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#### Your Guide to Immunotherapy

Lehigh Valley Health Network

ACCC Association of Community Cancer Centers

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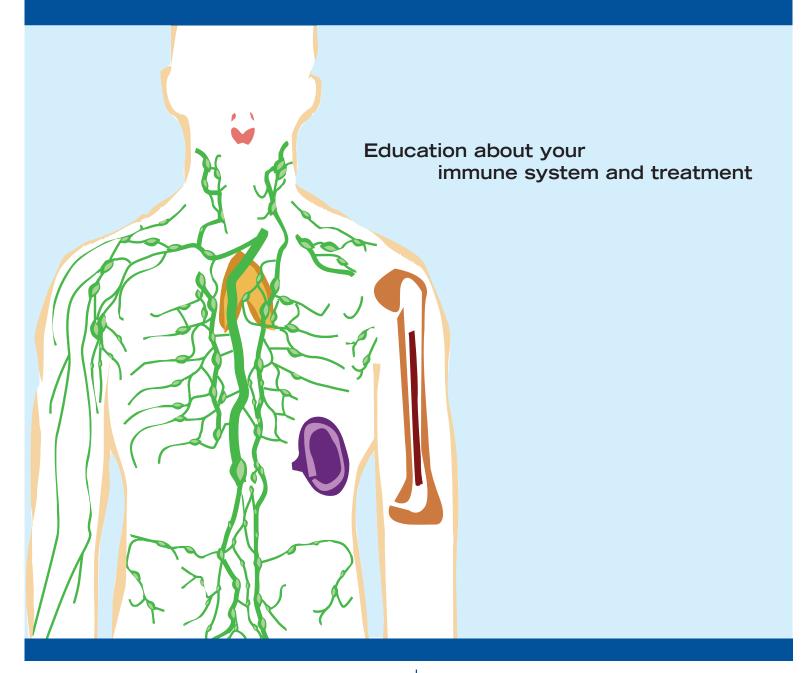
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# Your Guide to Immunotherapy







Association of Community Cancer Centers

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# Getting to Know Your Immune System

As old cells in your body die, your body forms new cells. This is normal. Some cells in your body form and divide more quickly than others such as the cells in skin, hair, mouth, stomach, and throat.

Cancer begins in your cells when this process of dividing cells goes wrong. New cells grow even when you do not need them, and old cells do not die when they should. Cancer cells are cells that divide quickly into more cancer cells and that can hide from your immune system.

These extra cells can form a mass called a tumor. Tumors can be benign or malignant. Benign tumors are not cancer. Malignant tumors are cancer. Cells from malignant tumors can invade nearby tissues. They can also break away and spread to other parts of the body. This is called metastasis.

The immune system is made up of white blood cells, tissues and organs. They work together to protect your body against disease by keeping germs that cause disease out of the body or finding germs or other disease cells and destroying them.

# What is Immunotherapy?

- Immunotherapy is a type of treatment that uses your own immune system to attack the cancer cells. It uses substances either made by the body or in a laboratory.
- The ways that your body's cells and fluids act when they come in contact with cells like cancer cells that are different from your body's normal cells is called an immune response.



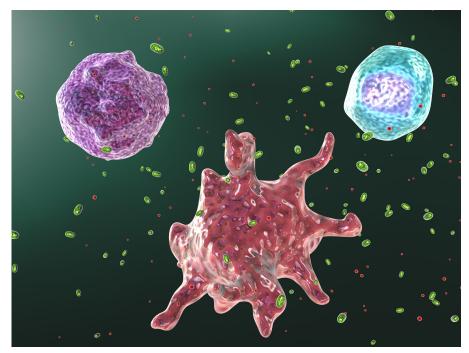
# Immunotherapy Work?

