

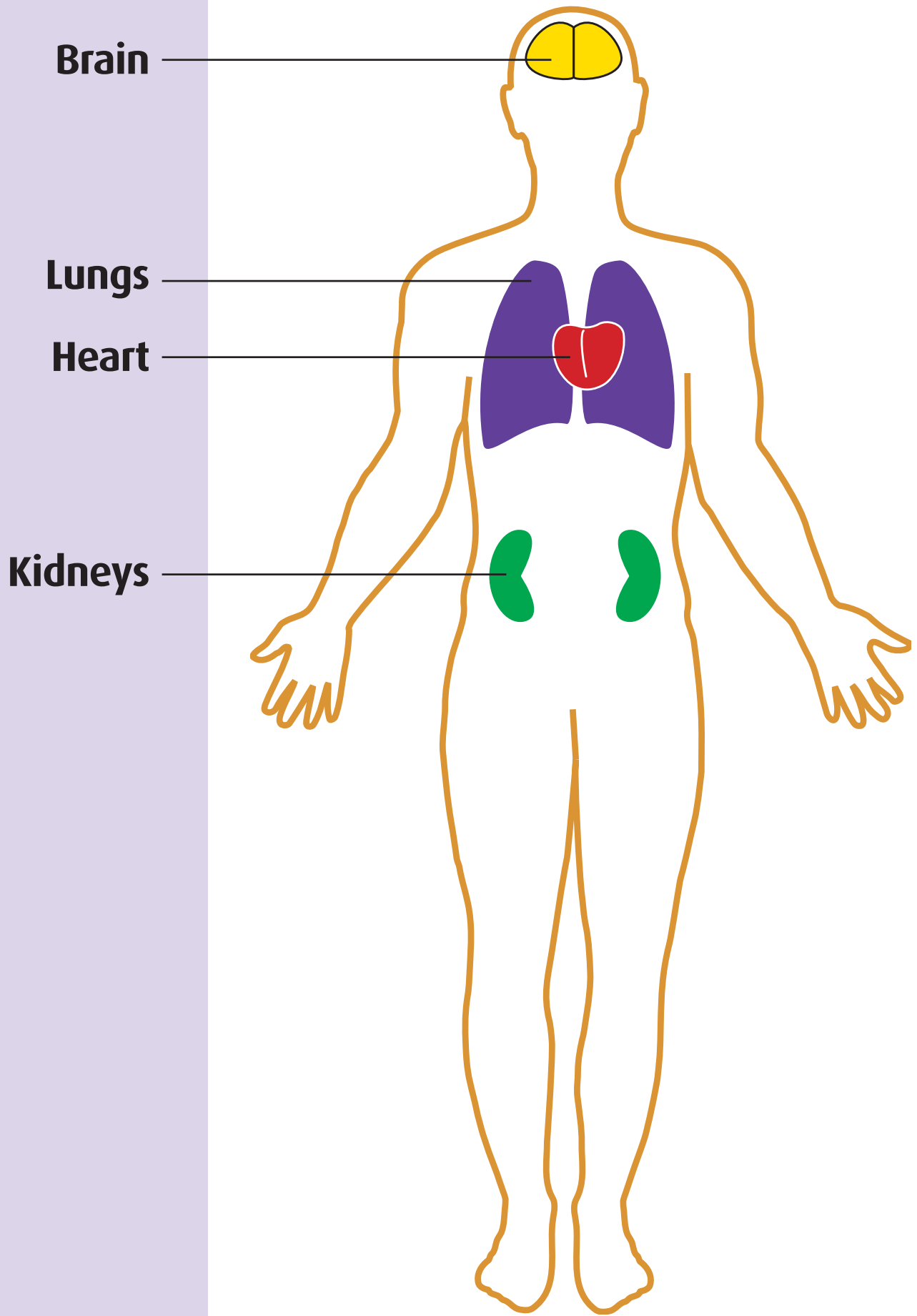
TUBEROUS SCLEROSIS COMPLEX
A GUIDE FOR YOU

