



Patient Guide to Immunotherapy and Immune Checkpoint Inhibitors

Fig. 1: T cell turned off by cancer cell

Like a shield, PD-L1 on the cancer cell binds to PD-1 on the T cell, stopping the T cell from killing it.

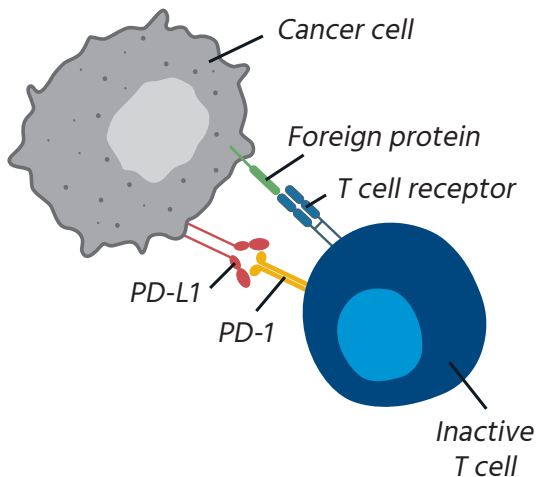
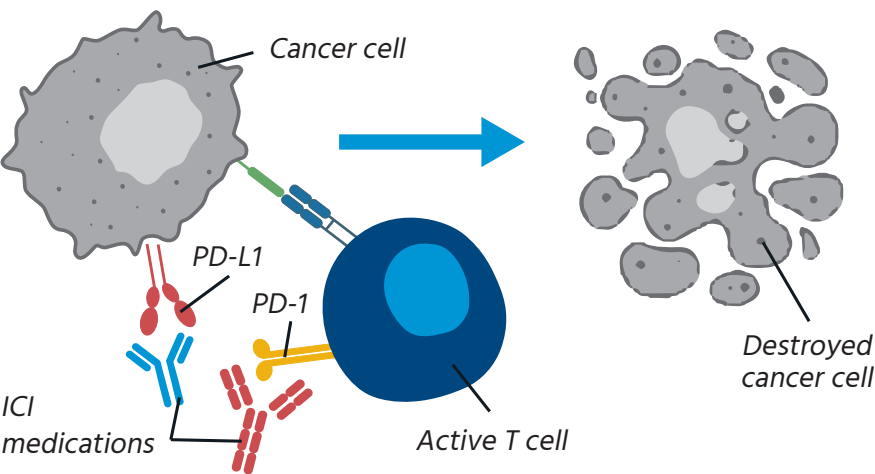


Fig. 2: T cell restarted with immune checkpoint inhibitor

Blocking PD-1 or PD-L1 with ICI medications allows T cells to recognize and kill tumor cells.



The Immune System and Cancer

The role of the immune system is to defend the body against microorganisms (bacteria, viruses, fungus) and cancer cells. Specialized immune cells (T cells) learn, remember and destroy foreign proteins found in our bodies (antigens).

Our immune systems recognize and eliminate many cancers, but some can trick our T cells into turning off. When T cells are turned off, some cancer cells can reproduce undetected (left, fig. 1).

Immunotherapy Basics

To avoid damage to healthy cells natural markers on our T cells, called immune checkpoints, help regulate our immune system. Cancer cells hijack these markers to turn our T cells off when they try to attack a cancer cell.

We use immunotherapies like immune checkpoint inhibitor (ICI) medications to restart our T cells, so they attack the cancer cells (left, fig. 2).

ICI Side Effects

Sometimes ICIs not only cause the immune system to attack cancer but can also cause it to attack healthy organs and tissues. This leads to side effects. Side effects from ICIs are very different from side effects of other medications. They can occur at any point during or after stopping treatment (even beyond a year).

Along with monitoring specific things during treatment such as liver function, kidney function, electrolytes, thyroid function, and blood counts, you and your oncologist should also be monitoring for signs and symptoms of ICI side effects.

Managing ICI side effects

Ochsner oncologists are very familiar with monitoring and treating ICI side effects. Fortunately, most go away with pausing therapy and/or treating them with medicines to tone down the immune system. Most can be treated with short courses of steroids, although certain side effects require specific treatments.

Most patients tolerate ICIs well. However, when side effects do occur, they must be addressed. Without appropriate treatment, severe immune-related side effects can be fatal.

