Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Managing Your Immunotherapy Side Effects

This information will help you manage the side effects from your immunotherapy.

Possible immunotherapy side effects

Your healthcare provider will go over this information with you and tell you which side effects you may have. You may have some, all, or none of these side effects.

Your nurse will write in the type of immunotherapy you got and the day you got it on the lines below:

You received _____ on _____.

You received _____ on _____.

About immunotherapy

Immunotherapy (IH-myoo-noh-THAYR-uh-pee) is different than chemotherapy. Immunotherapy is a form of cancer treatment that uses your immune system to attack cancer cells. This is similar to how it attacks bacteria or viruses. Immunotherapy can also cause the immune system to attack the body. This is what causes side effects. To learn how immunotherapy works in the body, watch the video Immunotherapy: How it Works.

Please visit www.mskcc.org/videos/immunotherapy-how-it-works to watch this video.

The side effects from immunotherapy treatment may be different from chemotherapy. To learn more about chemotherapy side effects, read *Managing Your Chemotherapy Side Effects* (www.mskcc.org/pe/managing-chemo-side-effects)

Fatigue

Please visit www.mskcc.org/pe/manage-fatigue-video to watch this video.

Fatigue is feeling more tired, weak, and like you have no energy. Fatigue from treatment can range from feeling a little tired to feeling extremely tired. Fatigue can start quickly or grow slowly over time. Fatigue may be caused by changes to the thyroid gland by immunotherapy. Your care team will check your thyroid levels to check for changes.

How to manage fatigue from immunotherapy

- If you feel tired, take a rest break. You can take short naps that are about 15 to 20 minutes long. Taking short naps will help with your fatigue throughout the day. Taking short naps will also help you sleep better at night.
- Try to be active to keep your energy levels up. For example, go for a walk outside or on a treadmill. People who do light exercise (such as walking), have less fatigue and can handle immunotherapy treatment better. To learn more about how to manage fatigue with exercise, read *Managing Cancer-Related Fatigue with Exercise* (www.mskcc.org/pe/fatigue-exercise)
- Plan tasks or activities on days and during times when you know you'll have more energy.
- Don't be afraid to ask for help. Ask your family and friends for help with tasks or activities that make you feel tired.
- Drink enough liquids. Drink 8 to 10 (8-ounce) glasses (or as directed) of non-caffeinated liquids every day. Water, juices diluted (mixed) with water, or liquids with electrolytes (such as Pedialyte®, Gatorade®, Powerade®, and other sports drinks) are good choices.

To learn more about how to manage fatigue, read *Managing Cancer-Related Fatigue* (www.mskcc.org/pe/managing-fatigue) and watch the video at the beginning of this section.

Diarrhea and immune-related (IR) colitis

Diarrhea is loose or watery bowel movements (poop), having more bowel movements than what's normal for you, or both. Immunotherapy can cause swelling or inflammation in the colon. This can cause diarrhea. When diarrhea is caused by immunotherapy it is called immune-related (IR) colitis (swelling of the large intestine).

How to manage diarrhea and IR colitis from immunotherapy

- Call your healthcare provider's office if you have more than 3 watery stools in a day. You should also call if your diarrhea starts to look different. For example, it can go from being in clumps to looking liquid and more watery.
- **Do not take any medicine to treat diarrhea without talking with your healthcare provider first.** Depending on the reason you're having diarrhea, taking medicine to stop it may be harmful. Your care team will give you a treatment plan based on your needs.
- Drink 8 to 10 (8-ounce) glasses of liquids every day. Make sure to drink both water and liquids with electrolytes (such as Gatorade, Pedialyte and broths).
- Call you healthcare team before taking any stool softeners or laxatives.
- Avoid:
  - Spicy foods (such as hot sauce, salsa, chili, and curry dishes).
  - High-fiber foods (such as whole-grain breads and cereals, fresh and dried fruits, and beans).
  - High-fat foods (such as butter, oil, cream sauces, and fried foods).
  - Drinks with caffeine (such as coffee, tea, and some sodas).
- Eat small amounts of soft, bland foods that are low in fiber. Examples are white bread, pasta, rice, and food made from white or refined flour. Eat your food at room temperature.

- You can try the BRATT (Banana, Rice, Applesauce, Tea, Toast) diet. This is not a long-term diet. This should be followed for 1 or 2 days. To learn more about the BRATT diet, read *BRATT Diet Phase 1* (www.mskcc.org/pe/bratt-1) and *BRATT Diet Phase 2* (www.mskcc.org/pe/bratt-2).

To learn more about how to manage diarrhea and what foods you should and shouldn't eat, read *Managing Diarrhea* (www.mskcc.org/pe/diarrhea).