Index

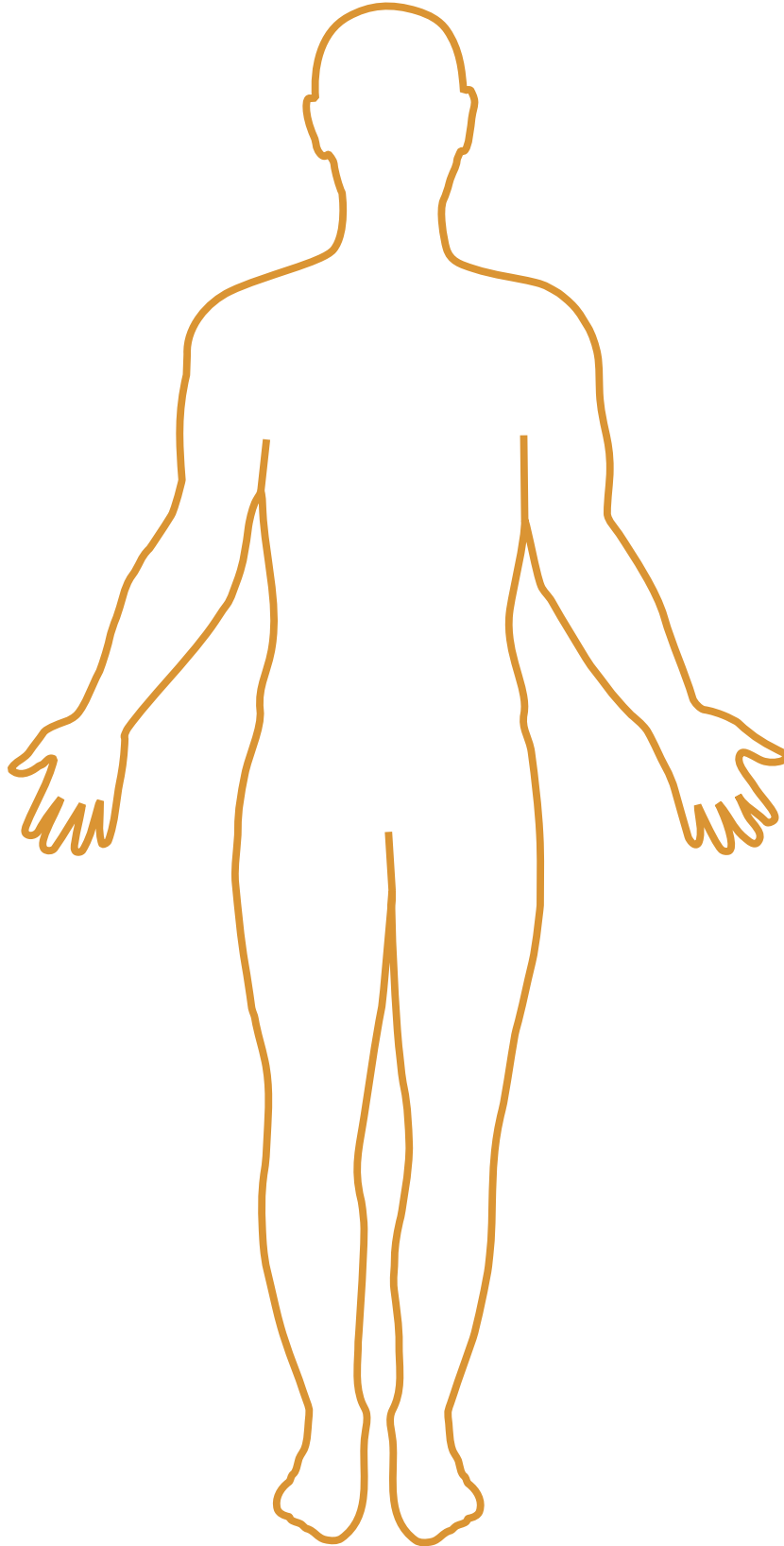
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We wish to acknowledge REACT for their advice on how to present this information.

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If there's anything you don't understand about how you are affected by TSC, ask your Doctor to draw in this picture how TSC affects you.



What is Tuberos Sclerosis Complex?

In this booklet we will use TSC to mean Tuberos Sclerosis or Tuberos Sclerosis Complex.

- TSC is a condition you are born with
- You may have lumps in different parts of your body
- You may have very few problems with TSC, or you may have a lot of problems
- You cannot catch it but it will not go away!



