



AAMAC
ACAAM

Aplastic Anemia & Myelodysplasia
Association of Canada

Association canadienne de l'anémie
aplasique et de la myélodysplasie

Newsletter - Summer 2023

for patients living with AA, MDS, PNH and the caregivers who support them

Message from the Executive Director

Time certainly moves along quickly, by the time you receive this we will be well into May and looking forward to the summer.

It was so wonderful to see some of you at our in-person meetings during the month of April and we are looking forward to two more in Halifax and Montreal in May. Plans are underway for meetings in the fall in Calgary and Winnipeg. Keep your eye on the website and upcoming newsletter for more details as they become available.

Patient stories are always wonderful to hear and this issue we introduce you to Sabine who underwent a Bone Marrow Transplant. Sabine is an active member of our Central Online Support Group and I know you will be inspired by her story. If you haven't joined one of our groups, I encourage you to do so. The relationship and encouragement that patients receive through these groups is so valuable. Information on the different groups and when they meet can be found on our website.

We continue to look for ways to ensure patients know about AAMAC and if you can assist in your area we would be so grateful. Check with your clinic as to whether you may be able to put up a poster or if there is an area for AAMAC brochures. If you need assistance with materials please email info@aamac.ca.

We are very sorry to be saying goodbye to Robyn Hodes who many of you have had the opportunity to speak with over the years. Robyn is moving on to a fulltime position with a Pension Company. Robyn's last day in the office will be Thursday, May 11th. We wish Robyn well in her new role. There will be some transition in the support from the office for a few weeks and we ask for your patience as we hire a replacement for Robyn.

We hope you enjoy this issue of our newsletter and wish you a wonderful summer.

Cindy

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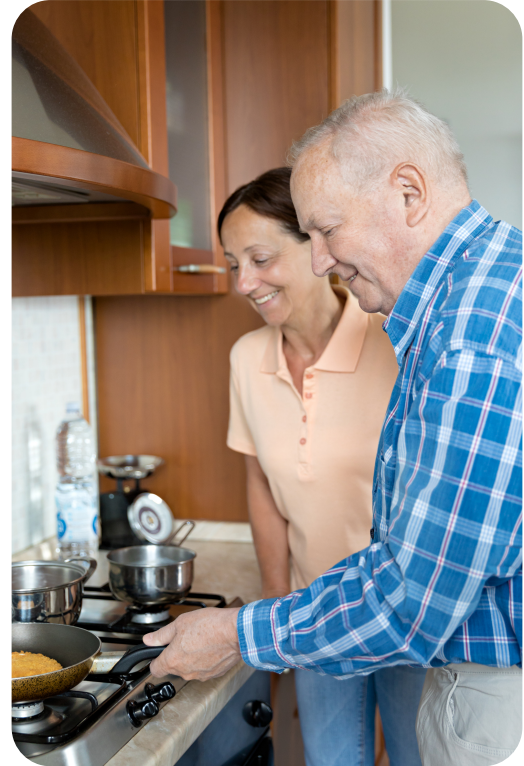


ARE YOU A CARE PARTNER?

By Fiona Lewis

Care partner is a new term that has entered the world of health care. It can be an alternative to the term caregiver which, for some, has a negative connotation. Caregiver can imply that the person receiving care is passive and unable to care for themselves. It suggests a one-way street in which one person gives care and the other receives it. In reality, most relationships which involve a person living with a medical condition are more nuanced and reciprocal than that.

In a care partnership, both people are contributing to the relationship, sharing responsibilities, and caring for each other. While the person living with a medical condition, such as MDS, might need extra support at times, he/she is often fully able to reciprocate by providing other types of support to the other person.



A care partner can be an adult child, a close friend, or a spouse. The care partner works closely with the person with the medical condition to assist him/her in managing the condition. The care provided may involve navigating the health system, assisting with tracking of test results, acting as a sounding board when healthcare decisions need to be made, or taking over some household responsibilities when fatigue sets in.

A care partner is one half of a partnership: he or she does not infringe on the autonomy of the other by making decisions on his or her behalf.

