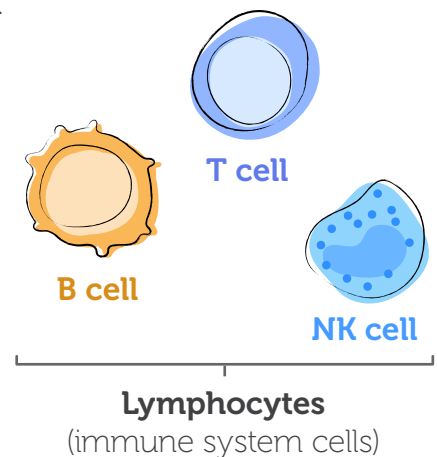


➤ What is PTLD? Post-Transplant Lymphoproliferative Disease or Disorder

'Lympho' refers to lymphocytes, a type of white blood cell.
'Proliferative' means growing or multiplying quickly.

PTLD is one of the **rare but serious** complications that can **happen after a transplant**. PTLDs can range from mild, benign growths to aggressive cancers.

In PTLD, your **lymphocytes grow out of control** after a transplant. Lymphocytes are part of the immune system. In most cases, the lymphocytes affected are the **B cells**.



PTLD is often linked to the Epstein-Barr virus (EBV).

If there is no link, it's called **EBV-negative PTLD**. If there is a link, it's called **EBV-positive PTLD**. EBV is a common virus that infects **B cells** in the body. The infection can cause some B cells to **multiply abnormally**.

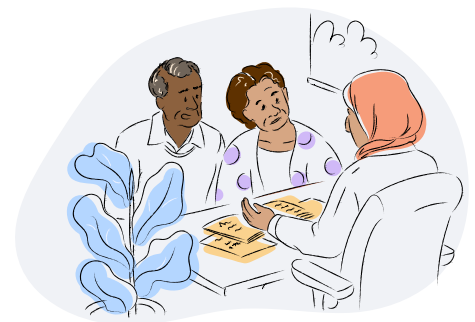


Epstein-Barr virus (EBV)

➤ Who is at risk for PTLD?

Anyone who is taking immunosuppressants after a transplant is at risk for PTLD. Immunosuppressants **must be taken** after a:

- **solid organ transplant** to prevent transplant rejection
- **blood stem cell transplant** from a donor to prevent graft-versus-host disease (GvHD).



Immunosuppressants protect the transplant by **weakening the immune system**.

Normally, the immune system **protects the body against foreign and harmful things**. Harmful things may include viruses, bacteria, and cells that have become abnormal. **After a transplant, a person's immune system is weakened. This can increase the risk of PTLD.** Patients should not stop taking immunosuppressants. They should talk to their transplant doctor about any questions or concerns.

➤ What are the symptoms?

The symptoms of PTLD are broad. They can overlap with symptoms of other conditions. Symptoms can be different in different people, and may include:

- a general change in how the patient is feeling
- swollen lymph nodes
- unexplained weight loss over a few weeks
- fever or night sweats
- sore throat
- fatigue
- chronic sinus congestion
- severe abdominal pain
- no appetite, nausea, or vomiting
- black or bloody stools



These symptoms may not mean PTLD, but they should be looked at by the patient's transplant team. **The transplant team needs to be aware of any signs or symptoms, so they can diagnose and treat PTLD quickly.**

➤ How is PTLD diagnosed?

The transplant team will review the patient's medical and transplant history. Patients may also have to meet other healthcare providers and go in for:



Biopsies (to take tissue samples)

e.g., blood, bone marrow, cerebral spinal fluid, etc.



Medical imaging

e.g., CT scan, PET scan, MRI, etc.

The transplant team will test the tissue samples and look at the results. Two important tests are **levels of EBV** and **how immune cells in the patient's body may have changed**.

> What types of treatments are there?

The treatment options available will depend on many factors, like medical history, the type of PTLD, previous treatments, and more. Some options include:



Adjusting the immunosuppressants

helps the immune system control PTLD while keeping the transplant healthy.



Antibody therapy

helps the immune system recognize and fight specific cells. In PTLD, it may be used to target B cells.



CAR T-cell therapy

is made from the patient's T cells. The patient's T cells are genetically modified in the lab to attack specific types of cancer cells.



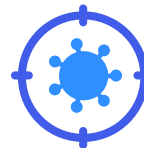
Chemotherapy

kills cells that grow and multiply quickly, including cancer cells. When it is used with antibody therapy, it's called chemo-immunotherapy.



Clinical trials

are research studies. In a clinical trial, patients may receive an existing treatment or a new treatment that is being studied.



EBV-directed therapy

targets and kills cells that are infected by EBV. It is used to treat diseases linked to EBV, including EBV-positive PTLD.



Surgery and radiotherapy

are not usually used to treat PTLD. They may be used to control or reduce symptoms.

➤ Types of support to consider

Each person's situation and needs for support are different, and may change over time. Consider reaching out for the following types of support:

- educational
- financial
- practical
- general well-being
- caregiver



➤ Where can I learn more?

Talk to the transplant team! They are experts on a patient's transplant history and immunosuppressants.



You can also visit
aboutPTLD.com



Information and resources include:

- types and risk factors
- links to find support
- videos

Acknowledgments

aboutPTLD is a collaboration of many different organizations who support transplant, rare disease, and cancer patients. We are so thankful to the patients and caregivers who worked with us to share their perspective and help us design resources that better meet their needs.

Information in this resource and on aboutPTLD.com is not meant to be a substitute for advice from a medical professional.

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