Living with NMO

TREATMENTS

NMO|UK

The Walton Centre in Liverpool and John Radcliffe Hospital in Oxford are recognised as specialist NHS centres in the diagnosis and care of patients with Neuromyelitis Optica (NMO) in the UK Please contact either centre if you have any further concerns regarding your diagnosis or symptoms.

This booklet can be provided in other formats including large print or as an audio file. Please contact either specialist centre for details or go to www.nmouk.nhs.uk

NMO Service
Walton Centre Foundation Trust
Lower Lane
Fazakerley
Liverpool L9 7LJ

Contact: 0151-529-8357

NMO Service
John Radcliffe Hospital
West Wing
Headley Way
Oxford OX3 9DU

Contact: 01865-231905

NMO SPECTRUM-UK
working to support the NHS and sufferers of NMOSD throughout the UK.
No MOre Suffering Alone

NMO SPECTRUM-UK
Registered Charity No 1158104

Your Medication

The purpose of this booklet is to give you some information about the medications we commonly use to treat NMO and what to expect from them including side effects, monitoring and things to avoid whilst taking these medication. If you have any questions after reading this booklet, please ask your specialist Nurse or Doctor

CONTENTS

Page	Medication
5	Prednisolone
11	Azathioprine
17	Mycophenolate
22	Methotrexate
28	Rituximab
34	Plasma Exchange/Immunoglobulins
35	Symptom Management

In NMO disabilities can accumulate with each acute attack including visual problems and/or paralysis of limbs. It is therefore important that relapses are treated quickly and effectively and preventative medications are put into place to reduce further relapses.

Management of NMO: NMO Treatment Algorithm

At present there is no cure for NMO so management focuses on the following key areas:

1. Treating acute attacks/relapses
2. Preventing relapses
3. Treating the residual symptoms of the relapse

Relapses/Attacks

A high dose steroid, Methylprednisolone (solumedrol) is usually given during a relapse. Steroids work by dampening the immune system and reducing inflammation around the site of nerve damage.

Preventing Relapses

Immunotherapies are powerful medicines that dampen down the activity of the body's immune system. Drugs such as Prednisolone, Azathioprine, Methotrexate or Mycophenolate are used to allow reduction of steroids. All these treatments increase the risk of serious infections therefore blood will be monitored for full blood count, kidney and liver function

Symptom management

Residual symptoms from a relapse can be treated with a variety of medication depending on the issue. Please ask your Doctor or Nurse specialist for more advice.

PREDNISOLONE

What are steroids?

Steroids（cortisone or corticosteroids） are hormones that occur naturally in the body. Steroids suppress the body's immune system by blocking a chemical called histamine（released during an allergic reaction）, decrease swelling and inflammation. Steroids used to treat disease are man-made corticosteroids and are different to anabolic steroids sometimes used in sports. Prednisolone is the most common steroid tablet. Oral steroids are used to treat a large number of conditions such as autoimmune diseases, joint and muscle disease, allergies and asthma.

How long do they take to work?

Prednisolone works quickly, usually within a few days.

What dose do I take?

Prednisolone is available in 1mg and 5mg tablets either as a plain or enteric coated tablet. Prednisolone is usually taken in the morning with food. Often you will start on a high dose e.g. 40-60mg and then slowly reduce to a lower daily dose. You may stay on a small maintenance dose indefinitely as relapses may return if the steroids are stopped.

Do not stop taking Prednisolone suddenly if you have been taking them for more than three weeks. It can be dangerous to stop steroids suddenly. Your body normally makes steroid chemicals, when you take Prednisolone your body may reduce or stop making its own steroid chemicals. If you stop taking Prednisolone, your body does not have any steroids. This can cause withdrawal symptoms such as weakness, tiredness, feeling sick, vomiting, diarrhoea, abdominal pain, low blood sugar, and low blood pressure which can cause dizziness, fainting or collapse. These side effects can be serious or even life-threatening. If the dose is reduced gradually, the body gradually resumes its natural production of steroids and the symptoms do not occur.

When taking steroid tablets you should carry a steroid card which records how much Prednisolone you are on and how long you have been taking it. If you become unwell or are involved in an accident you may require extra steroids.

What do I do if I miss a dose?

If you miss one dose take the usual dose when it is next due.

What are the possible side effects?

