

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

We hope this Winter 2021 newsletter finds you well and that you and your families are staying safe and healthy. BMTSS is the Blood or Marrow Transplant Survivor Study. The BMTSS is currently ongoing 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. In this newsletter, we will provide information on two topics (1) Neuropathy and (2) Cancer Screening. As a reminder, all of our older newsletters are available on our website: <https://www.uab.edu/medicine/icos/icos-research/bmt-study>.

This newsletter will give you an update on the study's progress and let you know how your information is helping us 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@uabmc.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

The Blood or Marrow Transplant Survivor Study (BMTSS) contributes toward understanding medical problems that can occur after blood or marrow transplantation (BMT). Recently, BMTSS researchers studied the cumulative effects of medical problems that occur on life expectancy after allogeneic transplant. This study was published in the journal *JAMA Oncology*, and focused on BMTSS participants who received an allogeneic BMT at the City of Hope, University of Minnesota, or the University of Alabama at Birmingham between January 1, 1974, and December 31, 2014 and survived 2 or more years after their BMT. A total of 4,741 individuals participating in BMTSS were included.

Over the 40-year timespan of the study, many changes occurred in the practice of blood or marrow transplantation. For example, in more recent times, fewer patients received total body irradiation or myeloablative (more intense) preparative regimens for transplantation. The researchers found an improvement in outcomes over the four decades for survivors who had their transplants at a younger age, and for those who were transplanted with bone marrow (as compared to peripheral blood stem cells). The researchers also found that compared with the general population, allogeneic BMT survivors had a decrease in life expectancy; however, the years of life lost declined over the study timespan, with 9.9 years of life lost for those in the earliest era of the study, compared to 4.2 years for those in the most recent group. The leading causes of death included cancer recurrence, infections, new cancers, cardiovascular disease, and pulmonary disease. The researchers emphasized that there is still a need to address the underlying causes of late mortality among patients who underwent transplantation at older ages and those who received peripheral blood stem cells.

For more information: Bhatia S, Dai C, Landier W, Hageman L, Wu J, Schlichting E, Siler A, Funk E, Hicks J, Bosworth A, Te HS, Francisco L, Bhatia R, Salzman D, Goldman FD, Forman SJ, Weisdorf DJ, Wong FL, Arora M, Armenian SH. Trends in Late Mortality and Life Expectancy After Allogeneic Blood or Marrow Transplantation Over 4 Decades: A Blood or Marrow Transplant Survivor Study Report. *JAMA Oncology*. 2021;7(11):1626-34. Epub 2021/09/10. doi: 10.1001/jamaoncol.2021.3676. PubMed PMID: 34499078; PMCID: PMC8430905.

Ask the Researchers

We received several great questions since our last newsletter. Here we share some answers with you. Please send your questions to the BMTSS Study Staff by emailing bmtstudy@uabmc.edu. We answer 1 to 2 questions that we receive, and publish the results in the newsletter.

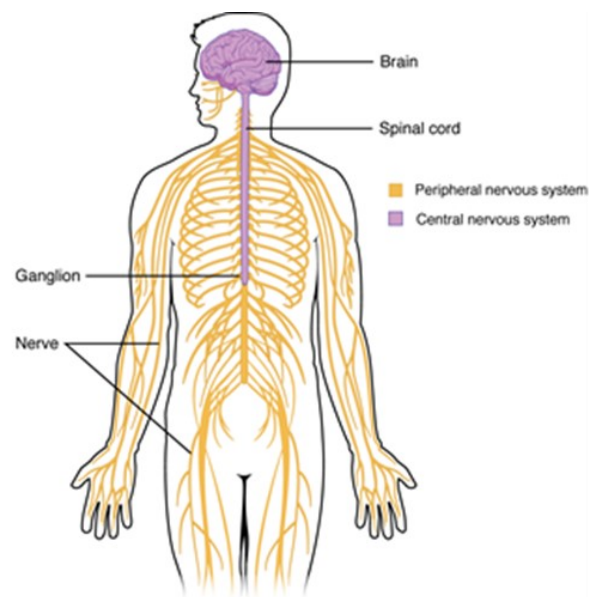
Question: How do I manage my peripheral neuropathy after BMT?

