

Why am I getting Total Body Irradiation Treatment?

Certain blood-related cancers and blood disorders are treated with a bone marrow or stem cell transplant. Total Body Irradiation (TBI) is given to prepare (condition) you for your bone marrow or stem cell transplant.

TBI gives a dose of radiation to your entire body. TBI can destroy cancer cells throughout the body. It also reduces your immune system so that your immune system will not attack either your cells or the donor's cells during the transplant.

TBI 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, TBI alone cannot be used to destroy large numbers of cancer cells. Instead, the conditioning for your transplant uses TBI along with chemotherapy.

What will happen on the day I come for my treatment planning?

Your first visit to the radiation therapy department is called your "treatment planning appointment". This will take about 45 minutes.

You will be x-rayed, measurements will be taken and markings will be placed on your skin. Your x-rays for treatment planning may be done by a CAT scanner. The x-rays do not hurt and you do not have to hold your breath. It is important that you lie still.

The measurements are used to make sure that the radiation you receive during the TBI is given evenly across your body. In some cases, shields need to be made to protect your lungs. The X-rays taken will help shape these shields.

Your Radiation Therapists will make every effort to make you comfortable during the x-rays. They will explain every step of what they are doing. The measurements and x-rays will be used to plan your radiation treatment.

Before you get up off of the x-ray bed, your Radiation Therapists will give you small tattoo marks. They are about the size of the tip of a pen and are permanent. You will have 2 tattoos on your chest and pelvis area as well as 4 tattoos on the sides of your abdomen. They will be used each treatment day to position you. After your treatment

planning appointment, you may have some extra ink on your skin. It can be washed off when you get home.

At your treatment planning appointment, your Radiation Treatment Team members will answer any questions you may have. These may include questions about side effects, when your treatments will start, skin care, or other questions. Many people find it helpful to bring someone along to this appointment.

How long will my treatments take?

Your transplant coordinator will give you a treatment schedule. Radiation treatments will start a few days after your treatment planning appointment. Once your treatments do begin, you should expect to have 1 to 6 radiation treatments. If you are having more than 1 treatment, the treatments are given twice a day. The first treatment is in the morning and the second is given at least 6 hours later in the day.

Each treatment will take about 45 minutes. This allows 20 minutes to get you into position and about 20-25 minutes of actual radiation treatment.

What will happen when I get my actual treatment?

Each time you come for treatment, the Radiation Therapist will get you into position on a special stretcher bed. You will be lying on your back. Your arms will be by your sides and a pillow will be under your knees. To make sure that your legs are close together, a small Velcro strap is put around your lower legs.

The Radiation Therapists will turn out the lights and will use laser lights to line up your tattoos. Measurements with a tape measure are done to make sure that you are in the same position as the day you had your Treatment Planning Appointment.

Once the therapists have finished lining up all your tattoos it is important that you stay very still. You do not need to hold your breath. 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.

Both sides of your body need to be treated and the therapist will begin by lining you up for your right side. Once you are in position, the shield for your lungs will be put in place. The shield is attached to a large frame that is put next to your side, about 2 feet away from you. After the right side is treated, the therapists will move the stretcher

and reposition you. They will check your tattoos and the lung shield to get ready for treatment of your left side. 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 all the time on a TV monitor. The therapist can also hear you over an intercom. The radiation therapists will be watching you and listening to you all the time.

What side effects might I have from the radiation treatments?

Short Term Side Effects:

TBI may have many possible side effects.

- **Nausea and Vomiting**

Most patients have nausea and possibly even vomiting as a result of their TBI treatments. Medications are used to help prevent the nausea and vomiting. Extra medications are used if nausea continues to be a problem.

- **Skin reaction**

The skin over your body may become dry and itchy, pink or even red. Some dark skinned patients may have increased darkening of the skin. You are allowed to gently wash and bathe. Your tattoo marks will not wash off. Try not to scratch or rub the affected area.

- **Fatigue (Tiredness)**

Fatigue caused by TBI is usually very noticeable. You will be more tired after an activity or may need to nap and rest each day.

- **Headache**

The radiation treatments may cause swelling in the brain which can cause headaches.

- **Hair Loss**

You may notice that the hair on your head and body may fall out as a result of your TBI treatment. Some patients may only notice a little thinning of the hair. The hair loss is temporary, which means that it will grow back.

- **Eye Irritation**

Your eyes may become dry and itchy after receiving TBI. You will be given artificial tears (eye drops) to help with eye irritation.

- **Dry and sore mouth/throat**

Your salivary glands may produce less saliva than usual, making your mouth feel dry. You may have trouble swallowing because your mouth may be dry or sore. You will need to take good care of your teeth, gums, mouth and throat. The transplant team will help offer suggestions for mouthcare.