Immunotherapy is a cancer treatment that helps your immune system fight cancer. It does this in two ways:

• By helping your body's own immune system fight the cancer better. (Your cancer team may refer to this as "boosting your immune system.")

or

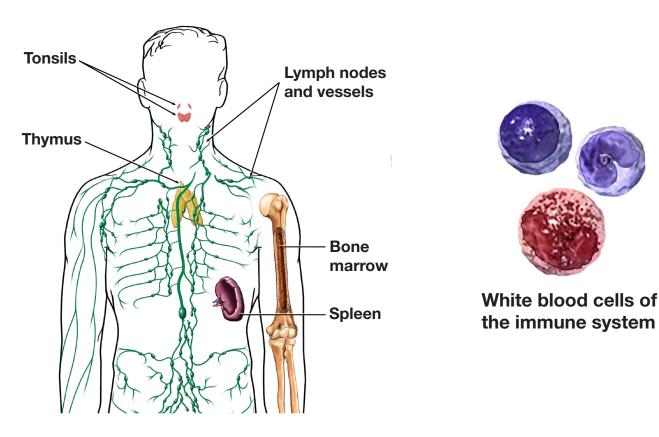
• By marking the cancer cells so it is easier for your immune system to find and destroy them. (Your cancer team may refer to this as "enabling the immune response.")



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## Is Immunotherapy the Same as Chemotherapy?

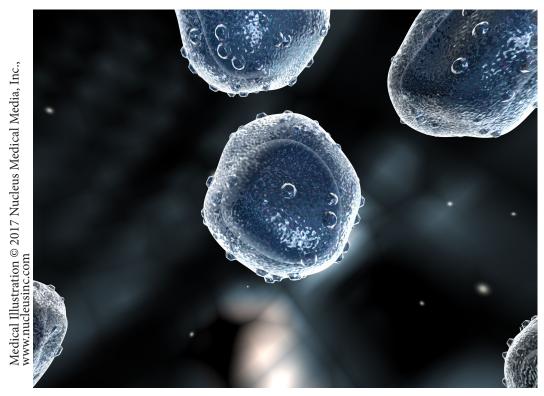
- No. Chemotherapy drugs kill rapidly dividing cells. Cancer cells are rapidly dividing. It can kill both healthy cells that divide rapidly and cancer cells. The death of the healthy cells leads to side effects such as hair loss, skin or nail changes, mouth or throat sores, nausea. vomiting, and diarrhea. These are side effects seen often with chemotherapy.
- Immunotherapy uses the different parts of the immune system to fight cancer and does not kill healthy cells. Immunotherapy can cause your immune system to attack normal organs and tissues in many areas of your body and can affect the way they work. Some organs and tissues that can be affected include lungs, intestines, liver, kidneys, and hormone glands. For more information on these side effects, please go to pages 10 to 30.



#### The Immune System

# Who Should Get Immunotherapy?

- Most Immunotherapies are given to people with cancers that have
  - Recurred (come back) and spread to other places in the body after getting a previous cancer treatment
    or
  - o Been diagnosed with advanced cancer (Stage III or IV)
- Many people have a good immune response to these agents, and some people have responses that are complete and long lasting. It is more common to have a partial response, meaning the tumor shrinks or stays the same size, but does not disappear.



This picture shows a T-cell. T-cells help your body fight diseases or harmful bacteria and viruses.



- Your oncology doctor will decide if you get your next scheduled dose after a missed dose. This decision is made after:
  - o Your office visit
  - o Checking your laboratory studies (blood work)
  - o Checking any side effects that you may be having
- Missing a dose does not mean treatment is done.

# How is Immunotherapy Given?

- Immunotherapy can be given in different ways.
  - o Intravenous catheter or IV
    - An IV is a thin catheter inserted into a vein in your arm or hand. This is the most common way.
  - o Injection
    - A sub-cutaneous injection is a shot that is put into the fatty part of your body. (Common injection sites: back of your arm, thigh or stomach). If you need to give yourself this type of injection, you will be taught how to do this.
  - o Peripherally Inserted Central Catheter or PICC
    - A PICC is a catheter with a long flexible tube that is placed in the arm and threaded through the vein until it reaches a large vein near the heart.
    - It is used to give medications, fluids, nutrients or blood over a long period of time, often for several weeks or more.
  - o Port-a-cath or port
    - A port is a small round disc made of plastic or metal that is placed under your skin.
    - A catheter connects the port to a large vein, most often in your chest.
    - Your nurse can insert a needle into your port to give you immunotherapy or to take blood.
    - A needle can be left in place for immunotherapy treatments that are given for more than one day.
    - Watch for signs of infection around your port. Signs of infection are redness, pain or swelling.

