

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 Spring 2020 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 provide you with information about the new coronavirus (COVID-19) and how it might relate to you as a transplant recipient (see page 2).** We also answer questions that some of you posed to us after the last newsletter. As a reminder, all of our previous newsletters can be found on our website: www.uab.edu/bmtstudy.

This newsletter will also give you an update on the study's progress and let you know how your information is helping us 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 January 2020, "**Pain in Older Survivors of Hematologic Malignancies After Blood or Marrow Transplantation: A BMTSS Report**" was published in the journal, *Cancer*. This article describes the experience of pain among older BMT survivors. We conducted this analysis based on responses to select questions from the BMTSS-2 questionnaire about the pain experience. We found that 5 years after BMT, nearly 40% of older BMT survivors reported pain. We compared BMT survivors to brothers and sisters of BMT survivors without cancer or BMT, and found that BMT survivors were 2-1/2 times more likely to report pain than were the brothers and sisters. BMT survivors also reported higher use of both prescription pain medications (17.8% vs. 9.3%) and opioid pain medications (6.5% vs. 2.2%) We also found that the pain experienced by older BMT survivors is associated with impaired physical performance, frailty, and greater use of prescription and opioid pain medications as compared with siblings. Findings from the study suggest that it is important for survivors to be aware of any pain that they may be experiencing, to learn safe pain management techniques, and to communicate with their health care providers regarding their pain symptoms.

Study participants reported 4 types of pain:

- Non-minor everyday pain
- Moderate to severe bodily pain
- Prolonged pain
- Moderate to extreme pain interference (extent to which pain hinders lifestyle)

For more information: Farrukh N, Hageman L, Chen Y.... Bhatia S. Pain in older survivors of hematologic malignancies after blood or marrow transplantation: A BMTSS report. *Cancer*. 2020 Jan 1; 126(9): 2003-2012



How COVID-19 Could Affect BMT Survivors?

As you are probably aware, COVID-19 is a new and highly contagious virus that has affected many people all over the world. As a BMT survivor, you may be wondering about how the virus might affect you and your health. We have made an effort to summarize some information here. However, new information is always emerging about this virus, and it is good to keep up with current information from sources such as the Centers for Disease Control and Prevention (CDC). COVID-19 is a respiratory illness that is transmitted via respiratory droplets that can stay in the air and on surfaces for extended periods. BMT survivors need to be aware of ways to protect themselves from COVID-19. Taking these same steps will also be useful during flu seasons.

How to protect yourself:

- **General:** If possible, try to work or take classes from home. Stay inside when possible, practice social distancing (staying 6 feet apart from others) and wear a face mask if leaving home.
- **Grocery store:** Limit your time in the store by only purchasing essential items. Wash fruits and vegetables before consumption, and wipe down other store items. Try to set up a delivery service for any prescriptions you need.
- **Personal hygiene:** Wash your hands with soap for at least 20 seconds at least 10 times a day. Wash commonly used items such as hand towels and blankets frequently. Avoid touching your face. Cover your nose and mouth with a tissue or your elbow when coughing or sneezing.
- **Household hygiene:** Clean high-touch surfaces in your home, such as door knobs, light switches, bathroom areas, and electronics once a day.
- **Exercise:** Participating in yoga (free classes online), stretching, taking a walk or being active for at least 15 minutes a day can help both your mental and physical health.
- **Eat well** and get a good amount of **sleep** (at least 7 hours a day).

Symptoms to watch out for:

- Fever
- Dry cough
- Difficulty breathing or feeling short of breath
- Body aches
- Fatigue
- Loss of taste or smell



What to do if you have symptoms:

- Call ahead before going to the hospital or healthcare provider
- **Tell all healthcare providers that you have had a BMT**, and inform them of any other chronic health problems that you have

Here are some tips to take care of your mental/emotional health, which is especially important during a stressful event:

- **Mental health providers:**
 - The National Alliance on Mental Illness (NAMI) HelpLine: Monday-Friday, 10 am-6 pm ET, 1-800-950-NAMI (6264) or info@nami.org
- **Social support:**
 - Call family/friends to schedule virtual meals, game nights, or simply to catch up
 - Meditation apps offer free content to help ground yourself during these uncertain times
 - Support Groups: www.bmtsupport.org/what-is-bmtsg/



Ask the Researchers

Question: What information is available about eye health after BMT?

