Is my disease cured?
There is no cure. Your disease may be better controlled.

Can I have more radiation?
More radiation is possible. Please discuss this with your doctor.

What if the side effects become severe?
Treatment is stopped or put on hold until your side effects clear up. You and your health care team will discuss other options.

Follow-up
Your follow-up care depends on where you live. You may see your family doctor, dermatologist, hematologist or your health care team at the Juravinski Cancer Centre. You will also be given contact information of your nurse and radiation therapist at the Juravinski Cancer Centre.

Total Skin Electron Beam Radiation, TSEB

What is Total Skin Electron Beam Radiation, or TSEB?
TSEB is used to treat Cutaneous T-Cell Lymphoma. TSEB delivers a specific amount of radiation beam to all of your skin. It may be the only treatment you need, or it may be used with other treatments.

Your health care team:
- Radiation Oncologist
- Radiation Therapists
- Radiation Therapy Nurses and Primary Care Nurses

Every day during your treatments you will see your radiation therapist who will ask how you are doing and answer any questions you may have. Every week during your treatment you will be seen by your doctor and team. If you feel that you need more care and support, radiation therapy nurses are also available to help.

How can I prepare myself?
There is a lot to think about before you start your treatments. Discuss your needs with your family and friends before you start. They can help with such things as meals and driving. Have a supply of books and movies, or other activities that keep you entertained while you rest. Avoid activities that involve using your hands a lot.

Listen to your body, not everyone reacts in the same way. Take one day at a time. If you have any questions, please ask – do not wait.

Before you start, you will be taken on a tour of the radiation room. Before each treatment, you will be asked your name and address or date of birth.
**How often do I get treatment?**

Treatments are usually given each weekday (Monday to Friday) for up to 6 weeks. The total number of treatments is determined by your radiation oncologist and depends on:

- the extent of your disease
- your overall condition, and
- your reaction to the treatment

Treatments are booked for 1 hour each day, the actual time you are exposed to the radiation beam is only a few minutes. It takes time to get you ready for the radiation.

**What happens during treatment?**

Radiation therapists will help you get ready. They will explain what you need to do. Please ask them your questions or let them know your concerns.

The radiation therapist, with your permission, will need to touch you to help get you ready. Pieces of styrofoam are placed in any skin folds. This helps expose all surfaces of your skin to the radiation. Women may be asked to bring a cotton bra that will be modified and worn during treatment.

For a few days, small radiation monitors will be placed in some natural skin folds. These folds, called patch areas, may include the breasts, buttock, groin and perineal areas. These monitors tell us how much radiation is given in these areas.

If needed, the radiation oncologist will prescribe more radiation to these patch areas, so that the skin receives the same amount of radiation. Some patches, for example the perineum, will be treated at the same time as the TSEB. Other areas may also be treated at the same time or may be added at the completion of the TSEB.

**Call**

- You will be given a card with contact information.
- Call your radiation therapist or primary nurse for any changes to your condition or concerns that you have.
- There is also a supportive care department at JCC that includes dietitians, social workers, chaplains, mental health nurses and psychiatrists. Let your primary team know if you would like the help of any of these professionals to help you deal with your disease and treatment.

**How do I care for myself after the radiation is done?**

Radiation continues to work after you have completed treatment. You may still see skin changes for several months after radiation. Slowly return to normal activities, as you feel able.

Avoid direct sunlight until after your initial follow up with the primary care team. This is usually 4 to 6 weeks after completion of treatment. Your primary care team will advise you on how long you should stay in the sun and how to protect your skin from too much sun.

**When will I notice that the treatment has worked?**

You may notice that your skin lesions are different – lighter in appearance. They may look like they are fading away. You may be less itchy.

**Will my skin problems come back?**

Yes, they may come back but no one can say when this may happen.
**Eating and drinking**
Eating a balanced diet by following Canada’s Food Guide during treatment helps. We also recommend taking one multi-vitamin daily. You may find that you may not want to eat as it takes too much effort. Plan on having snacks, and small simple meals.

Ask to see a Registered Dietician if you have concerns about your diet and how to get the most out of the foods you eat during treatment.

**Shower or bath**
Gently bathe and shower every day using a mild soap such as Dove soap. No brisk rubbing when washing or drying. Pat skin gently. Use a mild shampoo such as baby shampoo to wash your hair.