# Can I Take Other Medicine, Vitamins, or Supplements While Getting Immunotherapy?

- Some medicines, vitamins, herbs and supplements can affect how immunotherapy works.
- Tell your oncology doctor about all the medicine, vitamins or supplements you take whether it is ordered by another doctor or if you buy it at a store, such as:
  - o Laxatives
  - o Allergy medicines
  - o Cold medicines
  - o Pain relievers like aspirin, acetaminophen or ibuprofen
  - o Herbs
  - o Supplements
- Only take medicine that is approved by your doctor.
- Tell your oncology doctor right away about any changes to your medicine you are taking. The oncology doctor will make sure the medicine does not affect your immunotherapy treatments and your health.

# How Will I Know if Immunotherapy is Working?

- The best way to know if your immunotherapy is working is by your provider:
  - o Doing a physical exam
  - o Checking medical tests such as blood tests and x-rays
  - o Asking you how you feel

#### Important to remember:

- Side effects have nothing to do with how well the immunotherapy is fighting your cancer.
- Some people think that severe side effects mean that the immunotherapy is working well, or that no side effects mean that the immunotherapy is not working. This is not true.
- Tumors can respond differently to immunotherapy based on how well your immune system can find the cancer cells.
- If a CAT scan, x-ray or PET scan is taken and your tumor appears larger:
  - o It may not always mean that immunotherapy is not working
  - o It may be that your immune system is working on the tumor

# How Much Does Immunotherapy Cost?

- Cost depends on:
  - o The type of immunotherapy used
  - o The dose of immunotherapy used
  - o How often it is given
  - o How long it is given
  - o Where you get your treatment
  - o Where you live or the part of the country you live in.

# How Do I Find Out if My Health Insurance Will Pay for Immunotherapy?

- Talk to your insurance company. Ask:
  - o What costs it will pay for.
  - o About the steps you need to do to get your treatment approved for payment.
    - Once you and your doctor agree on your treatment plan our insurance coordinators will be in contact with your insurance company to check on the coverage.
    - Allow time for a thorough review of your insurance coverage, this process can take 5 business days.

# *What if My Health Insurance Will Not Pay for Immunotherapy?*

- If your treatment plan is not covered by your insurance company, you will be referred to (asked to speak with) our financial coordinators.
- Our financial coordinators will work with you to find the best coverage for your treatment.
- If you need help with paying for treatment, be aware that our coordinators will need a confidential copy of your most recent income tax returns.

# Tips for Meeting with Your Doctor or Nurse

**Make a list of questions.** Do not be afraid to ask questions. We want you to ask questions. The more you know, the better you can take care of yourself!

- Bring a family member or trusted friend to your appointments. This person can help you remember what you talked about at your office visit.
- Ask for printed information about your type of cancer and immunotherapy. This will make it easy to read about it at any time.
- Take notes.
- Know how to contact your oncology provider in an emergency.

# What Should I Know About Side Effects?

#### What are side effects?

- A side effect is an unexpected medical problem that happens during treatment with a drug or other therapy.
- These effects may be serious and should not be ignored.
- Do not treat side effects with any medicine without talking your oncology provider.
- Please call your cancer care team if you have any of the side effects listed on pages 11 to 30.

#### What causes side effects?

- Immunotherapy can cause your immune system to attack normal organs and tissues and affect the way they work.
- Remember immunotherapy works by helping your immune system work better. (Your oncology team may refer to this as "revving up" or stimulating your immune system.)
- This can cause your immune system to affect your organs and produce side effects.