Care partners may experience many of the same stressors as caregivers and can benefit from the caregiving resources available. However, they may also benefit from the sense of cooperation and shared purpose that the care partnership provides. They may even find that being a care partner strengthens the bond with the person they are partnering with.

Please check out some of the resources below which may assist you in your journey as a care partner. Although some have not yet shifted their language to the more egalitarian nature of the care partnership, they provide useful tips and strategies to assist you in your role.

PROVINCIAL CAREGIVER/CARE PARTNER RESOURCES

Caregivers Alberta

<https://www.caregiversalberta.ca/>

Family Caregivers of B.C.

<https://www.familycaregiversbc.ca/>

The Ontario Caregiver Organization

<https://ontariocaregiver.ca/>

Caregivers Nova Scotia

<https://caregiversns.org/>



Saskatoon Council on Aging: Caregiver Information and Support

<http://www.saskatooncaregiver.ca/index.html>

Winnipeg Regional Health Authority: Powerful Tools For Caregivers

<https://wrha.mb.ca/groups/powerful-tools-for-caregivers/>

AO Support Services: Caregiving with Confidence (Winnipeg)

<https://www.aosupportservices.ca/our-three-pillars/counselling-services/caregiving-with-confidence/>

Appui Proches Aidants (Services in Quebec in English and French)

<https://www.lappui.org/en/>

Social Supports New Brunswick: Supports for Caregivers

https://socialsupportsnb.ca/en/simple_page/supports-caregivers

Seniors Newfoundland

<https://seniorsnl.ca/family-friend/family-friend-support/must-reads-family-friends-support-articles/>

Hospice PEI Caregiver Support Program (for anyone caring for someone with a life-limiting illness)

<https://hospicepei.ca/how-we-help/caregiver-support/>

Federal Government Caregiver Resources

<https://www.canada.ca/en/employment-social-development/corporate/seniors/forum/care-conversation.html>

Territories: Although there are no generic caregiver support programs in the territories, there are programs geared towards specific groups. Please see the full list here: <https://canadiancaregiving.org/caregivers/caregiver-resources/>



LIVING WITH MDS - MY STORY

By Sabine Urban

My disease is called Myelodysplastic syndrome (MDS), a cancer of the bone marrow and the blood, and although it was invisible, the signs were everywhere.

This type of cancer is hard to detect because the symptoms (extreme fatigue, low energy, shortness of breath) are similar to so many other diseases.

A stem cell donor was needed. My family members were not compatible. It was finally in the donor's bank that three 100%-matches (with 10/10) were found in Europe.

Before the transplant I was not afraid or worried if the transplant would work or not. I received aggressive chemotherapy for 1 week. This set my body to zero for everything, like a newborn. I tolerated it not too badly, although I had no appetite and felt nauseous and had diarrhea. I did end up in Intensive Care the day before the transplant because of a high fever. The next day, back in my room, I took a shower, put on makeup and was ready to start my new life. I received the stem cell transplant, which looks like a blood transfusion: there were six bags and every time they injected the donor's stem cells I was asked to breathe very deeply. I passed out because of water filling my lungs and ended up back in intensive care, losing two days of my life. For a couple of hours my family did not know if I was still alive. The following days were hard because I could not eat. The rest was just hoping the transplant would work. And it did.

The problems started and I became fearful when I developed GvHd (Graft versus Host disease - when the donor's immune system becomes active). Almost every day there was a new problem. Three other patients who had had their bone marrow transplants at the same time died, something that was very discouraging for me. I was put on a high dose of Tacrolimus and Prednisone which made me shake and feel like a zombie. It was a very hard time with thoughts of suicide and emergency visits.

Seven months after my transplant I broke my leg and was tied to a chair for three months. It took a very long time to heal and it threw me back in my recovery. After the bone marrow transplant my skin turned paper-like. It became sensitive to everything. It reacted with outbreaks of all kinds - it constantly peeled, there was depigmentation, and many permanent scars formed.





