# Life After BMT

Updates from the Blood or Marrow Transplant Survivor Study

## **BMTSS Progress**



The University of Alabama at Birmingham

We hope this summer 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) chronic fatigue and (2) Human Papillomavirus (HPV). As a reminder, all of our older newsletters are available on our website: <a href="https://www.uab.edu/medicine/icos/icos-research/bmt-study">https://www.uab.edu/medicine/icos/icos-research/bmt-study</a>.

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 [Summer 2021]

For More Information:

Call:

855-903-2136

Mail:

Blood or Marrow Transplant Long-Term Follow-Up Study 1600 7th Ave South Lowder 500 Birmingham, AL 35233

Email: BMTSS2@uabmc.edu

moved or changed your phone number. **We encourage you to update your contact information by sending us an email at BMTSS2@uabmc.edu or calling us at 855-903-2136.** Thank you so much for participating in BMTSS and helping us with this important research!

### **Recent BMTSS Publications**

A BMTSS study, published in *Blood* (the Journal of The American Society of Hematology) in 2013, evaluated the sexual health of BMT (blood or marrow transplant) recipients before and up to 3 years after BMT. Just before BMT, 61% of men and 37% of women reported that they were sexually active. Three years after BMT, the proportion of survivors reporting that they were sexually active declined to 54% for men but increased to 52% for women.

Both men and women reported that sexual satisfaction was lower 3 years after BMT, especially among survivors who received an allogeneic transplant, due primarily to chronic graft-versus-host disease in both male and female survivors, and total body irradiation in male survivors. The results of this study highlight the importance of communication between BMT survivors and their healthcare providers about sexual health, so that experts can provide the guidance to address these issues.

**For more information:** Longitudinal trajectory of sexual functioning after hematopoietic cell transplantation: impact of chronic graft-versus-host disease and total body irradiation. F. Lennie Wong, Liton Francisco, Kayo Togawa, Heeyoung Kim, Alysia Bosworth, Liezl Atencio, Cara Hanby, Marcia Grant, Fouad Kandeel, Stephen J. Forman, and Smita Bhatia. *Blood*. 2013;122(24):3973-3981.



### 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 BMTSS2@uabmc.edu. Although the study is still collecting data, we will do a preliminary analysis regarding 1 to 2 topics or questions that we receive, and publish the results in the next newsletter.

### Question: How do I manage chronic fatigue after BMT?

Chronic fatigue is a common side effect of cancer treatments such as chemotherapy, radiation, and BMT. People with chronic fatigue may feel weak and run down. They may report low levels of energy and a feeling of exhaustion that is out of proportion to their activity level. A combination of cancer therapies, medications, anxiety, depression, nutritional issues, hormonal imbalance, pain, and low levels of physical activity may contribute to fatigue in BMT survivors.

Some research studies suggest that this type of chronic fatigue may be a result of the body's need for more energy to repair damaged tissues. Chronic fatigue may affect a survivor's physical ("tired all the time"), emotional ("feeling drained or overwhelmed"), and cognitive ("too tired to think clearly") functioning. Transplant-related fatigue does not always improve with sleep, and it may persist for months or years after treatment. It can disrupt normal activities and lower quality of life.



#### Ways to manage transplant-related fatigue:

- Eat right. A healthy balanced diet that contains foods rich in vitamins and nutrients can give your body the nutrition and energy it needs.
- Plan. Schedule time for activity and rest. A consistent routine may improve sleep and increase energy.
- **Get physically active.** Light to moderate physical activity for at least 3 hours per week may help to reduce fatigue. Physical activity such as walking, yoga, and dancing can help to increase energy.
- Talk with a professional. Counseling from a mental health professional can help address issues that may worsen transplant-related fatigue, such as stress or fear that cancer may return

Check-in with your healthcare provider: If you have chronic fatigue, it is important to talk with your healthcare provider about how fatigue affects your daily activities, and what seems to minimize fatigue or what makes it worse.

## Here are some questions you might consider asking during your next visit:

- What is most likely causing my fatigue?
- Are there treatments or medicines that could help me feel better?
- What should I keep track of and share with you, so we can develop a plan to help me feel better?



### **Preventive Health**

The human papillomavirus (HPV) is the most common sexually transmitted infection in the United States. The Centers for Disease Control and Prevention estimate that 80% of sexually active men and women will be infected with HPV at some point during their lives. There are many different types of HPV. Some types can cause serious health problems, including genital warts and cancer.

Most people who get HPV never develop symptoms or signs of infection. This makes the infection easier to spread from person to person. In healthy people, HPV infection often goes away by itself. However, in people who have received immunosuppressive therapy that weakens the immune system – including BMT survivors – HPV infection is more likely to persist. Persistent HPV infection with certain HPV strains can cause warts, pre-cancers, and cancers. Common cancers caused by HPV include cervical cancer, head and neck cancer, squamous cell skin cancer, and cancers of the vagina, vulva, penis, and anus. BMT survivors are more likely to develop these HPV-related health problems than people who have never had a BMT.

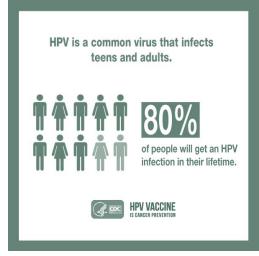
#### How can I protect myself against HPV-related health problems?

