Utah Hematology Oncology
OGDEN CLINIC

IMMUNOTHERAPY
EDUCATION
PACKET

Contents

Meet Your Care Team

You are now part of a team. Some patients consider us family, others call us part of their support team—we are honored to be called both. One of our goals is to help you to be prepared to manage any side effects of your therapy and disease, both physically and mentally. Communication is important: we can't help problems we're unaware of. Please feel free to ask questions and tell us your concerns. This is a vital part of your treatment.

Care Team Directory

Oncologists/Hematologists	Dr. Carl Gray and Dr. Joshua Ramsay
Our Nurse Practitioners & Physician Assistants	Alicia Skaggs, PA-C; Lynn Larsen, NP-C; Kylie Money, PA-C; Kelly Mikesell, PA-C; Skyler Nicholas, FNP-BC
Registered Oncology Nurses	They administer chemotherapy and immunotherapy, assist in education, help manage side effects, and will answer your questions about your diagnosis and treatment.
Receptionists & Schedulers	They greet you when you arrive and help schedule your appointments.
Billing Office	They assist with billing and insurance issues and can be reached at 801-689-3900 or at Ogden Clinic's main billing line, 801-475-3500.
Patient Financial Specialist	They are onsite and able to answer your questions. Please use the main phone line at 801-476-1777 and select your provider's medical assistant from the phone menu.

Directory for Medical Needs & Questions

Medication Refills	Call our main line at 801-467-1777 and select your provider's name from the phone menu. Please have the bottle with you when you call to ensure the correct strength and dosage. Please do not wait until you are completely out before calling for a refill. If possible, have refills completed at your doctors' visit. Once you have left a request, please allow 48-72 hours for refill processing and call the pharmacy. If you want to check the status of your request, please contact the pharmacy.

Questions & Concerns	Call our office at 801-476-1777 Your calls are important to us and we will do our best to answer them promptly. If you are asked to hold, please know we are assisting other patients. If you cannot hold, please leave us a message.
Questions after-hours & urgent needs	If you need to reach us after hours or in case of an emergency, please use the main phone line at 801-476-1777 Be aware that we use an on-call provider during non-business hours. If no one is picking up the phone, you may leave us a message which will be automatically sent to our team. We will call you back as soon as we are able.
Patient Portal (lab results, notes, etc.)	You'll soon receive an email to register for our eCW Patient Portal. Once set up, you can always refer to this portal for lab results and other information.
Appointments Going Forward	Please check in at the receptionists' desk at least five minutes before your appointment. They will give you further instructions. If blood needs to be drawn, a lab tech phlebotomist from our lab may draw it or if you have a port it may be an RN, or if you just need a CBC or PT/INR the MA will draw it. We recognize your time is just as valuable as ours. Keep in mind that you may not be called back in the order that you arrive as there are multiple schedules going on.
Our Website	utahhemonc.com

About Clinical Trials at UHO

Clinical Trials-Community Cancer Trials of Utah (CCT), LLC is an independent, community practice-based research organization intended to provide cancer patients with access to high-quality clinical trials in their own community, away from the stresses, inconveniences and high cost of an academic medical center or hospital-based system. (CCT) is affiliated with Utah Hematology Oncology, PC and CCT's activities are conducted in cooperation with UHO's providers and staff and at UHO facilities. Your providers are in the best position to determine whether or not a specific trial is right for any given patient. While it may be appropriate to enquire about one of our trials for your condition, participation may not be a possibility due to defined selection criteria.

Cancer Goals and Treatment

Cancer is the uncontrolled growth and spread of abnormal cells in your body. Normal cell growth is usually controlled. Cancer cell growth is not only uncontrolled, but the cells that are growing and dividing are abnormal. Cancer cells divide more frequently and live longer than normal cells.

Cancer does not always present itself as a tumor. Some types of cancer cells circulate in our blood or lymphatic fluids. They create problems by taking up space that should be occupied by normal blood or lymph cells. These are cancers like leukemia or lymphoma. Biopsies or specific blood tests are often necessary before a diagnosis can be confirmed.

The smallest clinically detectable mass or tumor has at least 10 billion cells. This is why even after we no longer see cancer, treatment may continue for a period of time. A person who has had cancer is considered to be in remission when there is no evidence of that disease for at least five years.

There are more than 100 different types of cancer. Approximately one in three people will have a type of cancer at one time in their lives. Four out of 10 people with cancer will be cured.

Goals of Treatment

Three possible goals with Immunotherapy treatment are:

- Cure: Absence of disease
- Control/Maintain: To prevent further spread of disease
- Palliation: Relief of symptoms produced by cancer

What is the immune system?

The immune system consists of cells, tissues, and organs in the body which protect it from infection and some diseases. It is a very complex system where the different parts work together to identify and kill:

- organisms that invade the body such as bacteria and viruses
- abnormal cells that develop in the body such as cancer cells.

The immune system recognizes these organisms or abnormal cells as being different to normal healthy cells. It then tries to kill or destroy them through a series of events known as an immune response.

The immune system and cancer

The role of the immune system is to defend the body against threats, including microorganisms (bacteria, viruses, fungi), and cancer cells.

After the physical/chemical barriers of the body, the next line of defense comprises white blood cells **(leucocytes)** that look for, and attack, microorganisms or abnormal cells (including cancer cells).