When I was sick looking at myself in the mirror, I felt so lost. My eyes were lifeless, with dark circles of the darkest gray. My skin tone was greenish, yellow, and gray. I had not a shred of health. My appearance truly projected how I felt. My muscles were weak and unable to function properly. I was so swollen! I experienced and still experience brutal fluid retention - a reminder of how deficient my kidneys were and a swollen abdomen that showed the accumulation of iron overload.

After the transplant I lost 20 kilos. It depressed me to be able to see my bones. I had no muscle mass at all and was able to wrap the blood pressure monitor around my arm three times. All my clothes were huge on me and my bones showed. It was exasperating not being able to recover my weight. Seeing myself like this made me feel sicker, even though I felt better than I had in many years. It has been a frustrating battle between forcing myself to eat more and exercising. Little by little I gained almost three kilos in the first year, but I can still see my bones, a reminder of everything I lived through.

The body that I had then was not truly my body, but the one I have now does not feel like mine either. I'm still rediscovering who I am. I no longer identify with my clothes or my decorations. I don't know the person I see in the mirror. I am desperate to change. Some clothes I associate with a particular medical crisis. They still have stains that will never be removed from the fabric - or, indeed, from my mind. I finally threw them out and redecorated my house. Another thing I'm experiencing is menopause, which leaves me with immense body dryness. Also, my intimacy is not what it used to be.

Now, I take a walk every day. Something that should be such a routine activity still seems complex to me but is getting easier every day. Before, I was afraid I might need to climb a hill on all fours and ask for help to climb the stairs. Recently, I also started swimming.

I look at old photos of myself, and I don't understand how the person I see there was so happy. She was at her best and she didn't know it. She was not aware of how lucky she was. Her fears at the time were small compared to the nightmare she had to live through later in her life.

It does not show physically, but I suffer from "chemo brain". I experience distractibility, memory problems, and slow processing speed, among other things, every day. I tell myself my mind is working hard and doing its best, but my brain will never be the same again.

When we get sick, we get angry with our bodies. We feel that it "failed" us. We feel betrayed, because something that we care so much about and were confident would work well, did not. We look at friends our age who seem so perfect - their bodies have not made them angry.

We begin to speak to our bodies with anger, resentment, frustration, and impotence. Everything appears negative to us and we are unable to say, "I love my body, because it is

tolerating all this.” Apologizing, reconciling, and resisting pointing fingers is a long way away, but one day I will get there. I had a wonderful support team at the hospital but emotional support is something I do not have enough of.

It is not over, there is still a lot of discomfort (gums, stomach, lungs, skin, eyes...) and new medical problems, but I have passed the two-year-mark. I should receive my childhood vaccinations soon. With COVID still around, I am particularly vulnerable.

That’s what the disease does to you. It arrives, invades you, shakes you, and changes you inside and out. You never return to who you were. I have faith that I am on the right path to falling in love with myself. I should love my body even more because it survived death and allows me to continue serving others and be with my family, friends and loved ones.

Presently, I have gained even 2kg more than my original weight before the transplant (and I feel overweight!). I am grateful to be alive and to be able to meet my wonderful granddaughter.

I still do not know who saved my life, but I asked to contact him/her. I would love to say THANK YOU for saving my life.

DONATING STEM CELLS

Every year, hundreds of Canadian patients, like Sabine, wait for a life-saving blood stem cell transplant. If they are unable to find a match within their family, patients must rely on unrelated volunteer donors from a registry.

Please encourage family members, friends, colleagues between the ages of 17-35 to join the Canadian Stem Cell Registry in 3 easy steps:

STEP 1 Check Eligibility **1**

Answer a series of health related questions before registering


STEP 2 Register Online **2**

Create a stem cell registry profile

STEP 3 Swab & Send **3**

Once you have your cheek swab kit, follow the instructional steps in the kit then return your sample in the postage paid envelope

Go to <https://www.blood.ca/en/stemcells/donating-stemcells> or <https://www.hema-quebec.qc.ca/cellules-souches/donneur/don-unique-vie-unique/index.en.html> for more information.