Peripheral neuropathy results from the malfunction or damage of nerves that carry messages from the brain and spinal cord to the rest of the body, outside of the central nervous system. When nerve cells, known as neurons, are damaged, their ability to carry messages to the brain and body becomes impaired. For cancer survivors, certain chemotherapy drugs and/or nerve damage caused by tumors or surgery are often the cause of peripheral neuropathy. Most of the time peripheral neuropathy begins in the hands and feet, but it can affect other parts of the body.

To diagnose peripheral neuropathy, your doctor will typically complete a full history and physical exam including a detailed neurological exam, evaluating your coordination, reflexes, and muscle tone. Your doctor may also order blood work, imaging tests, or electromyography (EMG - which evaluates the electrical activity in your muscles) to better assess the condition of your nerves. Treatments for peripheral neuropathy may include medications and physical or occupational therapy, but there are also many ways you can help minimize your symptoms at home, including:

- Exercise - walking, gentle yoga, or stretching are great ways to get your body moving
- Eat a balanced diet
- If you smoke, quit now
- Avoid excessive alcohol use
- Wear padded, well-fitted, closed-toe shoes

Additionally, if you have peripheral neuropathy, clear pathways in your house to avoid falls. Inspect your feet regularly or have someone else do it for you. Look for any blisters, cracked skin, sores or other problem areas.



Symptoms of peripheral neuropathy can include:

- Intermittent numbness
- A tingling sensation in the hands/feet that can travel into the arms/legs
- Needle-point or sharp pain
- Sensitivity to touch
- Loss of sensitivity to hot and/or cold temperatures
- Pain with attempts to bear weight of the affected body part
- Loss of muscle strength
- Gastrointestinal and urinary symptoms
- Paralysis (can occur if the nerves that control movement [motor neurons] are damaged)



COVID-19 & Mental Health

The emergence of COVID-19 brought many new challenges to everyday life, with people everywhere simultaneously learning how to navigate this new era. Conflicting information, the abundance of unknowns, and the many changes to everyday living led to a crisis of its own: a major decline in mental health. Scientists around the globe are working diligently to understand these problems and to determine what can be done to counter the decline.

Studies of cancer patients during the COVID-19 pandemic found a decline in mental health, particularly related to emotional distress, anxiety, and depression. Increased loneliness was found to be a predictive factor for depression during the COVID-19 pandemic. Emotional distress among cancer patients is found to be correlated with disruption in healthcare services. Many adjustments to daily living were made during the first peak of the pandemic. The burdens of these adjustments has resulted in stress in many facets of life and created new challenges to overcome.

Although there is not an easy fix, the World Health organization offers some tips for keeping mentally well during the COVID-19 pandemic:

- Keep informed by listening to advice and recommendations from your national and local authorities.
- Maintain a routine or create a new one. This can include waking up and going to sleep at the same time every day, keeping up with personal hygiene, eating healthy meals at regular times, exercising regularly, and making time for things that you enjoy.
- Minimize newsfeeds by seeking the latest information at one or two specific times of the day.
- Social contact is important. If you are social distancing, keep in regular contact with family and friends by telephone or video chat.
- Limit alcohol and drug use.
- Be aware of how much time you spend each day looking at screens, and take regular breaks when doing so.

If you are struggling with mental health, reach out to someone that you trust, such as a friend, family member, or healthcare provider, to find support or resources for mental wellness. While many remain isolated, it is important to remember that you are not alone.

Resources for Mental Health

- Cancer Support Groups – www.cancer.org/treatment/supportprogramsservices/index
Online or in-person cancer support groups can help you manage cancer-specific issues.
- National Suicide Prevention Lifeline - 1-800-273-8255 -<https://suicidepreventionlifeline.org/>
Call to speak with a trained counselor 24 hours a day, 7 days a week.
- Crisis Text Line – Text “HOME” to 741741 - <https://www.crisistextline.org/>
Connect via text with a trained counselor 24 hours a day, 7 days a week.
- National Institute of Mental Health Resources - <https://www.nimh.nih.gov/health/find-help/index.html>
- American Psychological Association Directory - <https://locator.apa.org/>
Type in your zip code to find counselors and therapists located near you.
- American Psychiatric Association Directory - <http://finder.psychiatry.org/>
Type in your zip code to find a psychiatrist located near you



Preventive Health

Why are cancer screening tests important?