- T cells are white blood cells that play an important part in our immune response, in which each T cell learns, remembers, and is specific to a particular antigen. T cells are activated via a "lock and key" mechanism enabling them to recognize, attack and kill cancer cells.

Even though the immune system can recognize and kill some cancer cells, it can't always stop cancers from developing. Cancer may develop when the immune system is:

- unable to find cancer cells
- not strong enough to kill the cancer cells it finds
- tricked by the cancer cells to stop the immune system recognizing them.

Details about Immunotherapy Treatment Options

What is immunotherapy and how does it work?

Immunotherapy (also known as biological therapy) is a treatment that uses a person's own immune system to fight cancer. It uses drugs to change how the immune system works and help it to find and attack cancer cells. It can be administered via mouth as tablets or capsules, through a drip into a vein, by injection under the skin or into a muscle.

There are several types of immunotherapy drugs that work in different ways:

- **Monoclonal antibodies:** help the immune system recognize and attack cancer cells
- **Immunomodulators:** boost the immune system to be more active
- **Immune checkpoint inhibitors:** remove the barriers to the immune system and increase its ability to fight the cancer. These drugs basically take the 'brakes' off the immune system, which helps it recognize and attack cancer cells.
- **Angiogenesis inhibitors:** block the growth of new blood vessels to tumors (a process called tumor angiogenesis). A blood supply is necessary for tumors to grow beyond a certain size because blood provides the oxygen and nutrients that tumors need for continued growth.

Treatments that interfere with angiogenesis may block tumor growth. Some targeted therapies that inhibit angiogenesis interfere with the action of vascular endothelial growth factor (VEGF), a substance that stimulates new blood vessel formation. Other angiogenesis inhibitors target other molecules that stimulate new blood vessel growth.

- **CAR T-cell therapy:** takes some of the patient's immune cells (T-cells) and changes them so they will attack the cancer

Immunotherapy side effects:

- usually occur within the first 12 weeks of treatment but can happen at any time, even after treatment has finished
- may affect any part of the body
- may be mild but can get worse quickly and become severe

General side effects:

- Feeling more tired and confused
- Difficulty sleeping
- Feeling shivery or cold
- New or persistent headaches
- Feeling dizzy or lightheaded
- Change in your appetite
- Changes in your mood
- A loss or gain in weight
- Eyes become red or watery
- Pins and needles; leg weakness; issues with walking

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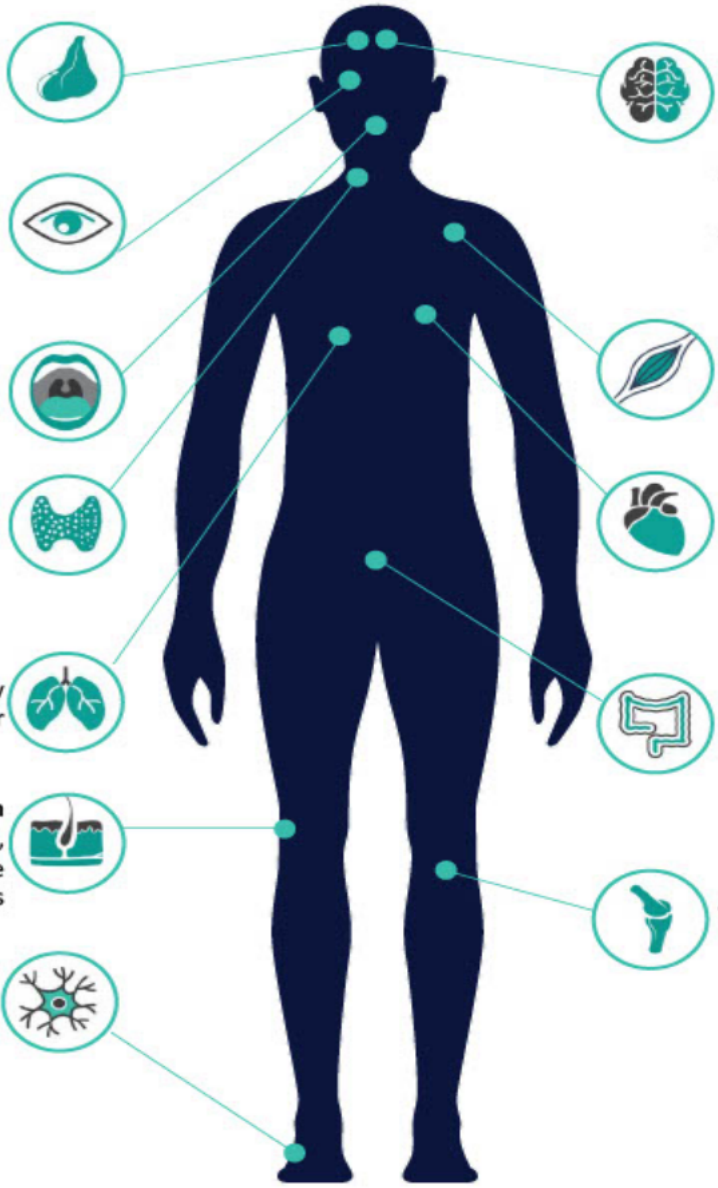
Immunotherapy Side Effects

Immune checkpoint inhibitors (a type of immunotherapy) offer a promising new way to treat certain cancers. But these medicines can cause your immune system to attack normal organs and tissues in your body, affecting the way they work. Serious side effects typically occur in less than 5% of patients, but certain mild side effects can occur in up to 30% – 50% of patients.