Call your healthcare provider if you have:

- Changes in the way your bowel movements look or an increase in how many times you go.
- Pain and cramping in your belly, along with diarrhea.
- Irritation around your anus or rectum that does not got away. The anus is the opening where poop leaves your body. The rectum is a holding area for poop.
- Blood in your bowel movements.

Mucositis

Some immunotherapy can cause mucositis (myoo-koh-SY-tis). Mucositis is redness, swelling, tenderness, or sores in your mouth, or on your tongue or lips. Symptoms can start 3 to 10 days after your first immunotherapy treatment.

How to manage mucositis from immunotherapy

- Rinse your mouth every 4 to 6 hours, or more often as needed.
- Use a mouthwash that does not have alcohol or peroxide. They can make your sores worse. Use a mouthwash with no alcohol or sugar (such as Biotène® PBF Oral Rinse or BetaCell™ Oral Rinse).
- You can also make your own mouthwash solution. To make your own solution, mix 1 teaspoon of salt with 1 quart (4 cups) of water. You can also add 1 teaspoon of baking soda.
    - Swish the mouthwash or solution in your mouth. Gargle and swish well for 15 to 30 seconds. Then spit it out. Do not swallow it. If you swallow it by

mistake, that's OK.

- Use a soft toothbrush for your teeth and gums.
- Do not eat acidic (sour), salty, or spicy foods.
- Do not smoke or use tobacco products.
- Don't eat foods that are hot to touch.
- Keep your lips moisturized with a lip balm.
- Ask your healthcare provider if oral cryotherapy is an option for you. Oral cryotherapy is a procedure that uses extreme cold to reduce side effects.

Call your healthcare provider if you:

- Get mouth sores often.
- Have pain when eating or swallowing.
- Can't drink enough liquids to keep yourself hydrated (getting enough fluid in your body).

To learn more about how to manage mouth sores, read *Mouth Care During Your Cancer Treatment* (www.mskcc.org/pe/mouth-care).

Neuropathy (numbness or tingling in your hands and feet)

Some immunotherapies can affect the nerves in your hands or feet. You may feel numbness or tingling (slight stinging or poking feeling) in your fingers, toes, or both. This can last for a short time or for the rest of your life. Your healthcare provider can give you medicine to help ease your symptoms.

How to manage neuropathy from immunotherapy

- Exercise regularly.
- Quit smoking, if you smoke.
- Avoid drinking alcohol.
- Wear gloves and warm socks in cold weather.

- Be very careful to not burn yourself when using the stove, oven, or an iron. You may not be able to feel heat as much as you used to.
- Wear safe shoes. Safe shoes have:
  - Heels that are 1 inch (1.6 centimeters) or lower.
  - A way to close the shoe so that it stays on your foot (such as shoelaces or Velcro®).
  - Thin, hard soles.
  - Soles that prevent slipping.
  - A supported heel collar, which grips your heel firmly.
- Walk carefully if your feet are tingling or numb.
- Ask about getting acupuncture. Acupuncture is a form of treatment in traditional Chinese medicine. It's done by applying very thin needles to certain places on your body. To learn more, read *About Acupuncture* (www.mskcc.org/pe/about-acupuncture).

Call your healthcare provider if you have:

- Tingling and numbness that's getting worse.
- Trouble handling small objects (such as holding a pen or buttoning a shirt).
- Pain, burning, numbness, or tingling in your fingers, toes, or both.
- Trouble walking or feeling the ground when you walk.

To learn more about neuropathy, read *Neuropathic Pain* (www.mskcc.org/pe/neuropathic_pain), *About Peripheral Neuropathy* (www.mskcc.org/pe/about-peripheral-neuropathy), and *Managing Peripheral Neuropathy* (www.mskcc.org/pe/managing_peripheral_neuropathy).

Skin changes

Immunotherapy can cause changes to your skin. You may also have general skin changes, such as dryness, itchiness, and rash.

How to manage skin changes from immunotherapy

- Keep your hands and feet moisturized. Use fragrance-free creams or ointments such as:
  - Eucerin®
  - CeraVe®
  - Aquaphor®

Use more than once a day if needed. Your doctor may prescribe a steroid cream if you have a rash or itching.

- Avoid direct sunlight. Do not expose your scalp or body to the sun. Wear hats with wide brims, light-colored pants, and long-sleeved shirts.
- Use a sunscreen with an SPF of 30 or higher every day.
- Wear gloves when gardening, cleaning, or washing dishes.
- Wear loose-fitting and comfortable clothing.

