. He saw potential where others saw obstacles. He lived his life from a place of hope and optimism. He demonstrated courage, resilience and grace even when he was sick. Every day was a gift for Dave, and he lived each moment of his life with purpose, fully and fearlessly, always striving to make a difference in the myeloma community.

Some of you who knew Dave will know what I mean when I say he was sometimes... "intense." He believed so much in the well-being of patients that he insisted that the snacks provided at each meeting should be healthy snacks. So, at each meeting we would have "carefully-cut, bite-sized pieces of carrots and celery," courtesy of Dave and Erika, and Dave grudgingly allowed us to bring chocolate cakes and samosas which he did not consume!

I cannot talk about Dave without talking about Erika. Dave loved Erika and I witnessed this each time they were together. In the way they looked at each other. The respect they had for each

other. How they travelled together to learn about myeloma and what they could do to keep this disease at bay. Theirs was a very precious relationship.

Erika - Dave spoke often about how lucky he was that you were his caregiver and that he could not do this journey without your incredible support and love. We all share in this loss Erika – the loss of your life’s partner. And know that we love you and are here for you.

Thank you, Dave, for everything you gave us. Thank you for being a beacon of hope, a source of inspiration, and a guiding light in our journey. You will be deeply missed, but never forgotten.

Rest in peace, my friend.

*Munira Premji, Member, Steering Committee,
Toronto & District Multiple Myeloma Support Group*

Tribute by Myeloma Canada

Martine Elias, CEO of Myeloma Canada, sent out an email to the wider myeloma community, advising of the passing of Dave McMullen. Below is the text of the email:

Past Chair of the Myeloma Canada PAC, Chair of the Toronto & District Multiple Myeloma Support Group Steering Committee, Co-founder of the Halton-Peel Support Group, Peer volunteer, Multiple Myeloma March organizer and participant, National and Ontario Advocacy committee member, prolific patient advocate, engaged volunteer, loving husband and friend, inspirational human being.

It is with great sadness that we announce the peaceful passing of David McMullen Friday evening, August 30th, 2024.

David’s extraordinary work and spirited engagement in empowering the Canadian myeloma community was exemplary.

When David was diagnosed with multiple myeloma in January 2012, a nurse handed him a copy of Myeloma Canada's "Multiple Myeloma Patient Handbook". He took the Handbook home, studied it, visited the Myeloma Canada website, discovered two support groups in Ontario, and within three weeks, met with both of them! It didn’t take long for David and his wife Erika to become very involved with both groups, and our organization.

David was a devoted ambassador of myeloma and Myeloma Canada. For more than 12 years, there was no ask too big or too small; David rose to every occasion to spread awareness and education of myeloma, advocate for patient representation and visibility. He fully immersed himself in the Canadian myeloma community, sitting on numerous patient and regulatory boards.

For his incredible advocacy work and volunteerism, David was the recipient of many prestigious awards. In 2018, David was awarded Myeloma Canada’s Notable Volunteer Award for Outstanding Engagement. In 2022, he was presented with Ontario’s distinguished June Callwood Outstanding Achievement Award for Voluntarism (Outstanding Volunteer category), as well as the Myeloma Canada Executive Director Award. In 2023, David was honoured with the CCRA’s illustrious award for [“Exceptional leadership in patient involvement in cancer research.”](#)

Over the years, David joined the Executive Team of the Toronto & District Multiple Myeloma Support Group and later become its Co-chair. In 2013, he helped to establish a new support group in Halton-Peel and participated in his first Myeloma Canada Scientific Roundtable. In 2014, David was asked to be the first Chair of the newly created Myeloma Canada Patient Advisory Council

For over a decade, David was a passionate support group leader and engaged committee member in over a half a dozen support groups in the GTA. His passion for supporting others also extended

to his role as peer volunteer in our Peer-to-Peer Support program. David was also instrumental in planning, executing and attending countless Multiple Myeloma Marches throughout Ontario, and participated in a few of the Montreal ones as well. David volunteered alongside Myeloma Canada at the Family Medicine Forum, took part in Awareness Days, served as a media spokesperson for Myeloma Awareness Month in the Hamilton region, and represented patients at the annual Myeloma Canada Scientific Roundtable. He was a dedicated member of the Ontario and National Advocacy Committees, and an active participant at Myeloma Canada's national support group leader events and conferences.

David earned the tremendous honour of being appointed one of 12 members of the [Patient and Community Advisory Committee of the Canadian Agency for Drugs and Technologies in Health \(CADTH\)](#) where he ensured the myeloma patient voice was heard in addressing healthcare needs across the country. Additionally, David was a highly valued patient representative within the [Canadian Cancer Trials Group \(CCTG\)](#) Hematology and Patient Representative Committees, and was a patient representative with BioCanRX.

Along-side his tremendous passion, dedication, and commitment, David demonstrated humility, selflessness, and gratitude in all that he did for his local and national myeloma community. David's compassion and respect for all, especially his wife and caregiver Erika, was beyond measure.

On a personal note, I am profoundly grateful for David's consistent and candid feedback on Myeloma Canada's importance to our community and how one of our core values needs to remain focused on the patient. David devoted many thousands of hours directly toward Myeloma Canada activities, well over a thousand hours helping to organize marches every year since 2013, and many more thousands of hours leading and supporting a number of support groups. It is very rare to find someone like David who is as devoted to, and such a public supporter of, Myeloma Canada. David was one in many thousands.

