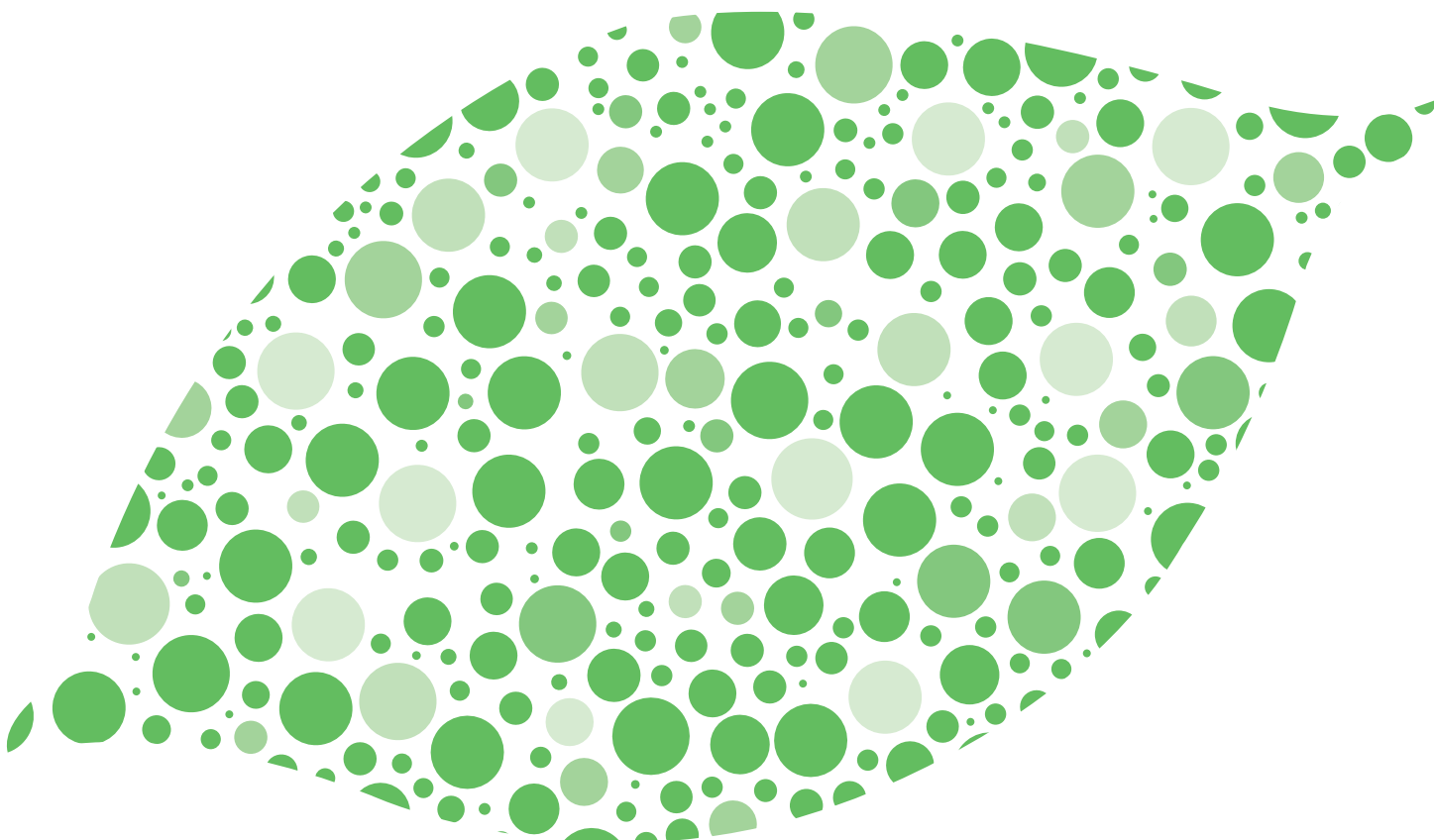


# UK guidelines for managing tuberous sclerosis complex

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A summary for people  
living with TSC

Easy read



## Contents

About this booklet .....	2
How doctors might find out if you have TSC .....	4
How doctors might look after you if you have TSC .....	8
What happened at your last visit to the doctor .....	16
About the Tuberous Sclerosis Association .....	19

## About this booklet

This booklet will help you know more about the tests, scans and medicines you might need if you are living with TSC. It is an easy read version of the doctor booklet 'UK guidelines for managing Tuberous Sclerosis Complex: A summary for clinicians in the NHS'.

The advice in this booklet was agreed by doctors who know lots about TSC. They wrote the advice to help other doctors look after people who are living with TSC. This way, people living with TSC can be looked after really well.

This booklet was written by the Tuberous Sclerosis Association (TSA).

