

# Alemtuzumab (Lemtrada)

**This factsheet is about alemtuzumab, a disease modifying therapy (DMT) for relapsing multiple sclerosis (MS). At the end of this factsheet you'll find out where you can get more information on this drug, other drugs for MS and the benefits of early treatment.**

This factsheet doesn't cover everything about this drug and shouldn't be used in place of advice from your MS specialist team. For more information speak to them and read the online information from the drug's makers (see the section **More information and support**).

## What is alemtuzumab?

Alemtuzumab is a cancer drug that used to be called Campath. In 2013 it was given a licence to be used in the UK against relapsing MS. In 2014 the National Institute for Health and Care Excellence (NICE) gave the go ahead for the drug to be used on the NHS.

Alemtuzumab is pronounced: allem-TOOZER-mab. Its brand name is **Lemtrada** (lem-TRAH-da).

## Can I have this drug?

Alemtuzumab is licenced for treating 'active' relapsing MS, defined in guidelines as two or more relapses in the last two years. But more and more MS specialists define 'active' MS as one recent relapse and/or signs on MRI scans that MS is active. These signs include new 'lesions' (areas of damage) in your brain.

This drug is usually offered to you if your MS is very active, especially if other DMTs haven't controlled it.

In some circumstances alemtuzumab might be

your first DMT. But because of the risk of serious side effects it's usually given if another DMT fails to control your MS. Read more on side effects in the section **What side effects might I get?**

In April 2019 the European Medicines Agency advised that alemtuzumab should only be given to people with very active relapsing MS. This is a short-lived step while they investigate reports of new but rare and serious side effects. For more details go to **What side effects might I get?** Below is who could have this drug before this restriction was announced.

## So you can take alemtuzumab if you have:

### Scotland, Northern Ireland and Wales

- relapsing MS and, despite taking another DMT, you've had a relapse in the last year and MRI scans show new signs that your MS is active (you have new 'lesions')
- alemtuzumab can be used as your first DMT if you've had a recent relapse and/or MRI scans show new signs that your MS is active. In these cases it can be used whether you've tried another DMT or not

### England

You're usually offered this drug only if:

- despite taking another DMT, you've had a relapse in the last year or MRI scans show new signs that your MS is active (you have new lesions)

You might be offered alemtuzumab as your **first** DMT if you meet one of the following conditions:

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- you've had two relapses in the last two years
- or you've had two or more relapses in one year and MRI scans show new signs that your MS is active (you have new lesions). This is called 'rapidly evolving severe relapsing remitting MS'.
- or you've had a relapse in the last two years and MRI scans show new signs that your MS is active (two or more new lesions have appeared over a year)

In rare circumstances you might be offered alemtuzumab in England if you've had a recent relapse and/or MRI scans show new signs that your MS is active.

If you decide to take this drug, you and your neurologist must be happy to accept its higher risk and the need for extra blood and urine tests.

Whether you'll be offered this drug depends on if you qualify for it based on guidelines used by your neurologist.

These guidelines come from the Association of British Neurologists (ABN) and NICE. In England there are rules from NHS England about who can have the different DMTs and when. Scotland, Wales and Northern Ireland also have their own guidelines for many DMTs.

If you can have a drug also depends on whether the NHS where you live will pay for it. NHS guidelines on this tend to follow what NICE says.

### You won't get this drug if:

- you're already on another DMT that's controlling your MS well. You can't take more than one DMT at a time
- you have progressive MS

Alemtuzumab won't work if you don't get relapses. So you won't be offered it if you have primary or secondary progressive MS. But several drugs are being tested to see if they work against these non-relapsing, progressive types of MS.

You might not be able to take this drug if you have some health conditions. So tell your MS specialist your full medical history, including any other health problems and medications you're taking.

You shouldn't be taking this drug if you're a

woman trying to have a baby or not using contraception.

But if you've stopped taking alemtuzumab, then it's safe to get pregnant after four months have passed since your final dose (see the sections **What side effects might I get?** and **I want a child. Can I take alemtuzumab?**).

## How do I take it?

You're given alemtuzumab in hospital through a drip (an 'infusion'). You sit in a chair or lie on a bed while it's pumped into your bloodstream through a needle into a vein in your arm or leg. Most people only need two infusions, spaced 12 months apart.

For the first infusion you go to hospital for five days in a row. Each day you have an infusion that takes about four hours. You might go home every day two hours after your infusion, or stay in hospital for your treatment.

You have the second treatment a year later, over three days in a row, again for about four hours each day. After the second treatment many people don't need to take this drug again. But between three people in ten and four in ten need a third or fourth infusion before the drug works.

## How does it work?

Your immune system fights off infections. But with MS it attacks the nerves in your brain and spinal cord by mistake. This leads to inflammation and damage, especially to the coating that covers your nerves (myelin).