All of us at Myeloma Canada, alongside David's loved ones, mourn his passing. We will always be honoured to have had David within our Myeloma Canada family. Our heartfelt condolences, love and support go out to Erika. May David's memory bring strength to all who knew him.

Martine Elias, Chief Executive Officer, Myeloma Canada

4) Walk & Talk: MM Walking Groups

Walk to connect outside of meetings, get exercise, enjoy nature and enhance mental health! Our walks are geared to accommodate people of differing levels of physical ability and are most often on flat areas, though some walkers may want to explore more varied terrain. In all cases, please ensure your own safety and comfort by wearing appropriate shoes and outerwear and using hiking poles or other walking aids as needed.



Everyone is welcome to join our MM Walking groups. For further information and to confirm location, dates, and times please contact one of the following:

Earl Bales: Every second Tuesday at 10:30 AM

Contact: Suzanne Jordan - suzannejordan@hotmail.com (416 709-4418)

High Park: Every second Thursday at 10:30 AM

Contacts: Rosa Bergman - rbergman@rogers.com (416 662-5671)

Patrick Taylor - pdmtaylor@gmail.com (416 522-8538)

If you are interested in participating in a walk and talk group for myeloma patients and caregivers on a different day or in a different location, please contact Patrick Taylor (pdmtaylor@gmail.com).

5) Social Outings – Picnic at Earl Bales

On September 4, support group members met at Earl Bales Park for a late summer picnic. Planned long before the sad news about Dave McMullen, the event became a celebration of Dave’s longstanding contribution to the support group. There was a good turn out, and participants shared wonderful memories of Dave, his encouragement of others, and his positive approach to life. It was a very healing experience.



In past years the support group has organized various social outings, including picnics in parks, lunches in homes and restaurants, and boat tours of Toronto harbour. If you have ideas for a particular group activity, feel free to discuss it with a member of the Steering Committee.

6) Rinat Avitzur Shares her Journey for Blood Cancer Awareness Month

Rinat Avitzur, chairperson of the Toronto and District Multiple Myeloma Support, was featured in a recent issue of *Healthing.ca*, a Postmedia newsletter focusing on health matters. Rinat was diagnosed with high-risk multiple myeloma during the COVID lock-down and had two back-to-back transplants. However, she was determined not to feel sorry for herself, “It was like, if that’s what needs to happen and I need to go through this, then I will go through it.” With the support of her family and healthcare team, she regained her strength and found a new purpose for her life – to make the journey easier for herself and other people who deal with cancer. Rinat is committed to supporting new research and emphasizes that clinical trials, like the one she is currently on, are saving many lives. She wants more people to be aware of multiple myeloma and the importance of early diagnosis. “I’m the biggest advocate for early diagnosis of multiple myeloma,” she states. “If you think something’s off, get checked and get your blood work done.”



Read more about Rinat's story: "[What it Feels Like: 'I will find ways to make cancer easier for people like myself'](#)"

7) Canadian Myeloma Research Group (CMRG) Patient Education Series



This excellent patient webinar series was presented jointly by Dr. Donna Reece, CMRG Chief Medical Officer, and Suzanne Rowland, an experienced Princess Margaret Cancer Centre nurse practitioner.

To view CMRG webinars, see the CMRG website, linked here: [patient-webinars](#). They may also be viewed on YouTube at the links below:



Webinar 1: [Myeloma 101](#)

Webinar 2: [Lab Results and Imaging Studies: Pt I](#)

Webinar 3: [Lab Results and Imaging Studies: Pt II](#)

Webinar 4: [Living with Myeloma, Striving for Excellent Quality of Life](#)

Webinar 5: [Current Myeloma Treatment Landscape, and Stem Cell Transplants](#)

Webinar 6: [ASCT Continued - Belantamab mafodotin](#)

Webinar 7: [Bispecific T-Cell Engagers \(BiTEs\) in Myeloma](#)

Webinar 8: [Myeloma Symptoms Management](#)

Webinar 9: Car-T (to be posted)

Webinar 10: Other drugs / CELMoDs etc. (to be posted)

Webinar 11: End of Life Care / Medical Assistance and Dying (MAID) (to be posted)

8) Respiratory Infections

Respiratory infections continue to be a concern for immunocompromised persons, including most people with myeloma. These include COVID-19 variants, influenza, respiratory syncytial virus (RSV) and other respiratory infections such as measles. **Persons already vaccinated should be sure to get an updated COVID-19 vaccination to target the JN.1 and KP.2 COVID strains when vaccinations become available this fall.**

In addition to keeping their vaccinations up-to-date, myeloma patients should always assess their risk in determining when they should mask and/or avoid crowds and indoor spaces.

COVID-19 vaccines are available as mRNA vaccines (Pfizer and Moderna) and a non-mRNA vaccine (Novavax). Vaccines can be booked online at Government of Ontario COVID-19 booking portal ([covid-19.ontario.ca](#)), by calling the Provincial Vaccine Contact Centre at 1-833-943-3900, or by contacting participating hospitals, clinics, and pharmacies.

If a person with myeloma contracts COVID, regardless of the severity of the symptoms, they should contact their health care providers as soon as possible after the onset of symptoms to determine if they are eligible to receive one of several available treatments. If administered within five to seven days of onset, depending on the treatment, they provide significant protection from severe outcomes.

