Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Full Dose Total Body Irradiation

This information will help you get ready for full dose total body irradiation (TBI) 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 TBI. Use it as a reference in the days leading up to your treatments so that you can get ready as much as possible. Bring this resource to your simulation appointment and 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. You won't see or feel the beams.

Radiation therapy 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 TBI

TBI is radiation therapy that's given to your entire body. Many people have TBI before their stem cell transplant. TBI may be given for any or all of the following reasons:

- To destroy cancer cells in areas where chemotherapy can't easily reach

(such as your nervous system, bones, skin, or testes).

- To decrease the response of your immune system. If you're having an allogeneic stem cell transplant (getting bone marrow or stem cells from a donor), your body may see the cells as foreign. If this happens, your immune system will try to destroy them. Having TBI before your transplant can help keep this from happening.
- To create space for new bone marrow to grow (engraft).

You will be admitted to the hospital for your TBI treatment.

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.

Your simulation appointment

Before you start TBI, you will have a treatment planning procedure called a simulation. This is done to make sure that your treatment area is mapped out and you get the right dose of radiation. You will also have imaging scans and skin markings during this appointment.

Before your simulation appointment

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.

The day of your simulation appointment

On the day of your simulation appointment:

- Wear your hospital gown or comfortable clothes that are easy to take off.
- Don’t wear jewelry or metal objects (such as rings or hairpins).
- Don’t wear powders or lotions.

When you arrive for your appointment, 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 may 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.

Simulation

If you're not wearing a hospital gown, you will change into one. The temperature in the room is usually cool. Tell your radiation therapists if you're cold.

Your radiation therapists will help you lie down on the simulation table. Once your simulation starts, try not to move or speak, because these things may change your position. However, if you're uncomfortable or need help, tell your radiation therapists.

During your simulation, 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 may 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 speaking to each other as they work, and they will tell you what they're doing.

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

Imaging scans

You will have a chest x-ray and a CT scan to map your treatment area and plan your treatment. The scans won't be used for diagnosis or to find tumors.

- The chest x-ray will be done with a machine called a simulator. You will

be standing up during the scan. It will take about 20 minutes.

- The CT scan will be done in a different room. You will be laying down during the scan. It will take about 10 minutes.

During your imaging scans, you will hear the x-ray and CT machines turn on and off. Even if the noise seems loud, your radiation therapists will be able to hear you if you talk to them.

Skin markings (tattoos)

Your radiation therapists will draw on your skin with a felt marker. You can wash off the felt markings after your simulation.

You will also get permanent skin markings called tattoos. The tattoo marks are no bigger than the head of a pin. You will get 2 tattoos: 1 on your upper back and 1 on your upper chest.

Your radiation therapists will use a sterile needle and a drop of ink to make each tattoo. Getting them will feel like a pinprick. **The tattoos are permanent and won’t wash off.** If you’re concerned about having tattoos as part of your radiation treatment, talk with your radiation oncologist.

After the tattoos are made, your radiation therapists will take several photographs of you in your simulation position. The photographs and tattoos will be used to position you correctly during each of your treatments.

Appointment scheduling

Your radiation oncologist will plan your exact treatment schedule. A member of your radiation therapy team can give you more information. You can write notes in the space below.

You will have a total of 11 treatments over 4 days. This means you will have 2 to 3 treatments each day.

Your TBI treatments

A patient escort will bring you from your hospital room to your treatments.

- Wear your hospital gown or comfortable clothes. Don’t wear clothes with metal.
- You can keep your socks on, but you must take off your shoes or slippers.
- Don’t wear jewelry or metal objects (such as rings or hairpins). These may increase the radiation dose to that area.
- Don’t wear powders or lotions.

Before your first treatment, you will have a set-up procedure. Your set-up procedure and first treatment will take about 90 minutes. The rest of your treatments will take about 60 minutes.

Set-up procedure

If pain medication was helpful during your simulation, you may want to take it before this procedure.