What to know about ICI side effects

In this booklet you will find some ways to deal with the most common ICI side effects. There are also some rare and more dangerous side effects. That is why it's important to let your cancer care team know of any new symptoms right away.



Levels Of ICI Side Effects

- **Grade 1 (mild):** Usually treated without interrupting or discontinuing treatment
- **Grade 2 (moderate):** You may need to skip one or more treatments and take steroids if side effects persist.
- **Grade 3 (severe) or Grade 4 (very severe):** Your treatment is typically discontinued, and steroids started. You will likely be referred to a specialist for further care, for example to a dermatologist for severe rash, or to a gastroenterologist for severe diarrhea.

Common Immune-Related Side Effects

Fatigue

Fatigue is a common side effect in cancer patients. It can be from ICI treatment or as a result of the cancer. Fatigue from ICIs is often mild and usually improves with future treatments, but it can also be a symptom of a more serious ICI side effect.

- Fatigue is common within the first month of ICI therapy.
- **If the fatigue is severe or gets worse, contact your cancer team right away.** Your oncologist may want to order additional blood work.
- Severe fatigue that occurs with low blood pressure, cold or heat intolerance, weight changes, or electrolyte imbalance could be a sign of inflammation in your endocrine organs (thyroid gland, pituitary gland, adrenal gland, etc.). Sometimes this combination of symptoms requires replacement of specific hormones and expert care from an endocrinologist.

Rash

Rashes are a common side effect from ICIs. Usually these are mild, however more serious skin problems can occur.

- Along with fatigue, rashes are one of the earliest side effects to appear (2-5 weeks after your first ICI treatment).
- The most common rashes can be red, scaly, and itchy. Sometimes they can cause vitiligo (a loss of skin color) or even look like psoriasis.
- Rashes usually go away with prescription steroid ointments or creams. Your provider may recommend non-steroid pills to control itching.
- If a rash develops over a significant portion of your body, blisters, or develops inside your mouth or nose, you may need specialty care from a dermatologist. Talk to your cancer care team.

Diarrhea

Diarrhea from ICIs occurs when the immune system attacks your colon causing inflammation inside your intestine, also known as colitis. Colitis is the most common serious side effect from ICIs and can include diarrhea (most common symptom), nausea, blood or mucous in your stool, or abdominal cramping/pain.

- Colitis usually occurs 5-10 weeks after the first dose of ICIs but can occur at any time.
- **If you develop diarrhea with four or more watery bowel movements over a 24-hour period, contact your cancer care team immediately.**
- You may have to provide a stool sample to rule out infection. You may also receive steroid treatments, either by pill or by IV (in a vein) in the hospital.
- **If the diarrhea is not resolving after 3 days of steroid treatment, be sure to contact your oncology team again.** There are other very effective treatments that target the immune system in the colon if steroids are not working.

- Colitis from ICIs responds very well to immunosuppressive therapies if we start them early.
- Tell your cancer care team right away if you have any symptoms of colitis. Uncontrolled inflammation can lead to perforation of the bowel and can even be fatal.

Trouble Breathing

Inflammation of the lungs, also called pneumonitis, is another serious potential ICI side effect that can be fatal if left untreated.

- Pneumonitis is not as common as colitis but does occur in 4-7% of patients.
- Contact your cancer care team if you have shortness of breath, cough, chest pain, or low oxygen level, or if these symptoms get worse.

Joint or muscle problems

Inflammation in the joints (arthritis) or muscles (myositis) from ICIs can lead to body aches, muscle weakness, and joint stiffness.

- Arthritis is common and usually improves with steroids or other anti-inflammatory treatments.
- A rheumatologist may prescribe other medications if you are unable to wean off steroids.
- Myositis is rarer but can be more severe and can happen with other nerve-related or heart-related side effects. These sometimes mean you will be admitted to the hospital. Talk to your cancer care team if you have muscle pain. More severe effects can be ruled out with a routine blood test (CK levels). Your provider may recommend more aggressive treatment than steroids for myositis.

Nerve-related problems

Nerve-related, or neurologic, complications from ICIs are rare but can be severe. These side effects occur in less than 1% of patients but they can be fatal and often require more aggressive treatment than just steroids.

- Pay attention to any weakness, vision changes, numbness/tingling, altered behavior, confusion, memory impairment, speech changes, or seizure.