### Disclaimer

We have tried to make sure that this information is correct. We do not accept liability for any mistakes or any information not included. For up to date information about medicines and treatments you should talk to your doctor.

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## Why you should read this booklet

This booklet can help you learn about how your doctor might look after you. You can use this information to talk to your doctor about any scans, tests or medicines that you might need.

This might help you to be healthy and feel better.

## How this booklet is organised

This booklet is in two parts.

In the first part, this booklet shows what your doctor might do to find out if you have TSC.

In the second part, this booklet shows how your doctor might check different parts of your body to see how TSC might be affecting you. The second part also talks about the different medicines and treatments your doctor might give you.

## Everyone living with TSC is different

Remember that one person who lives with TSC might need looking after very differently to another person who also lives with TSC.

Your doctor might not do all of the tests or ask all of the questions in this booklet. That is ok. This is because everyone with TSC is different.

## How doctors might find out if you have TSC

This part of the booklet shows what your doctor might do to find out if you have TSC.

Your doctor might ask you lots of questions. Try and answer the questions if you think you are able to.

You might have scans and tests on different parts of your body. This is normal.

Your doctor might not ask all of the questions, or do all of the scans and tests, in this part of the booklet. That is ok. This is because everyone with TSC is different.

### Your doctor might check different things in your body to see if you have TSC:



How your body is made



Skin



Seizures and fits (epilepsy) and how you feel and act



Mouth



Kidneys



Heart



Lungs



Eyes



## How your body is made (genes)

Your doctor might test your genes (the things that make up the body) to see if you have TSC.

Your doctor might ask your family if they have TSC. Your doctor might test their genes too.

If you are old enough to have a baby, your doctor might tell you how they can check if babies have TSC before they are born.



## Seizures and fits (epilepsy) and how you feel and act

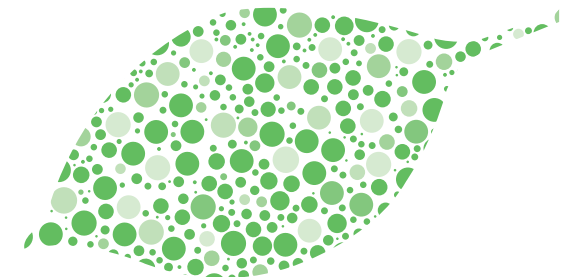
You might have a scan of your head. This is to check for any lumps on your brain.

You might be asked if you have ever had any seizures or fits.

Your doctor might talk to you, your parents or other adults about how to tell if you are having a fit or seizure.

You might see a special doctor, who knows lots about looking after people who have fits or seizures.

Your doctor might ask you questions about how you feel and act. Try and answer the questions if you think you are able to.





## Kidneys

You might have a scan of your tummy. This is to see how healthy your kidneys are and if there are any lumps on them.

You might need more than one type of scan on your tummy. It depends what the first scan tells your doctor.

You might have your blood checked to see how quickly it moves around your body (your 'blood pressure').

Sometimes, your doctor can check for different things in one scan. If your doctor does a scan of your tummy to check your kidneys, they might also check your liver at the same time.



## Lungs

Your doctor might talk to you about why smoking is dangerous.

You might have a scan of your chest. This is to check for any lumps in your lungs.

If you are a woman, your doctor might talk to you about avoiding a special chemical (hormone), called 'oestrogen'.



## Skin

Your doctor might check your skin very carefully using a special lamp, called a 'Wood's light'. This is to check for lumps and rashes on your skin.



## Mouth

Your doctor might check your teeth and mouth very carefully. This is to check for any marks or bumps.



## Heart

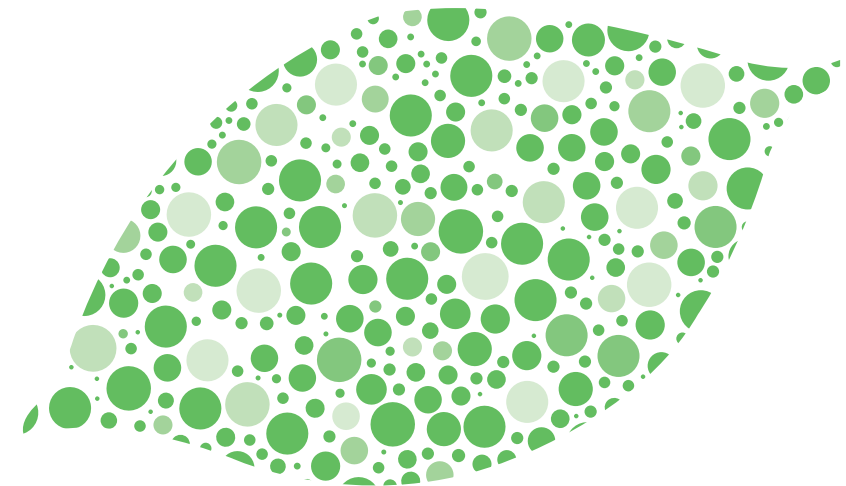
You might have a scan of your chest. This is to check for any lumps on your heart and to see if it is beating normally.

