

Life After BMT

Updates from the Blood or Marrow Transplant Survivor Study

BMTSS Progress

UAB INSTITUTE FOR CANCER
OUTCOMES & SURVIVORSHIP

The University of Alabama at Birmingham

Hello everyone! BMTSS is the Blood or Marrow Transplant Survivor Study. The BMTSS is currently in progress at the University of Minnesota, the University of Alabama at Birmingham, and City of Hope. You are receiving this newsletter because you are a BMTSS participant. Since our last newsletter, our study team received the good news that the study has been awarded a large grant from the National Cancer Institute. This will allow us to expand the study to include people who have been treated for cancer, but who have not received a blood or marrow transplant. This will help our research team to better understand what long-term outcomes are due to cancer treatments given before BMT, and what outcomes are due to the BMT itself.

We are sending you this newsletter to keep you updated on the study's progress and to let you know how your information is helping researchers to make further progress in understanding life after BMT. We do not require any action in response to this newsletter unless you have moved or changed your phone number. We encourage you to update your contact information by sending us an email at BMTStudy@peds.uab.edu or calling us at 855-903-2136. Thank you so much for participating in BMTSS and helping us with this important research!

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For More Information:

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Recent BMTSS Publications

In August 2019, "**Risk of venous thromboembolism in patients with non-Hodgkin lymphoma surviving blood or marrow transplantation**" was published in the journal, *Cancer*. Venous thromboembolism is a blood clot that starts in a vein. Most blood clots start in the legs or arms and stay in one place, but sometimes blood clots can break loose and can move to the lungs (which can damage the lungs and make it difficult for the body to get enough oxygen). This article describes the risk of blood clots in patients with non-Hodgkin Lymphoma (NHL) who have had a BMT. Previous research has shown that NHL patient are at increased risk for developing a blood clot, and that the clot frequently occurs around the time that NHL is diagnosed and treatment with chemotherapy begins. However, most studies have not looked at the risk for developing blood clots years after treatment ends. Our study found that at 10 years after BMT, about 8% of NHL survivors who had BMTs experienced a blood clot. While this is a relatively small percentage, it is about twice as high as was seen in comparison group of brothers and sisters of BMT survivors (about 4%). This study suggests that NHL BMT survivors are at higher risk of having a blood clot. Therefore, it is important for survivors to be aware of the signs of a blood clot and to seek medical attention if those signs occur.

Signs of Blood Clots:

- Sudden swelling of the leg or arm
- Swollen area is warm to the touch
- Chest pain, especially sharp pains while taking a deep breath
- Difficulty breathing
- Rapid heart rate

For more information: Gangaraju R, Chen Y, Hageman L....Bhatia S. Risk of venous thromboembolism in patients with non-Hodgkin lymphoma surviving blood or marrow transplantation. *Cancer*. 2019 Aug 30. [Epub ahead of print].



Ask the Researchers

We received a lot of great questions that we wanted to answer and share. Please send in your questions to the BMTSS Study Staff by emailing BMTStudy@peds.uab.edu. Although the study is still collecting data, we will do a preliminary analysis on 1 to 2 topics or questions that we receive, and publish the results in the next newsletter.

Question: How did the blood or marrow transplant affect my brain?

You may have heard of the term “chemo brain,” which is a term used to describe changes in memory and thinking, such as difficulty concentrating and mental foggy, that may occur during or after chemotherapy. Chemo brain is also known as **neurocognitive impairment** or **neurocognitive deficit**, and can also be associated with other cancer treatments, including radiation and BMT.

Neurocognitive Deficits:

This is a broad term used in the scientific community to cover negative changes in brain function or ability to store and process information. This includes loss of skills like concentrating, processing and recalling information, physical coordination, and motivation.

In the early stages of diagnosis and treatment for cancers or blood disorders, there are many factors that may help to explain neurocognitive deficits, such as increased anxiety, lack of sleep, or factors related to treatment (such as anemia or infection).

Scientists are still trying to find out exactly what causes long-term neurocognitive problems in order to find ways to prevent them from happening.