Contact your health care provider right away if you think you may be experiencing ..



Pituitary gland
Low cortisol causing fatigue, loss of appetite, muscle weakness

Eyes
Blurred or distorted vision, blind spots, eye pain or redness, itchy or bulging eyes, new floaters

Mouth
Dry mouth, pain or burning, sores, changes in taste

Thyroid gland
Weight loss or gain, rapid heartbeat, fatigue, sweating, anxiety, constipation, dry skin, sensitivity to cold

Lungs
Shortness of breath, dry cough, chest pain, fever

Skin
Rash, itching, blisters, psoriasis, reddish-purple bumps and patches

Nerves
Numbness or tingling in hands or feet; unusual weakness in legs, arms, or face

Brain or spinal cord
Confusion, changes in behavior, headaches, seizures, short-term memory loss, problems speaking or reacting, sensitivity to light, neck stiffness, sensory problems, pain, fever, nausea or vomiting

Muscles
Muscle weakness, aches, pain, or stiffness

Heart
Fatigue, chest pain or pressure, irregular heartbeat, shortness of breath, swollen legs, ankles, or feet

Bowel Watery stools, cramping, urgency, stomach-area pain, fever, blood or mucus in stool, nighttime bowel movements

Joints Joint pain or swelling, stiffness after rest, improvement with activity

Pituitary Gland–Related Side Effects of Immunotherapy

When immunotherapy causes the immune system to attack the pituitary gland, a condition called **hypophysitis** can occur. Because the pituitary gland is the "master gland" that controls most of the body's hormones, its inflammation can lead to a wide range of symptoms. Common side effects:

- Persistent headaches
- Visual changes
- Extreme fatigue
- Profound weakness
- Low blood pressure
- Dizziness when standing
- Changes in mood or mental clarity

Managing these side effects focuses on replacing the hormones that the pituitary gland is no longer producing. Unlike some other immunotherapy side effects, pituitary damage is often permanent; meaning long-term hormone replacement therapy such as thyroid medication, testosterone or estrogen, or daily steroid pills (hydrocortisone) is typically required. In the early stages of inflammation, doctors may prescribe high-dose steroids to reduce swelling and manage acute symptoms like severe headaches.

Monitoring

What to Watch For	**Immediate Actions**
Severe or unusual headaches	Notify the oncology team immediately.
Extreme fatigue or "crashing"	Do not skip doses of prescribed hormone replacements.
Dizziness or fainting	Carry a medical alert card identifying you have adrenal insufficiency.
Visual blurring or loss	Seek urgent evaluation to check for gland swelling.

Ocular Changes

Immunotherapy can sometimes cause the immune system to affect the eyes, leading to inflammation or changes in vision. While these side effects are less common than skin or digestive issues, they require prompt attention to protect your eyesight. The most common "eye changes" are:

- **dry eye syndrome**: where the eyes feel gritty, itchy, or irritated
- **uveitis:** serious inflammation inside the eye

- **episcleritis**: redness on the white of the eye

Watch for blurred or distorted vision, new "floaters" (spots moving in your field of vision), or increased sensitivity to light (photophobia). You might also notice redness, pain, or a change in how you see colors. Because some of these symptoms can overlap with common eye strain, it is vital to report any *new* or *worsening* eye symptoms to your oncology team right away, as early treatment is the best way to prevent permanent vision loss.

Management & Self-Care

Issue	**Management Strategy**	**What You Can Do**
Dry / Gritty Eyes	Artificial tears or prescription drops (like cyclosporine) to restore moisture.	Use preservative-free artificial tears; avoid rubbing your eyes.
Inflammation (Uveitis)	Steroid eye drops or, in more severe cases, oral steroids or local injections.	Wear sunglasses outdoors to reduce pain from light sensitivity.
Vision Changes	Referral to an **ophthalmologist** (eye MD) for a specialized exam.	Keep a log of when the changes started and if they affect one or both eyes.
Red/Swollen Eyelids	Warm compresses and eyelid hygiene.	Use a clean, warm, damp cloth on closed eyes for 15 minutes twice daily.

Oral Changes

Mouth changes from immunotherapy—often called **oral immune-related adverse events**—happen when the treatment causes the immune system to target the lining of the mouth or the salivary glands. This most commonly presents as **mucositis** (painful mouth sores) or **xerostomia** (dry mouth). Unlike chemotherapy sores, which usually appear and heal in a predictable cycle, immunotherapy mouth changes can appear at any time during treatment and may persist if not managed with the help of your oncology team.

You may notice white or red patches on the tongue or inner cheeks, a burning sensation when eating, or changes in how food tastes (such as a metallic or "off" flavor). If the salivary glands are affected, the mouth may feel sticky or "cottony," making it difficult to swallow dry foods like crackers or bread. Early intervention is key to preventing these symptoms from interfering with your ability to eat and drink.