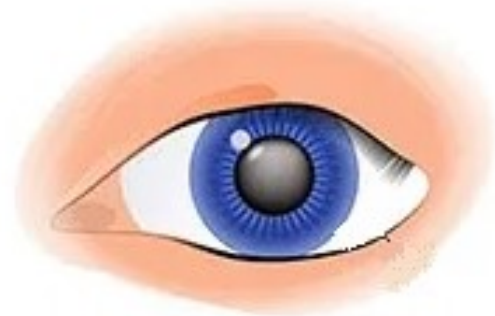
People who have had a blood or marrow transplant often experience dry eyes. Dry eyes after BMT can be due to decreased production of tears as a result of radiation or chronic graft-versus-host disease. Although dry eyes can be irritating, eye drops that moisten the eyes (artificial tears) can help soothe and comfort dry eyes. If you are having problems with dry eyes, be sure to talk with your health care team.

A cataract is clouding of the lens of the eye, making it more difficult to see clearly. Although cataracts often occur as a result of the normal aging process, BMT survivors may develop cataracts at a younger age, due to the effects of radiation. A yearly examination by an eye specialist (ophthalmologist or optometrist) is helpful so that cataracts can be detected and treated before they interfere with vision.

Everyday ways to keep your eyes healthy:

- Wear sunglasses when outdoors
- Limit exposure to blue light (such as cellphones and other electronic devices)
- Do not smoke

Eye with cataract





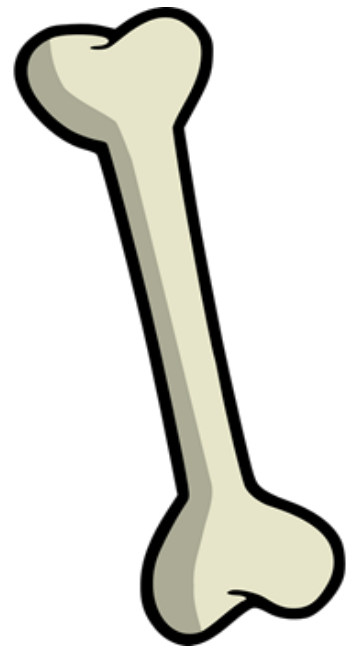
Preventive Health: Bone Health

Your bones have many important functions. Bones support physical movement, protect your internal organs from injury, and store minerals (such as calcium and phosphorus) inside your body. It is essential for you to know what you can do to keep your bones healthy.

How does having a BMT affect my bone health?

Research has found that having a BMT can increase the risk of a loss of bone density, which may lead to a bone disease called osteoporosis (thinning of the bones). Although men can be affected by osteoporosis, women are generally at higher risk. Other risk factors include:

- Older age
- Having a family history of osteoporosis
- Being of Caucasian or Asian ethnicity
- Having a smaller body size



What can I do to lower my risk of osteoporosis?

There are several steps you can take to lower your risk of osteoporosis:

- **Get plenty of calcium and vitamin D.** Eat calcium-dense foods such as dairy, green leafy vegetables, and calcium-fortified foods, such as orange juice. Include sources of Vitamin D in your diet, such as fish, eggs, and fortified dairy products. Additionally, your healthcare provider may recommend calcium and vitamin D supplements to support your bone health.
- **Avoid tobacco and excessive alcohol use.** Support your bone health by cutting out smoking or heavy drinking. Smoking has long been associated with an increased risk for thinning of the bones. Heavy alcohol consumption can interfere with calcium balance and vitamin D absorption, leading to bone loss.
- **Get active!** Movement such as walking, jogging, and hiking can support bone health. Weight resistance training, such as using resistance bands, free weights and weight machines, can also increase bone strength.

How do I discuss bone health with my healthcare provider?

- Create a plan for prioritizing your bone health
- Review your personal risk factors for osteoporosis
- Ask your provider if you need to take supplements such as calcium and vitamin D to support your bone health

For more information, visit: <https://www.bones.nih.gov/health-info/bone/osteoporosis/overview#c>