Some suggestions are:

- Drink plenty of fluids to keep lining of mouth moist. Water is great because it doesn't damage teeth.
- Brush your teeth with a fluoride toothpaste right after meals and at bedtime. Use a toothbrush with soft bristles. Your gums may bleed after brushing. Keep brushing unless they bleed for longer than 2 minutes.
- If you are not able to brush your teeth, keep your teeth and gums clean by wiping them carefully. Wrap a moist gauze around your finger and gently rub your teeth and gums to wipe away any food or plaque.
- After cleaning your teeth: rinse, swish and spit with salt or baking soda solution.
- Frequent mouth rinses/gargling is an important part of your mouth care. You can use one of the following solutions:
 - non flavored soda water like Club soda
 - 1/2 teaspoon of table salt with 8 oz water
 - 1/2 teaspoon of baking soda with 8 oz waterRinse and swish approximately 1 tablespoon of solution around your mouth after you brush your teeth, after meals and at bedtime.
Rinsing your mouth more frequently may help keep your mouth moist.

- **Swollen glands (Parotitis)**

Parotitis is a swelling of one or both of your parotid glands, the major salivary glands located on either side of the face just in front of your ears. Your parotid glands may become swollen and tender as a result of your TBI treatment.

- **Veno-Occlusive disease of the liver (VOD)**

Your chemotherapy and TBI 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 produced 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**

The chemotherapy and TBI will cause myelosuppression. Myelosuppression is a decrease in the production of blood cells. Normal blood contains 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) and you may have small bruises or a greater chance of bleeding.

- **Fertility**

The chemotherapy and radiation you get as part of your transplant regime usually prevents you from being able to get pregnant/father a child. Options for storing eggs or sperm should be discussed before you start treatment if you are interested in having children.

- **Sexual Health Changes**

As with other treatments for transplant, TBI can cause a number of sexual health and relationship changes. Most people experience loss of sexual interest and desire, and the inability to become aroused for weeks to months to years. How long this lasts usually depends on side effects, fatigue, emotional health and general recovery. While you are experiencing fatigue, most people have no sexual interest. Many people find that their sexual interest returns after they recover from other side effects and they are no longer fatigued.

Men:

A man's ability to get or keep an erection may change with TBI. Damage to tissue and blood vessels in the penis usually begins slowly, after the radiation is complete. Most damage happens by the end of year 2. Talk to your caregivers if you are experiencing erection problems. It is usually better to start addressing these changes sooner rather than later. Men may notice changes in their ability to ejaculate or orgasm. If these are concerning, ask to talk to a health professional who deals with sexual health changes.

Women:

Most women are pushed into menopause with transplant treatment (if they haven't already gone through menopause). For a very few women (usually under the age of 30), this may be temporary. Because the treatment causes early menopause due to damaged ovaries from the chemotherapy and radiation, it is very common for women to experience more frequent and severe side effects. Common side effects are hot flashes, fatigue, depression, mood swings, irritability, loss of concentration, vaginal dryness, urinary changes and inability to sleep well. Hormone replacement therapy (HRT) is often prescribed to women, particularly younger women, so that their bones are protected from osteoporosis. HRT will usually also stop symptoms of menopause.

Vaginal Changes: Radiation in the vaginal area can cause irritation, sores, dryness and bleeding. It may also cause the vagina to narrow and shorten (as can menopause). If you are experiencing burning, discomfort, pain (pain with intercourse), discharge, bleeding, you should have your doctor or nurse practitioner examine you. There are a variety of measures that may be considered to relieve these problems. It is usually better to start addressing these changes sooner rather than later, so talk a health professional as soon as these symptoms start.

Long term Side Effects:

TBI treatment may cause long term side effects. These do not happen very often but may be very serious. Your radiation oncologist should talk to you about your risk of getting side effects and what to expect. Your radiation oncologist will ask you to sign a consent form before you begin TBI treatment.

What is Supportive Care?

Cancer is a physical disease but it also can 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 feelings at this time. You may feel anxious, frightened, worried, angry or depressed.

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

At any time you can ask your Radiation Oncologist, Nurse or Radiation Therapist to refer you to this support team. You will then receive a call from a member of the 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 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:

1. Do I have to do anything to prepare for my radiation markings or treatment?
2. Can I bathe or wash?
3. What should I expect to happen during my treatments?
4. Will the treatments affect my breathing?
5. How will I cope with the side effects?
6. How will I know if the treatments are working?
7. What happens when the treatments end?
8. Do I need to come back for a checkup?
9. Will I have any long-term side effects from my treatments?
10. 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?
11. Is there a research study for my cancer type that might be appropriate for me? (or that I could be involved in?)