#### Will I get side effects?

- Everyone's experience may be different.
- Side effects depend on the immunotherapy you are getting and how your immune system reacts to the treatment.
- It is important to tell your cancer care team how you feel.

#### When do the side effects occur?

- The side effects may happen at any time during treatment or even after your treatment has ended.
- Inflammation (swelling) is a common side effect. Know that inflammation can happen in any organ and may not be easily seen.

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your provider right away if you have any of the side effects listed on pages 11-30.

#### What can be done about side effects?

- Since the side effects are caused as a result of the immune system working harder, the best way to treat these side effects is to calm the immune system.
- Calming the immune system is often done with high dose, intravenous medicines called steroids. You may need to be admitted to the hospital to receive this medicine.

# Possible Effect on the Intestinal Tract – Colitis

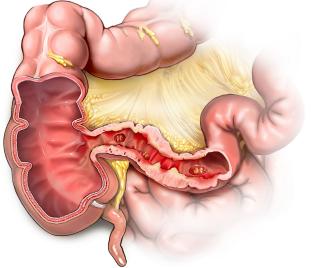
#### What is Colitis?

• Inflammation of the intestines

#### Side Effects

- Feeling less hungry than usual or loss of appetite
- Nausea or vomiting
- Diarrhea (loose stools) or more bowel movements than normal
- Blood in your stool or dark, tarry, sticky stools
- Constipation or difficulty having a bowel movement
- Abdomen (stomach) pain, tenderness or cramping
- Pain on the right side of your abdomen (stomach) area

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.



#### Management

• CAT scan of the abdomen

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- Blood work
- You may need treatment with high dose, intravenous steroids.
- If the colitis is severe, you may have to be admitted to the hospital.

# **Possible Effect on the Lungs – Pneumonitis**

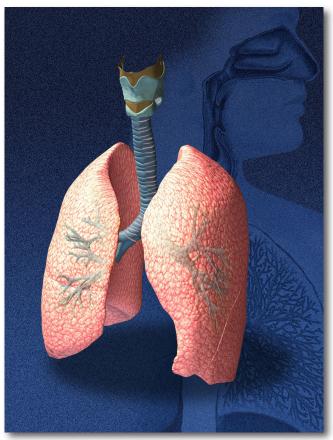
#### What is pneumonitis?

• Inflammation of the lungs

#### Side Effects

- New or dry cough
- Chest pain
- Shortness of breath
- Drop in oxygen level (pulse ox)

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.



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#### Management

- Chest X-ray
- CAT scan of chest
- Blood work
- You may need treatment with high dose, intravenous steroids.
- If the pneumonitis is severe, you may have to be admitted to the hospital.

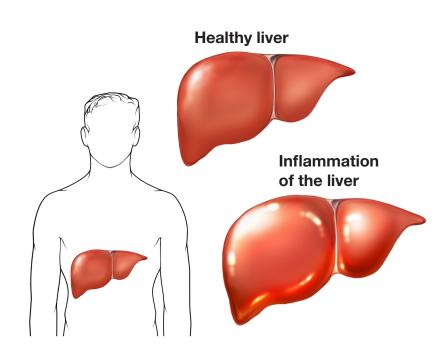
# *Possible Effect on the Liver – Hepatitis*

#### What is Hepatitis?

• Inflammation of the liver

#### Side Effect

- Yellowing of your skin or the whites of your eyes
- Nausea or vomiting
- Pain on the right side of your stomach area (abdomen)
- Sleepy
- Dark urine (tea colored)
- Bleeding or bruising more easily than normal
- Feeling less hungry than usual



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These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work
- You may need treatment with high dose, intravenous steroids.
- If the hepatitis is severe, you may have to be admitted to the hospital

# **Possible Effect on the Kidneys – Nephritis**

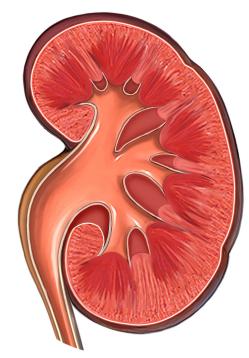
#### What is Nephritis?