To help keep your mouth clean, neutralize acids, and soothe any sensitivity that may develop during your immunotherapy treatment, we recommend using a gentle salt and soda rinse throughout the day.

The "Baking Soda & Salt" Rinse Recipe

- **1 teaspoon** of salt
- **1 teaspoon** of baking soda
- **1 quart (4 cups)** of warm water

- *Instructions:* Swish and spit every few hours. Do not swallow.

Management & Oral Comfort Strategies

Symptom	**Patient Action**	**Clinical Management**
Mouth Sores	Use a "Baking Soda & Salt" rinse 4–6 times a day. Avoid alcohol-based mouthwashes.	Your doctor may prescribe a "Magic Mouthwash" or topical steroid gels.
Dry Mouth	Sip water frequently and use sugar-free gum or lozenges to stimulate saliva.	Saliva substitutes or prescription stimulants may be used for severe dryness.
Taste Changes	Experiment with different flavors; if meat tastes metallic, try plastic utensils.	Most taste changes resolve after treatment, but keeping the mouth clean helps.
Oral Thrush	Watch for a "cottage cheese" coating on the tongue or redness.	This is a fungal infection and requires a prescription antifungal rinse or pill.

Thyroid Changes

Thyroid changes are among the **most common** side effects of immunotherapy. The immune system can cause the thyroid gland to become overactive (**hyperthyroidism**) or, more frequently, underactive (**hypothyroidism**). Often, individuals will go through a brief phase of an overactive thyroid before the gland slows down permanently. Because the thyroid regulates your body's "metabolism," these changes can make a you feel like your internal engine is either racing or stalling.

While these symptoms can be bothersome, they are highly treatable. Unlike some other side effects, thyroid issues rarely require stopping immunotherapy; instead, they are managed by balancing hormone levels with medication.

Symptoms to Monitor

Underactive Thyroid (Hypothyroidism)	**Overactive Thyroid (Hyperthyroidism)**
Feeling unusually cold all the time	Feeling shaky or having tremors
Weight gain despite no change in diet	Rapid or "fluttering" heartbeat (palpitations)
Extreme fatigue and sluggishness	Unexplained weight loss
Dry skin and brittle hair	Increased sweating or heat intolerance
Depression or "brain fog"	Anxiety, irritability, or trouble sleeping

Management of Thyroid Changes

1. **Routine Blood Work:** We will monitor **TSH (Thyroid Stimulating Hormone)** and **Free T4** levels checked before every infusion. Often, the blood work will show a problem before symptoms are even felt.
2. **Hormone Replacement:** If the thyroid becomes underactive, a daily pill (such as **Levothyroxine**) is prescribed to replace the missing hormone. This is usually a lifelong medication.
3. **Symptom Control:** For an overactive thyroid, doctors may prescribe "beta-blockers" to slow a racing heart or decrease tremors until the inflammation settles.
4. **Consistency:** Take thyroid medication on an **empty stomach**, typically 30–60 minutes before breakfast, to ensure it is absorbed correctly.

Lung Changes

When immunotherapy causes the immune system to attack the lungs, it results in an inflammation called **pneumonitis**. While it is less common than other side effects, it is considered one of the most important to catch early because lung inflammation can interfere with oxygen levels quickly.

Pneumonitis often starts subtly. The most common signs are a **new or worsening cough** (usually dry and hacking) and **shortness of breath** that feels out of proportion to activity level. For example, you might notice you are winded just walking to the mailbox or climbing a few stairs that used to be easy. Some patients may also experience chest pain or a low-grade fever.

Monitoring & Management

Because lung symptoms can mimic a common cold, the flu, or even COVID-19, it is vital that you report *any* new respiratory symptoms to the oncology team immediately rather than waiting for your next infusion.

Symptom Severity	Typical Management	Patient Instructions
Mild (Grade 1)	May hold immunotherapy and monitor closely with repeat scans.	Report even a "slight" cough; don't assume it's just allergies.
Moderate (Grade 2)	Immunotherapy is held. Steroids (like Prednisone) are started and tapered slowly.	Use a pulse oximeter at home if provided to monitor oxygen levels.
Severe (Grade 3-4)	Hospitalization, oxygen support, and high-dose IV steroids.	Seek emergency care for severe "air hunger" or gasping.

Skin Changes

Skin changes are the most common side effect of immunotherapy, often appearing within the first few weeks of treatment. These reactions happen when the immune system becomes overactive and affects the skin cells. The most frequent issues are **pruritus** (itching) and **maculopapular rash** (red, bumpy patches). While most rashes are mild, they can significantly impact quality of life by causing discomfort or interfering with sleep.

Be aware of less common changes, such as **vitiligo** (loss of skin pigment resulting in white patches), which is particularly common in melanoma patients, and increased sensitivity to sunlight, even a "minor" rash should be reported, as it allows the oncology team to intervene before the skin breaks down or becomes infected.

Scented products are the enemy during immunotherapy. Even if you've used a certain soap for years, switching to a **hypoallergenic, fragrance-free** regimen now can prevent a lot of irritation later.

