

# PATIENT & CAREGIVER EDUCATION Electron Beam Radiation Therapy for Skin Lymphoma

This information will help you get ready for electron beam radiation therapy to your skin at MSK. It will help you know what to expect before, during, and after your treatment. It will also help you learn about side effects and how to care for yourself during your treatment.

Read through this resource before you start radiation therapy. Use it as a reference in the days leading up to your treatments so you can prepare as much as possible. Bring this resource to all future appointments with your radiation oncologist. You and your radiation therapy team will refer to it throughout your treatment.

# **About Radiation Therapy**

Radiation therapy uses high-energy beams to treat cancer. It works by damaging the cancer cells and making it hard for them to reproduce. Your body is then naturally able to get rid of the damaged cancer cells. Radiation therapy also affects normal cells. However, your normal cells are able to repair themselves in a way that cancer cells can't

#### About electron beam radiation therapy

Electron beam radiation therapy is used to treat lymphoma in your skin (cutaneous lymphoma). Electrons don't go deep in your body. The dose of radiation to deeper tissues is minimal.

There are 2 ways electron beam radiation therapy can be given:

- Spot treatment. This is when 1 or more spots on your body are treated. If you're having spot treatment, you might have a treatment planning procedure called a simulation before you start treatment. For more information, read the "Simulation" section.
- Total skin electron beam (TSEB) therapy. This is when the entire surface of your skin is treated. If you're having TSEB therapy, you won't have a treatment planning procedure. This is because the entire surface of your skin will be treated. You might have extra treatments called compensation treatments. These are done to make sure that every area of your skin gets treatment. For more information, read the "Compensation treatments" section.

#### Your role on your radiation therapy team

Your radiation therapy care team will work together to care for you. You're a part of that team, and your role includes:

- Getting to your appointments on time.
- Asking questions and talking about your concerns.
- Telling someone on your care team when you have symptoms related to your treatment.
- Telling someone on your care team if you're in pain.
- Caring for yourself at home by:
  - Quitting smoking if you smoke. MSK has specialists who can help you quit smoking. For more information about our Tobacco Treatment Program, call 212-610-0507.
  - Caring for your skin based on your care team's instructions
  - Drinking liquids based on your care team's instructions.
  - Eating the foods your care team suggests.
  - Staying around the same weight.

# **Before Your Treatment**

## □ Simulation

Before you start your electron beam therapy spot treatments, you will have a treatment planning procedure called a simulation. If you're having TSEB therapy, you won't have a simulation. You can skip to the "Treatment schedule" section.

Simulation is done to make sure that:

- Your treatment area is mapped out.
- You get the right dose of radiation.
- The radiation dose to nearby tissue is as small as possible.

Your simulation appointment will take about 2 to 3 hours.

## Take devices off your skin

You may wear certain devices on your skin. Before your simulation or treatment, device makers recommend you take off your:

- Continuous glucose monitor (CGM)
- Insulin pump

If you use one of these, ask your radiation oncologist if

you need to take it off. If you do, make sure to bring an extra device to put on after your simulation or treatment.

You may not be sure how to manage your glucose while your device is off. If so, before your appointment, talk with the healthcare provider who manages your diabetes care.

## Getting ready for your simulation

- During your simulation, you will be lying in one position for a long time. If you think you will be uncomfortable lying still, you can take acetaminophen (Tylenol®) or your usual pain medication before your simulation.
- If you think you might get anxious during your procedure, ask your doctor if medication might be helpful.
- Wear comfortable clothes that are easy to take off. You will need to change into a hospital gown.
- Don't wear jewelry, powders, or lotions.

To help the time pass during your simulation, your radiation therapists can play music for you.

#### Day of your simulation Once you arrive

A member of your radiation therapy team will check you in. You will be asked to state and spell your full name and birth date many times. This is for your safety. People with the same or a similar name can be having care on the same day as you.

Your radiation therapist will greet you. They will take a photograph of your face. This picture will be used to identify you throughout your treatment.

Your radiation therapist will then explain what to expect during your simulation. If you haven't already signed a consent form, your radiation oncologist will review everything with you and ask for your signature.

#### **During your simulation**

You will need to change into a hospital gown for your simulation. You should keep your shoes on. If you wear a head covering (such as a wig, turban, or cap), you might need to remove it.