• Inflammation of one or both kidneys

#### Side Effects

- Decrease in the amount of urine
- Blood in urine
- Swelling in your ankles
- Loss of appetite

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.



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#### Management

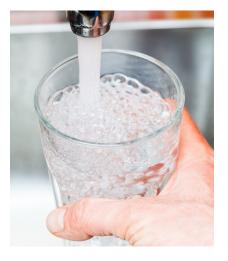
- Blood work (if needed)
- You may need treatment with high dose, intravenous (IV) steroids.
- If the nephritis is severe, you may have to be admitted to the hospital.

#### What is Hyperglycemia/Diabetes Mellitus?

• An increased blood sugar and the body's inability to produce insulin effectively

#### Side Effects

- Excessive thirst and hunger
- Frequent urination
- Fasting blood sugar over 200mg/dL
- Random blood glucose over 250mg/dL



These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work
- Insulin or oral anti-diabetic agents

#### What is hypothyroidism and hyperthyroidism?

• Hypothyroidism is when the thyroid gland can't make enough thyroid hormone. Hyperthyroidism is when they thyroid gland makes too much thyroid hormone.

#### Side Effects

- Headaches that will not go away or unusual headaches
- Extreme tiredness
- Weight gain or weight loss
- Changes in mood or behavior such as decreased sex drive, being irritable or forgetful
- Dizziness or fainting
- Hair loss
- Feeling cold
- Constipation or difficulty having a bowel movement
- Voice gets deeper

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These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

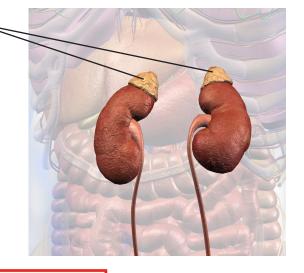
- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- You may need treatment with thyroid medication (example: Levothyroxine, (Synthroid)

#### What are adrenal gland abnormalities?

• An over or under secretion of hormones from the adrenal gland or pituitary gland

#### Side Effects

- adrenal glands 👡
- Abnormal hormone levels
- Extreme tiredness (fatigue)
- Mood changes (irritability, forgetfulness)
- Decreased appetite, weight loss
- Skin darkening- hyperpigmentation
- Muscle weakness
- Hair loss
- Low blood pressure
- Low blood sugar



These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

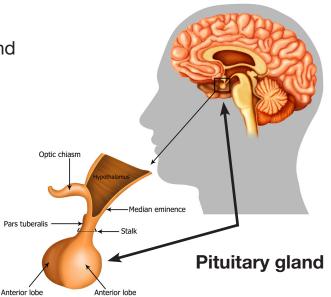
- Blood work
- You may need treatment with high dose, intravenous steroids.
- If the endocrine abnormalities are severe, you may need to be admitted to the hospital.
- You may need lifelong cortef replacement with steroids (Example- dexamethasone, prednisone, or hydrocortisone)

#### What is Hypophysitis?

• Inflammation of the pituitary gland

#### Side Effects

- Headache
- Nausea and vomiting
- Photophobia (eyes are very sensitive or hurt due to light)
- Dizziness
- Abnormal hormone levels



These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work
- You may need treatment with high dose, intravenous steroids
- If the hypophysitis is severe, you may need to be admitted to the hospital



#### What it dermatitis?

• A rash, also known as dermatitis, is inflammation of the skin.

#### Side Effects

- Rash
- Itching
- Blisters or skin ulcers

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.



#### Management

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- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- If the side effect of the skin is severe, you may have to be admitted to the hospital.