Although HPV is common, it is also preventable. Take these steps now to protect yourself from HPV-related health problems:

- **Get vaccinated.** The HPV vaccine protects against the strains of HPV that are most likely to cause cancer. HPV vaccination is recommended for all people between 9 and 26 years of age, and is licensed for adults up to age 45 years. A 3-dose HPV vaccine series is recommended for BMT survivors. The HPV vaccine is available at most doctor's offices, clinics, pharmacies, and public health departments.
- Get screened.
  - Females: Cervical cancer screening typically begins at age 21 and is done every 3 to 5 years through age 65. In some cases, more frequent screening may be needed. Check with your healthcare provider to determine the schedule that is best for you. You should continue getting screened even if you have been fully vaccinated against HPV. This is because the HPV vaccine does not protect against all types of HPV that can cause cancer, and the vaccine cannot protect against pre-existing HPV infections.
  - Males: Screening is not routinely recommended; however, some healthcare providers offer screening for men at increased risk for anal cancer. Check

with your healthcare provider to determine whether screening is recommended for you.

- Practice safer sex. If you are sexually active, use a latex condom each time you have sex, particularly when you are with a new sex partner. Avoid contact with anyone who has genital warts or sores. Consider being in a mutually monogamous relationship or limiting the number of sexual partners you have, to reduce your chances of exposure to HPV.
- See your healthcare provider. If you have questions, or if you develop any new or unusual growths such as warts, lumps, or sores in your genital area, anus, mouth, or throat, see your healthcare provider for an evaluation as soon as possible.





### COVID-19 and BMT Survivors

COVID-19 is 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 summarized some information for you here. Since new information is frequently evolving, we also suggest that you keep up with current information from resources such as the Centers for Disease Control and Prevention (CDC).

#### **COVID-19 Vaccine FAQs**

- As a BMT survivor, should I get the COVID-19 vaccine? Yes, you should strongly consider getting the vaccine. You should also encourage everyone in your household to get the vaccine, as soon as they are eligible to receive it. If you have questions about how you or your household members can get a vaccine appointment, we recommend speaking with your primary care physician.
- Is the vaccine safe for both allogenic and autologous transplant survivors? Yes
- Can the vaccine cause a flare up of GVHD? No
- Is there a preference for a certain vaccine type for transplant patients? No, all COVID-19 vaccines approved for use in the United States are safe for transplant patients. If you have a history of a severe allergic reaction to a vaccine component (such as polyethylene glycol or polysorbate), talk to your primary care physician to determine which vaccine formulation is best for you.
- **Do I need to get the flu vaccine this year?** Yes, definitely the flu vaccine is even more important this year, since flu can also cause severe respiratory infection. We recommend that you and everyone in your household get the flu vaccine as soon as it is available in your community.

#### How else can I protect myself against COVID-19 infection?

Until you are fully vaccinated, continue to follow these precautions to lower your chance of COVID-19 infection:

**Social distancing:** Limit your time in public places, and stay 3-6 feet away from people when you are outside the home. Avoid crowds and social gatherings. Avoid poorly ventilated indoor spaces. Avoid contact with anyone who is sick. If possible, avoid travel.

**Facemask:** Wear a facemask that covers your nose and mouth when in the vicinity of people outside of your household. Use a disposable mask or wash your cloth mask after use.

## After you are fully vaccinated (at least 2 weeks after your last vaccine dose):

The risk of getting COVID-19 depends on many factors, including the vaccination rates in your community. These factors are likely to change over time. Continue to follow the current COVID-19 precautions for vaccinated people as advised by your national and/or local authorities.

# What to do if you or someone in your home has been exposed to COVID-19:

Stay at home and call your Primary Care Provider

Monitor yourself for a fever, cough, loss of taste or smell, shortness of breath

## Signs of medical distress needing emergency attention:

- Pressure and/or pain in the chest
- · New onset of confusion
- Lips turning a bluish color

٠



## COVID-19 and BMT Survivors (Continued)

We also recommend that you continue to follow these tips for staying healthy.

#### Personal hygiene:

- Wash your hands often with soap and water for at least 20 seconds. If soap and water are not available, use a hand sanitizer that contains at least 60% alcohol.
- Avoid sharing utensils and personal items with other members of your household.

Healthy habits: Eat right, get plenty of sleep, and reduce stress as much as possible.

**Exercise:** Being physically active for at least 15 minutes a day can help your overall physical and mental health. If you need some exercise ideas, try searching free online tutorials from the comfort of your home.

#### **Additional Resources:**

#### COVID-19

- American Cancer Society: Questions about COVID-19
- American Society of Hematology: COVID-19
- Support groups: Coronavirus
- Financial: COVID-19 Financial Resources

#### **Chronic Fatigue**

- Fatigue and Cancer Treatment Side Effects National Cancer Institute
- Fatigue and Transplant: New Insights | BMT Infonet
- Fatigue (PDQ) Patient Version National Cancer Institute

#### **HPV**

- HPV and Cancer
- HPV Vaccination: What Everyone Should Know
- Genital HPV Infection Fact Sheet
- What Should I Know About Screening?