After you change, your radiation therapists will bring you to the simulation room and help you lie down on the table. They will do everything they can to make sure you're comfortable and have privacy. The table will have a sheet on it, but it's hard and has no cushion. Also, the room is usually cool. If you feel uncomfortable at any time, tell your radiation therapists. If you haven't taken pain medication and think you might need it, tell your radiation therapists before your simulation starts.

Once your simulation starts, don't speak or move. Speaking or moving can change your position. However, if you're uncomfortable or need help, tell your radiation therapists.

During your simulation, you will feel the table move into different positions. The lights in the room will be turned on and off and you will see red laser lights on each wall. Your radiation therapists will use these laser lights as a guide to help position you on the table. Don't look directly into the laser lights, because they can damage your eyes.

There will be an intercom (microphone and speaker) and a camera inside the simulation room. Your radiation therapists will walk in and out of the room during your simulation, but there will always be someone who can see and hear you. You will hear your radiation therapists talking to each other as they work, and they will talk to you to explain what they're doing.

## Positioning

Depending on the area of your body that's being treated, you might lie on your stomach or on your back. Your arms might be raised above your head or at your sides. The position that you are in during your simulation will be the same position you will be in for your spot treatments. If you need an immobilization device, your nurse and radiation therapist will explain it to you.

#### After your simulation

At the end of your simulation appointment, we will schedule an appointment for your set-up procedure and first treatment.

#### **Treatment schedule**

- Spot treatment is given \_\_\_\_\_ times a week over \_\_\_\_\_weeks. You should plan to be in the department for 60 to 90 minutes for each treatment.
- TSEB therapy is given 2 times a week over
   \_\_\_\_weeks. You should plan to be in the
   department for 60 to 90 minutes for each treatment.

If you're having compensation treatments, they will be given for an extra 2 to 4 weeks after your regular treatments are finished.

# **During Your Treatment**

#### What to expect

For each of your treatments, check in at the reception desk and have a seat in the waiting room. When your radiation therapists are ready for you, you will be shown to the dressing room and asked to change into a hospital gown. Keep your shoes on during your treatment.

Your radiation therapists will bring you into the treatment room. They will help you get into position for your treatment.

- If you're having spot treatment, you will be lying in the same position that you were in during your simulation.
- If you're having TSEB therapy, you will be standing on a platform that rotates. This is so the entire surface of your skin can be treated from different angles.

Once you're positioned correctly, your radiation therapists will leave the room, close the door, and start your treatment. You won't see or feel the radiation, but you might hear the machine as it moves around you and is turned on and off. You will be in the treatment room for \_\_\_\_\_, depending on your treatment plan. Most of this time will be spent putting you in the correct position. The actual treatment only takes a few minutes. You will be alone in the room during your treatment, but your radiation therapists will be able to see you on a monitor and hear you through an intercom at all times. They will make sure you're comfortable during your treatment.

Breathe normally during your treatment, but don't move. However, if you're uncomfortable or need help, tell your radiation therapists. They can turn off the machine and come in to see you at any time, if needed.

Neither you nor your clothes will become radioactive during or after treatment. It's safe for you to be around other people.

#### Compensation treatments

After your regular treatments are done, your radiation oncologist might want you to have compensation treatments to areas of your skin not covered during TSEB. These areas include the soles of your feet, your perineum (area between your vagina and anus or scrotum and anus), your scalp, and the skin folds under your breasts and on your stomach area.

You will have \_\_\_\_\_\_ to \_\_\_\_\_ compensation treatments over 2 to 4 weeks. You should plan to be in the department for 60 to 90 minutes for each treatment.

#### Weekly visits during treatment

Your radiation oncologist and nurse will see you each week to ask you about any side effects you're having, talk with you about your concerns, and answer your questions. This visit will be before or after your treatments each \_\_\_\_\_\_. You should plan to be at your appointment for about 1 extra hour on these days.

If you need to speak with your radiation oncologist or radiation nurse between these weekly visits, call your radiation oncologist's office. You can also ask the support staff or your radiation therapists to contact your radiation oncologist when you come in for treatment.

# Vitamins and dietary supplements during radiation therapy

It's OK to take a multivitamin during your radiation therapy. Do not take more than the recommended daily allowance (RDA) of any vitamin or mineral.