Some people may experience subtle neurocognitive changes, while others may find that these changes are significant enough to affect work or school. A study done at City of Hope found that 3 years after transplant, about 1 in 3 people who received an allogeneic transplant (stem cells from another person) had neurocognitive impairment. The researchers also found that among people who had received an





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allogeneic transplant, the odds of not returning to work were nearly 10-fold higher for those with neurocognitive impairment.¹

Over time, memory problems associated with transplant may improve. Several studies have found that after one year, a significant number of BMT survivors have returned to pre-BMT levels of memory and cognition.² Another study examined survivors of allogeneic BMT and found that many areas of brain function, such as speech and decision making, improve 1 to 5 years after BMT.³

For those who may be currently experiencing neurocognitive problems, these tips from the American Cancer Society may be helpful:

- Use your smartphone or a paper planner to make daily schedules and lists of important dates or tasks
- Make sure you are getting enough sleep
- Eat a balanced diet with plenty of fruits and vegetables
- Participate in regular physical exercise
- Make a set of daily habits and routines
- Limit multi-tasking
- Write down your memory problems- this will give you insight in areas you are struggling with, as well as provide information for your doctor
- Talk to your doctor about any potential problems affecting your ability to think, focus, or remember
- Tell friends and family members, so they can help provide support

For more information:

1. Sharafeldin N, Bosworth A, Patel SK, Chen Y, Morse E, Mather M, Sun C, Francisco L, Forman SJ, Wong FL, Bhatia S. Cognitive Functioning after Hematopoietic Cell Transplantation for Hematologic Malignancy: Results from a Prospective Longitudinal Study. *Journal of Clinical Oncology* 2018 Feb 10;36(5):463-475.
2. Buchbinder D, Kelly DL, Duarte RF.... Shaw BE. Neurocognitive dysfunction in hematopoietic cell transplant recipients: Expert review from the late effects and Quality of Life Working Committee of the CIBMTR and complications and Quality of Life Working Party of the EBMT. *Bone Marrow Transplant.* 2018;53(5):535-555.
3. Syrjala KL, Artherholt SB, Kurland BF.... Dikmen S. Prospective neurocognitive function over 5 years after allogeneic hematopoietic cell transplantation for cancer survivors compared with matched controls at 5 years. *Journal of Clinical Oncology* 2011 Jun 10;29(17):2397-2404.

VIDEO:

<https://www.bmtinfonet.org/video/cognitive-effects-cancer-treatment-chemobrain-and-how-treat-it-1>

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Preventive Health: Keeping Your Heart Healthy



The heart is the most important muscle in your body, and is responsible for pumping blood and oxygen to every part of your body. That's why keeping your heart healthy is an important priority.

How does having a BMT affect my heart?

Our research has found that having a BMT can increase the risk of heart disease, especially if you had an allogeneic transplant and if you had graft-versus-host disease. We also found that a BMT can increase the chance of having one or more of the three main risk factors for heart disease:

- High blood pressure
- High cholesterol
- Diabetes

What can I do to lower my risk of heart disease?

First, if you have high blood pressure, high cholesterol and/or diabetes, make sure you are getting the treatment you need to get these conditions under control. This usually involves healthy eating, regular exercise – and in many cases, taking medication – in order to maintain a healthy blood pressure, and to keep your cholesterol and blood sugar levels under control. If you don't have any of these risk factors, make sure to get regular check-ups that include monitoring for these three conditions. That way, if you develop any of these conditions, you can get them under control right away.

What else can I do to keep my heart healthy?

- ✓ See your doctor at least once a year for a check-up. Your doctor will tell you if you need to be seen more often.
- ✓ Lead a "heart healthy" lifestyle including plenty of exercise (at least 30 minutes per day)
- ✓ Don't smoke (if you smoke, quit)
- ✓ Eat a balanced diet with foods that are low in fat and salt
- ✓ Stay at a healthy body weight
- ✓ Keep stress to a minimum

For more information:

Armenian SH, Sun CL, Vase T Bhatia S. Cardiovascular risk factors in hematopoietic cell transplantation survivors: role in development of subsequent cardiovascular disease. *Blood*. 2012 Nov 29;120(23):4505-12.