RSV vaccines require a prescription from a medical practitioner and can be booked at participating hospitals and pharmacies. RSV is a common respiratory virus that typically causes mild, cold-like symptoms, but can lead to severe illness in infants and older or immunocompromised individuals. Although RSV is not yet fully funded, the Government of Ontario

has approved funding RSV vaccines for high-risk adults aged 60 or older, including people who have had a stem-cell transplant (see: <https://www.ontario.ca/page/respiratory-syncytial-virus-rsv-prevention-programs>). If you have not yet received an RSV vaccine, speak to your hematologist to find out if you qualify for a free vaccine and where you can get one.

MMR vaccinations are provided by medical practitioners. The MMR vaccine is a live vaccine and is recommended for some post-transplant myeloma patients one or two years after transplant. Your hematologist may recommend that you do a titration test to determine if you have antibodies before recommending that you get the vaccine.

Timing Vaccinations: Myeloma patients should contact their hematologist, oncologist, or health provider for advice on the timing of vaccinations in relation to their current treatment regimen and risk profile.

VaxFacts+: VaxFacts+ is a service offered by Scarborough Health Network to provide timely, accurate information about vaccinations. To make an appointment to speak to a doctor by phone see the VaxFacts+ website at <https://www.shn.ca/vaxfacts+>.

COVID-19 Antibody Tests: COVID-19 vaccines are generally not as effective for myeloma patients as they are for the wider population, and, in addition, are less effective over time. Myeloma patients may therefore wish to consider taking the COVID-19 spike protein test (SARS-COV-2 Antibody Panel) available at Dynacare Labs at a cost of \$80. You will need a requisition signed by your oncologist or family doctor. The test indicates if you have antibodies to COVID-19 because of previous exposure to vaccines, or to COVID-19. It does not indicate the actual ability of your immune system to resist infection. For further information and to download the requisition form see the Dynacare website: <https://www.dynacare.ca/covid19-antibody-test.aspx>.

Online Resources

Canada's National Advisory Committee on Immunization (NACI):

[NACI Statements and Publications](#)

[Immunization of Immunocompromised Persons](#)

9) Myeloma Canada News

New Myeloma Canada InfoSheet

"Managing Anemia Associated with Myeloma and its Treatment" >> [Download InfoSheets](#)

10) Myeloma Canada Resources

Myeloma Canada Website: www.myelomacanada.ca

The Myeloma Canada patient-friendly website is the go-to source of information for Canadian patients and caregivers who need material relevant to the Canadian healthcare context. The website has excellent, accessible information on multiple myeloma, including information for newly diagnosed patients and persons living with myeloma and their caregivers. In addition to links to support groups—including virtual support groups—there is a comprehensive resource library with digital tools, information sheets and guidebooks that can be downloaded, and links to educational webinars and videos. There is also a helpful myeloma glossary along with many other useful resources.

>> Access the [myeloma resource library](#)

Myeloma Canada Lounge

MC Lounge provides a private and secure social platform that includes online patient and caregiver support groups, the latest myeloma news, upcoming educational events, the Myeloma Canada resource library, and the Myeloma Canada YouTube channel. MC Lounge also allows you to privately message individual members and Myeloma Canada staff, and to find volunteer opportunities. You can sign up to MC Lounge on the Myeloma Canada website: [Join MC Lounge](#)



Myeloma Canada Webinars

Myeloma Canada webinars provide important, timely information on multiple myeloma. For an up-to-date list of webinars and videos of past webinars, see the following link:

<https://www.myelomacanada.ca/en/news-events/infosessions-and-meetings/webinars>

Past Myeloma Canada webinars, along with webinars hosted by our support group, are posted on the [Myeloma Canada channel on YouTube](#). Some of these are listed here:

- The Role of Palliative and Supportive Care after a Myeloma Diagnosis – [view recording](#)
- Navigating through a Cancer Diagnosis and Employment – [view recording](#)
- Living Solo with Myeloma - [View recording](#)
- Understanding Clinical Trials – [view recording](#)
- Multiple Myeloma and Immunotherapy Made Simple – [view recording](#)
- Sexual and Gender Diversity in Cancer Care – [view recording](#)
- Myeloma Physiotherapy Consensus Recommendations: What Patients and Caregivers Need to Know – [view recording](#)
- Empowering Yourself on the Myeloma Journey - [view recording](#)
- Following & Understanding Your Serum Free Light Chain Test Results - [view recording](#)

Myeloma Canada Peer Support Program

Myeloma peer support volunteers help individuals with myeloma and their caregivers better understand, manage, and cope with myeloma. They come from within the myeloma community and have first-hand experience living with myeloma. Understanding what you are going through, they can listen to your concerns and provide helpful perspectives, ideas, and insights. Volunteers are trained to provide confidential, one-on-one peer support at no cost to participants.

- Peer support information: [Peer Support Program](#)
- Signup for peer support: contact@myeloma.ca (indicate Myeloma Peer Support in the subject line)

Myeloma Canada Mailing List

We recommend that anyone affected by myeloma consider joining the Myeloma Canada email list. This way, you can keep up to date with the monthly Myeloma Matters newsletter and receive any bulletins, notices, or other information emailed from Myeloma Canada. You can sign-up through the Myeloma Canada website at the following link: [Myeloma Canada News](#).

11) Your Toronto Group

Volunteering for the Support Group

The work of the Toronto and District Multiple Myeloma Support Group is sustained by the many dedicated patients and caregivers who provide peer support, attend meetings, set up the meeting

room equipment and Zoom meetings, greet new members, organize the kitchen and refreshments, assist with secretarial work, and participate on the Steering Committee. Your assistance in all these areas is greatly appreciated by all support group members. Please contact our chairperson, Rinat Avitzur, or any member of the steering committee if you are interested in volunteering. Special thanks to all those who already contribute on a regular basis.