Genetics

- You may not be the only one in your family to have TSC
- Because it is part of you, your children may have it too



Most people with TSC want to see a specialist Doctor (called a Geneticist).

A Geneticist will help you to understand about TSC in your family.

You can ask your GP to arrange this.



Name of your GP and how to contact them

Name of your Geneticist and how to contact them

Skin

- You may have white skin patches
- You may have some lumps on your skin
- You may have lumps on your face
- Your lumps may be red
- Your lumps may be pale
- You may have lumps around your fingernails
- You may have them on your toenails
- You may have a large lump on your back





You might want to see a Doctor who knows about skin.

He is called a Dermatologist.

You can ask your GP to arrange this.

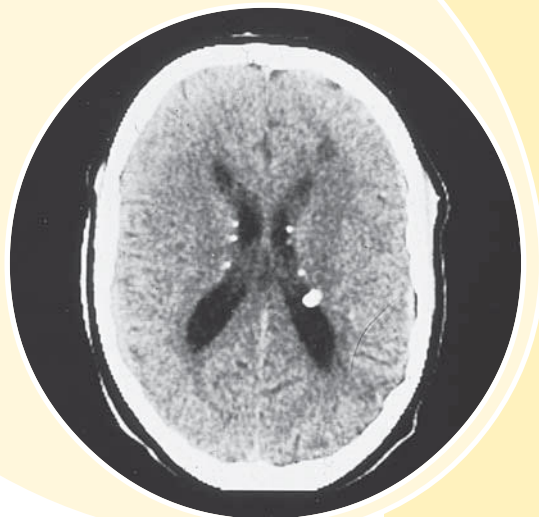
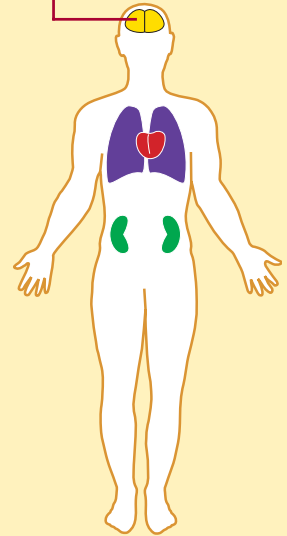
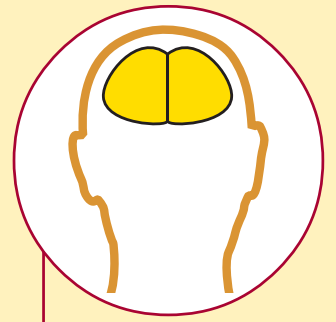


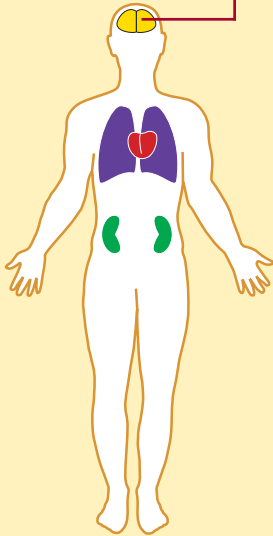
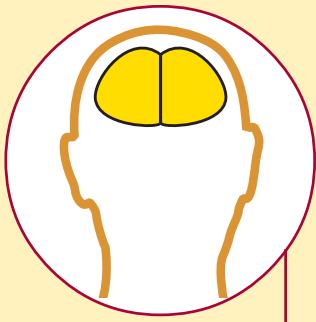
Name of your Dermatologist and how to contact them



Brain

- You may have lumps on your brain
- These lumps may cause seizures. This is called Epilepsy (see page 10)
- These lumps may cause learning difficulties for some people
- Sometimes these lumps may affect behaviour
- Sometimes these lumps may make it hard for you to talk to other people
- These lumps can get bigger in a few people and make them feel unwell (see page 12)
- These lumps show up on a special photograph of your brain called a scan





You might want to see a specialist Doctor who knows about the brain.

He is called a Neurologist.

You can ask your GP to arrange this.