Do not take any other dietary supplements without talking with a member of your care team. Vitamins, minerals, and herbal or botanical (plant-based) supplements are examples of dietary supplements.

# **Side Effects of Treatment**

You might have side effects from radiation therapy. The type and how severe they are depends on many things. These include the dose of radiation, the number of treatments, and your overall health.

You might start to notice side effects after you start treatment. They can get worse during treatment, but they will slowly get better after you finish treatment. Some side effects might take longer to go away. Follow the guidelines in this section to help manage your side effects during and after treatment.

Below are the most common side effects of electron beam radiation therapy. You might have all, some, or none of these. Your nurse will talk with you about the side effects you're most likely to have. They will also check the boxes next to that section.

#### Changes to your skin, hair, and nails

You might have side effects that involve the skin, hair, and nails in the area being treated. Your skin can become:

- Red
- Dark
- Dry

- Irritated
- Itchy

You might lose hair on your whole body (including your scalp, eyebrows, under your arms, and pubic area). The hair loss is usually temporary. Hair should start to grow back 3 to 6 months after your treatment is done. You might want to buy a wig before your treatment begins.

Your nails might fall off in the areas being treated. As your old nails fall out, new ones will be growing in underneath. Keep your nails neatly trimmed during this time.

Your nurse will teach you how to care for your skin. They will apply special dressings (bandages) or creams, if needed. Your doctor might stop your treatment until your skin heals.

Follow the guidelines below to care for your skin. Keep following them until your skin gets better. These guidelines refer only to the skin in the treatment area.

## Keep your skin clean

 Bathe or shower every day. Use warm water and a mild, unscented soap (such as Neutrogena<sup>®</sup>, Dove<sup>®</sup>, baby soap, Basis<sup>®</sup>, or Cetaphil<sup>®</sup>). Rinse your skin well and pat it dry with a soft towel.

- When washing, be gentle with the skin in the treatment area. Don't use a washcloth, scrubbing cloth, or brush.
- Don't use alcohol or alcohol pads on the skin in the treatment area.

#### Moisturize your skin often

Start using a moisturizer when you start treatment. This can help minimize skin reactions. You can use an over-the-counter (not prescription) moisturizer.

- Use a moisturizer that doesn't have any fragrances or lanolin. Your nurse can suggest a moisturizer for you to use.
- Don't use more than 1 moisturizer at a time, unless your nurse tells you to use more.

Apply the moisturizer 2 times each day. The best time to do it is right after bathing, while your skin is still a little damp. Rub the moisturizer in your hands to soften it. Apply it to your entire body. Pay special attention to your hands and feet. Ask a family member or friend to help rub the moisturizer into your back.

Don't wash off the moisturizer before your treatments. Your skin could become irritated.

#### Avoid irritating your skin

- If your skin is itchy, don't scratch it. Apply moisturizer. Ask your nurse for recommendations on how to relieve the itching. They can give you a prescription for medication to treat itchy skin.
- Wear loose-fitting cotton clothing and undergarments in the area being treated. Avoid underwire bras or tight clothing that will rub against your skin.
- Use only the moisturizers, creams, or lotions that you have discussed with your radiation oncologist or nurse.
- Don't use makeup, perfume, powder, or aftershave on the skin in the treatment area.
- Don't use deodorant if your skin is open, cracked, or irritated. You can use deodorant on intact skin in the treatment area. Stop using it if your skin becomes irritated.
- Don't shave in the treatment area. If you must shave, use only an electric razor. Stop if your skin becomes irritated.
- Don't put tape on the treatment area.
- Don't let the skin in the treatment area come into contact with extreme hot or cold temperatures. This includes hot tubs, water bottles, heating pads, and ice

packs.

- If you don't have any skin reactions, you can swim in a chlorinated pool. Shower right after you get out of the pool to rinse off the chlorine.
- Avoid tanning or burning your skin. If you're going to be in the sun:
  - Use a PABA-free sunblock with an SPF of 30 or higher.
  - Wear loose-fitting clothing that covers as much of the skin in the treatment area as possible.

#### Fatigue

Fatigue is feeling very tired or weak. When you feel fatigue, you may not want to do things. You may have trouble focusing, feel slowed down, or have less energy than usual.