Support Group Brochure

Our brochures, along with our website and by word of mouth, are the main ways in which newly diagnosed patients and their caregivers find out about the support group. The brochures are being distributed to all oncology centres in the GTA as well as to clinics and cancer support organizations. If you know of any place where brochures are needed, or if you would like some to give to people who might be interested in the group, you may contact any member of the steering committee or pick up copies at our next in-person meeting. Pdf copies are also available on the home page of the support group website: myelomatoronto.ca.

Support Group Website

Our website, myelomatoronto.ca, includes a "Useful Links" page, which provides links to organizations that provide information and resources for myeloma patients. It also contains current and past newsletters, as well as information on upcoming meetings and events.

Support Group Facebook Page

Our Facebook page, www.facebook.com/Toronto-and-District-Multiple-Myeloma-Support-Group, provides information about the support group for Facebook users or others who may not have found our regular website. The Facebook page is passive and refers Facebook users to our website. The support group relies principally on its website, newsletters, and emails when communicating with support group members and the public. Anyone interested in active Facebook engagement with other patients and caregivers is encouraged to join one of Myeloma Canada's virtual support groups on Facebook, linked here: <https://myelomacanada.ca/en/find-support/virtual-support-groups>.

Videos from Previous Support Group Presentations

Videos from previous presentations at our support group meetings are posted on Myeloma Canada's YouTube channel: <https://www.youtube.com/@myelomacanada>. Our videos have a red gerbera daisy flower on the title page.

Suggestions or Requests

If you have a topic that you would like included in future meetings or newsletters, or have any other suggestions or requests, please contact a member of the Steering Committee.

Living Solo with Myeloma

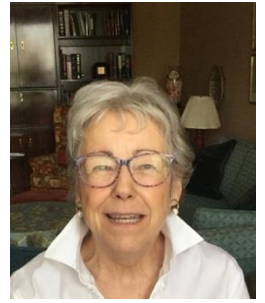
Heather Walker

I have been attending Toronto & District Multiple Myeloma Support Group meetings since I was diagnosed with smouldering myeloma in 2016. I am very grateful for the lectures and Share & Care meetings during this time. They are informative about treatments and offer advice on how to navigate our myeloma journeys. There is also the newsletter which always carries a patient's story. These are stories of courage, resilience and gratitude, and almost always express

appreciation for a spouse's (or live-in family member's) help and support. A common sentiment is, "I couldn't have done it without this help."

As someone who lives alone, I was struck by that. I wondered what it is that living with someone provides that a solo person might need, and how can it be gotten?

My search for answers to this question started with various myeloma websites and I found that despite the many resources provided for patients and caregivers, the specific topic of living solo with myeloma was rarely addressed directly.



In 2022 when I started treatment - daratumumab, lenalidomide and dexamethasone (I'm transplant ineligible) - I also started to identify those gaps and planned to close them.

First, I wanted to ensure I could live in my own home. Within a few months, I had moved to a new apartment that was close to my treatment centre at St. Michael's Hospital, on the subway line, and within walking distance of groceries, pharmacies, banking, etc. Even if a time came when I couldn't drive, everything would be very accessible. And I knew that if I had to bring in caregivers, they would appreciate a client close to a subway stop. My new apartment has 24-hour security which means deliveries are made to my door, and if I need attention during the night, security personnel are there.

That is the physical environment, but what about coping with daily life when you need support for hospital visits, food shopping and preparation, emotional support? Ensuring you take your medication? I wondered what other solo patients in our support group do to manage. I asked Bob McCaw, Vi Heyworth and Rosa Bergman what works for them as solo patients.

Like me, Bob moved homes to be closer to the hospital. And he makes sure that if there is an emergency, medical information is on his fridge for Emergency Services, and his will and other important information is kept current and available. Bob also emphasized how important it is to have a routine; for example, every Sunday he prepares his medications for the week. I have missed doses precisely because I have not adopted a routine. Living solo means there's no one to remind you.

Vi is adamant that she stay in her own home and she does most of her day-to-day chores. But Vi's one complaint is that while she prepares healthy meals, she doesn't like eating alone! In her ninth decade, it's clear that Vi's independent spirit makes living alone tenable.

Rosa, like Bob, has friends in the apartment building who can be called upon if needed. This gives a great sense of security if your health is precarious. As Rosa pointed out, if you don't feel well, being on your own can be scary.

When I have felt unwell, I have called Cancer Ontario for advice and reassurance. A common refrain for many of us is a reluctance to ask for help. Bob gave very good advice stating that we should not be afraid or indeed ashamed to ask for help when we need it.

Preparing for this article, I returned to looking on-line for advice on filling those gaps when living alone, and found a useful Myeloma Canada spotlight on Germain Nadon and a webinar called "Living Solo with Myeloma" featuring her.* Nadon very successfully navigated her journey by embracing each challenge and finding solutions. These include asking for financial assistance from charities and enlisting girlfriends in her hometown of Kelowna to stay with her during her stem cell transplant in Vancouver. Whether you live alone or not, any myeloma patient can benefit from Nadine's tips on managing medication timetables, multiple appointments, and tracking side-effects by drug and condition.

Whether you have family, friends or the myeloma community in your life, remember that you may live solo, but you needn't be alone.

