

Progressive multifocal leuko-encephalopathy

The aim of this information sheet is to answer some of the questions you may have about progressive multifocal leuko-encephalopathy (PML). You will be given this leaflet if you are being considered for treatment with a drug called rituximab (brand name Truxima® or Mabthera®). This leaflet is designed to address a very rare complication of rituximab therapy in more detail. You will be given additional information about rituximab itself including a patient alert card for individuals treated for non-cancer conditions.

What is PML?

PML stands for **progressive multifocal leuko-encephalopathy**. It is an extremely rare but life threatening condition so it is very important that you are aware of the signs and symptoms. It is also advisable to inform any partners or carers about your treatment as you may not notice some of the symptoms. PML may develop several months after treatment. It has also been associated with other drugs such as mycophenolate, but again this is very rare.

PML is caused by the re-activation of a virus called JC virus. The virus is named after the initials of the first patient with PML in which the virus was identified. The JC virus does not normally cause any problems and is present in up to 90 out of 100 adults. However, when the immune system is suppressed by rituximab, the JC virus may activate and PML can develop very rapidly. PML progressively damages the brain and spinal cord.

How common is it?

It is important to remember that although serious, PML is very rare and the vast majority of people treated with rituximab will not develop it. PML is not only associated with rituximab. There are reports of PML in patients treated with azathioprine, cyclophosphamide, leflunomide, corticosteroids (such as prednisolone), methotrexate and mycophenolate. You may have already been treated with one or more of these medicines. The table below indicates the chance of developing PML in various groups.

General population	1 in 500,000
Patients with rheumatoid arthritis	1 in 250,000
Patients with rheumatoid arthritis treated with rituximab	1 in 25,000
Patients with systemic lupus erythematosus	1 in 25,000
Patients with vasculitis	1 in 50,000

What are the signs and symptoms?

If you notice any of the following new symptoms, you must report them to your doctor as soon as possible:

- pins and needles
- shaky movements
- loss of vision
- changes in behaviour or mood
- difficulty with movements (face, arms or legs)
- weakness
- unsteady on feet
- problems with speech

Do I need any tests to confirm the diagnosis?

If your doctor is concerned that you may be developing PML, they may arrange for further investigations. These may include testing a small sample of fluid (cerebrospinal fluid or CSF) from the spinal cord for the JC virus. You may have an MRI scan and you may have neurological assessments. If you have any questions about these investigations, ask your doctor.

What are the treatments for PML?

At present there are no treatments available for PML and it is not possible to predict who will develop the complication.

Where can I get more information?

If you have any questions or concerns about PML, please contact your consultant or clinical nurse specialist via the hospital switchboard on 020 7188 7188. There is a voice recognition system and you will be asked to say the name of the member of staff you wish to speak to.

Contact us

If you have any questions or concerns about PML, please contact your **consultant** or **clinical nurse specialist** via the hospital switchboard on **020 7188 7188**.

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

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