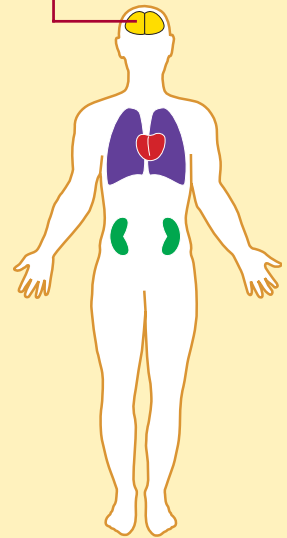
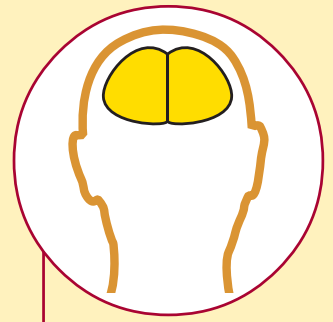
Name of your Neurologist and how to contact them

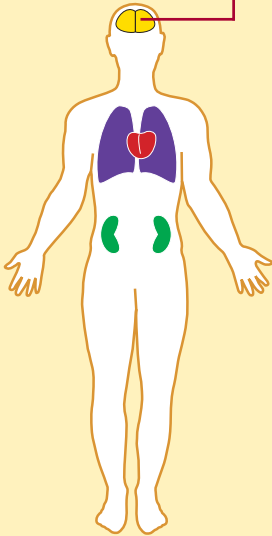
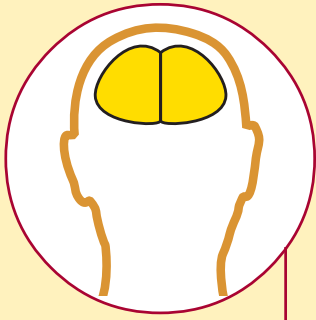
Epilepsy

- You may have seizures. This is called Epilepsy
- Seizures are also called fits, convulsions or sometimes funny turns
- There are different kinds of seizures

You may:

- Stop what you are doing and stare for a few moments
 - Walk around in a daydream
 - Have pins and needles
 - Smell a strange smell
 - Taste a strange taste
 - Hear a funny noise
 - Go stiff, fall down and jerk
 - Wet yourself – you can't help this
- After a seizure you may be tired or have a headache and need to sleep for a while
 - You may need to take medicine or tablets to try and stop the seizures





If you have any of these problems, you must ask to see a specialist Doctor who knows about epilepsy.

He is called a Neurologist.

You can ask your GP to arrange this for you.



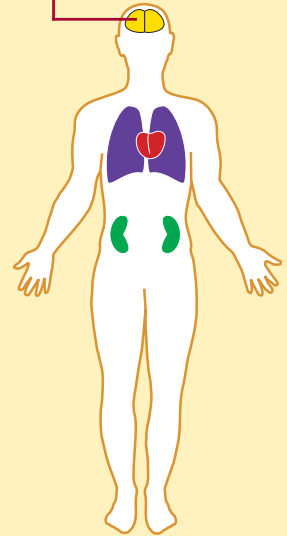
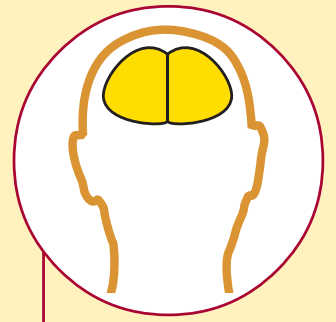
Name of your specialist Doctor and how to contact them

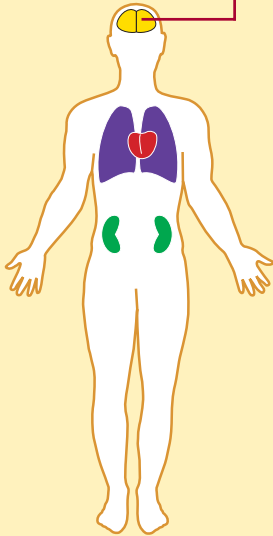
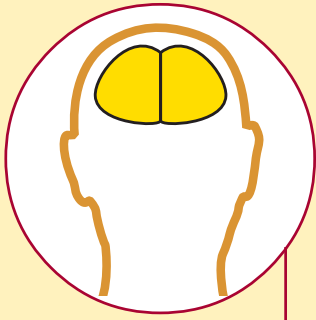
Lumps in the brain that grow

- Lumps that grow are called tumours

When they grow, you may suddenly start:

- Having bad headaches
- Having problems seeing
- Having problems walking
- Feeling sick
- Feeling dizzy
- Avoiding bright lights
- Not feeling hungry
- Feeling very tired all the time
- Wetting yourself





If you have lots of these problems which are not getting better, you must go to your Doctor straight away.