Management & Skin Care Guidance

Symptom	**Patient Self-Care**	**Clinical Treatment**
Itching (Pruritus)	Use thick, fragrance-free moisturizers (like CeraVe or Eucerin) twice daily.	Oral antihistamines or prescription-strength steroid creams.
Rash	Bathe in lukewarm water; use "soap-free" cleansers. Pat skin dry; do not rub.	Topical steroids for mild cases; oral steroids (Prednisone) for widespread rashes.
Sun Sensitivity	Wear SPF 30+ daily and protective clothing (hats/long sleeves).	Avoid direct sun during peak hours (10 AM – 4 PM).
Dry/Peeling Skin	Apply moisturizer immediately after bathing while skin is still damp.	Evaluation for secondary infections if the skin is "weeping" or cracked.

Red Flags: When to Call Immediately

Call the clinic or go to the ER if you experience:

- **Blistering or Peeling:** Skin that looks like a burn or starts to peel away.
- **Mouth/Eye Involvement:** Painful sores inside the mouth or on the eyelids accompanying a rash.
- **Rapid Spread:** A rash that covers more than 30% of the body or is associated with a high fever.

Nerve Changes

When immunotherapy affects the nervous system, it is known as **neurological toxicity**. This happens when the immune system mistakenly attacks the protective coating of the nerves or the nerves themselves. These side effects can range from mild tingling in the hands and feet to more serious issues with muscle strength or coordination.

The most common nerve-related side effect is **peripheral neuropathy**, which is described as a "pins and needles" sensation, numbness, or a burning feeling in fingers or toes. While often manageable, it is crucial to report these sensations early so the oncology team can prevent the symptoms from progressing or becoming permanent.

Monitoring Nerve Changes

Sensory Changes	**Motor & Balance Changes**
Numbness or tingling in hands/feet	New weakness in the legs or arms
Burning or "electric shock" sensations	Difficulty "finding your feet" or loss of balance
Sensitivity to touch or temperature	Difficulty buttoning a shirt or picking up coins
Sharp, stabbing pains	Drooping of the face or eyelids (Ptosis)

Guillain-Barré-like Syndrome: If you begin to experience a rapid, ascending weakness (starting in the feet and moving up the legs) or have trouble breathing or swallowing, you must seek **Emergency Care** immediately.

Management & Safety Strategies

1. **Early Reporting:** with a new onset of numbness, the medical team may "hold" the immunotherapy to allow the nerves to recover.
2. **Medications:** Doctors may prescribe specialized nerve medications (like **Gabapentin**) or a course of **steroids** to reduce the immune attack on the nervous system.
3. **Physical Safety (Fall Prevention):** wear sturdy, closed-toe shoes and to remove "trip hazards" like throw rugs at home.

Central Nervous System Changes

When immunotherapy affects the **Central Nervous System (CNS)**—the brain and spinal cord—it is a rare but serious side effect. This occurs when the immune system causes inflammation in these delicate areas, leading to conditions like **encephalitis** (brain inflammation) or **myelitis** (spinal cord inflammation).

Because these symptoms can affect your personality, movement, or basic bodily functions, it is vital for both you and caregivers to be vigilant. Changes can happen quickly, and early treatment with high-dose steroids is the key to a full recovery.

Symptoms to Watch For

Area Affected	**What the Patient or Caregiver May Notice**
Brain (Encephalitis)	Confusion, memory loss, "personality changes," or acting "not like themselves."
Physical Coordination	Extreme sleepiness, seizures, or difficulty walking/stumbling.
Spinal Cord (Myelitis)	Sudden weakness or heaviness in the legs, or "bands" of pain around the chest.
Autonomic Function	New loss of bowel or bladder control (not being able to "go" or "hold it").

Management & Patient Safety

1. **Caregiver Involvement:** Unlike skin or mouth changes, CNS side effects often make the patient confused. Call the clinic if they notice the patient is confused, disoriented, or sleeping significantly more than usual.
2. **Diagnostic Testing:** If these symptoms occur, the oncology team will likely order an **MRI** of the brain or spine and may perform a **lumbar puncture** (spinal tap) to rule out infection or cancer progression.
3. **Treatment:** Management almost always involves hospitalization, stopping immunotherapy, and starting high-dose IV steroids. In some cases, other treatments like IVIG (intravenous immunoglobulin) are used to "calm" the immune system.

Emergency "Red Flags"

Call 911 or go to the nearest ER for:

- A sudden, severe headache (the "worst headache of your life").
- New seizures or tremors.
- Sudden inability to move or feel your legs.
- Total confusion or inability to recognize family members.

Muscular Changes

When immunotherapy affects the muscles, it most commonly causes inflammation known as **myositis**. This is different from the general "aches and pains" often associated with treatment; it is a specific immune attack on the muscle fibers that can lead to significant weakness. Because the heart is also a muscle, inflammation can occasionally occur there as well (**myocarditis**), making muscle changes a priority for early reporting.

If you can no longer stand up from a chair without using arms for support, or if you have trouble holding your head up, these are signs of muscle inflammation rather than simple fatigue.

Signs of Muscle and Heart Inflammation

Symptom	**What it Feels Like**	**Why it Matters**
Proximal Weakness	Difficulty climbing stairs or reaching overhead to brush hair.	Sign of **myositis** (muscle inflammation).
Eyelid/Jaw Changes	Drooping eyelids (ptosis) or double vision; trouble chewing or swallowing.	Can be a sign of **Myasthenia Gravis**, a specific nerve-muscle issue.
Chest Symptoms	Chest pain, shortness of breath, or a racing/skipping heartbeat.	Could indicate **myocarditis** (heart muscle inflammation).
Muscle Pain	Severe tenderness or swelling in the thighs, shoulders, or upper arms.	Different from joint pain; the muscle itself feels "bruised" or tight.

