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Coronavirus and TSC: Information for the TSC community

Last updated: 13 March 2020. This page will continue to be updated with the latest information if government advice changes.

There is widespread coverage across the UK media about coronavirus (also known as Covid-19). If you or a member of your family have TSC, you may have questions or feel anxious about how the virus may affect someone who is living with TSC.

The TSA has spoken with doctors from TSC clinics across the UK to ask for their advice, and they have shared the following information with us.

Remember, the TSA support line is here to provide support on all TSC-related topics and you should never feel alone. You can contact our friendly team by phone (0808 801 070), email (support@tuberous-sclerosis.org) or post (TSA, Unit 56, 1 Emma Street, London E2 9FP, or send to 'Freepost TSA').

Who is at risk?

Having TSC does not make you more likely than anyone else to catch coronavirus, and it does not necessarily mean that you are at greater risk of developing severe symptoms.

However, if you have TSC and you are in one of the following 'at risk' groups (sometimes called 'higher risk' or 'vulnerable' groups) then you should try to avoid the infection if possible because your symptoms might be more severe if you do get sick:

- If you are taking everolimus or sirolimus tablets or liquid
- If you have lymphangiomyomatosis (LAM) or reduced lung function

How can I stay safe and what should I do if I feel ill?

Advice from the UK Government on how to stay safe and what to do if you feel ill will be updated regularly based on the best available evidence. You can use the following link to keep up-to-date with the latest guidance from the NHS, including [answers to the most common questions](#).

If you have TSC and you are in one of the 'at risk' groups listed above, then you should pay attention if the Government asks people who are at greater risk from coronavirus to take additional steps to avoid becoming ill. You can find information here about what to do if you're [asked to self-isolate](#).

I am taking everolimus or sirolimus tablets or liquid. What should I do?

If you are taking everolimus or sirolimus tablets or liquid, you should check with your doctor what is best to do.

Your doctor's advice may change from week-to-week depending on the Government's assessment of the risk to the UK population from the virus (this is assessed as low, moderate or severe), how many people in the general population have already caught the virus, and how the virus is affecting people (which may change over time).

The advice from your doctor may also be different based on why you are taking the drug:

- If you are taking the drug for kidney angiomyolipomas (AMLs) or subependymal nodules (SEGAs), then there may be less risk associated with you taking a break from treatment if you are exposed to coronavirus or become ill. Your doctor may recommend that you stop taking the drug for a short period if you are exposed to the virus or until you get better if you become ill
- If you are taking the drug for refractory epilepsy or LAM, then there may be more risk associated with you taking a break from treatment if you are exposed to coronavirus or become ill. Your doctor will wish to discuss what to do with you, taking into account your medical history and weighing up the respective risks from epilepsy or LAM and coronavirus, so you can make an informed decision about what to do

I am using sirolimus cream. What should I do?

Using sirolimus cream (sometimes called topical sirolimus) should not increase your risk of serious symptoms if you catch coronavirus. You should be able to keep using the cream as normal.

I have LAM or reduced lung capacity. What should I do?

If you have LAM or reduced lung capacity then you may be at greater risk of developing severe symptoms if you become ill. You should follow advice from the Government and NHS for 'at risk' individuals and consult your doctor if you are worried.

You may find this information published by the LAM Foundation (a specialist charity based in the US) helpful.

You may find this information published by the British Lung Foundation for people with lung conditions helpful.

I have epilepsy. What should I do?

Currently there is no information to say that people with epilepsy are more severely affected than people without health conditions.

You may find this information published by Epilepsy Action for people living with epilepsy helpful.

Make a one off or regular donation

£10 Means that we can send a support pack to a family who has just received a life-changing TSC diagnosis, ensuring that they do not go through this time alone.

£25 Can help us develop materials that are included in our support services, flagship events or campaigns.

£50 Can provide laboratory equipment for a day's research into the causes, symptoms, management or treatment of TSC.



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To provide help for today and a cure for tomorrow.

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