TREE OF LIFE

The beautiful carved tree hangs on the wall at the National Office. The Tree of Life is a way of recognizing those who have been affected by AA, MDS or PNH.

You may make a tax-deductible donation of \$150 or more to have a special person's name inscribed on the Tree. To purchase a leaf, please contact the National office at: 1-888-840-0039 or info@aamac.ca

In Honour of:

Alan Patt
Barbara Doiron
Beatrice & David Murphy
Bernice Teasdale
Bill Gryba
Bill Hunt
Calogero Ciccarelli
Cameron Root
Caroline Laughlin
Carrie Plotzke Cleghorn
Chris Meyer
Cindy Bell
Don McIntyre
Dr. Melvin Freedman
Gord Sanford
Heather Parsons
Karlee May
Kris Plotzke
Liz Lemire
Lois Henderson
Lori Lockwood
Paul Coad
Pietro Di Ilio
Renee Levine
Rumi Guzder
Ryan Rutherford
Silvia Marchesin
Taylor-Marie Coupland
Trevor Thompson

William Laughlin
Yvette Aloisi

In Memory of:

Albert H. Stahlke
Alexander Bowen
Alexandre Castonguay
Angela M. Poto
Aristotle John (Telly) Mercury
B. Elaine Pond
Barbara Culbert
Barbara Jean Cronyn
C. Donal Leach
Claude Francoeur
Constantine Deplares
Craig Allen
Daniel Orara
Danny Carrick
David Charles Williams
Deborah Armstrong
Dennis Kadatz
Donald J. Highfield
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Dr. Peter McClure
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Elizabeth Rose Herman
Elmer Kerbes

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John Maxwell Cameron
John R. Barton
Joseph MacDonald
Judy Bridges
Keith Curry
Kenneth Kwok Shing Mok
Kenny Wentzell
Laurel Burgess
Lauren Renaud
Linda O'Brien
Marcelle Gai Thomas
Marian Elizabeth Peters
Marilynne Convey
Marko Lyshak



In Memory of:

Marnie Douglas
Megan Locke
Nastor W. Bill Gryba
Nicole Wilson
Nicky Renaud
Olive Lilian Sündal
Pam Wishart
Paul Ullrich

Paul van Bolderen
Philip Doiron
Pietro Di Ilio
Robert M. MacDonald
Rodney W. Crocker
Roger Fortin
Sheila Rivest
Sheryl Hylton
Stanley Foch Willis
Stephanie Dawn Temple

Sterling Ruggles
Susan Laughlin
Talsa Coon
Trevor Thompson
Valdemars Jankovskis
Vern Coles
Walter Salamandyk
Wilfred Hinchey
William Slawson
William Terry McEvoy



SEVERE APLASTIC ANEMIA (SAA) SURVEY - ELTROMBOPAG

WE NEED YOUR INPUT: AAMAC is looking for individuals with severe aplastic anemia (SAA) and individuals who have been treated with eltrombopag to talk about their experience.

Please go to <https://www.surveymonkey.com/r/saa-eltrombopag> for more information and to complete the survey.

PLEASE COMPLETE THE SURVEY BY JUNE 21





FEDERAL GOVERNMENT TAKES ACTION ON DRUGS FOR RARE DISEASES

On March 22, 2023, the federal Minister of Health announced a \$1.5 billion investment in support of the first-ever National Strategy for Drugs for Rare Diseases. Some of this money will go to the provinces and territories to support enhanced access to existing drugs as well as early diagnosis and screening for rare diseases. Additional funds will go towards research and to improve the use of evidence to support decision-making about drug funding. This announcement is the result of feedback from a consultation with patients, families, and organizations like AAMAC. You can read the full announcement at <https://www.newswire.ca/news-releases/government-of-canada-improves-access-to-affordable-and-effective-drugs-for-rare-diseases-847022399.html>.

IN-PERSON MEETINGS RESUME

Our in-person spring meetings are currently in full swing. Forming new relationships and running into familiar people in person has been amazing. A pandemic does not prevent health-related problems from occurring, as with any other issue!