The longer you are taking prednisolone and the higher the dose, the more likely you are to have problems. The most common side effects are:

- **Weight gain:** you may also develop puffiness around the face.
- **An increased risk of duodenal and stomach ulcers:** You are usually prescribed medication (Lansoprazole, Omeprazole) to reduce these effects. Tell your doctor if you develop indigestion or abdominal (stomach) pains.
- **Osteoporosis:** (thinning of the bones) you are usually prescribed a medicine called Alendronic acid and calcium supplements, to help prevent bone loss. Make sure your calcium intake is at least 1500mg per day.

Vitamin D supplements may also help. If possible do at least 30minutes of weight bearing exercise each day.

- **Increased chance of infections;** as steroids suppress the immune system you are more likely to develop infections. Signs of infection can be disguised by prednisolone. If you come into contact with, or develop chicken pox or shingles you should report to your doctor as soon as possible as you may need anti-viral treatment.

- **Skin problems:** such as acne, stretch marks. Poor healing after injuries, thinning skin, and easy bruising.
- **Increased blood pressure;** have your blood pressure checked regularly, it can be treated if it becomes high.
- **High blood sugar:** (diabetes), your doctor may arrange a yearly blood sugar test to check for diabetes, in particular, if you have a family history of diabetes.
- **Mood and behavioural changes:** some people actually feel better in themselves when taking steroids. However, steroids may aggravate mental health problems such as depression, confusion or irritability, some people may develop delusions or suicidal thoughts. Seek medical advice if any worrying mood or behavioural changes occur.
- **Eye problems:** steroids may exacerbate glaucoma, papilledema or cataracts.
- **Sleep problems:** steroids can disturb your sleep so it is best to take them in the morning to minimise this.

These side-effects may affect **some** people who take steroids. **There is often a balance between the risk of side-effects against the symptoms and damage that may result if not treated.**

Can I take other medicines along with Prednisolone?

Prednisolone may be prescribed along with other drugs in treating your condition. You should not take anti-inflammatory painkillers e.g. ibuprofen or neurofen, as together they may increase the risk of a stomach ulcer developing. Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

Do I need any special checks while on Prednisolone?

Your doctor may check your general condition such as weight, blood pressure and sugar level. You may have a bone density scan.

You should let your dentist know you are on steroids if you are having any dental treatment and your pharmacist when collecting any prescriptions for you.

Alcohol

It is safe to drink alcohol in moderation whilst on Prednisolone, but it may aggravate indigestion.

Vaccinations

It is recommended that you should not be immunised with 'live' vaccines such as yellow fever. Pneumovax and yearly flu vaccines are safe and recommended.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you what to do about your Prednisolone therapy. If you do need an operation, you may need to increase the dose of Prednisolone for a short time. This is because the body requires more steroids during physical stress.

Is Prednisolone OK in pregnancy and breastfeeding?

Although it is best not to take Prednisolone during pregnancy, it is safer than many drugs and the benefit of treatment with Prednisolone may outweigh the risks. Please discuss with your doctor.

Prednisolone appears in small amounts in breast milk but maternal doses of up to 40mg daily are unlikely to cause systemic effects in the infant.

3 Important things to remember whilst taking steroids

- Always carry your steroid card.
- Never stop steroids abruptly or alter your dose without discussing with your doctor first.
- If you have any other illness (like an infection) while you are taking steroid tablets; the dose may have to be increased.

AZATHIOPRINE (Imuran, Azopress)

What is Azathioprine?

Azathioprine is an immunosuppressant drug, it reduces the activity of the body's immune system (the defence system) dampening down the underlying disease process with the aim of preventing further relapses rather than treating symptoms. Azathioprine is used in many other conditions apart from NMO such as rheumatoid arthritis, systemic lupus erythematous (SLE), psoriasis and organ transplants.

How long does it take to work?

Before starting Azathioprine you may have a blood test for Thiopurine Methyl Transferase (TPMT) to establish if you have adequate levels of this enzyme. TPMT is used to breakdown Azathioprine and low levels may mean you are at more risk of side effects.

Azathioprine does not work immediately, it can take up to 8 - 12 weeks to take effect. Azathioprine cannot cure the condition and you may need to take it for several years to keep your relapses under control.

What dose do I take?

Azathioprine is taken in tablet form once or twice per day. It is taken with or after food (it can cause stomach irritation if taken on an empty stomach).

The dose starts at 25mg per day, increased in increments of 25mg every 3 days up to 100-250mg depending on your body weight (2-3mg/kg). Your doctor will advise you about the correct dose and this may be changed depending on your response to the medication.

What do I do if I miss a dose?

Take your next dose at the normal time. Do not double the dose. If you take too much Azathioprine, tell your doctor

Can I take other medicines along with Azathioprine?