*Some sites directed at solo patients are listed below:

1. Germaine Nadon and Anna Giulione, "[Living Solo with Myeloma](#)," Myeloma Canada Webinar (YouTube).
2. "[Spotlight-on-Germaine-Nadon: Living Solo with Myeloma](#)," Myeloma Canada, July 2023.
3. [Living Solo and Strong Virtual Support Group](#), International Myeloma Foundation.
4. "[Living Well with Myeloma: Spotlight on Living Alone](#)," Myeloma UK.

Fundraising Events

MM5K Walk or Run, Princess Margaret Cancer Centre

Every year, many members of our support group participate in the Journey to Conquer Cancer in support of the excellent multiple myeloma research program at Princess Margaret Cancer Centre. Joining thousands of walkers and runners representing different cancers, MM5K team members make their way through downtown Toronto and past Princess Margaret to the cheers of supporters and volunteers before returning for a fun-filled celebratory closing event. Patients and family, friends and co-workers, doctors and nurses, all join together to raise funds to improve the lives of multiple myeloma patients. Some patients and supporters also participate virtually.



This year, the event started and ended at the athletic field at Hart House, University of Toronto, where children's activities, refreshments, and a plentiful supply of before- and after-walk snacks could be found. The MM5K is always a family-friendly affair, with a spirit of celebration and hope in the air, and much gratitude for the improvements in treatment options and outcomes that myeloma patients are experiencing. This year's walk raised over \$410,000 for myeloma research at Princess Margaret.



Next year's MM5K Walk or Run takes place on **June 15, 2025**. You can register and or/support your fellow walkers and runners at the following link (be sure to select the MM5K group): [Journey to Conquer Cancer 2025](#).

View great photos from this year's event on the [MM5K Facebook page](#) and the [Journey to Conquer Cancer photos website](#).

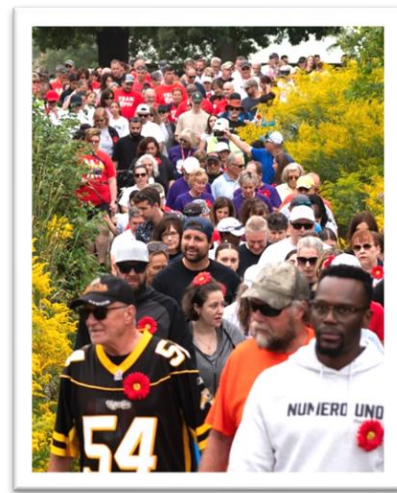
16th Annual Myeloma Canada Multiple Myeloma March



Myeloma Canada's Multiple Myeloma March takes place every fall in more than 30 communities across Canada to build community, spread awareness and raise funds for clinical research and accelerated, equitable access to new, life-changing therapies, treatments, and programs for Canadians living with myeloma. Locations around the Greater Toronto Area attract a lot of participation from support group members. Like the Princess Margaret MM5KWalk, these are opportunities for family and friends to get together, make new friends and have fun supporting research and building awareness for a cause that is of the utmost importance to so many of us. The Multiple Myeloma

March empowers participants and celebrates life, hope, and resilience.

The 2024 March continues to support the Research Fund-Sharing Partnership Program introduced last year. Myeloma researchers and associated myeloma treatment and research centers can apply to partner with their nearest Myeloma Canada Multiple Myeloma March and be awarded a research grant of up to 50% of the net March proceeds. This year's March was again very successful and across Canada over \$750,000 has already been raised. Find out more about the Multiple Myeloma March and Research Fund-Sharing Partnership Program in the [2024 March Mini Mag](#) and [Myeloma Canada March website](#).



Marches in Southern Ontario took place in Barrie, Brampton, Coburg, Cornwall, Hamilton-Niagara region, Kingston, Kitchener-Waterloo, Mississauga, Oshawa and Newmarket. There is still an opportunity to participate in the [Scarborough March](#) which takes place on October 5, while the [Virtual March](#) continues.

Fabulous photos of the 2024 March from across Canada can be viewed at the following link:

<https://www.flickr.com/photos/135746311@N08/albums>.

For information on Myeloma Canada fundraising events, see the [Myeloma Canada fundraising website](#).

Charitable Contributions

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

Email: info@myeloma.ca

1255 TransCanada Hwy., Suite 160
Dorval, QC H9P 2V4

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

Princess Margaret Cancer Foundation – Myeloma Research Fund

The Princess Margaret Cancer Foundation
610 University Avenue, Toronto, ON M5G 2M9

Email: info@thepmcf.ca
Telephone: 1-866-224-6560

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
4400 Coldwater Canyon Ave, Suite 300
Studio City, CA 91604, USA

Tel: 800-452-CURE

Donations may be made online at <https://www.myeloma.org>. 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

Highlights of Presentation at Support Group Meeting – August 10, 2024



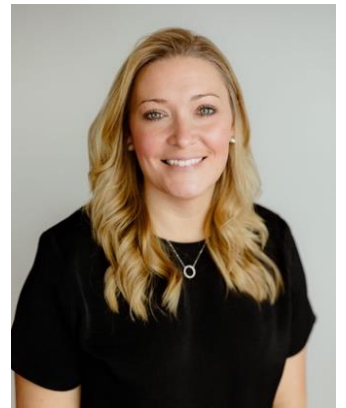
Being a VIP – a Very Informed Patient: How to Advocate for Yourself

Chantel Wicks

Regional Community Engagement and Development Manager for Ontario, British Columbia, Alberta, Manitoba, Saskatchewan, the Territories and Newfoundland, Myeloma Canada

Hi everybody. My name is Chantel. I work for Myeloma Canada, and I started last year in July, after leaving my teaching career of 12 years. I was the Myeloma Canada regional manager of Ontario for the last year and about two weeks ago, my territory expanded. So, now I'm Ontario, BC, Alberta, Manitoba, Saskatchewan, the territories and Newfoundland.