This damage interferes with how signals travel along these nerves. Over time this affects your control over many parts of your body and causes symptoms of MS.

It's thought that much of the damage we see with MS is caused by white blood cells or 'lymphocytes', especially ones called T cells and B cells.

Alemtuzumab protects your nerves from damage by killing these immune cells before they get into your brain and spinal cord. Your immune system replaces these cells but the new ones are less likely to attack your nerves.

Alemtuzumab does what other DMTs don't. It makes a permanent change to your immune system. The drug 'resets' it for good, so its

positive effects can last years after your last dose.

## How well does it work?

When DMTs, including alemtuzumab, are working well you have:

- fewer and less serious relapses
- fewer new or bigger 'lesions' (or 'plaques') in your brain and spinal cord (lesions can be seen on MRI scans)

- a slowdown in your disability getting worse

Like other DMTs, alemtuzumab works best the sooner you start it after you're diagnosed with MS.

Taking it later can also have benefits but it can't undo any permanent disability that you may already have.

**DMTs can be split into three groups, according to how big their effect can be.**

### High (they can work very well):

- **alemtuzumab (Lemtrada)**
- natalizumab (Tysabri)
- ocrelizumab (Ocrevus) when used for relapsing MS\*
- haematopoietic stem cell transplantation (HSCT)

### Good (they can work well):

- cladribine (Mavenclad)
- dimethyl fumarate (Tecfidera)
- fingolimod (Gilenya)

- ocrelizumab (Ocrevus) when used for relapsing MS\*

### Moderate (they can work fairly well):

- glatiramer acetate (Copaxone and Brabio)
- five different beta interferons (Avonex, Betaferon, Extavia, Rebif and Plegridy)
- teriflunomide (Aubagio)
- ocrelizumab (Ocrevus) when used for early primary progressive MS

\*ocrelizumab is new, so it's too soon to be sure how to rank it when it's used for relapsing MS. It'll either be 'high' or 'good', so we've put it under both.

## The effectiveness of alemtuzumab is classed as 'high'



### Relapses dropped by: 50-55% compared to beta interferons

This means that in trials, on average, people saw a 50-55% drop in the number of relapses they had. This was compared to people who took beta interferons, a standard treatment for MS.

### How many people stayed free of relapses when they took this drug?

#### Trial one

78% of people who took alemtuzumab in one trial stayed free of relapses for two years. They'd never taken a DMT before.



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59% of people on beta interferon stayed free of relapses.



### Trial two

65% of people who took alemtuzumab in another trial stayed free of relapses over two years. They'd taken a DMT before that hadn't controlled their relapses.



47% of people on beta interferon stayed free of relapses.



 = no relapses

Disability getting worse was slowed down by: up to **42%** compared to beta interferons

This means that in one trial, on average, people saw a 42% drop in the risk of their disability getting worse. This was compared to people who took beta interferons.

**How many people's disability didn't get worse when they took this drug?**

### Trial two

Disability didn't get worse over two years for 87% of people who took alemtuzumab.



Disability didn't get worse for 80% of people who took beta interferon.



 = disability didn't get worse

In the other trial, people taking alemtuzumab saw a 30% drop in the risk of their disability getting worse. But this drop wasn't big enough to be seen as 'significant'. In other words, it could have happened by chance and not because of the drug.

The figures here for relapses and disability come from two trials: CARE-MS I and CARE-MS II. Each trial lasted two years, following over a thousand people in total. But in the first of these trials people taking alemtuzumab didn't see a significant drop in the risk of their disability getting worse.

Alemtuzumab might work much better for you than these average results - or it might not work as well.

**Long-term effects:** We don't have years of evidence about this drug's longer term effects. It's only been widely used since 2013. But a study of 87 people over seven years found it had a long lasting effect for the majority of people. For most their disability didn't get worse and relapses happened much less often. A larger study of 349 people over five years found similar results.

## What side effects might I get?

Like all drugs, alemtuzumab can have side effects, but not everyone gets them. Not many people stop taking this drug because of side effects.

The more effective a DMT is, the more risk of serious side effects. Alemtuzumab is, along with natalizumab, the drug that controls MS best but with the biggest risk of side effects. You might get them for a few years after your last treatment. So you'll need to be aware of this and have tests for four years after your last infusion (see **What tests will I need?**).

Alemtuzumab affects your immune cells that fight infections, so most people taking this drug get more infections. But these tend not to be serious and are relatively mild and easily treated. Up to four in ten people get a more serious side effect: a thyroid problem.

Alemtuzumab might harm unborn babies. If you're a woman you'll need reliable contraception (like the 'pill' or condoms) while you're taking this drug.