Azathioprine may be prescribed along with other drugs in treating your condition. Some drugs interact with Azathioprine, such as Allopurinol (used for treatment of gout) antibiotics e.g. Trimethoprim and Co-trimoxole (often used in urine infections), so you should always tell any doctor treating you that you are taking Azathioprine. Do not take over-the-counter preparations

or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

What are the possible side effects?

The most common side-effects of Azathioprine are sickness, diarrhoea, vomiting or abdominal (stomach) pain, dizziness and hair loss (however, hair often re-grows even if you carry on taking it). These side effects often occur at the beginning of treatment but settle as you become used to the medication.

Azathioprine can affect the production of some of the cells in the bone marrow. This can make you more prone to infections, or cause problems with clotting of your blood or wound healing.

There is a slightly increased risk of certain types of cancer with Azathioprine. Discuss this with your doctor. Because of the small increase in risk of skin cancer, you should avoid exposure to strong sunlight and protect your skin with sun block or sunscreen.

What do I do if I experience side effects?

If you experience any signs of illness or side effects such as infection, unexplained bruising, bleeding, sore throat, mouth ulcers, fever or malaise, contact your nurse, doctor, or pharmacist. It may be necessary for you to have a blood test to check how your body is coping.

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should contact your doctor as soon as possible. This is because chickenpox and shingles can be severe in people on treatment such as Azathioprine which effects the immune system. Therefore you may require antiviral treatment.

Vaccinations

It is recommended that you **should not** be immunised with 'live' vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary (for example rubella immunisation in women of childbearing age), in which case your doctor will discuss the possible risks and benefits of the immunisation with you.

Pneumovax and yearly flu vaccines are safe and recommended.

Do I need any special checks whilst on Azathioprine?

Azathioprine can affect the white cell count, and may cause liver or kidney problems. It is important to have your blood regularly checked for early signs of changes. These blood tests show if the medication is working to control the inflammation or if you are developing any side effects.

We recommend the following blood tests;

- full blood count including platelets
- urea and electrolytes
- liver function tests

Initially bloods are taken weekly for 6 weeks, fortnightly for 6 weeks, monthly for 6 months and then 2 monthly, unless problems occur and then bloods will be monitored more frequently.

The blood tests can be done at the clinic or, with agreement of your GP at your local surgery.

You may be asked to keep a record booklet with your blood test results. Bring this with you when you visit your GP, hospital or dentist.

Alcohol

It is safe to drink alcohol in moderation whilst on Azathioprine, however, it may aggravate nausea.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you what to do about your Azathioprine therapy. If you do need an operation, in most cases you will be advised to continue taking the Azathioprine.

Is Azathioprine OK in pregnancy and breastfeeding?

You should discuss with your doctor if you are planning to become pregnant whilst on Azathioprine. There are rare reports of premature birth and low birth weight following maternal exposure, particularly in combination with corticosteroids. Low white cell count have been reported in a proportion of neonates, extra blood monitoring is advised during pregnancy.

Azathioprine may pass into breast milk in small amounts, there is no evidence of harm in small studies.

MYCOPHENOLATE MOFETIL (CellCept)

What is Mycophenolate Mofetil?

Mycophenolate is an immunosuppressant drug, it reduces the activity of the body's immune system (the defence system) dampening down the underlying disease process with the aim of preventing relapses, rather than treating symptoms.

Mycophenolate is used in many other conditions apart from NMO such as organ transplants, rheumatic disease, systemic lupus erythematosus (SLE) and vasculitis (inflammation of blood vessels).

How long does it take to work?

Mycophenolate does not work immediately it can take up to 8 - 12 weeks to take effect. Mycophenolate cannot cure the condition and you may need to take it for several years to keep your relapses under control.

What dose do I take?

Mycophenolate is usually taken in capsule form twice a day. The capsules should be swallowed whole and taken with a glass of water or with food, **do not** crush or chew the capsules.

The dose starts at 500mg twice a day, increased in increments of 500mg every week up to 1gram twice a day. Your doctor will advise you about the correct dose and may be changed depending on your response to the medication.

What do I do if I miss a dose?

Take your next dose at the normal time. Do not double the dose. If you take too much Mycophenolate tell your doctor.

Can I take other medicines along with Mycophenolate?

Mycophenolate may be prescribed along with other drugs in treating your condition. Some drugs interact with Mycophenolate, such as anti-bacterial e.g. Metronidazole or Rifampicin so you should always tell any other doctor treating you that you are taking Mycophenolate.

Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

What are the possible side effects?

The most common side-effects of Mycophenolate are taste disturbance, nausea, or gastro-intestinal (stomach) inflammation or pain and weight loss.

These side effects often occur at the beginning of treatment but settle as you become used to the medication. Mycophenolate can affect the production of some of the cells in the bone marrow. This can make you more prone to infections, or cause problems with clotting of your blood or wound healing.

There is a slightly increased risk of certain types of skin cancer with Mycophenolate, avoid exposure to strong sunlight and protect your skin with sun block or sunscreen.

What do I do if I experience side effects?

If you experience any signs of illness or side effects such as infection, unexplained bruising, bleeding, sore throat, mouth ulcers fever or malaise, contact your nurse, doctor, or pharmacist. It may be necessary for you to have a blood test to check how your body is coping.

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should contact your doctor or nurse as soon as possible. This is because chickenpox and shingles can be severe in people on Mycophenolate, which effects the immune system, and you may require antiviral treatment.

Vaccinations

It is recommended that you **should not** be immunised with 'live' vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary (for example rubella immunisation in women of childbearing age), in which case your doctor will discuss the possible risks and benefits of the immunisation with you.

Pneumovax and yearly flu vaccines are safe and recommended.

Do I need any special checks while on Mycophenolate?

Mycophenolate can affect the white cell count, and may cause liver or kidney problems. It is important to have your blood regularly checked for early signs of changes. These blood tests show if the medication is working to control the inflammation or if you are developing any side effects.

We recommend the following blood tests;

- full blood count including platelets,
- urea and electrolytes
- liver function tests

Initially bloods are taken weekly for 6 weeks, fortnightly for 6 weeks, monthly for 6 months and then 2 monthly and more frequently if problems occur.

The blood tests can be done at the clinic or, with agreement of your GP at your local surgery. You may be asked to keep a record booklet with your test results. Bring this with you when you visit your GP, hospital or dentist.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you what to do about your Mycophenolate therapy. In most cases you will be advised to continue taking the Mycophenolate.

Alcohol

It is safe to drink alcohol in moderation whilst on Mycophenolate, however, it may aggravate liver problems.

Is Mycophenolate OK in pregnancy and breastfeeding?

Mycophenolate can harm the unborn child and it is very important not to become pregnant whilst taking it, therefore reliable contraception is essential. If you are planning a family you should not become pregnant for at least **6 weeks** after stopping mycophenolate. If you become pregnant whilst taking Mycophenolate, you should stop immediately and discuss with your doctor straight away.

METHOTREXATE

What is Methotrexate?

Methotrexate is an immunosuppressant drug, it reduces the activity of the body's immune system （the defence system ） dampening down the underlying disease process with the aim to prevent further relapses, rather than treating symptoms.

Methotrexate is used in many other conditions apart from NMO such as rheumatoid arthritis, psoriasis, crohns disease.

How long does it take to work?

Methotrexate does not work immediately it can take up to 8 - 12 weeks to take effect. Methotrexate cannot cure the condition and you may need to take it for several years to keep your relapses under control.

What dose do I take?

Methotrexate is **only taken once a week** on the same day each week. The tablets/capsules should be swallowed whole and taken with a glass of water after food, do not crush or chew the capsules.

Methotrexate is usually prescribed in **2.5mg tablets.** However, it is also available as 10mg tablets, the two strengths are different shapes but similar colour. To avoid confusion it is recommended that only 2.5mg tablets are used.

The dose starts at 7.5mg weekly increasing to maximum 25mg weekly.

Your doctor will advise you about the correct dose and may be changed depending on your response to the medication.

A vitamin called folic acid has been shown to help your body cope with the Methotrexate and reduce some of the side affects you may experience. Folic acid tablets are taken once per week on a different day to Methotrexate.

What do I do if I miss a dose?

If a dose is missed on the normal day, you can take it one or two days later. **Do not take** the dose if it is **three** or more days late. For the following week take the dose on the **usual** day. Do **not** double the dose. If you take too much Methotrexate tell your doctor immediately.

Can I take other medicines along with Methotrexate?

Methotrexate may be prescribed along with other drugs in treating your condition. Some drugs interact with Methotrexate, such as non-steroidal anti-inflammatory medications e.g. Ibuprofen, Aspirin, Diclofenac, Naproxen, and anti-bacterial e.g. Ciprofloxacin and Trimethoprim. Always ensure any Doctor is aware you take Methotrexate Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

What are the possible side effects?

