

# Lemtrada (Alemtuzumab) Infusion Patient Guide

This leaflet explains 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 set of infusions is given over five days and the second set of infusions is given over three days.

## Where do I need to go?

The infusions are given in our Infusion Lounge which is situated on McKissock Ward, Second 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 Lounge each day at 8.30am and will be in 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 several 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.

Screening	Completed	Date
Lemtrada specific blood tests		
Chest X-ray		
MRI scan		
Appointment 1 with TB team		
For women: Cervical Smear Test (within the last 12 months)		
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 receive my appointment date?**

You will be contacted by the MS Infusion Nurses by telephone to organise a date for your pre-screening appointment and with a date to start treatment. If a letter is needed, this can be provided on request.

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

When all your screening has been completed you will be contacted with a start date for your infusions and you will be given a date to start your listeria-free diet. These phone calls will show as a withheld or private 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 nurses will introduce themselves to you. They will ensure that all necessary checks are complete 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. If 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 you prepare 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 lounge. If you prefer you can bring your own food each day. There are also shops selling food throughout the hospital such as Marks and Spencer, Pret a Manger, Peabody's and the hospital canteen. However, we prefer for you to stay on the infusion lounge once the infusion has been started.
- The infusion days can be quite long and so we suggest that you bring plenty of things to do such as books to read, a tablet to watch films, puzzle books, colouring books, music to listen to, your phone or your laptop. Wi-Fi is available.

- To help protect patients and staff from Coronavirus (Covid-19) visitors are not allowed to stay on the infusion lounge once the infusion has started. 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 so 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.
- You will be advised to shield for some time after your treatment due to the risk of infection with Covid-19.
- 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 requires vaccination, please contact your MS nurse for individual advice.
- You will be required to attend four weekly blood and urine monitoring tests at St George's Hospital for four years post treatment start date. Our phlebotomist is available **on Tuesdays and Fridays 8.30am to 12.00 midday and 1.00pm to 4.00pm in the Willow Annex, Perimeter Road** and **on Thursdays 8.30am to 12.00 midday in Neurology Outpatients, Ground Floor, Atkinson Morley Wing**. When our phlebotomist is on annual leave you will be notified whether your appointment will be rescheduled or if you will be required to attend Phlebotomy in Lanesborough Wing.
- For up to four years after your last 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 Lakeish Francis 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 advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:

Monday, Tuesday and Thursday between 10am and 4pm

Friday between 10am and 2pm.

The Walk-in and Advisory telephone services are closed on Wednesdays.

Please contact PALS in advance to check if there are any changes to opening times.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

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

### NHS UK

The NHS 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

### AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website ([www.accessable.co.uk](http://www.accessable.co.uk)). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