Management & Safety

1. **Lab Monitoring:** Your oncology team will monitor a blood enzyme called **Creatine Kinase (CK)**. If your muscles are inflamed, this level will rise. If heart involvement is suspected, we also check **Troponin** levels.
2. **Activity Adjustment:** If myositis is diagnosed, you will be advised to rest the affected muscles. Aggressive exercise during active inflammation can sometimes worsen the damage.
3. **Treatment:** Treatment involves holding immunotherapy and starting **steroids** to stop the immune attack. If the weakness affects the muscles used for breathing or swallowing, hospitalization is required for close monitoring.

Cardiac Changes

When immunotherapy affects the heart, it causes inflammation known as **myocarditis**. While this is a rare side effect, it is considered a high-priority "Red Flag" because the heart is responsible for pumping oxygen to the rest of the body. Inflammation can interfere with the heart's rhythm or its ability to squeeze effectively.

Heart symptoms can often feel like "just being tired" or "being out of breath," it is vital to report any new chest or breathing sensations.

Symptoms to Watch For

Symptom	How a Patient Might Describe It
Chest Pain	Pressure, tightness, or a sharp pain in the chest that may spread to the neck or arm.
Arrhythmia	A feeling that the heart is "skipping a beat," racing, or fluttering in the chest.
Shortness of Breath	Feeling winded while resting or during very light activity (like dressing).
Fluid Retention	New or worsening swelling in the ankles, feet, or legs.
Lightheadedness	Feeling dizzy, faint, or "blacking out" suddenly.

Management & Clinical Steps

1. **Immediate Evaluation:** If heart changes are suspected, the oncology team will order an **EKG** to check the heart's rhythm
2. **Treatment:** Immunotherapy is almost always stopped immediately. Treatment involves high-dose steroids to calm the immune system. In some cases, other immune-suppressing medications may be added.
3. **Activity:** You may be placed on "activity restriction" to let the heart muscle rest and heal while the inflammation is being treated.

If you experience sudden, severe chest pain or feel like you are going to faint, call 911 immediately. Tell the emergency responders and the ER staff that you are on IMMUNOTHERAPY.

Gastrointestinal Changes

Diarrhea

When immunotherapy affects the bowels, it causes inflammation known as **colitis**. This is one of the most common and important side effects to manage because it can lead to severe dehydration or damage to the colon if left untreated. Unlike a typical "stomach bug," immunotherapy-related colitis does not usually go away on its own and requires medical intervention.

An increase of two or three bowel movements a day over your baseline is something the oncology team needs to know about.

Symptoms to Monitor

Symptom	What to Watch For
Increased Frequency	Any increase in the number of stools per day (e.g., going 4 times instead of 1).
Consistency Changes	Stools that become loose, watery, or soft.

Symptom	**What to Watch For**
Pain & Cramping	New abdominal pain, bloating, or "crampy" feelings.
Blood or Mucus	Any bright red blood, dark/tarry stools, or mucus in the bowel movement.
Urgency	Feeling a sudden, intense need to go to the bathroom immediately.

Management & Patient Instructions

- **Hydration:** Drinking a lot of clear liquids (water, broth, or electrolyte drinks like Gatorade) will prevent dehydration. Avoid caffeine and alcohol, which can irritate the bowels.
    - The recommended fluid intake per day ranges from 1.5 to 3.5 liters. (1quart is about 1 liter)
    - One way to figure out how much you need is to divide your weight in pounds by 2. This is the number of ounces you need for one day. (8 ounces =1 cup)
    - You may need more fluids if you are experiencing increased demands of disease and treatment; have increased metabolic activity, have a fever, or experiencing diarrhea.
    - Water should be the mainstay of your fluid intake.
    - How do you know if you are drinking enough?
        - There are a couple of ways you can tell if you are drinking enough:
            - Check your urine color. Darker urine means you are not drinking enough while clear or very pale yellow means you are getting adequate fluids.
            - Dizziness when changing positions, i.e. from sitting to standing, may be a sign of dehydration.
- **Dietary Adjustments (BRAT Diet):** While symptoms are active, suggest "bland" foods like bananas, rice, applesauce, and toast. Avoid high-fiber, spicy, or fatty foods.
- **Clinical Treatment:** Mild cases may be managed by holding immunotherapy. Moderate to severe cases require **corticosteroids** (like Prednisone). If steroids don't work, a specialized "biologic" medication (like Infliximab) may be used.

Immodium (loperamide):
Take 2 caplets (4 mg) first episode of diarrhea.
Then 1 caplet (2 mg) every 2 hours
(or 1 with each episode of loose stool)

May take up to 8 tablets (16 mg) daily

*****If Diarrhea is still not controlled, contact our office immediately***

BRAT Diet-
Bananas
Rice (white)
Applesauce
Toast (white)

Red Flags: Seek Immediate Care

- Severe abdominal pain or a "rigid" stomach.
- Fever accompanying diarrhea.
- Inability to keep fluids down.
- Blood in the stool.