You may start to feel fatigue after 2 to 3 weeks of treatment. It can range from mild (not bad) to severe (very bad). It may be worse at certain times of day. Fatigue may last 6 weeks to 12 months after your last treatment.

There are lots of reasons you may feel fatigue during your radiation therapy. They include:

• The radiation's effects on your body.

- Traveling to and from your treatment appointments.
- Not getting enough restful sleep at night.
- Not getting enough protein and calories.
- Having pain or other symptoms.
- Feeling anxious (nervous) or depressed (unhappy).
- Side effects of some medicines.

#### Ways to manage fatigue

- If you're working and are feeling well, it's OK to keep working. But working less may help you have more energy.
- Plan your daily activities. Pick the things you need or really want to do. Do them when you have the most energy. For example, you may choose to go to work but not do housework. You may choose to watch your child's after-school event but not go out to dinner.
- Plan time to rest or take short (10- to 15-minute) naps during the day, especially when you feel more tired.
- Try to sleep at least 8 hours every night. This may be more sleep than you needed before you started radiation therapy. You may find it helpful to:
  - $\circ\,$  Go to sleep earlier and get up later.
  - Be active during the day. For example, if you're

able to exercise, you could go for a walk or do yoga.

- Relax before going to bed. For example, read a book, work on a puzzle, listen to music, or do another calming hobby.
- Ask family and friends to help with chores and errands. Check with your health insurance company to see if they cover home care services.
- You might have more energy when you exercise. Ask your radiation oncologist if you can do light exercise, such as walking, biking, stretching, or yoga. Read *Managing Cancer-Related Fatigue with Exercise* (www.mskcc.org/pe/fatigue\_exercise) to learn more.
- Eat foods that are high in protein and calories. Read *Eating Well During Your Cancer Treatment*  (www.mskcc.org/pe/eating\_cancer\_treatment) to learn more.

Some things can make your fatigue worse. Examples are:

- Pain
- Nausea (feeling like you're going to throw up)
- Diarrhea (loose or watery poop)
- Trouble sleeping
- Feeling depressed or anxious

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If you have these or any other symptoms or side effects, ask your radiation oncologist or nurse for help.

#### Changes to your sweat glands

After your treatment, your sweat glands might not work as well as before. This means that you might not sweat enough and you might be more at risk for heat exhaustion.

Do the following to prevent this:

- When the weather is very hot, stay indoors with the air conditioning turned on.
- Ask your radiation oncologist about doing activities such as housework or gardening. Also, ask about what kinds of exercises are safe.
- Don't use saunas, steam rooms, or hot tubs.
- Drink plenty of liquids during warm weather.

## Swelling and stiffness

During your treatment, you might have swelling in your hands, legs, ankles, and feet. Sometimes, this swelling can be very uncomfortable. Tell your radiation oncologist or radiation nurse if this happens to you. You may need to limit your activities or take medication to help with these symptoms. Your nurse or a clinical dietitian nutritionist may also recommend changes to your diet, such as cutting down on salt.

You might still have swelling and stiffness after your treatment is over. Try to keep doing your usual activities as best as you can. Your radiation oncologist can recommend physical therapy to prevent further stiffness.

#### Appetite loss

Your appetite might decrease while you're receiving treatment. However, your body needs protein and calories. They help repair the normal cells injured from radiation. Also, if you use a mold during your treatments, it might not fit correctly if your weight changes. Try not to lose weight during your treatment.

• Be selective about what you eat to be sure you increase your calories and protein. We will give you the resource *Eating Well During Your Cancer Treatment* 

(www.mskcc.org/pe/eating\_cancer\_treatment). It contains many suggestions. Try the foods that are recommended.

- Try to eat small meals often throughout the day.
- If you never seem to feel hungry, set up a schedule to make sure you eat regularly. For example, set a schedule to eat every 2 hours.

- Eat your meals in a calm place. Take your time eating. Eat with family or friends whenever you can.
- Choose foods with different colors and textures to make your meals more appealing.
- Bring snacks and drinks to your treatment appointments. You can have while while you're waiting or while you're coming to and from your appointments.
- Drink liquid nutritional supplements if you're not eating enough food. There are many products available, and they come in many flavors. Ask your doctor or nurse which product is best for you.