Vision or eye issues

ICIs can sometimes affect the eyes. These side effects range from dry eyes to severe inflammation that may cause changes to your vision.

- Contact your cancer care team or an eye doctor (an ophthalmologist, not an optometrist) if you develop dry/red eyes, vision changes, eye pain, pain with bright lights, or floaters. These require care by an ophthalmologist, but usually can be treated with eye drops.

Other issues

Patients taking ICIs may have inflammation anywhere in the body. This inflammation can cause potential side effects beyond those described in this booklet.

Talk to your cancer care team right away if you experience or are diagnosed by another provider with any of the following:

- Dry mouth
- Type 1 diabetes
- Sarcoidosis
- Infusion reactions
- Acute kidney injury
- Nephritis (inflammation of the kidney)
- Myocarditis (inflammation of the heart)
- Low blood counts

Talk To Your Cancer Care Team

Immunotherapy side effects are unpredictable and can be severe or even fatal. If your health changes in any way after ICI treatment, contact your oncologist or nurse through MyOchsner or MyChart, or by calling the clinic at 504-842-3910.

Let us know if you need help setting up a MyOchsner or MyChart account. Ask at your next appointment or contact MyOchsner Support at 1-877-339-2637.



Medications

Before starting immunotherapy, talk to your oncologist about all of your medications. Drugs for conditions such as psoriasis, lupus, certain types of arthritis, Crohn's disease, multiple sclerosis, and other autoimmune disorders can interact or interfere with your immunotherapy.



Be sure to tell your other providers that you are receiving immunotherapy before taking new prescriptions or over-the-counter medicines.

Other medications can also affect the immune system. This includes steroids, such as cortisone, prednisone, dexamethasone or related drugs.

New medications or changes in current medication

Before starting any new medication, it is essential to discuss it with your care team. This includes

- **Steroid Treatments:** Any type of steroid medication.
- **Over-the-Counter Medications:** This includes items such as probiotics and medications for acid reflux.
- **Vitamins and Supplements:** Any vitamins, dietary supplements (including mushroom extracts), and herbal remedies.

Call the clinic at 504-842-3910 or ask your pharmacist if you have any questions or concerns.

Diet Recommendations

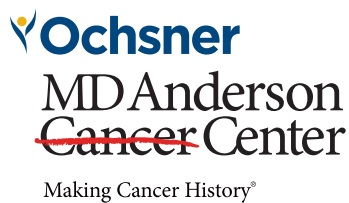
- **High-Fiber Diet:** Consider following a high-fiber diet, such as the Mediterranean diet.
 - **Alcohol Intake:** Limit your alcohol consumption.
 - **Sugar Alternatives:** Avoid low-calorie sweeteners such as sucralose, aspartame, and saccharin.
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Sexual Activity and Contraception

Patients of childbearing potential should use effective birth control during and for at least 5 months after the final dose of immunotherapy. The effect of immunotherapy on human reproductive function is unknown.

What to Expect on Treatment Day

- **Location:** Immunotherapy treatments are given in the infusion center. The specific location may vary, so please refer to your appointment confirmation for details. These medications will be given by a certified Immunotherapy/Chemotherapy nurse.
- **Medication Preparation:** Medications are typically prepared when you arrive at the infusion center. Please be aware that delays may occur due to pharmacy mixing times or if you are late to your appointment.
- **Daily Medications:** Please take all prescribed daily medications unless instructed otherwise.
- **Eating and Drinking:** Fasting is not necessary on the day of your treatment. You may eat or drink during your infusion and can bring food or drinks from outside. Snacks like chips, cookies, juices, and soup are available for patients only.
- **Visitors:** You are allowed one visitor during your infusion. The visitor must be 18 or older, show no signs of illness, and stay with you to respect the privacy of other patients.
 - You have the right to choose who may visit you and can change your mind at any time.
 - Visitors not following Ochsner safety guidelines may be asked to leave the infusion center and could lose visiting privileges.
 - Infants and children under 18 years old are not allowed in the infusion center.
- **Noise Levels:** Please be mindful of noise levels. You are welcome to bring laptops, tablets, or books for entertainment; headphones are encouraged.
- **Smoke-Free Environment:** All Ochsner facilities are smoke-free. Smoking indoors is not allowed.



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