Constipation

Constipation is defined as irregular or infrequent hard stools that cause discomfort. You know what is normal for you. It may be normal for you to have a stool every second or third day. Constipation can also be a side effect of some treatments along with pain medications. Decreased activity, decreased fluid intake, or decreased nerve stimulus to your bowel because of a medication can leave you constipated.

If your stool is not hard and does not cause you discomfort, you are not constipated. However, if you generally have a stool every morning and you miss a day you might consider some action.

To help prevent or deal with constipation:

- Increase fluid intake.
- Increase fiber in your diet.
- Respond to the urge to go to the bathroom.
- Avoid cheese, chocolate and eggs.
- Increase your activity, if possible.
- If you are taking a prescription of pain medicine, you should also take a stool softener daily such as Colace (Docusate sodium). Laxatives such as Miralax (Polyethylene Glycol), Milk of Magnesia, or Senna may also be recommended. Ask your doctor or nurse.
- Do not use an enema without your doctor's approval.

Call us if:

- You are concerned about your bowel status.
- You are oozing liquid stool.
- You start vomiting, feel nauseated and have not had a stool for more than three days.
- Your stomach is distended, feels very full or hard.
- You notice any blood in your stool.

Nausea and Vomiting

- Eat small snacks five or six times a day. You may be able to eat sweet or salty foods better
- Rest after meals. Excess movements may increase the nausea.
- If you recline after meals, make sure your head is four inches higher than your feet.

  - Drink fluids often throughout the day.
  - Strong odors from fragrances/foods can increase nausea.
  - Sucking on lozenges and chewing gum may also help.
  - Foods to have on hand for nausea:
    - Popsicles, Jello, Broths, Tea, Saltines, 7-up/Sprite, Ginger ale, Ginger snaps

If you are not keeping food and fluids down, please call and schedule to come into our office for possible IV hydration and IV anti-nausea medication.

- *About Anti-Nausea Medication You May Be Prescribed*
  - Take anti-nausea pills preventatively as directed or at the first feeling of nausea. Do not wait until you are vomiting, they can't help you if they don't stay down.

Joint changes

When immunotherapy affects the joints, it causes inflammation known as **inflammatory arthritis**. While many cancer treatments cause general "aching," immunotherapy-related joint issues are different because the immune system is actively attacking the joint lining. This can lead to swelling, stiffness, and pain that is often worse in the morning.

Unlike some other side effects, joint pain can sometimes appear much later in treatment or even after treatment has finished. If managed early, we can usually protect the joints from long-term damage and keep patients mobile.

Exercise reduces fatigue and elevates mood. Research has demonstrated that those who moderately exercised regularly had 40% to 50% less fatigue, the primary complaint during treatment. Exercise is known to improve cardiovascular function and to protect bones. It also elevates mood, offering drug free relief for the feelings of depression that may accompany a cancer diagnosis. It can also help with constipation.

Your goal should be at least 30 minutes of aerobic exercise five days a week or more. If you do not have the energy to exercise a full half hour, break it up; try three 10-minute walks during the day.

Symptom	**What the Patient Experiences**
Morning Stiffness	Feeling "locked up" or stiff for more than 30–60 minutes after waking up.
Joint Swelling	Visible puffiness, redness, or warmth in the knees, wrists, or small joints of the hands.
Reduced Range of Motion	Difficulty fully clenching a fist, reaching behind the back, or squatting.

Symptom	What the Patient Experiences
Migrating Pain	Pain that "moves" from one joint to another (e.g., the shoulder hurts one day, the knee the next).

Management & Comfort Strategies

1. **Stay Moving:** "motion is lotion" for inflammatory arthritis. Gentle stretching or walking often helps more than total bed rest.
2. **Heat and Cold:** Use warm compresses or a morning shower to loosen stiff joints. Cold packs can be used for "hot," swollen joints after activity.
3. **Medication:** Mild cases are often treated with NSAIDs (like Ibuprofen). Moderate cases require a course of **steroids**.

Medications, Safety, and Alternatives

- Before starting treatment, make sure you tell your doctor about any other medications you are taking (including prescription, over-the-counter, vitamins, herbal remedies, etc.). Some of these may interfere with your treatment or cause more side effects.
- You may continue to use over-the-counter cold, bowel, headache, and skin care medications as needed, unless otherwise directed.
- ONLY If you are told your platelet counts are low then, avoid Ibuprofen, Aspirin, Meloxicam and herbs such as; cat's claw, dong quqi, evening primrose, feverfew, garlic, ginkgo, red clover, horse chestnut, green tea, ginseng (all have antiplatelet activity). Discuss with your doctor when it might be safe to resume.
- Do not receive any kind of immunization or vaccination without your doctor's approval while receiving treatment.
- Inform your health care professional if you are pregnant or may be pregnant prior to starting treatment.
- For both men and women: Barrier methods of contraception, such as condoms, are recommended. Discuss with your doctor when you may safely become pregnant or conceive a child after therapy.
- Do not breast feed while undergoing treatment.
- Some medications can cause visual changes, dizziness and tiredness. If you have any of these symptoms, use caution when driving a car, using machinery, or anything that requires you to be alert.