It's important to protect against pregnancy during each course of treatment and for four months after. For more information on getting pregnant see **I want a child. Can I take alemtuzumab?**

Your neurologist, GP or MS nurse can give you advice about ways of dealing with side effects.

## Very common side effects

(more than one in ten people get these)

- **less serious infections**
  - of your chest, throat, urinary tract and sinuses (the spaces around your nose)
  - most likely in the first month of treatment
- **reactions after your infusion** (most people get these)
  - including headache, rash, fever, feeling or being sick, hives (a skin rash), itching, red dening of the face and neck, and feeling tired
  - these are usually mild and short lived but can be serious for about three in 100 people
  - they can happen during the infusion or in the next 24 hours
- **a drop in your white blood cells** (lymphocytes which fight infections. The drug is meant to make this happen so almost everyone gets this)
- other side effects could include sore throat, diarrhoea, pain in your joints, back, stomach, pain or tingling in your arms and legs, dizziness and trouble sleeping

Your doctor should give you steroids to reduce infusion reactions and medication to prevent 'cold sores'. You'll be monitored during the infusion and for two hours after.

## Serious infections

This drug puts you at higher risk of getting a serious (but usually treatable) infection. In trials less than one person in 30 got a serious infection. Your neurologist may recommend extra tests or medicines to lower this risk.

Possible serious infections include:

- varicella zoster virus infections (shingles, chickenpox and types of inflammation of the brain). Only about one in 300 people got these in trials. If tests show you haven't already had this virus, you'll be vaccinated before you start alemtuzumab
- pneumonia
- genital warts caused by Human Papilloma Virus (HPV). Some types of HPV can cause pre-cancerous changes in a woman's cervix, so women on this drug should be checked once a year
- tuberculosis (TB) - your doctor may test you for this. Only about one in 300 people in trials got TB
- appendicitis
- it's not yet clear but it's possible you might be more at risk of thyroid, blood or skin cancer

Tell your doctor straight away if you have signs of an infection such as fever, chills or swollen glands.

## **Autoimmune conditions**

Alemtuzumab makes you more likely to get autoimmune conditions (when your immune system attacks your body by mistake).

The one seen most often is a problem with your: **thyroid**

- up to **four out of ten people** get this
- your thyroid gland, in your neck, makes hormones and controls your metabolism (one thing this controls is how fast you burn calories)
- symptoms include sweating a lot, putting on or losing weight, your eyes swelling, nervousness, fast heartbeat, feeling cold, tiredness or constipation
- most people need life-long medication. Some need their thyroid taking out
- if you get a thyroid problem you can carry on taking alemtuzumab

Much rarer problems are:

### **immune thrombocytopenic purpura (ITP)**

- ITP is when there aren't enough platelets in your blood so you bleed too much
- between one and three people in a hundred on alemtuzumab get this
- untreated ITP may lead to serious health problems or death but caught early, it's usually treatable

symptoms of ITP include:

- small red, pink or purple spots on your skin
- bruising easily
- bleeding that takes a long time to stop (eg, from your gums or nose)
- coughing up blood
- for women, bleeding between periods or having periods more often, or they're heavier or last longer
- you'll get regular blood tests to check for ITP but call a doctor straight away if you have these symptoms

### **kidney problems such as anti-GBM (anti-glomerular basement membrane) disease**

- around one in 300 people get these problems
- symptoms include:
  - blood in your urine, turning it red or the colour of tea
  - your legs or feet swell
  - you cough up blood
  - left untreated this can cause kidney failure, leading to dialysis, a transplant or death
  - you'll get blood and urine tests each month to check for kidney problems but call a doctor straight away if you have symptoms

### **rare conditions involving red or white blood cells**

- these can be diagnosed from regular blood tests and treated

### **serious reactions when you have your infusion**

- very rarely a person has a serious allergic reaction to alemtuzumab. This causes their mouth or throat to become swollen, with heart or breathing problems or a rash

## Stroke and tears in blood vessels

After being given alemtuzumab some people have had a stroke or had blood vessels break in their head or neck. This has happened within a day of their first infusion (for one person it happened within three days of it). This could cause someone to become permanently disabled or even kill them.

By the end of 2018 there had been reports of 13 people around the world having this side effect (one person died). This means less than one in a thousand people get this side effect when they first take this drug.

Get emergency medical help if you or those looking after you notice any of these suddenly happening:

- numbness or weakness in your face, arms, or legs, especially if it's on only one side of your body
- confusion, trouble speaking or difficulty understanding what people are saying
- trouble seeing in one or both of your eyes
- trouble with walking, dizziness or losing your balance or coordination
- severe headache or pain in your neck

In April 2019 the European Medicines Agency announced it was looking into these side effects. It was also looking at others, such as rare but possibly fatal problems affecting people's livers, hearts and immune systems.

