

TY SABRI

Tysabri (Natalizumab) is a class of drug known as selective adhesion molecule (SAM) inhibitors. Tysabri works differently to disease modifying drugs (DMDs).

How does Tysabri work?

It is thought that in MS, immune cells leave the blood vessels, cross the blood brain barrier and enter the central nervous system (CNS), where they cause inflammation and damage to myelin.

Tysabri works by binding to specific adhesion molecules on the immune cells. This stops the cells from crossing the blood brain barrier and entering the CNS, therefore reducing inflammation and damage.

Who is eligible for Tysabri?

Tysabri is licensed for those with rapidly evolving severe relapsing remitting MS. Rapidly evolving severe RRMS is defined by two or more disabling relapses in one year along with an increase of lesions on an MRI.

How is Tysabri administered?

Tysabri is given by intravenous infusion every four weeks. An infusion delivers fluid directly into the bloodstream through the vein. The infusion must be given at an infusion centre or infusion clinic within a hospital. Not all hospitals are able to administer infusions; you may have to travel to your nearest one. You should discuss this with your neurologist or MS Nurse.

Your blood pressure, temperature and pulse will be checked before your infusion. You will also be asked a number of questions prior to every infusion to ensure you are suitable for the treatment. The actual infusion takes approximately an hour, although you can expect to be in hospital for anything from a few hours to all day depending on your circumstances.

What are the side effects of Tysabri?

Progressive Multifocal Leukoencephalopathy (PML)

Taking Tysabri can increase the chance of someone developing PML. PML is a rare brain infection, caused by the JC virus, which can cause serious disability or death. The JC virus is commonly found in the general population however it only leads to PML if the immune system is weakened, either naturally by a disease such as AIDS or because it has been suppressed by a drug treatment. The immune system contains cells which protect the brain from the JC virus. When PML occurs in those taking Tysabri, it is believed that these cells are stopped from crossing the blood brain barrier by the adhesion molecules.

The chances of developing PML are quite small and currently the incidence rate of PML in those taking Tysabri is 1.62 per 1000. To date 145 people have contracted PML and 29 people have died from the condition. (Figures correct as of 18th July 2011).

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Due to the risk of PML, patients taking Tysabri are monitored very closely throughout the process. A test designed to determine the risk of patients contracting PML is currently in trial in the US. It is thought that if the JC virus is present in the system prior to being prescribed Tysabri, then the risk of PML is considerably higher than in those who do not have the JC virus in their system. It will not be able to tell a person whether or not they will contract PML; especially given that a person can become infected with the JC virus at anytime. However, it aims to be able to give the patient a more accurate idea of their chances of contracting PML.

Other serious side effects

Other serious side effects with Tysabri include allergic reactions – itching, rash, trouble breathing, chest pain, dizziness, nausea etc. Usually allergic reactions occur within two hours of infusion and during your first infusion you will be monitored closely for signs of these reactions. However, allergic reactions can occasionally happen any time after your infusion. If you show any signs of an allergic reaction you must consult your doctor immediately.

Common less serious side effects

Common side effects of Tysabri are headache, urinary tract infection, joint pain, tiredness, diarrhoea and depression. If you find it difficult to cope with any of these symptoms, or if they persist for a long time, contact your doctor.

Is Tysabri worth the risk?

Tysabri has been proven to reduce the frequency of relapses, disease progression and lesions. At the end of a two year study, Tysabri had reduced relapses by 67% compared with those taking the placebo. Of those on the trial, 7 out of 10 people had no relapses at all. 8 out of 10 people saw no disease progression at all during the two year study.

There are several Tysabri User Diaries on our website where those who have decided to take Tysabri record their thoughts and results. Some people have seen very dramatic results relatively quickly. Here are a few extracts from their diaries:

*"Two weeks after my first infusion I started to feel like getting out of bed and I started feeling interested in the outside world. I even started thinking about having a Christmas Party! How weird – I hadn't thought past having my breakfast for over a year! For my 2nd infusion I'd gone into the hospital in a wheelchair at 10am. I left at 7.30pm and WALKED back to the car – about half a mile through the hospital corridors. One year on and NO relapses, NO time in hospital, NO steroids and I have had two holidays. I can walk 1km with my dog and I feel better all round!"
Christine*

"To be completely honest, the thought of getting back to my life with some sense of control overrides any concerns I may have had and the risks seem somehow more remote." Richard

You can read the Tysabri user diaries in full on our website.

Tysabri has shown excellent results for many people. However, there are risks and you must weigh up the potential risks against the potential benefits. Discuss things with you family, friends healthcare professionals and make the decision that is right for you.

'Was Tysabri responsible for this or was it my body fighting back? Was it the miracle of prayer? The answer will never be known, all I know is I do not want to come off Tysabri!' Daniel