Call your healthcare provider if:

- Your skin is peeling or blistering.
- You have a rash or itching.
- You have any new bumps or nodules (lumps) on your skin.

Immune-related (IR) side effects

Immunotherapy uses your immune system to attack cancer cells. It can also cause your immune system to attack healthy cells. There is a group of side effects you may get from immunotherapy called immune-related (IR) side effects

Immune-related (IR) side effects can happen right away or up to 2 years after treatment ends.

If you have any of the side effects listed in this section, call your healthcare

provider right away. They may stop or pause your treatment to treat these side effects. You will need lab work (such as blood tests) so your care team can monitor your symptoms.

Immune-related (IR) side effects	Signs and symptoms
Pneumonitis (NOO-moh-NY-tis) (inflammation of lungs)	• New or worsening cough (dry or with phlegm). • Shortness of breath (with activity or at rest). • Chest pain. • Swelling in the hands or feet.
Arthralgia (ar-THRAL-juh) (joint pain) and myalgia (my-AL-juh) (muscle pain)	• New, changed, or increased pain at joints or muscles. • Stiffness (hard to move) at joints. • Swelling at joints or limbs.
Hepatitis (HEH-puh-TY-tis) (inflammation of the liver)	• Jaundice (yellowing of skin). • Severe nausea (feeling like you're going to throw up). • Severe vomiting (throwing up). • Pain in the right side of your stomach area. • Drowsiness, falling asleep. • Tea-colored urine (pee). • Bleeding or bruising anywhere on your body. • Feeling less hungry than usual.
Colitis (koh-LY-tis) (inflammation of the colon)	• Diarrhea (loose stools) or more bowel movements than normal. • Blood in stool or black, tarry, or sticky stool. • Severe abdominal pain, cramping, or tenderness.

Hormone or gland problems, especially the thyroid, pituitary, and adrenal glands and the pancreas	• Headaches that will not go away. • Extreme tiredness. • Weight gain or weight loss. • Dizziness or fainting. • Changes in mood or behavior such as decreased sex drive, irritability, or forgetfulness. • Hair loss. • Feeling cold. • Constipation (having fewer bowel movements than usual). • Voice getting deeper. • Feeling more thirsty than usual. • Urinating (peeing) more often than usual. • Abdominal (belly) pain.
Uveitis (YOO-vee-I-tis) (eye and vision problems)	• Blurry vision, double vision, or other vision problems. • Eye pain or redness. • Seeing floating objects in your vision (floaters). • Photophobia (sensitivity to light). • Headaches. • Eye infections.
Meningitis (MEH-nin-JY-tis) or encephalitis (en-SEH-fuh-LY-tis) (inflammation of the brain). This is a very rare and serious side effect.	• Headaches. • Fever. • Confusion or memory problems. • Hallucinations (seeing or hearing things that are not there). • Severe muscle weakness. • Extreme sensitivity to light. • Neck stiffness.

New medicines or changes in your current medicine

It is important for you to talk with your care team before you start any new medicine. This includes:

- medicines prescribed by other providers outside of your care team.
- Any type of steroid treatment or steroid medicine.
- Over-the-counter medicine (medicines you get without a prescription).
- medicines you may take other than by mouth, such as topical (medicine you put on your skin) or injectable medicines. You may get some of these medicines from other providers.
- Any vitamins, dietary supplements, and herbal remedies.

You may need to stop taking certain medicines before starting immunotherapy. Some medicines may affect your treatment.

How can I lower my risk of infections?

How to manage

- Don’t be near people who are sick.
- Wash your hands with soap and water for at least 20 to 30 seconds.
- Cover all parts of your hands with an alcohol-based hand sanitizer. Rub your hands together for 20 to 30 seconds, or until they’re dry.
- Remember to always clean your hands with soap and water for at least 20 seconds or using an alcohol-based hand sanitizer (such as Purell®).
    - Before eating a meal.
    - After touching something that may have germs (such as after using the bathroom, touching a doorknob, or shaking hands).
- Do not eat raw or undercooked meat, poultry, seafood (including sushi), eggs, and meat substitutes (such as tempeh and tofu).

Call your healthcare provider if you:

- Have a fever of 100.4 °F (38 °C) or higher.
- Are shaking or have chills.
- Start to get other signs or symptoms of infection, such as:
  - Redness, swelling, warmth, or pus near an injury, surgical wound, or at a catheter insertion site.
  - A new cough.
  - A sore throat.
  - A burning feeling when you urinate (pee).

To learn more about ways to keep from getting an infection, read *Hand Hygiene and Preventing Infection* (www.mskcc.org/pe/hand-hygiene)

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

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

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