

TSC Symptom Tracker

Tell your doctor about changes to your health

It is always important to talk with your doctor about any change in your tuberous sclerosis complex (TSC) signs or symptoms. This checklist can help your specialists understand what TSC symptoms you have had or your loved one has had since your last visit.

Remember, not all people with TSC have all its signs and symptoms. Some people may have just a few tumors in one place, such as the kidneys, while others may have many tumors in several places, such as the brain and lungs. The severity of the symptoms varies, too. Some people have very mild symptoms, while others have serious ones. But it is good to keep track of any new or existing symptoms so your doctor can help you.

Doctor(s):

Date(s) of last checkup:

Month/Day/Year

Next visit(s):

Month/Day/Year

Keep this sheet to compare to your next visit.

Make the conversation count

Check all new or worsening signs and symptoms.

Leave the area blank if you or your loved one does not have the sign or symptom.



BRAIN

Headaches

Seizures

If yes, how many per day? _____

Has this number gone up or gone down since your last doctor visit?

Number has gone up Number has gone down

Do you think your seizures are not as controlled as you would like?

Yes, the seizures are as controlled as I would like.

No, the seizures are not as controlled as I would like.

Sleep problems

What have you been doing to help yourself go to sleep? _____

Behavior problems, such as tantrums, poor eye contact, or mood swings

Psychiatric problems, such as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, depression, or anxiety

Intellectual problems, such as low IQ

Difficulty in school with reading, writing, spelling, or math

Social concerns, such as aggression

Other _____



KIDNEYS

- Blood in the urine
- Back or side pain



SKIN

- Bumps on my face
- Light-colored spots
- Skin tags
- Bumps or marks on my lower back
- Bumps around my fingernails or toenails
- Other _____



LUNGS

- Shortness of breath
How often? (For example, how many times a day or week?) _____
- Chest aches
How often? _____
- Frequent cough/wheezing
How often? _____
- Is the cough or wheezing related to a cold or the flu? Yes No



EYES

- Lesions or tumors in the back of my eye (only an eye specialist, called an ophthalmologist, can see these)
- Problems with sight



TEETH

- Bumps (growths) over a tooth or gum
- Pitting (dents) in teeth (this is often found by dentists)

Do you have other concerns that you would like to discuss with your doctor? Write them down in the space below.

Remember, these signs and symptoms are not the only clues to your TSC health. TSC can cause changes in your body that you don't even feel. For instance, when TSC kidney tumors occur, there are no signs or symptoms. So along with tracking changes that happen to your body, it is very important to keep your regular doctor appointments and get your recommended scans and tests.

To learn more, visit www.tuberous-sclerosis.com today!