I'm here to talk to you about being a VIP – a very informed patient. I want to give you my medical history as a background. At the age of 20, I was diagnosed with inflammatory bowel disease (IBD), which is an autoimmune disorder. Other autoimmune disorders you might have heard of are lupus, MS, psoriasis, or arthritis. IBD is an umbrella term for Crohn's disease and ulcerative colitis. It is different from IBS, which is irritable bowel syndrome. Similar to how myeloma patients and caregivers are getting frustrated when myeloma is confused with melanoma, the IBD community gets very frustrated when we get confused with IBS.



I've been a patient in the healthcare system for over 17 1/2 years as a chronically ill person. Since my diagnosis with IBD, I've been diagnosed with quite a number of other things as well.

So, it's been a journey. I have had good healthcare professionals and bad ones – haven't we all? Everybody has good days and bad days. That's kind of the way it works. I will say I started out living in the dark about my disease. To be honest, when I was diagnosed at the beginning of my university days, my focus was on needing to graduate. Nothing was going to slow me down. I had to stop playing volleyball, unfortunately. And it was difficult, and I didn't ask any questions. I took my medication, and I thought, "You know what, in a couple of months, I'll be better. I must be really sick, but I don't know how sick I am." I put the blinders on, and off I went. That was a terrible way to be. And I learned the hard way.

Now, I don't live in the dark. What I call myself is a VIP. I have changed what that stands for, and I say that VIP stands for "very informed patient." So, my presentation today is about helping all of you to be very informed patients or very informed patient supporters, VIPs. While this presentation may appear to be aimed at patients because I sometimes will say patients or sometimes say those of us who are sick or unwell, please understand that I'm talking to every

single person in this room, whether you are a caregiver, a loved one, a friend, a daughter, whoever it is, I'm speaking to all of you. Being a VIP is very important.

So, a disclaimer: the information I'm sharing is widely from my own experience as a chronically ill patient for the last 17 years of my life, as well as being a caregiver to a number of family members who have been quite ill in the past. I am not claiming to have all the answers. I shared with you earlier that I was recently not doing well; I am learning how to be a better VIP in this period of my life because things that I was dealing with before are now different today. It's an ongoing process and I don't have all of the answers or solutions, but my hope is that I can help and that you can take something away from here today.

Patient Advocacy

Being a VIP is really just being a self-advocate or an advocate for someone that you love. Basically, it's the ability for patients or caregivers to take an active role in their healthcare decisions, to express their needs and assert their rights to ensure that they receive the best possible care. It is not a one-time event. Being a self-advocate is a continuous process. You may have times where you don't have to advocate as much because things are going the way they should, and then you may have times where your self-advocacy has to skyrocket because there are decisions to be made, there are blips in your health, there are things going on and you've got to step up to the plate to make sure you know where to go from there.

How many of you are aware that there is a Patient's Bill of Rights? Like you, I did not know that. I am not going to go through all of the individual rights, but I have bolded some of them here:

- It is your right to be fully informed about your medical condition.
- It is your right to be advised on the treatment options that are available to you.
- It is your right to be involved in treatment decisions.
- It is your right to receive considerate, compassionate and respectful care.
- It is your right to have access to personal copies of your healthcare records.
- It is your right to designate a person to make decisions on your behalf or to be a part of the decisions that you are making.
- And most importantly, arguably, it is your right as a patient to a second opinion.

Myeloma Canada has a [Myeloma Canada Advocacy Handbook](#). It's only available online in PDF. It goes over the [Patient's Bill of Rights](#). It's a fantastic resource. I just encourage everybody to read it.

Possible Challenges

I like to start off by talking about the stuff that's difficult and get it out of the way. So, possible challenges. You will face communication barriers. This is a challenge that you could face when it comes to being a self-advocate. You could face conflicting information from people who you've spoken to with lived experience, things you've read online, things that your nurse has said, that your doctor has said, things that your family doctor has said. There could be conflicting information that makes being an advocate difficult.

Power imbalances and fear of confrontation: Nobody wants to upset their doctor or hurt their doctor's feelings. By the end of this presentation, I hope you will learn to get over that because there are ways to be fantastic and respectful with your health care team and work together and still advocate for yourself in a way that's best for you.

Time constraints: Appointments are sometimes really quick. You don't have enough time. Sometimes you don't have time to make an informed decision. I am in that place right now. I

don't have a couple of weeks to sit around and twiddle my thumbs. I need to decide quickly because we need to get my new treatment started.

Lack of confidence: That was a big one for me. This could be a challenge.

Insurance issues are a whole other presentation, so I'm not even going to talk about them, but there are insurance issues as well that could prevent you from advocating in a particular way.

So, the whole point of my presentation is about building your VIP toolkit and I'm going to give you some things that I think you should keep in your toolkit, and which I hope will help you overcome these challenges and become a better VIP.

Educational Resources

The most important thing is that you need to educate yourself and then you need to keep educating yourself. This is not like learning the Pythagorean Theorem where once you've got it, that's it. A good problem we have in the myeloma world is that treatments are so quickly evolving. It just becomes a little bit harder when it comes to educating yourself because there are so many more options that are coming so quickly. So, you need to research your medical condition, your treatment options, potential side effects, etc.