He may send you to hospital.



You will then see a specialist and have tests.



You may need an operation.

If you need help telling your Doctor about these things, ask the TSA to help.



Name of your specialist Doctor and how to contact them

Kidneys

- Everyone has two kidneys in their body
- Kidneys help to wash our bodies from the inside
- Kidneys make our urine (wee)
- You may have lumps on your kidneys
- Usually these lumps do not cause any problems
- These lumps may cause problems

You may notice:

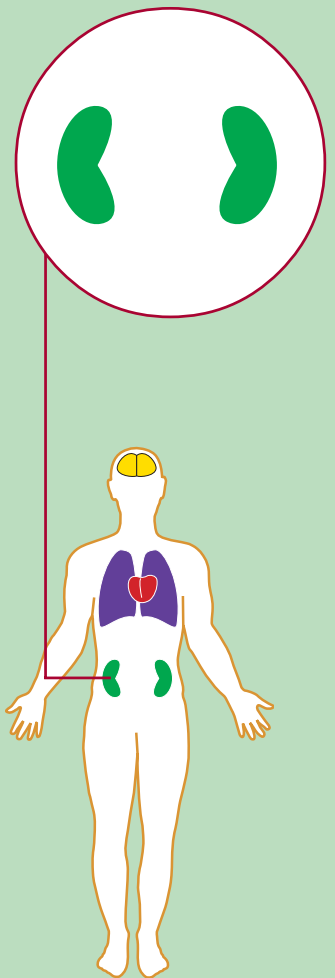
Tummy pain

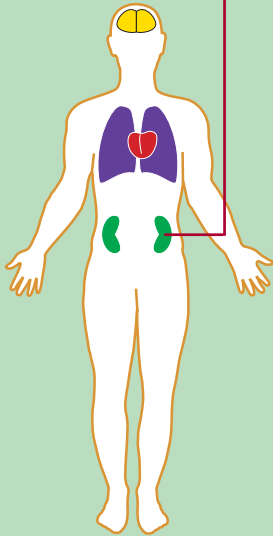
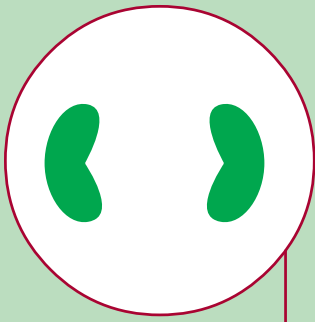
Back pain

Tiredness

Blood in your urine (wee) which makes it turn pink

- People with lumps on their kidneys may be feeling generally unwell





You need to know if you have any lumps on your kidneys.

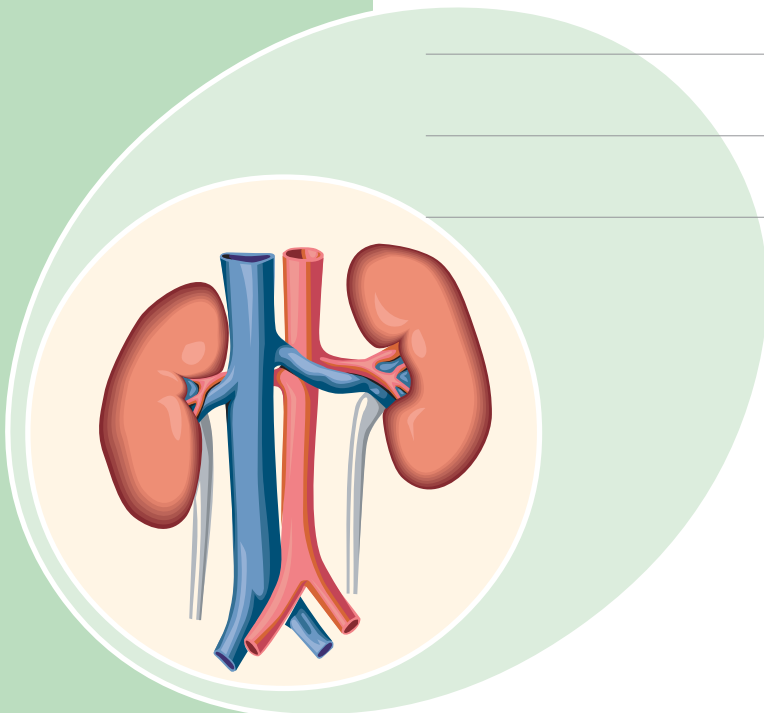
You can ask your GP to book a special test called an ultrasound scan.