You might need more than one type of scan. It depends what the first scan shows your doctor.



## Eyes

Your doctor might check your eyes. This is to see how healthy they are.



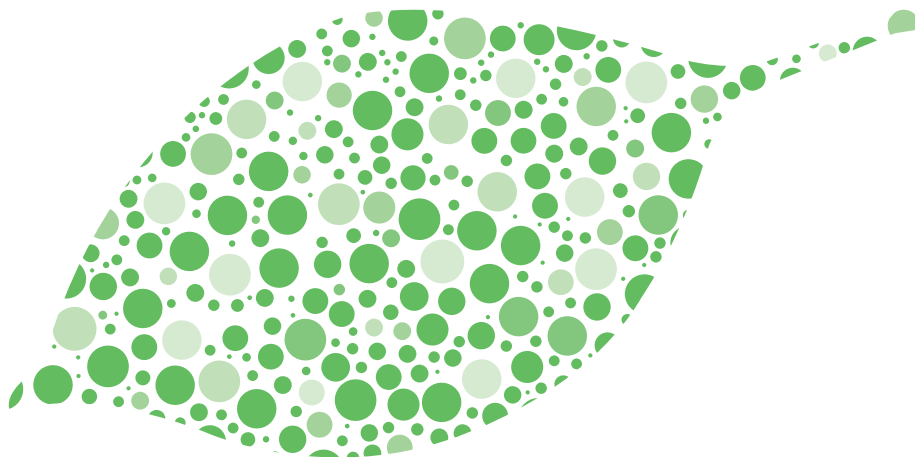
## How doctors might look after you if you have TSC

This part of the booklet shows how your doctor might look after you if you have TSC.

Your doctor might ask you lots of questions. Try and answer the questions if you think you are able to.

You might have scans and tests on different parts of your body. You might also need to take medicine or have other treatments to stay healthy. This is normal.

Your doctor might not ask all of the questions, or do all of the scans and tests, in this part of the booklet. You might not be given the medicines listed here. That is ok. This is because everyone with TSC is different.



Your doctor might check different things in your body to see if you have TSC:



How your body is made (genes)



Lungs



Lumps on the brain



Skin



How you feel and act



Mouth



Seizures or fits (epilepsy)



Heart



Kidneys



Eyes



Liver and pancreas



## How your body is made (genes)

Your doctor might ask your family if they have TSC. Your doctor might test their genes too.

If you are old enough to have a baby, your doctor might tell you how they can check if babies have TSC before they are born.



## Lumps on the brain

If you are aged 24 or younger, you might have a scan of your head every 1-3 years. This is to check for any lumps on your brain.

If you have any lumps on your brain that are big or growing, you might have scans of your head more often.

You might need to keep having scans at different doctor visits, until your doctor decides that you do not need them anymore.

**Most lumps on the brain stop growing when a person is aged 25 or older.**

Your doctor might talk to you and your family or other adults about how to tell if you have a big or growing lump on your brain.

Your doctor might also talk to you and your family about medicines or treatments for big or growing lumps on your brain.

**If you have a lump on your brain that is getting bigger, it can sometimes make you have fits or seizures. The lump might also change how you feel and act.**



## How you feel and act

Your doctor might ask you questions about how you feel and act. This is to see if your TSC might be changing how you feel and act. Try and answer the questions if you think you are able to.

Your doctor might ask questions about how you feel and act when you are at different ages:

- Before school age (0-3 years)
- Nursery and reception (3-6 years)
- Primary school (6-11 years)
- Secondary school and older (12-18 years)

Your doctor might talk to you about medicines and treatments that can help you to feel and act more like you normally do.

Your doctor might want you to talk with a special doctor who knows lots about looking after people who are not feeling or acting like they normally do.



## Seizures or fits (epilepsy)

If your doctor thinks that you have been having seizures or fits, you might have a scan of your head to see why. You might need to wear a monitor for a day to check why you are having seizures.

You might be given a medicine to help stop or reduce seizures. If the medicine does not work, your doctor might suggest other medicines.

If you have tried two medicines and your seizures are still not better, your doctor might talk to you, your family or other adults about other options. This might include a different medicine (called 'everolimus').

**Your doctor will talk to you and your family or other adults about what to do if you have a seizure. This is important because a seizure might make you very poorly.**

Your doctor might want you to talk with a special doctor who knows lots about looking after people who have seizures.