I'm a big believer that knowledge empowers you. It empowers you to make informed decisions, which I'm extremely passionate about. An informed decision is not "Doc, what do you think is best?" You can ask your doctor that, but ask your doctor that after you have an informed opinion of what you want to do and then ask for their opinion.

You need to stay informed about your condition, treatments and new medical advances. This is hard for myeloma patients because there's a lot of evolving information, but to keep on top of things you can sign up for [Myeloma Canada's newsletter](#). It comes out once a month and we try to keep you up to date.

Make sure you ask your healthcare professionals or organizations like Myeloma Canada for reliable resources. As a Grade 7 and 8 teacher for twelve years, I can tell you Wikipedia is not reliable. Don't get your information from Wikipedia. You need to make sure that you're using trustworthy and reputable sources. For example, organizations like Myeloma Canada, the International Myeloma Foundation (IMF) and Myeloma UK. Your hospital websites will often have a resource library online with links to resources. These are safe, reputable sources that you should be using. I'm just going to mention when you get to myeloma organizations like the IMF, which is American, or Myeloma UK, keep in mind that these are based in two completely different countries. So, medications and treatments that may be available could be completely different.

Google is a great, terrible place, right? You know, there is great information that you can get, but there are also terrible things that you get from Google that are inaccurate. And with the myeloma world moving so quickly, Google doesn't usually keep up.

Also, when you are reading about other patients' journeys, remember that everybody's journey is different. Even if someone is on the same medication as you or has the same symptoms as you, their experience may be different. Someone else's journey isn't necessarily going to be your journey or how your life will be.

Work with your healthcare team to explore treatment options. The wonderful thing about myeloma is that there are treatment options to explore: but make sure that you understand the risks and the benefits of each. I implore you all to be active participants in the decision-making process, and not just about the treatment.

Those are other decisions you have to make as someone with myeloma or who loves someone with myeloma. Myeloma Canada has a Myeloma Decision-Making Guide in the Treatment section of its [Resources webpage](#) that you can download. There are two different versions. There's an online form and there's a PDF form. If you get to a point where you have decisions to make, this guide can help you list the questions you want to ask, and, at the same time, it may spark other questions that are important to you.

Myeloma Canada has an abundance of resources that we continue to build. For example, one of the newest resources that we've just added is a [Side Effects Infosheet Series](#). By the end of the year, we're hoping to have twelve. Currently we have three; one is about constipation and diarrhea, one is about nausea and vomiting, and one is about anemia. Our resources are constantly being updated and expanded.

We have an online [Glossary](#) on our website where you can type in the word or the treatment and it will give you an easily understood definition. We also have a [YouTube channel](#) that has extensive patient stories and presentations.

Your Support Team

You need to build a support team. As someone who is going through an illness of any kind, do not navigate this journey alone. You may be somebody who is alone, let's say you don't have a partner or significant other, or you may have a partner or significant other who cannot be your support team member right now because they have their own things that they're going through. A support team can include family members, friends, caregivers, medical patients, other patient advocates, or people online that you've met that have experienced the same things or similar things to you. Members of your support team can help gather information, help ask questions, provide emotional support, attend appointments with you, cook your dinner, clean your house, do your laundry, etc. Your support team does not need to be large; your supporters just need to be useful.

Your Medical History

Document everything. You need to keep records of your medical history, your test results, conversations you have with your medical team on treatment plans, changes in your condition, your symptoms. These last two are the ones that we all forget because we take a medication, we have a symptom for a couple of days, and we think "I'll remember to mention this to the doctor when I see them in three weeks." And we often forget. This information can be very valuable if you seek a second opinion. It's also important if you need to switch healthcare providers. What happens if you move?

Myeloma Canada has developed an app called the [Myeloma Monitor](#) where you can keep absolutely everything. The app is device specific, for safety reasons, which means if you put the app on your phone and on your iPad the two apps don't talk to each other.

Preparation for Appointments

Be prepared for your appointments. Our appointments come quickly and are over very quickly. We're there, then we're out. Please write down what you want to ask before you get to your appointments; this will ensure that you cover everything. Record the answers to your questions while you're in the appointment, not after you leave. Or bring someone with you who writes it down for you. Bring a friend or family member with you to all your appointments, preferably somebody who is an active listener, who is fully engaged in everything and is also able to actively respond when issues arise.

Effective Communication at Appointments

You need to communicate effectively. When you communicate with your healthcare professionals, make sure that you are an active listener. Sometimes when you have questions rolling around in your brain, you ask the first question, you're hearing the answer, but you're thinking about the two other questions you have to ask. So, you're not actively listening. But if you're writing down answers, then you are.

Ask questions. I don't mean to offend any of you here, but if you go to an appointment and you don't ask a single question, you have not done your job. Your question might be simple, but you should be asking questions all the time.

You need to make sure you express your concerns, your preferences and your goals, in a clear and assertive manner. When we hear the word "assertive," we think it is a bad word. That's not what assertive means. Being assertive and being clear means that you are saying what you need to say and you're saying it in the way it needs to be said. Get to the point.

You also need to make sure that you are expressing your healthcare goals. You need to make sure that your goals are realistic and achievable. One of the first goals I set for myself when I got sick was the most unrealistic goal I could have thought up. I don't even think it would have been realistic if I were healthy. And that killed me emotionally and mentally because I didn't reach my healthcare goal; but I wasn't realistic from the beginning. Make sure your healthcare goals are realistic and achievable. And please make sure you tell your healthcare team. It's really important for them to know what your expectations and goals are.