#### What is Neuropathy?

• Inflammation of the nerves

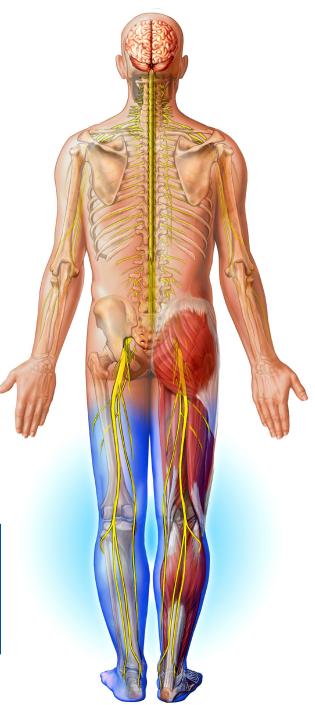
#### Side Effects

- Changes in eyesight, taste, smell, or hearing
- Severe or constant muscle or joint pains
- Severe muscle weakness
- New numbness or tingling

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work (if needed)
- If the neuropathy is severe, you may have to be admitted to the hospital.



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#### What is Myasthenia Gravis?

A condition often seen by weakness and rapid fatigue of certain voluntary muscles (muscles you can control).



#### Side Effects

- Drooping of one or both eyelids
- Altered or slurred speaking
- Difficulty swallowing or problems with chewing
- Limited facial expressions
- Weakness in your neck, arms or legs

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Neurological exam
- Electromyography
- Blood work (if needed)
- CAT scan or MRI
- You may need treatment with high dose, intravenous steroids.
- If the myasthenia gravis is severe, you may need to be admitted to the hospital.

#### What is Guillain-Barre?

A rare disorder often seen by your body's immune system attacking your nerves



#### Side Effects

- Weakness and tingling of extremities that can spread rapidly
- Weakness typically starts in the lower body first (feet) and then spreads to the upper body (arms)
- Pins and needles-like sensation in your fingers or toes
- Difficulty with bladder control or bowel function
- Difficulty with eye or facial movements (speaking, chewing, swallowing)

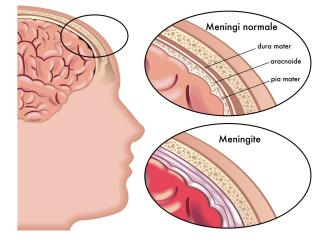
These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Electromyography
- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- If the Guillain-Barre is severe, you may need to be admitted to the hospital.

#### What is Aseptic Meningitis?

Inflammation of the tissue covering your brain and spinal cord



#### Side Effects

- Headache
- Photophobia (eyes are very sensitive or hurt due to light)
- Neck stiffness
- Nausea and vomiting

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- MRI of the brain
- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- If the aseptic meningitis is severe, you may need to be admitted to the hospital.

# Possible Effect

on the Neurologic System

What is Encephalitis? Inflammation of the brain



#### Side Effects

- Flu-like symptoms (headache/fever)
- Altered behavior
- Seizures
- Short-term memory loss
- Problems with speech
- Confusion or loss of consciousness
- Muscle weakness

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- MRI of the brain
- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- If the encephalitis is severe, you may need to be admitted to the hospital.

#### What is transverse myelitis?

Inflammation of both sides of one section of the spinal cord



#### Side Effects

- Pain in the lower back
- Abnormal sensations (numbness and tingling; coldness or burning)
- Weakness in the arms or legs
- Bladder and bowel problems

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

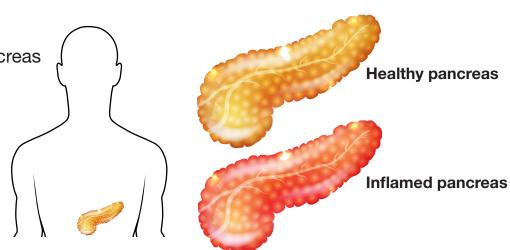
#### Management

- MRI of spine and brain
- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids
- If the transverse myelitis is severe, you may need to be admitted to the hospital

### **Possible Effect on the Pancreas**

What is Pancreatitis?

