Patient & Family Guide

2018

Information for Patients Receiving Radiation Therapy: Total Marrow Irradiation (TMI)



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Why am I getting Total Marrow Irradiation treatment?

Certain blood cancers and blood disorders are treated with a stem cell transplant (this used to be called a bone marrow transplant). Total Marrow Irradiation (TMI), like chemotherapy, is given to get your body ready for the stem cells.

TMI focuses the radiation beams on your major bones. By focusing the beams only on your bones, the treatment targets your biggest areas of bone marrow. Bone marrow is the soft, sponge-like tissue found inside most bone.

TMI gives larger doses of radiation to bone marrow and lower doses to nearby normal, healthy organs. This can help limit side effects from radiation. In the past, radiation had an equal effect on bone marrow and all other body organs. This treatment was called Total Body Irradiation (TBI).

TMI can reach cancer cells in the body that chemotherapy may not reach. However, the dose of radiation must be low enough that the body's healthy cells can recover. For this reason, TMI alone cannot be used to destroy large numbers of cancer cells. Instead, TMI is used along with chemotherapy.

What will happen when I come for my treatment planning?

Your first visit to the radiation therapy department is called your 'treatment planning appointment' or your 'simulation appointment'. This will take about 1.5 hours.

During your simulation appointment, a mask and a foam cradle will be made for you. The mask covers your head and shoulders while the firm cradle goes under your legs and hips. The mask and cradle will help you stay in the same position every time you come for treatment.

What are your questions? Please ask. We are here to help you.

After your mask and cradle are made, you will have 2 CT scans done. One will scan the top part of your body and one will scan the bottom part of your body. The CT scans do not hurt and you do not have to hold your breath. It is important that you lie still.

Your radiation therapists will make every effort to make you comfortable during your X-rays. They will explain everything they are doing. The measurements and X-rays they take will be used to plan your radiation treatment.

Before you get up from the X-ray bed, your radiation therapists will give you some small tattoo marks. They will be about the size of a pen tip and are permanent. You will have 3 tattoos on your chest and 3 tattoos on your pelvis. These tattoos are used to position you for each treatment. After your treatment planning appointment, you may have some extra ink on your skin. You can wash it off when you get home.

At your treatment planning appointment, your radiation treatment team members will answer your questions. Please ask any questions you have about side effects, when your treatments will start, skin care, or other questions. Many people find it helpful to bring someone to this appointment with them.

How long will my treatments take?

Your transplant coordinator will give you a treatment schedule. Radiation treatments will start about 4 weeks after your treatment planning appointment. Once your treatments start, you should expect to have between 1 and 6 radiation treatments. If you are having more than 1 treatment, the treatments will be given twice a day, one in the morning and one at least 6 hours later in the day. The day before your treatments start you will need to come for a "mock" appointment. This appointment takes about 1 hour and is done to make sure all your measurements are correct and that all your positioning is good for treatment. Each treatment will take about 2 hours.

What will happen when I get my treatments?

Each time you come for treatment, the radiation therapists will help you get in the correct position using your mask and foam cradle.

The radiation therapists will turn out the lights and use laser lights to line up your tattoos. Once they have lined up all your tattoos, it is important that you stay very still and breathe normally. During the treatment, you will not see or feel the radiation.

Although you will be alone in the room when the beam is turned on, the therapists will be watching you the whole time on a TV monitor. The therapists will also be able to hear you over an intercom. If you need to cough or move, just tell or signal to the therapist. The radiation therapist will turn the machine off and help you. You will wear your mask for the first part of your treatment. Once the first part of your treatment is finished, the mask can be taken off and you will be given a break. The second part of your treatment will be done in a different position and will be quicker than the first part.

What are the possible side effects from these radiation treatments? Short-term side effects:

TMI may have many possible side effects.

- Nausea and vomiting
 Most patients have nausea (feeling sick to your stomach) and possibly even
 vomiting (throwing up) because of their TMI treatments. Medications are used
 to help prevent nausea and vomiting. Extra medications are used if nausea
 continues to be a problem.
- Skin reaction
 Your skin may become dry and itchy, pink, or even red. Some dark-skinned patients may notice their skin get darker. You can gently wash and bathe. Your tattoo marks will not wash off. Try not to scratch or rub the affected areas.
- Fatigue (tiredness)
 Fatigue caused by TMI is usually very noticeable. Some people will have mild fatigue, while some will have moderate or severe (bad) fatigue. This can last for weeks or months. There are ways to manage your fatigue. Please talk about this with your healthcare team.
- Headache
 The radiation treatments may cause swelling in your brain which can cause headaches.
- Hair loss
 The hair on your head may fall out because of your TMI treatment. Some patients may only notice a little thinning of their hair. This hair loss is temporary and your hair will grow back.
- Eye irritation
 Your eyes may get dry and itchy after having TMI. You will be given eye drops to
 help with this.