Cancer screening tests are used to find cancer before a person has symptoms of cancer. Cancer screening can detect cancer early, when it may be more easily treated. Although cancer screening tests do not guarantee cure, the likelihood of recovery increases with early detection of cancer.

Breast Cancer Screening

Breast cancer occurs in tissue within the breast. A mammogram is the most common breast cancer screening test. A mammogram captures images of breast tissue in order to find small tumors or abnormal growth of cells. **Women who have received radiation to the chest, axillae, or total body (TBI), or have a personal history of breast cancer, a family history of breast cancer, or a gene linked to breast cancer should get a breast MRI and a mammogram every year beginning at age 25 to 30.**

Breast cancer screening guidelines for women with no additional risk factors:

Age	Recommendation
40-44	Yearly mammogram (based on shared decision-making between patient and healthcare provider)
45-54	Yearly mammogram
55 and older	Yearly or every other year (based on shared decision-making between patient and healthcare provider)

Colorectal Cancer Screening

Colorectal cancer occurs when cancer develops in the colon or rectum. The most common colon cancer screening test is a colonoscopy. When a colonoscopy is conducted, a small tube-like camera travels through the rectum and into the colon to find abnormal growths. Another option for colorectal cancer screening is the multitarget stool DNA test. This test requires a stool sample and if it is positive, it should be followed by a colonoscopy.

Colorectal cancer screening guidelines for people with no additional risk factors:

Age	Recommendation
45-75	Colonoscopy every 10 years or multitarget stool DNA test every 3 years
76-85	Colonoscopy (based on shared decision-making between patient and healthcare provider)

Some people may need to start colorectal screening sooner than age 45 or need screening more often. **People who have received radiation to the abdomen, pelvis, spine, or total body (TBI), should begin regular colorectal cancer screening at age 30 or 5 years after radiation, whichever occurs last.** People with a personal history of colorectal cancer, a personal history of inflammatory bowel disease (ulcerative colitis or Crohn's disease), or a family history of colorectal cancer should undergo colorectal cancer screening as advised by their healthcare provider.



Preventive Health Continued...

Cervical Cancer Screening

Cervical cancer develops in the uterine cervix. Infection with human papillomavirus (HPV) is associated with the development of cervical cancer. HPV is contracted through sexual activity. The Pap test and the HPV test are commonly used for cervical cancer screening. The Pap test is conducted by gently removing a small sample of cells from the cervix and vagina. The cells are then examined under a microscope to detect any abnormality or disease. The HPV test is a similar procedure but it identifies specific HPV types that may cause pre-cancer or cancer.

Cervical cancer screening guidelines for women with no additional risk factors:

Age	Recommendation
21-29	Pap test every 3 years
30-65	Pap test and HPV test every 5 years (optimal) OR Pap test every 3 years (alternative)
Over 65	Testing can stop for those who had regular screening for 10 years and normal test results

Additional cervical cancer screening tests may be recommended for individuals with abnormal test results, or those with additional risk factors.

Lung Cancer Screening

People who have had radiation to the chest, axillae, or total body (TBI) AND who smoke; and people age 50-80 years with a 20 pack-year smoking history (regardless of radiation exposure), should discuss the benefits and risks/harms of lung cancer screening with their healthcare provider.

Screening for lung cancer involves an annual low-dose spiral CT scan of the lungs.

Considerations for Cancer Screening

It is important to discuss cancer screening test options with your healthcare provider. Here are some things to consider:

- What are my cancer screening test options?
- What are the risks and benefits of certain screening tests?
- How do you prepare for your cancer screening test?
- How often should you receive cancer screening tests?

Sources: American Cancer Society | Information and Resources about for Cancer: Breast, Colon, Lung, Prostate, Skin; Children's Oncology Group Long-Term Follow-Up Guidelines, Version 5.0; U. S. Preventive Services Task Force.