Inflammation of the pancreas



#### **Side Effects**

- Upper abdominal pain
- Abdomen (stomach) pain that can extend to your back and may feel worse after eating
- Tenderness when touching the abdomen
- Fever
- Nausea and or vomiting

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work
- CAT scan of the abdomen
- Fasting (nothing to eat or drink)
- You may need treatment with high dose, intravenous steroids.
- If the pancreatitis is severe, you may have to be admitted to the hospital

# Possible Effect

# on the Musculoskeletal System

#### What is inflammatory arthritis?

Inflammation of the joints



#### Side Effects

- Pain, swelling, warmth and tenderness of joints
- Morning joint stiffness that lasts for more than one hour

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids
- If the arthritis is severe, you may need to be admitted to the hospital

# Possible Effect

### on the Musculoskeletal System

#### What is Myalgia's/Myositis?

Muscle pain and inflammation



#### Side Effects

- Muscle pain
- Muscle weakness
- Muscle pain and weakness may interfere with your activities of daily living (ADLs).
- General tiredness and fatigue.

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- If the muscle pain and weakness is severe, you may need to be admitted to the hospital.



on the Eyes

What is ocular toxicity?

Inflammation of the eye



#### Side Effects

- Blurred vision
- Conjunctivitis (Pink eye)
- Inflammation of the cornea

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

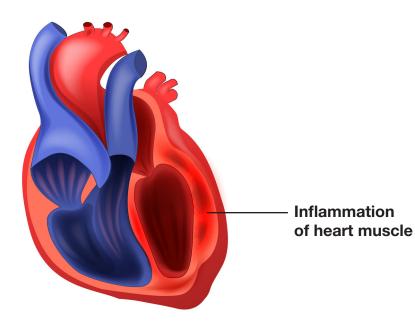
#### Management

- Steroid eye drops
- Artificial tear eye drops
- Blood work (if needed)
- You may need treatment with high dose, intravenous steroids.
- If the eye inflammation is severe, you may need to be admitted to the hospital.

# Possible Effect on the Heart

#### What is Myocarditis?

Inflammation of the heart muscle



#### Side Effects

- Shortness of breath
- Chest pain or pressure
- Heart palpitations
- Tiredness (Fatigue)

These side effects can be very serious or even life-threatening. Side effects can often be treated. Telling your provider early will lead to faster treatment. Please tell your oncology provider right away if you have any of the side effects.

#### Management

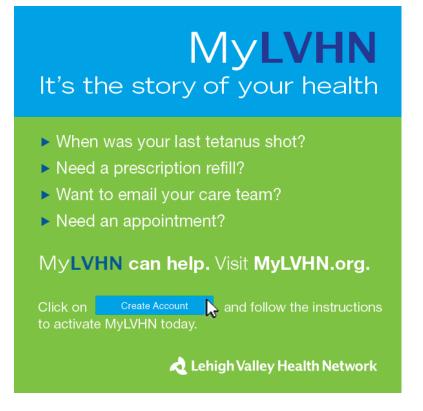
- Blood work
- Electrocardiogram (EKG)
- Chest X-ray
- You may need treatment with high dose, intravenous (IV) steroids.
- If the myocarditis is severe, you may have to be admitted to the hospital.

# **Steroid Information**

- Steroids can be given orally (by mouth)) or intravenously (IV)
- If given orally, prednisone is commonly prescribed
- While the immunotherapy agent(s) that you received "boost" your immune system to fight the cancer, the steroid is used to do the opposite. The steroid will suppress (weaken) your immune system but not against the cancer. This can help decrease or alleviate autoimmune side effects that you may experience.
  - Steroids should always be taken exactly as prescribed
  - This usually involves tapering (starting at high doses and then slowly decreasing the dose of steroid gradually over several days or weeks)
  - If at any point during the steroid taper you notice the autoimmune side effects returning, notify your oncologist immediately. Your dose of steroids will likely be increased again

#### Side Effects

- Increased appetite
- Weight gain
- Low potassium
- Facial swelling
- Increased heart rate
- Mood changes
- Depression
- Abdominal pain, nausea, vomiting
- Increased blood sugar
- Feeling jittery, shaky or dizzy
- Restlessness
- Difficulty sleeping
- Increased risk of infection



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