You will stand in your treatment position for your set-up procedure. Special x-rays called beam films will be taken to make sure your position and the area being treated are correct. Beam films may also be taken before some of your other treatments. They aren’t used to see how your tumor responds to the treatment.

After your set-up procedure, you will have your TBI treatment.

Positioning

It’s important that you’re in the correct position during your TBI treatments. Your radiation therapists will help you.

- You will be positioned on a platform. You will stand over a seat that’s like a bicycle seat and place your hands on handles next to your hips (see Figure 1). Infants and very small children will be wrapped in a papoose board on a table.

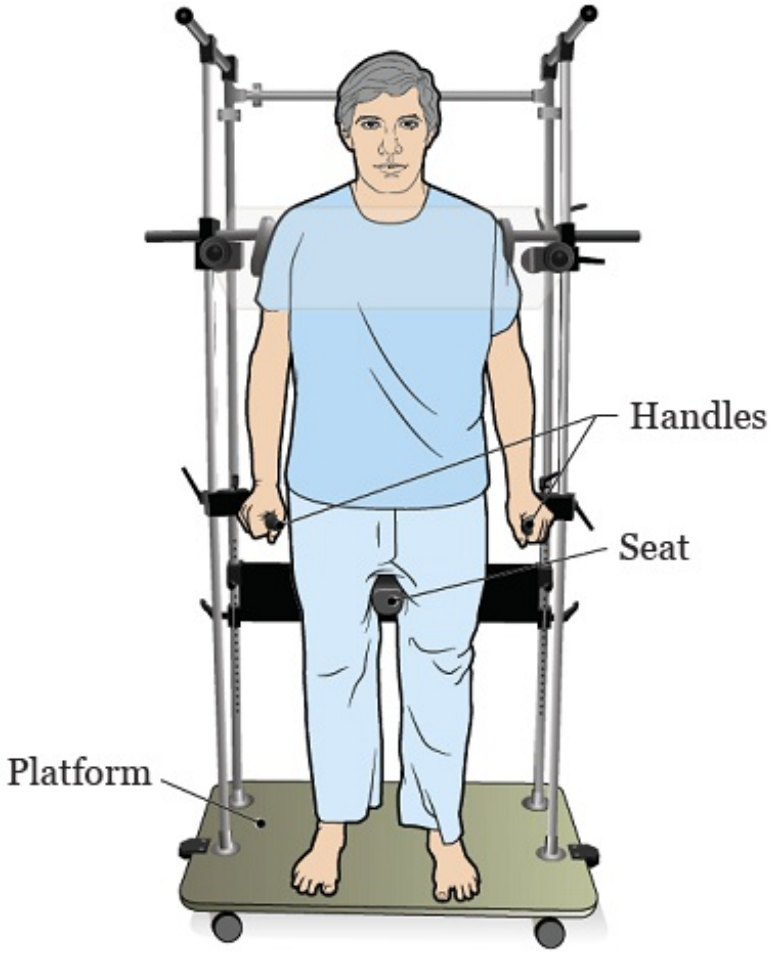

Figure 1. Treatment position for older children and adults

- Lung blocks will be placed on a board that hangs in front of your chest. They won’t touch your body. The lung blocks will lower the amount of radiation that your lungs receive. Your lungs are very sensitive to radiation and can’t get the same dose as the rest of your body.
- A large Plexiglass® screen will be placed in the front of your body. The Plexiglass will make sure that the radiation is evenly distributed.

You will face the machine for the first half of your treatment and will be turned away from it for the second half.

During your TBI treatments

Once you're in the correct position, your radiation therapists will leave the room, close the door, and start your treatment. You won't see or feel the radiation, but you may hear the machine as it moves around you and is turned on and off.

You will be alone in the room during your treatment, but your radiation therapists will 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.

Boosts and compensation

You may get extra doses of radiation to specific areas of your body.