Please do not be afraid to ask questions. I do know in our society and in many societies, we hold our healthcare professionals in high esteem, as we should. They spend a lot of years in school and dedicate their lives to helping us. However, that doesn't mean we can't ask them questions or have a discussion.

It's important to request clarification or to have things explained in simpler terms. Don't sit there and think that you're being polite by saying yes, "I totally understand." If you do not understand, make sure you clarify things. This actually comes back to the part where I told you to write down the answers. At the end of your appointment, summarize what you've written down with your healthcare provider. If you have misunderstood something, your provider can then correct you. Myeloma Canada has a [Discussion Guide for newly diagnosed patients](#) and one for [relapsed patients](#). Again, the questions on these discussion guides may not be the questions you want answered, but they may trigger ones for your appointment.

Request additional time if needed. You're probably not getting more time right there that day at that moment. If you need more time, request to have another appointment to discuss your concerns thoroughly.

Make good use of your appointment time. This also helps with the problem of not having enough time. Highlight or put a star beside the questions that are the most pressing and start with those questions first. Be concise and to the point. Don't talk about your holiday. Get to the point and get to your question.

Your Healthcare Team

Build a relationship with your healthcare team. Your healthcare team is not just your doctor; it's your nurses, your pharmacist, your social worker. It's the administrative person at the front desk. It's your doctor's secretary. It's the clinic lead. It's the research nurse. It's the librarian at your centre. They are not your friends, but you should have a good rapport with them. You need to communicate openly and honestly with your healthcare team. You cannot expect the people who

are taking care of you to do their best work if you are not telling them everything. It is not your job to decide what is relevant to tell your doctor and what isn't. Tell your doctor everything and let them decide if it's relevant.

Part of your VIP toolkit is to understand that your healthcare team should be culturally competent. Healthcare providers should strive to be culturally competent and respectful of the diverse backgrounds of their patients.

When to Seek Help

You need to know when to seek help, not just about your physical symptoms, but also your mental and emotional well-being. It is my belief that with every diagnosis, we should all be given a referral for additional support and other professionals who can help guide us and help us deal with the mental and emotional implications of being chronically ill. Unfortunately, it doesn't work that way.

In pediatrics, at Sick Kids Hospital, for example, they do a fantastic job of this. When a child is diagnosed with something, multiple specialists, including mental health specialists, are assigned to that child as needed. They check on the child as well as the child's family. However, that doesn't happen as often in the adult system. We're expected to be adults; we should know what to ask help for. So, keep in mind that you need to know when to seek help.

It is important to recognize the emotional toll that a chronic illness takes on you and on the people that love you. It is very hard to be sick. It is very hard for the people that love us to watch us be sick and not be able to help. You cannot take care of your physical self if you're emotional and mental well-being is also not being taken care of. There are professionals who help people with the emotional and mental tools for what they're going through. You should be utilizing them. And I mean patients, caregivers and loved ones, family members, everyone. Finding healthy coping strategies is extremely important. Myeloma Canada has a guide for [Mental Well-being and Relapse](#) that can be downloaded in the Wellness section of its Resources webpage.

The Power of Community

This is the last part of the toolkit: the power of community. IBD support groups have quite literally saved my life. They have added so much value to my life. They've added value now to my husband's life because he comes to support groups. I really encourage you to stay involved in the Myeloma community. Come even when you feel like you don't need the support because someone else needs you. And selfishly, it does help make you feel better. Truly, it does.

Myeloma Canada has introduced something called [MC Lounge](#). It is a private, safe platform somewhat like Facebook. We have six virtual groups on Facebook, but we introduced MC Lounge because people don't want to be on Facebook but want to talk to people virtually. We review your application, and you are allowed in.

There are multiple groups in MC Lounge. There's a private group that's just for caregivers. There's a patient space. There's a LGBTQ2+ space. There's a veteran's space. There are lots of different groups on MC Lounge, and it's for all people connected to myeloma across the country. We just launched in February and there are over 600 people on MC Lounge already, both patients and caregivers. There's a really cool map feature where you can zoom into your province or your area and identify other people living in that region. You can privately message them, or you can post on the wall just like Facebook.

We also have a [Peer-to-Peer Support phone program](#). You fill out an application and you are matched with either a caregiver or patient that has similarities to you and has been trained to be a mentor. You can have one-on-one phone call conversations with them.

Your Body, Your Journey

In summary, you need to acknowledge that there are going to be some difficulties along the way to becoming a VIP or to being a VIP consistently, but you also need to understand that this is your body, and this is your journey. Effective self-advocacy requires proactive involvement. It's constant. It's ongoing in your healthcare journey. And be open and honest in communication with your healthcare team. Don't forget to practice self-compassion and self-care. Learning to advocate for yourself or for someone that you love is an ongoing process.

I know it's exhausting and I know sometimes you just want to throw a plate against the wall. Let those emotions come out. Don't suppress them, but then pick yourself up and continue. Being well informed, being assertive and being confident in expressing your needs and asking the right questions can lead to better healthcare outcomes and a more positive patient experience. And that goes back to the education piece. How can you ask well informed questions if you haven't learned anything about what's going on? You are not going to learn this in one night. It doesn't work that way. It comes with experience, and you will continue to learn over time.
