

MS Essentials Tips

PML (Progressive Multifocal Leukoencephalopathy)

Some disease-modifying therapies (DMT) used to treat multiple sclerosis can result in a rare brain infection called PML. This infection is caused by the John Cunningham (JC) virus. The JC virus doesn't normally cause any symptoms and most people are unaware that they have been exposed to the virus. The virus can become reactivated and cause PML if a person's immune response is suppressed during treatment with a DMT. PML is a life-threatening medical emergency. Symptoms may include changes in vision or sensation, worsening muscle weakness, balance problems, personality changes and mental impairment.

Your doctor will order a number of tests to determine if you have been exposed to the JC virus and, if so, your risk of developing PML. The risk of PML is minimal (about 1 in 10,000) if you are antibody-negative (meaning you have not been exposed to the virus). Periodic tests are needed because an antibody-negative person can become antibody-positive (called seroconversion).

Most adults will be antibody-positive (meaning they are harbouring the virus). In such cases, you will need to have periodic tests to evaluate your PML risk and to detect PML early if it is suspected. This will enable you and your doctor to make a more informed decision about the risks and benefits of your MS treatment. The frequency of these tests will depend on the DMT you are taking.

Test/procedure	What it involves	Why it is needed
Blood test	A small needle is used to take a sample of blood	To detect antibodies to the JC virus and determine your "serostatus" (positive or negative)
Magnetic resonance imaging (MRI) scan	You lie on a platform while a powerful magnet painlessly scans your brain and neck area	Obtained before and/or during treatment to ensure you do not have PML
STRATIFY JCV assay*	A small needle is used to take a sample of blood	To measure the level of JC virus antibodies your body is producing to determine your PML risk (see below)
Lumbar puncture ('spinal tap')	A needle is inserted into your lower back and a small sample of fluid from around your spine is removed. Can cause headache and back pain. Brief bed rest may be needed.	To ensure you do not have PML when switching from one DMT to another May be required if PML is suspected

* Only for people taking Tysabri

Determining the risk of PML

The level of PML risk is determined by the STRATIFY JCV test: a higher antibody index means a higher risk of PML. This test is used only for people taking Tysabri. It is not used for other MS medications that are associated with a risk of PML. For these medications (e.g. Gilenya, Tecfidera, Ocrevus), the PML rate is very low (less than 1 in 10,000 people).

The PML risk is very low if you have been taking Tysabri for a year or two. For people who have been taking Tysabri for two or more years, the risks are:

Test result	PML risk
Low	About 1 in 1,600
Intermediate	About 1 in 350
High	About 1 in 100

The relative benefits and risks of treatment will change during the course of your MS. Your neurologist will review these risks with you to ensure that you are fully informed.