

# Lemtrada (Alemtuzumab) infusion patient guide

This leaflet explains more about your Lemtrada infusions. If you have any further questions, please speak to a doctor or nurse caring for you.

## What is Lemtrada?

Lemtrada is a Disease Modifying Treatment (DMT) which is used to treat Relapsing Remitting Multiple Sclerosis. It is given yearly for two years. The first sets of infusions are given over five days and the second sets of infusions are given over three days.

## Where do I need to go?

The infusions are given on our Infusion Suite which is situated on McKissock ward, 2<sup>nd</sup> floor Atkinson-Morley Wing, St George's Hospital. The infusion is usually given as an outpatient unless otherwise agreed with your Consultant Neurologist. You will be asked to come to the infusion suite each day at 8.30 am and will be on the infusion suite for approximately eight hours.

The telephone number for the infusion suite is 020 8266 6430.

## What pre-screening needs to be done?

When you choose Lemtrada as your DMT, there are a number of pre-screening tests that will need to be completed prior to you starting the medication.

If you find it helpful – tick off the appointments/tests as they have been completed.

Pre-screening	Completed?	Date?
Lemtrada specific blood tests		
MRI scan		
Appointment 1 with TB team		
Appointment 2 with TB team		
For women: Cervical Smear Test (within the last 12 months)		
EDSS appointment		
Consent with Consultant Neurologist		

I will start my infusions on: .....

I must start my listeria free diet on: .....

I must stop my previous medication on: .....

## When will I get my appointment letter?

Your appointment letter for the infusion will not arrive until two weeks before you are due to start. If you require a letter before this date, please let your MS nurse know.

## What can I expect on the day of my infusion?

Once all of your pre-screening has been completed you will be contacted with a start date for your infusions and will be given a date to start your listeria-free diet. These phone calls will show up as a withheld number. Please let us know if you would prefer to be contacted via e-mail (you will need to sign our e-mail disclaimer form prior to any correspondence).

On the Monday the MS Therapies nurse will introduce themselves to you. They will ensure that all necessary checks have been completed and that they are happy for you to commence your infusion.

They will then insert a cannula (a small, plastic tube) into your arm and it is through this that you will have your infusion. The infusion will take around six hours in total as prior to the Lemtrada you will receive pre-medications that will help to reduce any side-effects you may experience.

During your infusion and for two hours afterwards your blood pressure and pulse will be monitored every 30 minutes. As long as they remain stable you will be discharged home and come back the following morning.

## Handy to know before your infusion:

Here is a list of suggestions to help prepare yourself for your infusion:

- Each day ensure you are wearing comfortable clothes with either short sleeves or sleeves that are easy for you to roll up
- Tea, coffee, water, biscuits and a limited selection of sandwiches are available on the infusion suite. If you prefer you can bring in your own food each day. We have both a refrigerator and microwave available. There are also shops selling food throughout the hospital such as Marks and Spencer, Pret a Manger, Peabody's and the hospital canteen.
- The infusion days can be quite long and so we would suggest that you bring plenty of things to do such as books to read, a tablet to watch films on, puzzle books, colouring books, music to listen to, your phone or your laptop. Wi-Fi is available but is charged.
- There is limited space on the infusion suite and so we ask that you kindly limit your visitors to one person at a time. They can come at any time during the day but may be asked to leave if the infusion suite is busy and there are no available seats
- If someone is driving you to your appointment each day, please let the MS Therapies nurse know and they will provide you with a parking form to reduce the parking cost to £10 per week.
- We don't advise driving yourself to your infusions, this is because people tend to be quite fatigued post-infusion.

## Handy to know after your infusion:

- After your infusion you are likely to feel quite tired for the next few weeks; this is normal and will improve over time. Many people plan to take a week off work following their infusion. You may feel tired for up to one month after your infusion and do discuss this with your employer in case adjustments need to be made. We can provide you with a doctor's note.
- You are likely to continue to experience a rash for about two days after your infusion; we advise that you take your antihistamine as directed for at least two days post-infusion.

- For 4-8 weeks after your infusion you are at an increased risk of infections or viruses and so we advise that if possible you don't have close contact with anyone with an infection such as a cold.
- Some people experience an exacerbation of their old MS symptoms after their infusion. This is normal but if you have any concerns contact your MS nurse.
- After Lemtrada you should not have any live vaccines. If you plan to go on a holiday that would require vaccination please contact your MS nurse for individual advice.
- You will be required to attend four weekly blood and urine monitoring at St George's hospital. On Tuesdays and Fridays 8.30-16.00 our phlebotomist is available on the Neuroscience day unit, 2<sup>nd</sup> floor, Atkinson Morley Wing. When our phlebotomist is on annual leave you will need to collect a blood form from Neuro Outpatients, ground floor, Atkinson Morley Wing and have the blood taken in phlebotomy which is situated in Lanesborough Wing. Urine samples can be left with outpatient's staff.
- For up to four years after your infusion you have a 36% chance of developing an over or under active thyroid gland, you have a 1% chance of developing a low platelet count which can cause excessive bleeding and you have a 0.3% chance of developing a kidney disorder. We monitor for this with blood and urine tests and so it is vital that you attend your monthly monitoring appointments. The MS Therapies nurses will go through what to look out for in more detail, if you have any concerns contact your MS nurse.

## Contact us

If you have any questions or concerns about your Lemtrada infusion please contact MS team Co-ordinator Alison McNally on 020 8725 2104 or your MS nurse directly.

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

**Web:** [www.nhs.uk](http://www.nhs.uk)

### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

**Tel:** 111

