

Drug information  
**Belimumab**

**BELIMUMAB**  
is used to treat lupus (SLE)

**VERSUS**  
**ARTHRITIS**

## Introduction

Belimumab is a drug used to treat lupus. It can reduce symptoms such as pain. You can discuss the benefits and risks of taking belimumab with healthcare professionals before you start treatment, so you're able to make an informed decision.

## What is belimumab and how is it used?

Belimumab, which is also known by the trade name Benlysta, is a type of drug called a biological therapy.

In lupus, the immune system produces harmful antibodies that attack the body's own tissues. Belimumab works by reducing the activity of a type of white blood cell called B-cells that produce the antibodies. This reduces the inflammation that causes the symptoms of lupus.

It's a long-term treatment, so it may be up to six months before you start to notice the benefits.

Belimumab can be prescribed by a consultant rheumatologist for adults with lupus. It's usually given alongside other treatments.

Belimumab won't be started if:

- your lupus isn't active
- you haven't tried other treatments for your condition first.

Your doctor may decide not to prescribe belimumab if you're pregnant or breastfeeding, or if:

- you have an infection or have had repeated or serious infections in the past
- you've had mental health problems such as depression or thoughts of suicide
- your lupus affects your kidneys or nervous system

- you have HIV
- your B-cell or antibody levels are low
- you've had hepatitis
- you've had any kind of transplant
- you've had cancer.

You'll have blood tests to check your antibody and possibly your B-cell levels before treatment and every few months from then on. Your doctor may also check for previous hepatitis infection as belimumab may increase the risk of hepatitis becoming active again.

Your doctor may decide not to prescribe belimumab if you're being treated with another drug that targets B-cells, such as rituximab, or if you're on cyclophosphamide.

## When and how do I take belimumab?

Belimumab is given through a drip into a vein, which is known as an intravenous infusion. This is done in hospital and usually takes about an hour.

The first three infusions will be two weeks apart, and after that they will be given monthly. You may be offered anti-histamines and paracetamol, which may help to reduce the chance of a reaction to the infusion.

Belimumab is a long-term treatment. So, unless you have severe side effects, it's important to keep taking belimumab:

- even if it doesn't seem to be working at first
- even when your symptoms improve, to help keep your condition under control.

If you haven't noticed any improvement in your symptoms after six months, your doctor may wish to discuss other treatment options.

## Possible risks and side effects

Some people may have a reaction to belimumab, usually during or just after having an infusion. These aren't usually serious and the person giving the infusion will be looking out for any problems. Tell them straight away if you feel sick, feverish, dizzy or short of breath, or if you have a headache, rash, itching or sudden swelling.

Occasionally, allergic reactions can be more serious, and the infusion may have to be stopped.

Sometimes people have side effects a few days after the infusion. Contact your healthcare team if you have any new symptoms such as:

- diarrhoea
- feeling sick
- fever
- headaches
- facial swelling
- muscle pains
- difficulty sleeping
- depression.

If you have a history of depression or thoughts of hurting yourself, talk to your doctor about this before starting treatment with belimumab. If your mood or behaviour changes after starting treatment, let your healthcare team know as soon as possible.

Because belimumab affects your immune system, you may be more likely to pick up infections. Tell your doctor if you have symptoms that may suggest you have an infection – such as a sore throat, runny nose, stomach upsets or a burning feeling when having a wee.

You should also tell your doctor if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. These illnesses can be more severe in people on biological therapies and you may need antiviral treatment.

In very rare cases, people treated with belimumab have developed a serious infection called progressive multifocal leukoencephalopathy (PML), which affects the brain. You must see your doctor immediately if you notice any of the following:

- problems with memory or thinking clearly
- difficulty walking
- dizziness or loss of balance
- speech problems
- loss of vision.

### Tips to reduce your risk of infection

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry around a small bottle of antibacterial hand gel.
- Keep your mouth clean by brushing your teeth regularly.
- Stop smoking if you're a smoker.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic, especially the kitchen, bathrooms and toilets.

## Taking other medicines

Belimumab is usually prescribed alongside other drug treatments for lupus but may interact badly with some other medicines.

- Check with your doctor before starting any new medicines, and remember to mention you're on belimumab if you're treated by anyone other than your usual rheumatology team.
- Don't take over-the-counter or herbal medicines without discussing this first with your healthcare team.

It's recommended that you carry a biological therapy alert card. Then anyone treating you will know that you've had belimumab and that your antibody levels may be low. Ask your rheumatology team for a card.

## Vaccinations

It's best to discuss vaccinations with your healthcare team and, if possible, to have any vaccinations you may need before you start belimumab.

Live vaccines should generally be avoided once you've started on belimumab and for 30 days before starting belimumab. Live vaccines include measles, mumps and rubella (MMR), tuberculosis (BCG), yellow fever and shingles vaccines.

Pneumococcal vaccines, which help to protect against pneumonia, and yearly flu vaccines – except for the nasal flu vaccine – are fine and are usually recommended, although they may not be quite so effective if you have them after starting belimumab.

## Having an operation

If you're planning to have an operation, you should discuss with your specialists whether you need to stop or delay any of your drug treatments for a time before and after surgery. The decision will be based on the timing and the type of surgery you're having.

## Alcohol

You can drink alcohol while on belimumab but keep within the recommended limits for adults of no more than 14 units per week – unless your doctor advises a lower limit.

## Fertility, pregnancy and breastfeeding

There's limited information available about the effects of belimumab in pregnancy. Women who could become pregnant should use effective contraception while being treated with belimumab and for four months after stopping treatment.

It is not yet known whether belimumab passes into human breastmilk so you should talk to your rheumatology team if you're thinking of breastfeeding.

There is currently no information available on the possible effects of belimumab on male and female fertility.

## Where to go for more information

This leaflet is a guide to belimumab, its benefits and potential side effects. If there's anything else you'd like to know about this drug, just ask the healthcare professionals in charge of your care.

You can also call our free helpline on 0800 5200 520, where our trained advisors can offer information, support and advice on your type of arthritis.

 Visit our website [www.versusarthritis.org](http://www.versusarthritis.org) to find out more.

## Thank you!

We would like to thank Dr Toni Chan for helping us review this booklet.

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