## Kidneys

You might have a scan of your tummy. This is to see how healthy your kidneys are and if there are any lumps on them.

You might need more than one type of scan on your tummy. It depends what the first scan tells your doctor.

If your doctor sees lumps on your kidneys they might give you medicine, called an 'mTOR inhibitor'.

You might have a scan every 1-3 years of your tummy. This is to see if your kidneys have any lumps on them and to check on any lumps that are already there.



## Lungs

Your doctor might talk to you about why smoking is dangerous.

You might have a scan of your chest. This is to check for any lumps in your lungs.

Scans on your chest might be done every 5-10 years.

If lumps in your lungs are found by your doctor, you might get a different test every year. You might also get a medicine, called an 'mTOR inhibitor'.

If you are a woman, your doctor might talk to you about avoiding a special chemical (hormone), called 'oestrogen'.



## Skin

It is very important for you to wear sunblock/sun cream every day.

Your doctor might check your skin very carefully using a special lamp, called a 'Wood's light'.

This is to check for lumps and rashes on your skin.

If you have lumps and rashes on your skin, your doctor might give you a cream with medicine in it, called an 'mTOR inhibitor'. Your doctor might also talk to you about other treatments.



## Mouth

It is very important to brush your teeth twice a day and to look after your mouth.

Your doctor might check your teeth and mouth every 6-12 months for any marks or bumps.

Your doctor might talk to you about any medicines or treatments that you may need for your mouth.



## Heart

You might have a scan every 3-5 years on your chest. This is to check for any lumps on your heart and to see if it is beating normally.

If your doctor finds any lumps on your heart, you might need more scans.

Your doctor might give you medicine to look after your heart. One is called an 'mTOR inhibitor'. The other is medicine to help your heart beat normally, called an 'antiarrhythmic'.



## Eyes

Your doctor might check your eyes. This is to see how healthy they are.



## Liver and pancreas

If you get a scan of your tummy to check your kidneys, your doctor might check your liver and pancreas at the same time. This is to see how healthy they are.



## What happened at your last visit to the doctor

You can use this space to write down what happened at your last visit to the doctor and what will happen next:

I visited my doctor on \_\_\_\_\_

My doctor was called \_\_\_\_\_

We talked about \_\_\_\_\_

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I was asked about \_\_\_\_\_

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The tests I had were \_\_\_\_\_

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What will happen next \_\_\_\_\_

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Questions I have for my next visit \_\_\_\_\_

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My next doctor visit is on \_\_\_\_\_

Notes

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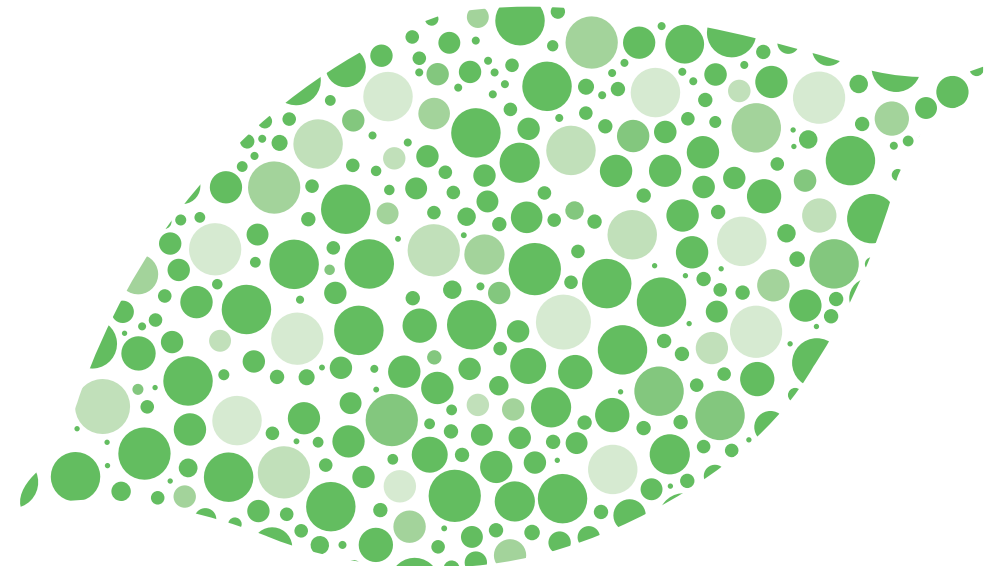
# About the Tuberous Sclerosis Association



The Tuberous Sclerosis Association (TSA) is a charity all about TSC. We try and help people who live with TSC.

**We do this by:**

- Making more people know about what TSC is
- Helping people who live with TSC to be healthier and happier
- Helping doctors and nurses know how to best look after people living with TSC
- Trying to find new medicines and treatments for TSC





## Tuberous Sclerosis Association

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