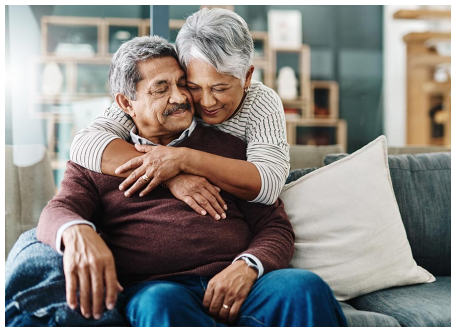

Let's Talk About the Burden of Blood Transfusions and MDS

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For those living with myelodysplastic syndromes (MDS), a group of blood cancers, blood transfusions are burdensome; even more so with the pandemic. Here, we shed light on what it's like to rely on transfusions to survive and why gaps in treatment options need to be addressed to improve patients' quality of life.

MDS occurs in the blood and bone marrow in which the DNA of stem cells is damaged and prevents the development of healthy, mature red blood cells (RBCs).¹ It usually develops in older people and is more common in men.² Approximately 86% of patients with MDS are aged 60+ when diagnosed.³

MDS is a serious health concern — 50% of patients succumb to the disease within six years of diagnosis.² “The usual clinical problem for patients with MDS is anemia, a condition caused by low red blood cells,⁴ or low hemoglobin,” explains Dr. Heather Leitch, hematologist at Providence Hematology and Clinical Professor at the University of British Columbia. Hemoglobin is the part of RBCs that carries oxygen.⁴ When someone has low hemoglobin levels, their tissue doesn't get enough oxygen and can't function properly.⁴

Gwen was diagnosed with MDS in 2007 at age 65 when a routine blood test showed her hemoglobin was below normal (for women, normal is 120-160 g/L⁴). Over the next year, with a wait-and-watch approach, her hemoglobin dropped below 80. Gwen had another therapy to help boost her hemoglobin. It worked until 2018, when her hemoglobin dropped again. She required several transfusions over the course of two months, and her dosage was increased to the maximum. If the medication stops working, Gwen has no other options. “Plan B is blood transfusions forever — until a treatment comes along that will reduce the blood transfusion burden,” Gwen says.

More than 90% of those with MDS report ongoing fatigue, a persistent exhaustion that interferes with their ability to carry on with everyday activities.⁵

Gwen has become used to it. “I really don’t feel any fatigue. They tell me that’s my new normal and I’ve adjusted to it.” She has other symptoms of anemia, including night sweats and a pale complexion.^{1,4,6,7} An avid swimmer for many years, she now has to use a mask and snorkel due to shortness of breath caused by her anemia.

“Anemia can result in symptoms such as weakness and shortness of breath,⁴ and it can exacerbate pre-existing conditions. For example, if a patient has coronary artery disease or congestive heart failure, it can put a strain on the lungs and heart and make those conditions worse. That’s why patients become transfusion-dependent or need other means to support their hemoglobin,” says Dr. Leitch.

Transfusions can help to relieve symptoms.^{8,9,10}

“After having a blood transfusion, I know what normal feels like. You definitely notice the difference,” says Gwen. According to Dr. Leitch, how long the improvement lasts varies from person to person and depends on their degree of bone marrow failure. “Some people require transfusions every four weeks or eight weeks, and others are there on a bi-weekly or even weekly basis.”¹¹ Often, the time between transfusions gradually gets shorter.¹¹

At this point, Gwen doesn’t require regular transfusions. She needed several when she got a bacterial infection from a small nick in her elbow. It took four months for her hemoglobin to come back over 80. She considers herself one of the lucky ones who do not need blood transfusions weekly or bi-weekly to stay alive. “But for people where the hemoglobin booster doesn’t work for them, their only recourse is repeated blood transfusions.”

For those who are transfusion-dependent, therapy is demanding, especially in this COVID-19 era.

“Transfusions are quite a burden,” explains Dr. Leitch. Some patients travel a long distance. They’re not feeling well. They have to come in the day before to be crossmatched for compatibility with the donor blood. “All these things add up. It’s quite an impact on their quality of life.”

A transfusion takes up to four hours and typically involves a trip to a hospital.¹² “No one wants to go in a hospital with this pandemic,” says Gwen. MDS patients have compromised immune systems, are typically older and at greater risk of serious consequences if infected with COVID-19.^{13,14,15} More transfusions mean more potential exposure to the virus.¹³

In Dr. Leitch’s centre, COVID-19 hasn’t had a major impact on their ability to deliver care to patients with MDS who require transfusions. She’s dealing with patients primarily by telehealth rather than in person. “But we all worry about what’s going to happen if and when the healthcare system becomes overwhelmed.”

While many MDS patients depend on regular transfusions to survive, the transfusions themselves can have complications.^{9,10,16,17}

Ongoing RBC transfusions put patients at risk of iron overload.^{9,10} RBCs contain iron, and as the donated blood cells wear out, that iron stays in the body.⁹ Too much can significantly damage the heart, liver and other organs if not treated with medications to take away excess iron.^{9,10}

Other risks associated with transfusions are fevers, allergic reactions and blood-borne infections.¹⁷ The body’s immune system can attack the donated blood, and people can have acute reactions such as sudden respiratory distress.^{17,18} “These are all kinds of reasons, including quality life, that we’d like to use other means to support the hemoglobin and induce transfusion independence,” says Dr. Leitch.

New approaches are needed to ease burdensome symptoms and reduce the need for frequent transfusions.

MDS often becomes hard to treat over time,¹⁹ and in about one-third of cases, the disease deteriorates into acute myeloid leukemia.²⁰ Luckily, Gwen’s MDS is low risk to turn into leukemia. As board member and Atlantic region coordinator of the Aplastic Anemia & Myelodysplasia Association of Canada, her advice is to keep fit and be careful about infections. “Until something comes along that treats this disorder, there’s not much else anyone can do. Everybody’s wish is to keep off blood transfusions and hope for a new treatment.”

As Dr. Leitch describes, “Unfortunately, our treatment options to boost hemoglobin are relatively limited right now, although there are new treatments under development that look promising for lower-risk MDS.”

Find more information about MDS, treatment and patient support at www.aamac.ca (<http://www.aamac.ca>).

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