Your GP should also check your blood pressure and take a little blood from you to make sure your kidneys are working well.

Your GP may arrange for you to see a specialist kidney Doctor called a Nephrologist.

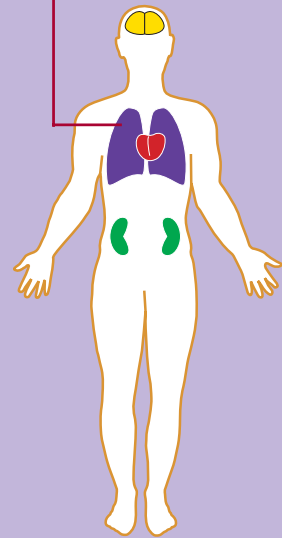
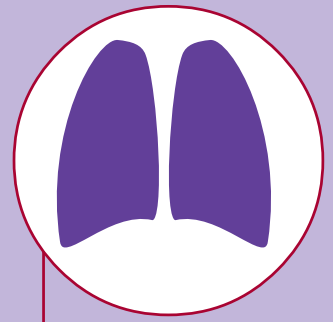


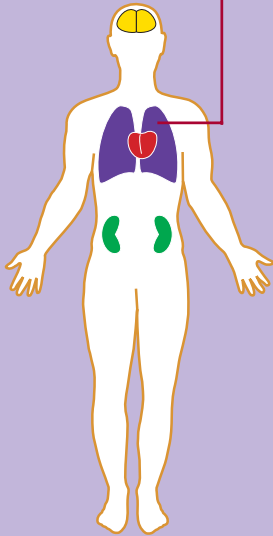
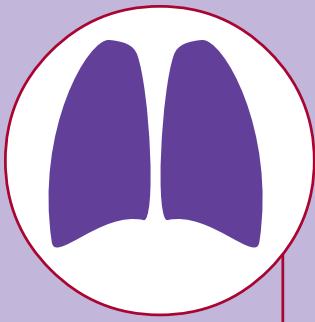
Name of your Nephrologist and how to contact them



Lungs

- You have two lungs in your body
- Our lungs help us to breathe
- Some women with TSC may have lumps inside their lungs
- Usually these lumps do not cause any problems
- Occasionally these lumps do cause problems
- You may notice:
 - Difficulty breathing
 - Bad pain across the shoulders
 - It's hard to take exercise
 - A cough that doesn't go away
 - Coughing up blood





If you have any of these problems you must see your GP straight away.

You will then have to see a specialist Doctor.



You may have to go to hospital.

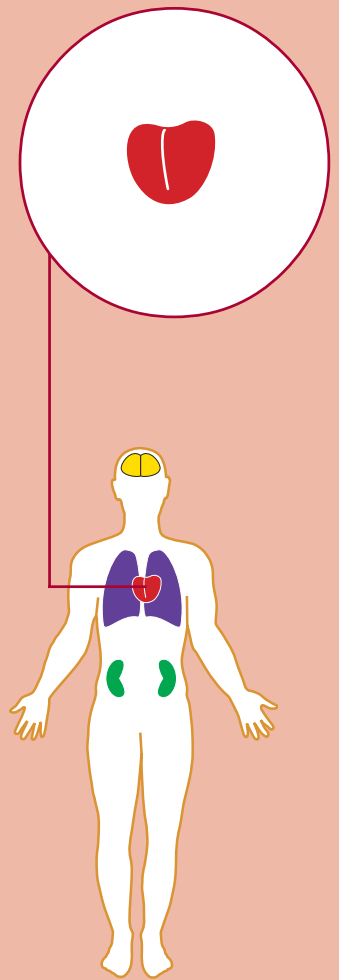


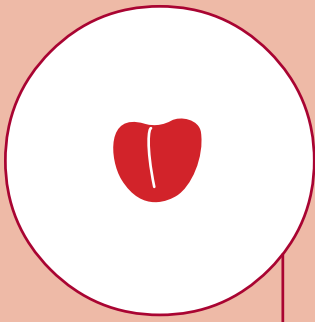
You may need an operation.