The most common side-effects of Methotrexate are sickness, vomiting or abdominal pain, diarrhoea. These side effects often occur at the beginning of treatment but usually settle as you become used to the medication. Methotrexate can affect the production of some of the cells in bone marrow. This can make you more prone to infections, or cause problems with clotting of your blood or wound healing. Rarely, Methotrexate causes inflammation of the lung. If you become breathless or develop a dry cough, you should see the doctor as soon as possible. Most people cope well on Methotrexate.

What do I do if I experience side effects?

If you experience any signs of illness or side effects such as infection, unexplained bruising, bleeding, sore throat or mouth ulcers, fever or malaise, contact your nurse specialist, doctor, or pharmacist It may be necessary for you to have a blood test to check how your body is coping

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should contact your doctor as soon as possible. This is because chickenpox and shingles can be severe in people on treatment such as Methotrexate which has effects on the immune system. Therefore you may require antiviral treatment.

Vaccinations

It is recommended that you **should not** be immunised with 'live' vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary（for example rubella immunisation in women of childbearing age），in which case your doctor will discuss the possible risks and benefits of the immunisation with you. Pneumovax and yearly flu vaccines are safe and recommended.

Do I need any special checks while on Methotrexate?

Methotrexate can affect the white cell count, and may cause liver or kidney problems. It is important to have your blood regularly checked for early signs of changes. These blood tests show if the medication is working to control the
inflammation or if you are developing any side effects. We recommend the following blood tests;

- full blood count including platelets,
- urea and electrolytes
- liver function tests

Initially bloods are taken weekly for 6 weeks, fortnightly for 6 weeks, monthly for 6 months and then 2 monthly, unless problems occur and then bloods will be monitored more frequently.

The blood tests can be done at the clinic or, with agreement of your GP at your local surgery.
You may be asked to keep a record booklet with your blood test results. Bring this with you when you visit your GP, hospital or dentist.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you what to do about your Methotrexate therapy. If you do need an operation, in most cases you will be advised to continue taking the Methotrexate.

Alcohol

It is safe to drink alcohol in moderation whilst on Methotrexate, however, it may aggravate liver problems.

Is Methotrexate OK in pregnancy and breastfeeding?

Fertility may be reduced for both males and females during therapy but this tends to be reversible. Methotrexate can harm the baby and it is very important not to become pregnant or to father a child whilst taking Methotrexate and for at least 3 months after Methotrexate is stopped, therefore reliable contraception is essential.

You should not breastfeed while taking Methotrexate. The drug could pass into the breast milk and risks to the baby are unknown.

RITUXIMAB (Truxima, MabThera)

What is Rituximab?

Rituximab is a drug known as a monoclonal antibody. Rituximab binds to the surface of a type of white blood cell, the B lymphocyte, which is involved in the making of antibodies by the immune system. The immune system produces antibodies and immune cells to attack viruses and bacteria. In autoimmune conditions such as Neuromyelitis Optica（NMO）, there is abnormal activity of the immune system. After taking Rituximab, B cells become undetectable in the blood for several months and then slowly return to normal levels.

Rituximab can be used where disease is severe and has not responded to other treatments. At present it is licensed for use in a related autoimmune disease called rheumatoid arthritis, non-Hodgkin's lymphoma or leukaemia.

How long does it take to work?

Rituximab takes 2-6 weeks to take effect.

Rituximab does not cure the condition and you may need to take it for several years to keep your relapses under control.

What dose do I take?

Rituximab is given by intravenous infusion, initially, **two** infusions are given **two weeks** apart. Subsequently, you may be given six monthly or a variable dosing regime depending on B cell production. The drug is infused in hospital over four to six hours on each visit. The cells that Rituximab affects help to fight infection. If you think you may have an infection, even a mild one such as cold, you should wait until the infection has passed before you have an infusion. If you are prescribed Rituximab it is recommended that you carry a therapy alert card, then if you become unwell, anyone treating you will know that you have had Rituximab and that your B-cell count may be low.

Can I take other medicines along with Rituximab?

Rituximab may be prescribed along with other drugs in treating your condition. Discuss any new medications with your doctor before starting them, and tell any other doctor treating you that you are taking Rituximab.

Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, nurse or pharmacist.

What are the possible side effects?