## □ Changes to your blood cell counts

It's very rare that electron beam radiation therapy affects blood cell counts. However, call your radiation oncologist or nurse immediately if you develop:

- A fever of 100.4 °F (38 °C) or higher
- Shaking chills
- Flu-like symptoms
- Bleeding

These things can mean that you have an infection. If you have an infection, you might need antibiotics. You might also have another problem related to a drop in your

blood cell counts.

#### Sexual health

You might have concerns about how cancer and your treatment can affect your sexuality. You aren't radioactive. You can't pass radiation to anyone else, so it's safe to be in close contact with other people.

You can be sexually active during radiation treatment, unless your radiation oncologist gives you other instructions. However, if you or your partner are able to have children, you must use birth control (contraception) to prevent pregnancy during your treatment.

The American Cancer Society has resources about sexual health issues during cancer treatment. The one for men is called *Sex and the Man with Cancer*. The one for women is called *Sex and the Woman with Cancer*. You can search for them at www.cancer.org or call 800-227-2345 for a copy.

MSK also has sexual health programs to help you address the impact of your disease and treatment on your sexual health. You can meet with a specialist before, during, or after your treatment.

• Female Sexual Medicine & Women's Health Program:

For more information or to make an appointment, call 646-888-5076.

 Male Sexual & Reproductive Medicine Program: For more information or to make an appointment, call 646-888-6024.

## **Emotional health**

Cancer diagnosis and treatment can be very stressful and overwhelming. You may feel:

• Depressed

Frustrated

• Helpless

- Anxious or nervous
- Afraid
- Alone
- Angry
- You might also worry about telling your employer you have cancer or about paying your medical bills. You may worry about how your family relationships may change, or that the cancer will come back. You may worry about how cancer treatment will affect your body, or if you will still be sexually attractive.

It's normal and OK to worry about all these things. All these kinds of feelings are normal when you or someone you love has a serious illness. We're here to support you.

- Numb
- Uncertain
- Worried

#### Ways to cope with your feelings

**Talk with others.** When people try to protect each other by hiding their feelings, they can feel very alone. Talking can help the people around you know what you're thinking. It might help to talk about your feelings with someone you trust. For example, you can talk with your spouse or partner, close friend, or family member. You can also talk with a chaplain (spiritual advisor), nurse, social worker, or psychologist.

Join a support group. Meeting other people with cancer will give you a chance to talk about your feelings and learn from others. You can learn how other people cope with their cancer and treatment and be reminded you are not alone.

We know that all cancer diagnoses and people with cancer are not the same. We offer support groups for people who share similar diagnoses or identities. For example, you can join a support group for people with breast cancer or for LGBTQ+ people with cancer. To learn about MSK's support groups, visit www.msk.org/vp. You can also talk with your radiation oncologist, nurse, or social worker.

**Try relaxation and meditation.** These kinds of activities can help you feel relaxed and calm. You might

try thinking of yourself in a favorite place. While you do, breathe slowly. Pay attention to each breath or listen to soothing music or sounds. For some people, praying is another way of meditation. Visit

www.msk.org/meditations to find guided meditations lead by our Integrative Medicine providers.

**Exercise.** Many people find that light movement, such as walking, biking, yoga, or water aerobics, helps them feel better. Talk with your healthcare provider about types of exercise you can do.

We all have our own way of dealing with difficult situations. Often, we use whatever has worked for us in the past. But sometimes this is not enough. We encourage you to talk with your doctor, nurse, or social worker about your concerns.

# **After Your Treatment**

Be sure to keep your follow-up appointments with your radiation oncologist. During these appointments, your radiation oncologist will evaluate your response to treatment. You might have blood tests, x-rays, and scans during these visits.

Before each follow-up appointment, write down your questions and concerns. Bring this and a list of all your

medications to your appointment. If you're running low on any medication you need, tell your radiation oncologist before you run out. You can also call your radiation oncologist or nurse at any time if you have any questions or concerns.