- Dry and sore mouth or throat Your salivary glands may make less saliva than usual, and your mouth may be dry. For a couple of weeks after treatment, you may feel pain or discomfort in your mouth and on your lips. You may have swelling of your gums and mouth tissue, and bleeding of your gums, and be at risk of mouth infection. Some people have trouble swallowing for a few days. Even if it is painful, it is important to brush your teeth to lower your risk of infection. The transplant team will teach you how to take care of your mouth and lips and help you manage discomfort and pain. Chemotherapy can also cause mouth side effects.
- Swollen glands (parotitis)
 Parotitis is the swelling of one or both of your parotid glands, the major salivary glands that are on either side of your face just in front of your ears.
 Your parotid glands may become swollen and tender because of your TMI treatment.
- Veno-occlusive disease of the liver (VOD)
 Your chemotherapy and TMI may cause VOD. This can cause weight gain, an enlarged and tender liver, fluid in your abdomen, and increased bilirubin.
 Bilirubin is found in bile and is made when the liver breaks down old red blood cells. Increased bilirubin may cause jaundice, which means yellow skin and eyes. VOD can be mild, moderate, severe, and even life-threatening.
- Myelosuppression
 Chemotherapy and TMI will cause myelosuppression. Myelosuppression is a decrease in how blood cells are made. Normal blood has large numbers of cells, including red blood cells to carry oxygen, white blood cells to fight infections, and platelets that help with blood clotting. In myelosuppression, the bone marrow makes too few of these cells. You will be less able to fight infection, you may be tired (anemic, have low iron), and you may have small bruises or a greater chance of bleeding.
- Fertility
 The chemotherapy and radiation you get as part of your transplant process usually makes you unable to get pregnant or father a child. If you are interested in learning about options for storing your eggs or sperm for the future, talk to the transplant team before you start your treatment.

Sexual health changes

TMI can cause a number of sexual health issues. This can change how you feel about yourself and your intimate relationships. Most people have a loss of sexual interest and desire and are unable to become aroused. This may last for weeks, months, or years. How long this lasts usually depends on your side effects, fatigue, emotional health, and general recovery. Most people who have fatigue have no sexual interest. Many people find that their sexual interest returns after they recover from other side effects and are no longer fatigued.

Long-term side effects:

TMI treatment may cause long-term side effects. These do not happen very often but may be very serious. Your radiation oncologist (cancer doctor) should talk to you about your risk of long-term side effects and what to expect. They will also ask you to sign a consent form before you begin TMI treatment.

What is supportive care?

Cancer is a disease of the body but it can also affect how you think and feel. Your emotional health and well-being are very important as you go through your treatments. It is normal for you and your family to have many different feelings at this time. You may feel anxious, frightened, worried, angry, or depressed.

There is support available to help you. A number of healthcare professionals may be available for you and/or your family. These can include a social worker, nurse, therapist, spiritual care counsellor, psychologist, and psychiatrist. They can help you cope with your cancer and the emotions you are experiencing, as well as help with stress management, lifestyle changes, financial concerns, or medication coverage.

Please ask your radiation oncologist, radiation therapist, or oncology nurse to refer you to this support team at any time. You will then receive a call from a member of this team to set up a separate appointment.

There are also Support and Wellness Groups available where you can talk with or listen to others who have had a similar experience, or learn more about cancer and how to live well with it. Information about these groups is available at the reception desk at your Cancer Centre or through the Canadian Cancer Society – Nova Scotia Branch.

Questions you may want to ask your Radiation Treatment Team:

- Do I have to do anything to get ready for my radiation markings (tattoos) or treatment?
- What should I expect during my treatments?
- Will the treatments affect my breathing?
- How will I cope with the side effects?
- What happens when the treatments end?
- Do I need to come back for a checkup?
- Will I have any long-term side effects from my treatments?
- Who can I talk to if I have questions about supportive care; for example, medication costs, insurance, home care, transportation, emotional concerns, or any other questions?
- Is there a research study for my cancer type that I could be involved in or learn more about?)

Looking for more health information?

Find this brochure and all our patient resources here: http://library.nshealth.ca/PatientGuides Contact your local public library for books, videos, magazines, and other resources.

For more information, go to http://library.novascotia.ca

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If you have any questions, please ask your health care provider. The information in this pamphlet is to be updated every 3 years or as needed.

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