- A boost is an extra dose of radiation given to an area that's included in the TBI treatment area. You may have boosts as an outpatient before you're admitted to the hospital for your regular TBI treatments.
- Compensation is an extra dose of radiation given to an area that wasn't included in the TBI treatment area. You will have lung blocks that cover your lungs during your treatments. To compensate (make up) for this, you will get 2 doses to the chest wall without the lung blocks.

Your inpatient care team

Any concerns you have during treatment will be managed by your inpatient team. Your inpatient team will contact your radiation therapy team, if needed. Tell your inpatient team if you have:

- Chills
- Painful, peeling, blistering, moist or weepy skin
- Any new or unusual symptoms

Weekly visits during treatment

Your radiation oncologist and radiation 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 _____.

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 them.

Vitamins and dietary supplements

Many people ask about taking vitamins during treatment. If you want to take a daily multivitamin, you can. Don't take more than the recommended daily allowance of any vitamin. Don't take any other vitamins or any supplements without talking to your doctor. This includes both nutritional and herbal supplements.

Side effects of TBI

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

Short-term side effects

The most common side effects happen days or weeks after your treatment and don't last very long. These include:

- Headache
- Nausea and vomiting
- Diarrhea

- Fatigue
- Skin reactions
- Bone marrow suppression (low blood counts)

Some people also have swelling of their salivary glands. This causes pain in front of their ear and in their jaw. This is a less common side effect.

Long-term side effects

Some side effects can happen months or years after your treatment and last for a long time. These include:

- Becoming sterile (not able to have a biological child). Your sexual function and pleasure won't be affected.
- Having lower amounts of thyroid hormones. Your doctor will check your thyroid hormone levels during your yearly check-ups. About half of people who have TBI will need thyroid supplements.

Other long-term side effects are rare but can happen. They include:

- Inflammation of the sac around your heart
- Inflammation of your lungs
- Cataracts
- New cancers

Managing side effects

Nausea, vomiting, and diarrhea

These side effects are worst during the first day of treatment. They usually start 1 to 2 hours after the first treatment. If you vomit, it usually happens less often as the treatment proceeds.

You may have diarrhea during the first few treatment days.

Tell your nurse if you have any symptoms. They may give you medication to help.

Skin and hair reactions

Your skin and hair in the treatment area may change. This is normal.

- After 2 to 3 weeks, your skin may become pink or tanned. Later in your treatment, your skin may become bright red or very dark.
- Your skin may feel dry, itchy, and look flaky.
- You may have a rash, especially in areas where your skin has been exposed to the sun. If this happens, tell your doctor or nurse. A rash can also be a sign of infection.
- You may lose some or all of the hair in the treatment area. The hair will usually grow back 3 to 6 months after you finish treatment.

Your skin will gradually heal after you finish treatment, but this often takes 3 to 4 weeks. Sometimes, skin reactions get worse during the week after you finish treatment. If this happens, call your radiation oncologist or nurse.

Your nurse will teach you how to care for your skin. They will apply special dressings (bandages) or creams, if needed. Follow the guidelines below to care for your skin during treatment. 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®, Dove®, baby soap, Basis®, or Cetaphil®). 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.
- The tattoo marks you got before your treatment are permanent and don’t wash off. If you got other markings during treatment (such as an outline of your treatment area with a purple felt-tipped marker), you can remove them with mineral oil when your radiation therapists say it’s okay.
- 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 TBI. 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 may suggest one for you.
- Don’t use more than 1 moisturizer at a time, unless your nurse tells you to use more.
- If you’re using a moisturizer, apply it to your entire body every night.

Avoid irritating your skin in the treatment area

- If your skin is itchy, don’t scratch it. Apply moisturizer. Ask your nurse for recommendations on how to relieve the itching. Your doctor or nurse may give you a prescription for medication to treat itchy skin.
- Wear loose-fitting cotton clothing and undergarments over the treatment area. 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 put tape on the skin in the treatment area.
- Don’t shave in the treatment area. If you must shave, use only an electric razor. Stop if your skin becomes irritated.
- 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 your skin as possible.