Emotional Changes and Fatigue

When someone is diagnosed with cancer, that person's entire collection of relationships is affected. It is said that the way you have tried to cope with other stressful times will be the way you try to cope with your illness and its treatment. This can be true for everyone involved.

Keeping family and friends informed and sharing how you feel will help you and may also help them to cope. Find a few special people to be your partners. They can help by listening, bringing you to appointments, helping with errands or other responsibilities. Try keeping a diary of what is going on and how you feel. This may increase your sense of control and help to put things in perspective. It is a well documented fact that people who try and hide their illness and have no extra emotional support do not fare as well as those with at least one confidant.

You will have good days and bad days. Take them one at a time. Set small, realistic goals for yourself each day. Do not consume yourself with anger over things you cannot control. Your energy needs to be focused on what is good for you.

Sometimes support groups may be helpful. You may ask the nurses and scheduling staff for information on what is available in your area. One out of three people develop some type of cancer. It is not something to be ashamed of or feel guilty about, but something to be informed about. There are more successful treatments now than ever before. We are committed to help you by offering the best medical treatment possible.

Relationships

Your spouse or most intimate friend might find they just don't know what to say. You might, however, find they are the only one who really listens. Remember that your illness affects all who love you. They too might feel angry, sad, confused or helpless The best practice is to be as honest as possible about your feelings. Accept the feelings of others and surround yourself with people who care about you.

Personal counseling to help you deal with all that is changing may be very beneficial. It is not a sign of weakness to reach out for help but rather a sign of strength. Having the support of at least one person during your treatment course is a proven advantage.

Sexual Intimacy

Couples may wonder about their sexual intimacy. Treatment itself can decrease your libido for a period of time, you may not feel interest in your partner's needs. Talk with your partner -- tell her or him how you feel. Good communications is an important part of maintaining a healthy sexual relationship with your partner. Vaginal dryness may also be a consequence of lowered hormone levels. A water-based vaginal lubricant may help. Sexual intercourse may not be an option for a while. Explore other ways to be intimate.

If you are receiving immunotherapy, remember that bodily secretions, especially urine, are considered to have the chemicals present for up to 48 hours. Please ask your medical staff for guidance if you have any questions.

Fatigue

Fatigue is a feeling of weakness, lack of energy and/or an increased need for sleep. Your body has a lot of hard work to do after therapy. It must get rid of the old cells and begin to make new ones. You can help your body deal with this demand by:

- Eating well
- Resting between periods of activity
- Decreasing the demand you place on yourself
- Discussing how you feel with your family and friends

Immunotherapy is not the only cause of fatigue. Fatigue may result from stress, depression, pain, anemia, fear or a sudden change in your lifestyle. Talk with your doctor or nurse to help identify the possible cause and then to work on possible solutions. It may be very easy to help you feel a lot better or it may be a temporary side effect you may need to adapt to until the demands of both the immunotherapy and the cancer are decreased.

When to Contact Your Doctor or Healthcare Provider

Seek emergency help immediately from your provider if you experience these symptoms.

- Shortness of breath, wheezing, difficulty breathing, closing up of the throat, swelling of facial features, hives (possible allergic reaction).
- Chest pain or pressure
- Development of confusion, hallucinations or seizure
- Fever of 100.5° F (38° C) or higher, chills (possible signs of infection).
- Urinary retention or inability to urinate
- Significant bleeding from nose, mouth, vagina, rectum that does not stop within 15 minutes.
- Symptoms associated with a possible blood clot, such as chest pain or pressure, pain in your arms, back, neck or jaw, numbness or weakness on one side of your body, trouble talking, sudden or severe headache, sudden vision changes.

These symptoms are less severe but still require medical attention. Contact your provider within 24 hours if you experience any of these symptoms.

- Nausea that interferes with ability to eat and is unrelieved with prescribed medication
- Vomiting more than 4-5 times in 24 hours
- Diarrhea more than 3-4 liquid bowel movements in a 24-hour period
- Constipation: 3+ days without a bowel movement (unless this is normal for you)
- Unable to eat or drink for 24 hours or have signs of dehydration: tiredness, thirst, dry mouth, dark and decreased amount of urine, or dizziness (particularly with standing)
- Extreme fatigue: Inability to carry on self-care activities or get out of bed
- Unusual bleeding or bruising
- Black or tarry stools, or blood in your stools
- Blood in the urine, pain or burning with urination
- Lip or mouth sores: Painful redness, swelling or ulcers, white patches or film in mouth
- Swelling, redness and/or pain in one limb (arm or leg)
- Yellowing of the skin or eyes.
- Cough, shortness of breath.
- Muscle cramps or twitching
- Swelling of the feet or ankles
- Changes in hearing, ear or sinus pain
- Dizziness, confusion, or visual changes
- Skin rashes
- Eye irritation
- Tingling or burning, redness, swelling of the palms of the hands or soles of feet
- Signs of infection including sweats, cough, flu-like symptoms, shortness of breath, blood in your phlegm, anal itching or pain, sores on your body, warm or painful areas on your body
- More sputum or change in color of sputum
- Redness or pain at the infusion or injection site

For more information, please visit ogdenclinic.com/specialties/cancertreatment-center or contact us at 801-476-1777.

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