In the meantime alemtuzumab will only be given to people whose MS is very active. People who have already started their treatment with the drug are advised to carry on taking it.

## Side effects: weighing up the risks of DMTs

Only you can decide what level of risk you're happy to take. You'll need to weigh up:

- ⚖ possible risks against the benefits you could enjoy
- ⚖ taking a DMT with fewer side effects but less impact, against a DMT with better results but maybe more serious side effects
- ⚖ the risk of not being treated.

This last point has recently become clearer. We now know that damage could be taking place in your brain between relapses, when it might seem nothing is happening with your MS. Before deciding, talk to others and get the information you need. Some ideas are in **More information and support**.

## What tests will I need?

You'll have blood and urine tests to diagnose and treat infections or autoimmune problems, for example, with your thyroid. These tests happen before you start treatment, then every month and for four years after your last infusion. Your specialist can also arrange:

- a blood test to see if you're at risk of getting the varicella zoster virus (it causes chickenpox and shingles). You'll need a vaccination if this test shows you've not already had this infection
- a blood test for TB
- for women, screening of the cervix (the neck of the womb) once a year

ABN guidelines say it's a good idea to have MRI scans to see how much difference the drug is making to your MS.

## When should I stop taking this drug?

Most people don't need to take this drug again after the second time. Between three in ten and four in ten people will need to take it three or four times (very rarely a person will need a fifth infusion). Your neurologist might recommend you stop taking this drug if you have bad side effects or, if after several courses, it hasn't worked.

You'll need to stop taking alemtuzumab if your MS changes to secondary progressive MS. DMTs available now can't help people if they don't have relapses. But clinical trials are underway testing drugs for progressive, non-relapsing types of MS.

You also need to discuss with your neurologist stopping alemtuzumab if you're a woman thinking about getting pregnant (see next section for more details).

## I want a child. Can I take alemtuzumab?

If you're a woman trying for a baby, you need to stop taking this drug and wait until the amount of it in your body drops to a safe level. The time this takes is called the 'washout period'. For alemtuzumab it's four months. Blood tests will check that the level of drug in your blood has dropped low enough.

Once you've had your very last infusion, and the drug has left your body four months later, you now have years during which it's safe to get pregnant.

It's safe to breastfeed four months after your last infusion, but not while you're still taking the drug as it can get into your breast milk.

Men and women with MS who want to have child should discuss this with their MS specialist. Talk to your neurologist if you're a woman and you think you may be pregnant.

## More information and support

[mssociety.org.uk/earlytreatment](https://mssociety.org.uk/earlytreatment)

On this web page you'll find more about treatment, a report on the evidence for early treatment and links to our basic guide to DMTs and fact-sheets on other DMTs.

New guidelines say everyone should have a review of their MS and treatment with a specialist at least once a year. But if you're not happy with the treatment you're offered, find tips about what to do on this link: [mssociety.org.uk/about-ms/treatments-and-therapies/getting-treatment-for-ms](https://mssociety.org.uk/about-ms/treatments-and-therapies/getting-treatment-for-ms)

Elsewhere on the MS Society site you'll find the latest updates on research into drugs for the different types of MS.

### Patient information leaflets

Every DMT comes with detailed information about doses, how to store and take it, side effects and results from trials. Find the one for this drug at [medicines.org.uk](https://medicines.org.uk) and search for 'alemtuzumab' or 'Lemtrada'. The circle with 'PIL' on it has information written for patients. The circle with 'SPC' on it has information for doctors.

### Your MS specialist team

Your neurologist, MS nurse and other members of your specialist team can give you information and support, as can your GP often. MS nurses, if you have one where you are, can be especially helpful if you need support taking a DMT.

### [mssociety.org.uk/forum](https://mssociety.org.uk/forum)

On this and other online forums you can talk to others thinking about treatment or already taking it.

## About this resource

With thanks to Louise Coghlin and all the neurologists and people with MS who contributed to this factsheet.

**Disclaimer:** We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. Availability and prescribing criteria for drugs in various parts of the UK may change. Be sure to seek local advice from the sources listed.

### Let us know what you think

If you have any comments on this information or on the work of the MS Society, please send them to [resources@mssociety.org.uk](mailto:resources@mssociety.org.uk)

## References

A list of references is available on request. Call 0300 500 8084.

## Further information from the MS Society

### Resources

Our award winning information resources cover every aspect of living with MS.

☎ 0300 500 8084

✉ [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)

🖥 [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

### Helpline

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

☎ 0808 800 8000 (closed weekends and bank holidays)

✉ [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

## Contact us

### MS National Centre

☎ 0300 500 8084

✉ info@mssociety.org.uk

### MS Helpline

☎ 0808 800 8000 (closed weekends and bank holidays)

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- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND.  
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This factsheet will be reviewed within three years of publication.