# When to Contact Your Radiation Oncologist or Nurse

Contact your radiation oncologist or nurse if you have:

- A fever of 100.4 °F (38 °C) or higher
- Chills
- Painful, peeling, blistering, moist, or weepy skin
- Discomfort in the treated area
- Pain not relieved by medication
- Any new or unusual symptoms

# **Support services**

#### **MSK support services**

#### **Counseling Center**

#### www.msk.org/counseling

#### 646-888-0200

Many people find that counseling helps them. Our counseling center offers counseling for individuals, couples, families, and groups. We can also prescribe

medications to help if you feel anxious or depressed. To make an appointment, ask your healthcare provider for a referral or call the number above.

#### **Integrative Medicine Service**

#### www.msk.org/integrativemedicine

Our Integrative Medicine Service offers many services to complement (go along with) traditional medical care, including music therapy, mind/body therapies, dance and movement therapy, yoga, and touch therapy. To schedule an appointment for these services, call 646-449-1010.

You can also schedule a consultation with a healthcare provider in the Integrative Medicine Service. They will work with you to come up with a plan for creating a healthy lifestyle and managing side effects. To make an appointment, call 646-608-8550.

#### **Nutrition Services**

#### www.msk.org/nutrition

#### 212-639-7312

Our Nutrition Service offers nutritional counseling with one of our clinical dietitian nutritionists. Your clinical dietitian nutritionist will talk with you about your eating habits. They can also give advice on what to eat during and after treatment. To make an appointment, ask a member of your care team for a referral or call the number above.

## **Rehabilitation Services**

#### www.msk.org/rehabilitation

Cancers and cancer treatments can make your body feel weak, stiff, or tight. Some can cause lymphedema (swelling). Our physiatrists (rehabilitation medicine doctors), occupational therapists (OTs), and physical therapists (PTs) can help you get back to your usual activities.

- Rehabilitation medicine doctors diagnose and treat problems that affect how you move and do activities. They can design and help coordinate your rehabilitation therapy program, either at MSK or somewhere closer to home. To learn more, call Rehabilitation Medicine (Physiatry) at 646-888-1929.
- An OT can help if you're having trouble doing usual daily activities. For example, they can recommend tools to help make daily tasks easier. A PT can teach you exercises to help build strength and flexibility. To learn more, call Rehabilitation Therapy at 646-888-1900.

## **Resources for Life After Cancer (RLAC) Program** 646-888-8106

At MSK, care does not end after your treatment. The RLAC Program is for patients and their families who have finished treatment.

This program has many services. We offer seminars, workshops, support groups, and counseling on life after treatment. We can also help with insurance and employment issues.

#### **Tobacco Treatment Program**

# www.msk.org/tobacco

212-610-0507

MSK has specialists who can help you quit smoking. For more information about our Tobacco Treatment Program, call 212-610-0507. You can also ask your nurse about the program.

## **Virtual Programs**

#### www.msk.org/vp

Our Virtual Programs offer online education and support for patients and caregivers. These are live sessions where you can talk or just listen. You can learn about your diagnosis, what to expect during treatment, and how to prepare for your cancer care.

Sessions are private, free, and led by experts. Visit our website for more information about Virtual Programs or to register.

## Radiation therapy support services American Society for Therapeutic Radiology and Oncology

#### www.rtanswers.org

800-962-7876

This website has detailed information about treating cancer with radiation. It also has contact information for radiation oncologists in your area.

#### **External support services**

There are many other support services to help you before, during, and after your cancer treatment. Some offer support groups and information, while others can help with transportation, lodging (a place to stay), and treatment costs.

For a list of these support services, visit www.msk.org/pe/external\_support\_services. You can also talk with an MSK social worker by calling 212-639-7020.

# **Contact information**

If you have questions or concerns, talk with a member of your radiation therapy team. You can reach them Monday through Friday from 9 a.m. to 5 p.m. at these numbers.

Radiation oncologist Phone number:	:
Radiation nurse: Phone number:	

After 5 p.m., during the weekend, and on holidays, call 212-639-2000. Ask for the radiation oncologist on call.

## Questions to ask your radiation oncologist

Before your appointment, it's helpful to write down questions you want to ask. Examples are listed below. Write down the answers during your appointment so you can review them later.

What kind of radiation therapy will I get?

How many radiation treatments will I get?

What side effects should I expect during my radiation

Will these side effects go away after I finish my radiation therapy?

What kind of late side effects should I expect after my radiation therapy?

## For more resources, visit www.mskcc.org/pe to search our virtual library.

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