**Sex**
You may be too uncomfortable to have or want sex.

**Activity**
Feeling fatigued or being very tired is common. Limit walking to help prevent feet from becoming swollen and painful. We recommend that you use a wheelchair while at the Cancer Centre. Save your walking for pleasure.

Fatigue is often associated with this treatment and may continue after treatment is completed.

How much activity you can do depends on the stage of your disease, how you feel and your skin’s reaction to the radiation treatment. Not everyone reacts in the same way. You will be the best judge about how much you can do – listen to your body.

For each treatment you will need to take all of your clothes and jewellery off. You are fully naked so that all of your skin is exposed to the radiation. You may be asked to stand in 3 different positions, alternating daily. Each position exposes all of your skin to the radiation beam. At the time of your first visit, the doctor will decide which positions are right for you.
Protecting sensitive body areas

On certain treatment days, sensitive body areas will be covered with a lead shield. Your doctor may decide to shield other areas not listed below. You will be shown how this is done before you start treatment.

**Feet**

If you need treatment to the bottom of your feet, you will need to sit or lie down on the treatment unit and place your feet in a plastic box.

Rice is poured over and around your feet to make sure that only the soles are treated.

Receiving treatment to your feet.

How do I take care of myself during the treatment?

**Washing your hands**

If possible, limit how often you wash your hands. You will be given a box of latex free gloves to use when toileting. At other times, you may wish to use cotton gloves to prevent getting your hands dirty while doing your regular activities.

**Trim hair and nails**

Before treatment, it is a good idea to trim your nails and hair.

**Feet**

Wear large comfortable slippers and shoes. Limit walking. Rest. Raise your legs and feet to above the level of your heart during the day. Do this several times a day.

**Shaving**

For facial hair men may use an electric razor before treatment, but we recommend not shaving during treatment. Do not shave legs, underarms or any other areas.

**Skin**

Wear loose clothing.

**Do not use adhesive tape or Band-Aids.** If dressings are needed, the radiation nursing staff will show you ways to protect your skin without using these products.

Avoid scrubbing or scratching your skin. For dry or itchy skin use Glaxal base lotion. Apply a thin amount of lotion 2 to 3 times during the day but **do not** apply 2 hours before your radiation treatment.

Do not use other lotions, deodorants, powders, perfumes or water sprays unless recommended by your primary team.

Use a cream on your skin and feet such as Glaxal or one that is recommended by the primary care team. If you do get blisters or swelling you may need to see a radiation nurse daily.

**Do not apply Glaxal or any cream 2 hours before your radiation treatment.**
What are some side effects from TSEB?

Side effects depend on the total amount of radiation you receive. The side effects of TSEB are mostly those of the skin. These include:

- skin surface
- hair
- nails
- sweat glands

Skin surface. Your skin may become red or pink, dry or flaky and it may itch. Open skin areas may occur; especially in skin folds, or on hands and feet. Open areas are at risk for infection and need to be closely watched. Sometimes treatment is needed.

Hair. Hair thinning or patchy hair loss may be noted. Hair generally begins to grow back 2 to 3 months after your treatment is done. Your hair may come back a different colour or texture. It may not be as thick as before.

Nails. Fingernails and toenails stop growing because of TSEB. Depending on the radiation dose you receive, it is possible that you may lose your nails. As new nails grow, the old nails become a bit thicker and may feel loose.

Sweat glands. You sweat less, may feel hot to the touch but cold inside.

These areas will be closely watched, and generally clear up in a few weeks after treatment.

Eyes

To protect the eyes and allow treatment of the eyelids, goggles and internal eye shields are used. These shields are like contact lenses. Not everyone needs internal eye shields, the doctor will decide if any and what type of eye shielding is needed.

Please do not drive for 30 minutes after treatment if eye shields are used.
For safety reasons, you will use the same equipment throughout your radiation treatments. Your name is on it, and no one else will use it.

**What if I need help while the radiation is being given?**

You will be alone in the room for a few minutes while the radiation is on. Radiation therapists will be able to see you through a TV screen and will be in constant contact through an intercom. If needed, they can turn the machine off and enter the room.

You will need to stand as still as possible and breathe gently. You will not be able to see, smell or taste the radiation beam.
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Lead shields cover the eyes.

Plain goggles are used when lead shields are worn.

Lead goggles are used when no lead shields are worn.
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