



Lymphangiomyomatosis (LAM)

Lymphangiomyomatosis, usually called LAM, is a rare condition that occurs almost exclusively in women. LAM mainly affects the lungs, but may also involve the kidneys and lymphatic system

What causes LAM?

The cause of LAM is currently unknown, although we do know a change in a gene causes abnormal growth of an abnormal cell type, called LAM cells.

LAM cells grow throughout the lungs, causing holes or cysts, blocking the airways and preventing the lungs from getting oxygen to the rest of the body. Sometimes, LAM cells also cause problems in the lymphatics and kidneys.

There are 2 ways that you can get LAM:

- on its own – this is called sporadic LAM
- with a condition called [tuberous sclerosis](http://www.nhs.uk/conditions/tuberous-sclerosis/) (www.nhs.uk/conditions/tuberous-sclerosis/)

Sporadic LAM is not inherited, and it is not passed on to children.

Many women who have tuberous sclerosis also get LAM. But most women with LAM do not have tuberous sclerosis.

As LAM is a condition that almost exclusively occurs in women, it's thought the female hormone oestrogen encourages LAM cells to grow.

What are the symptoms of LAM?

Symptoms include [breathlessness](http://blf.org.uk/breathlessness) (blf.org.uk/breathlessness), which may get worse the longer you have LAM and may vary with the menstrual cycle. Many women with LAM also feel fatigued.

Women with LAM may also develop [pneumothorax](http://blf.org.uk/pneumothorax) (blf.org.uk/pneumothorax) or collapsed lung. They may also have a bloated stomach and fluid around the lungs if lymphatic tissue gets blocked. If you have LAM you may get kidney tumours, called angiomyolipomas. These are benign but can be painful and cause bleeding around the kidneys.

How is LAM diagnosed?

Because LAM is rare, it may take some time to get a diagnosis. LAM is usually suggested when lungs cysts are seen on a [CT scan](http://www.nhs.uk/conditions/ct-scan/) (www.nhs.uk/conditions/ct-scan/) or in women with tuberous sclerosis. As there are other causes of lung cysts, you may also have blood tests or a [lung biopsy](http://blf.org.uk/support-for-you/breathing-tests/other-tests) (blf.org.uk/support-for-you/breathing-tests/other-tests).

If LAM is suspected, you should also have a CT scan of the abdomen to look for kidney angiomyolipomas and lymphatic problems.

How is LAM treated?

LAM progresses at different rates and not everyone will need treatment. People with a more active disease may be given rapamycin, also called sirolimus, that can slow disease progression if taken continuously. However, currently there is no cure.

If you are breathless, you may be prescribed inhalers and offered [pulmonary rehabilitation](http://blf.org.uk/support-for-you/keep-active/pulmonary-rehabilitation) (blf.org.uk/support-for-you/keep-active/pulmonary-rehabilitation). If your blood oxygen levels are low, you may also be assessed for [oxygen therapy](http://blf.org.uk/oxygen-therapy) ([blf.org.uk/oxygen](http://blf.org.uk/oxygen-therapy)). A lung transplant may be an option for those with a very severe disease.

In the UK, the National Centre for LAM is at Nottingham University Hospital. If LAM is suspected, it's likely you'll need to go there to be diagnosed and treated.

If you have a [pneumothorax \(collapsed lung\)](http://blf.org.uk/pneumothorax) (blf.org.uk/pneumothorax) or large or growing angiomyolipomas, you might need additional hospital treatment.

Useful resources:

- [National centre for LAM](http://www.nuh.nhs.uk/national-centre-for-lam) (www.nuh.nhs.uk/national-centre-for-lam) – the centre for LAM diagnosis in the UK, based in Nottingham
- [LAM Action](http://lamaction.org/) (lamaction.org/) – charity for those with LAM, their families and health care professionals

Get in touch with us to find support near you.

Helpline: 03000 030 555

Monday to Friday, 9am-5pm

Ringing our helpline will cost the same as a local call.

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blf.org.uk

British Lung Foundation
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Registered charity in England and Wales (326730), Scotland (038415) and the Isle of Man (1177)

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We value feedback on our information. To let us know your views, and for the most up to date version of this information and references, call the helpline – or visit blf.org.uk