Vancouver



Over 20 patients and family members were happy to be able to meet in person again at AAMAC's recent patient education day in Vancouver. Speakers for the event included Dr. Tom Nevill presenting New Treatment Options for PNH, Dr. Wendy Davis providing an Overview of MDS, and Dr. Heather Leitch reviewing the research on Iron Overload. Between presentations, attendees enjoyed time for networking and sharing.



The presentations from the event will be available on our website or you can email the office to request them. We are also pleased to highlight two websites that were recommended by our speakers as great resources for patients with MDS:

The **MDS Iron Road**¹ presents guidelines for the diagnosis and management of iron overload in MDS from the Canadian Consortium on MDS.

The **MDS Clear Path**² is a Canadian tool designed to help streamline care for MDS patients, from diagnosis and staging through to treatment.

Toronto

Around 25 patients and caregivers joined us in person in April in Toronto for only our second in-person meeting in over 3 years! We had a whole host of others joining us online as well. For those who missed it, or would like to watch it again, the recordings of the presentations have been posted to our website at <https://aamac.ca/videos/>.

Karen Yee, MD, MSc, FRCP(C) University Health Network – Princess Margaret Cancer Centre started the day by speaking about treatment and new developments for MDS, including classification changes and treatments over the past 2 years. She spoke about pushing for funding for gene testing for newly diagnosed MDS patients.

Dr. Monika Oliver followed with her talk on new developments in the treatment of Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria. She also spoke about treatments and new pharmaceuticals that have been approved in the US and EU.



We will continue to host in-person Patient Education Events across the country. Please check our website regularly for announcements of events near you.

¹ <https://www.mdsironroad.org/>

² <https://www.mdsclearpath.org/>



MEETINGS & EVENTS

Visit [AAMAC.CA](https://aamac.ca) for all meeting and event details and registration

Upcoming in-person Patient Support Group Meetings

MONTREAL

Date: Saturday May 27, 2023

Time: 9AM - 1PM

Location: Fairmont The Queen Elizabeth

Speakers:

- Dr. Lea Bernard - Overview of MDS - New Treatment Options
- Dr. Catherine Sperlich - Overview of PNH - New Treatment Options

The presentations will be in French

CALGARY

Date: Saturday October 14, 2023

Time: 9AM - 1 PM

Location: Wyndham Garden Calgary Airport

Speakers:

- Dr Michelle Geddes – Overview of MDS – New Treatment Options
- Dr Monika Oliver – Overview of PNH and AA – New Treatment Options

Virtual Patient Support Group Meetings

AAMAC offers monthly virtual patient support group meetings. Join us from the comfort of your home - patients and care partners welcome!

French Speaking Patient Support Group

Date: Wednesday June 7

Time: 7PM ET

This meeting will be held on the first Wednesday of each month

Central Canada Patient Support Group

Date: Wednesday, June 14

Time: 6pm ET

This meeting will be held on the second Wednesday of each month

Atlantic Patient Support Group

Date: Thursday, June 15

Time: 7pm AT

This meeting is held on the third Thursday of each month

Western Canada Patient Support Group

Date: Monday, June 19

Time: 6PM PT

This meeting is held on the third Monday of each month



AAMAC's 2023 Annual General meeting will take place virtually on **Saturday, October 14, 2023** at **1:00PM ET**



DONATE

You can help someone living with AA, MDS & PNH by making a donation. Patient support meetings, resources and programs are made possible by your thoughtful and generous donation. Thank you.

There are many ways to donate to AAMAC:



Call the National Office to donate by phone.



Click the 'DONATE' button on our website



Visit CanadaHelps.org

AAMAC NATIONAL OFFICE

2201 King Road, Unit #4
King City, ON
L7B 1G2
Phone: 1-888-840-0039
Email: info@aamac.ca

Regional Support

Phone: 1-888-840-0039

Central Canada:

ontariosupport@aamac.ca

Atlantic Canada:

atlanticsupport@aamac.ca

Western Canada:

bcsupport@aamac.ca

French Speakers:

soutienfrancophone@aamac.ca

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