Name of your specialist Doctor and how to contact them

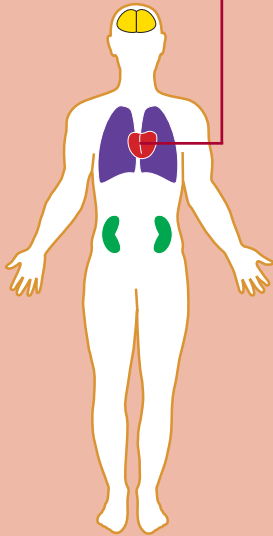
Heart

- You have one heart inside your body
- The heart pumps blood around your body
- You may have lumps in your heart
- These lumps are usually very small and don't cause any problems
- Very occasionally in babies and young children these lumps do cause problems
- Some children may see a specialist heart doctor called a Cardiologist

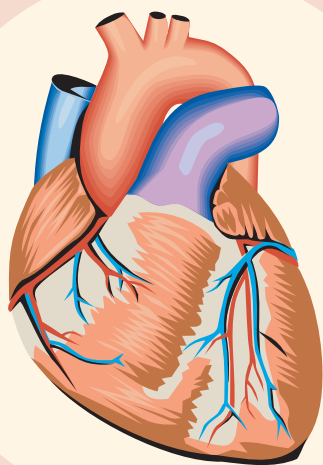




If you are having any kind of operation you should first have a test called an ECG



Name of your Cardiologist and how to contact them



How you feel and how you behave

- You may worry about having TSC – this is normal!
- It helps to know how TSC affects you
- You can then make sure the right people look after you
- You may find you can lose your temper quicker than other people
- You may find it hard to make friends
- You may find it hard to change your routines
- You may feel depressed
- You may feel that other people don't understand you
- You may feel sad
- You may find it hard to talk about yourself
- It's good to talk to others who also have TSC

You may want to see a specialist doctor who understands how you feel.



He is called a Psychiatrist.

You can ask your GP to arrange this for you.

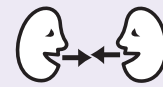


You might want to ask for help from your local Community Team for People with Learning Disabilities (CTLD).

You can ask your GP to arrange this for you.



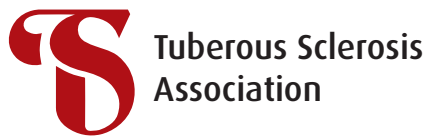
You might want to talk to someone from the TSA.



Name of specialist person who helps you and how to contact them



The TSA



- You may feel you would like support from the TSA
- The TSA knows lots of people with TSC and is happy to help them
- We can put people with TSC in touch with each other
- We can help you to tell your Doctor, Nurse, Social Worker or anybody else what you want or how you feel
- We can help you to find the best person to talk to
- We can tell you about Specialist TSC Clinics where the doctors know a lot about TSC



If you would like to find out how the TSA can help you, you can contact the following:

Glossary

- Cardiologist** – a specialist doctor who knows about heart problems
- Dermatologist** – a specialist doctor who knows about skin problems
- ECG** – electrocardiogram, a special test to check how your heart is working
- Geneticist** – a specialist doctor who knows about tuberous sclerosis complex
- Nephrologist** – a specialist doctor who knows about kidneys
- Neurologist** – a specialist doctor who knows about medical problems caused by the brain
- Psychiatrist** – a specialist doctor who knows about the effect the brain has on how we think and feel
- TSA** – Tuberous Sclerosis Association, a group of people who have tuberous sclerosis complex and their families and carers
- Ultrasound scan** – special photographs of the inside of someone's body



Tuberous Sclerosis
Association

Please visit the [TSA website](http://www.tuberous-sclerosis.org) for staff contact details
www.tuberous-sclerosis.org