Fatigue

Fatigue is feeling tired or weak, not wanting to do things, not being able to concentrate, or feeling slowed down. You may develop fatigue after 2 to 3 weeks of treatment, and it can range from mild to severe. Fatigue will gradually go away after your treatment is done, but it can last for several months.

There are many reasons why you may develop fatigue, including:

- The effects of radiation on your body.
- Not having enough restful sleep at night.
- Not eating enough protein and calories.
- Having pain or other symptoms.
- Feeling anxious or depressed.
- Side effects of certain medications.

You may find that your fatigue is worse at certain times of the day. Below are suggestions to help you manage your fatigue.

Ways to manage fatigue

- If you’re working and are feeling well, keep doing so. However, working less may help you have more energy.
- Plan your daily activities. Think about the things you need to do or that are most important to you. Do these activities when you have the most energy.
- Plan time to rest or take short (10 to 15 minute) naps during the day, especially when you feel more tired. When you nap, try to sleep for less than 1 hour at a time.

- Try to sleep for 8 or more hours every night. This may be more sleep than you needed before you started radiation therapy.
  - Being active during the day can help you sleep better at night. For example, if you're able to exercise, you can go for a walk, do yoga, or ride a bike.
  - Relaxing before going to bed can also help you sleep better at night. For example, you can read a book, work on a jigsaw puzzle, listen to music, or do calming hobbies.
  - You may also find it helpful to go to sleep earlier at night and get up later in the morning.
- Ask family and friends to help you with things like shopping, cooking, and cleaning. Check with your insurance company to see if they cover home care services.
- You may have more energy if you exercise. Ask your doctor if you can do light exercise, such as walking, stretching, or yoga.
- Eat foods and drink liquids that are high in protein and calories. For information about eating during your TBI, read *Eating Well During Your Cancer Treatment* (www.mskcc.org/pe/eating_cancer_treatment).
- Ask your radiation oncologist or nurse for help with any other side effects you have. Pain, nausea, diarrhea, trouble sleeping, or feeling depressed or anxious, can increase your fatigue.

Sexual health

You may have concerns about how cancer and your treatment may 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.

The American Cancer Society has excellent resources that discusses sexual health issues during 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:

- Anxious or nervous
- Afraid
- Alone
- Angry
- Depressed
- Helpless
- Frustrated
- Numb
- Uncertain
- Worried

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.

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 may 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.

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.

Resources

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.

Female Sexual Medicine & Women’s Health Program
646-888-5076
Cancer and cancer treatments can affect your sexual health, fertility, or

both. Our Female Sexual Medicine & Women's Health Program can help with sexual health problems, such as premature menopause or fertility issues. We can help before, during, or after your treatment. Call for more information or to make an appointment.

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.

Male Sexual and Reproductive Medicine Program
646-888-6024
Cancer and cancer treatments can affect your sexual health, fertility, or both. Our Male Sexual and Reproductive Medicine Program can help with sexual health problems, such as erectile dysfunction (ED). We can help before, during, or after your treatment. Call for more information or to make an appointment.

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.

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.

External resources

American Cancer Society (ACS)
www.cancer.org
800-ACS-2345 (800-227-2345)
Offers a variety of information and services, including Hope Lodge, a free place for patients and caregivers to stay during cancer treatment.

American Society for Therapeutic Radiology and Oncology
www.rtanswers.org
800-962-7876
A group of radiation oncology professionals that specializes in treating patients with radiation therapy. Provides detailed information on treating cancer with radiation and contact information for radiation oncologists in your area.

Cancer*Care*
www.cancercare.org
800-813-HOPE (800-813-4673)
275 7th Ave. (Between West 25th & 26th streets)
New York, NY 10001
Provides counseling, support groups, educational workshops, publications, and financial assistance.

Cancer Support Community
www.cancersupportcommunity.org
Provides support and education to people affected by cancer.

National Cancer Institute (NCI) Cancer Information Service
www.cancer.gov
800-4-CANCER (800-422-6237)
Provides education and support to people with cancer and their families. Publications are available online and in print.

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 therapy?

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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