- Rituximab can cause side effects. During or within the first 2 hours of the first infusion you may develop fever, chills and shivering. Other side effects **uncommonly** seen during infusion are itching of your skin, sickness, tiredness, headache, breathing difficulties, sensation of the tongue or throat swelling, itchy, runny nose, flushing, back pain and irregular heart rate. Pre-existing conditions such as heart disease may be affected and worsened. Paracetamol, anti-histamine and corticosteroid will be given prior to the infusion to reduce these effects.

  Tell the person giving you the infusion immediately if you develop any of these symptoms as the infusion may need to be slowed down or stopped for a while. When these symptoms go away, or improve, the infusion can be continued. The frequency of these reactions decreases during subsequent infusions.
- There is a theoretical risk of increased infections after Rituximab but this is very unusual in practice.
- Rituximab may rarely also cause abnormalities of

your blood and affect liver function.

- If you have had hepatitis B there is a risk of reactivation which may cause serious liver damage.
- Very rarely, patients have developed a serious brain infection, Progressive Multifocal Leukoencephalopathy（PML）, caused by a virus called JC virus, which has been fatal. **Tell your doctor immediately** if you have memory or visual loss, trouble thinking or difficulty walking.

Despite this list of side-effects, over a million patients worldwide have received Rituximab and serious side-effects have been rare. For the great majority of patients, Rituximab is safe and well-tolerated.

If you have not had chickenpox but come into contact with someone who has chickenpox or shingles, or if you develop chickenpox or shingles, you should contact your doctor as soon as possible. This is because chickenpox and shingles can be severe in people on treatment such as Rituximab which has effects on the immune system. Therefore you may require antiviral treatment.

Vaccinations

Immunisations should be given at least two weeks before Rituximab, as Rituximab removes antibody forming cell.

It is recommended that you **should not** be immunised with 'live' vaccines such as yellow fever. However, in certain situations a live vaccine may be necessary (for example rubella immunisation in women of childbearing age), in which case your doctor will discuss the possible risks and benefits of the immunisation with you. Pneumovax and yearly flu vaccines are safe and recommended.

Do I need any special checks while on Rituximab?

You will have a physical examination and blood tests in the 7 days prior to treatment *Full blood count *urea and electrolytes *liver function test *screen for hepatitis B and C *Pregnancy test *ECG *Chest x-ray.

Hepatitis screen, ECG or CXR do not need repeating before the second dose of each course unless there is new pertinent history or findings (eg cough with fever, jaundice). You will need to have monthly bloods taken whilst on Rituximab to check your full blood counts, immunoglobulins and CD markers to help us to plan when your next infusion should be given.

Alcohol

Yes, in moderate amounts.

What happens if I need an operation?

Let the doctor or nurse know so they can advise you. If the operation is planned Rituximab will be given at least 1 month before.

What if I am thinking of getting pregnant?

No one knows the risk of Rituximab to an unborn baby.

Rituximab is an antibody and can cross the placenta and may affect the baby. For female patients, we would generally recommend a gap of 6 weeks between having Rituximab and trying for a baby.

Do not breastfeed while on Rituximab. It is not yet known whether Rituximab could pass into the breast milk or the risks to the baby.

PLASMA EXCHANGE (PLEX)

If symptoms in relapses do not respond to steroid treatment, plasma exchange may be considered. This treatment aims to remove the harmful antibodies from the blood. Using a specialised technique, the blood is drawn out of the body and the plasma is separated. The blood and plasma are then returned back into the body without these antibodies. The process is very much like dialysis but removes antibodies instead of waste. Possible side effects during PLEX include feeling faint or light-headed, numbness and tingling around your mouth and nose or in your fingers during the treatment.

IMMUNOGLOBULINS (Ig)

Immunoglobulins are a blood product made from pooled plasma from many different people. Its mode of action is not completely understood, but it does block harmful antibodies and other immunological factors.

Immunoglobulin is given through an intravenous infusion at a rate, dose and time which is individualised for each patient. Possible side effects can occur with IVIg. These are usually mild such as headache and high blood

pressure and respond to changes in the rate of administration. A rash can sometimes develop. If the treatment is successful it may need to be repeated several times.

SYMPTOM MANAGEMENT

Your consultant may prescribe you medications to help to minimise symptoms of NMO. These are some of the most commonly used medications for our patients:

Used for pain and sensory issues:

Carbamazipine

Gabapentine

Pregabalin

Used for muscle spasms and spasticity:

E.g. Baclofen, Tizanidine

Used for overactive bladder and incontinence:

Anti-Musclarinic e.g. Solifenacin, Oxybutynin and Desmopressin spray

Last updated: April 2019
Next review: April 2021