

TSC Conversation Starter

Make the most of your doctor visits

Having a lifelong condition like tuberous sclerosis complex (TSC) can be challenging. The good news is that doctors can help you with each TSC concern every step of the way.

Use this tool to help you talk with your doctor. Review it before you go, and bring it with you to your appointment. Ask a close friend or family member who understands your medical needs to go with you and take notes during the appointment. Otherwise, make sure to take notes yourself.

It's okay to ask your doctor to repeat information or to slow down the conversation if you feel he or she is speaking too fast. And it is normal to feel anxious before and during your doctor appointments. But remember, the more comfortable you are sharing your health concerns, the better your overall well-being.

TSC care begins with you

Date: _____

1. The better prepared you are, the more you will get out of the doctor visit. Based on your most recent medical tests, check the signs and symptoms you or your loved one has now. Tell your doctor about these at your visit. There is space to write details under each medical concern. The more information you provide, the better your doctor can assess your health.

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| <p><input type="checkbox"/> Seizures <i>(Note if these have become more frequent or more severe. If you are taking antiepileptic drugs, or AEDs, note if they are working as well as you think they should.)</i></p> <p>_____</p> <p>_____</p> | <p><input type="checkbox"/> Light-colored spots on skin</p> <p>_____</p> <p>_____</p> |
| <p><input type="checkbox"/> Brain tumors <i>(You may not know you have a tumor until it is large and causes problems. Note if you are experiencing any signs like headaches, nausea, or vomiting.)</i></p> <p>_____</p> <p>_____</p> | <p><input type="checkbox"/> Skin tags or growths</p> <p>_____</p> <p>_____</p> |
| <p><input type="checkbox"/> Kidney tumors <i>(Note if you have had any pain in your side or your back. Also note if you have had any blood in your urine.)</i></p> <p>_____</p> <p>_____</p> | <p><input type="checkbox"/> Shortness of breath</p> <p>_____</p> <p>_____</p> |
| <p><input type="checkbox"/> TAND, or TSC-associated neuropsychiatric disorders <i>(This includes any big or small behavior, psychiatric, and intellectual problems; difficulty in school; and social concerns. Examples can include anxiety, depression, trouble concentrating, and aggression.)</i></p> <p>_____</p> <p>_____</p> | <p><input type="checkbox"/> Wheezing</p> <p>_____</p> <p>_____</p> |
| <p><input type="checkbox"/> Facial bumps</p> <p>_____</p> <p>_____</p> | <p><input type="checkbox"/> Frequent cough</p> <p>_____</p> <p>_____</p> |
| <p><input type="checkbox"/> Bumps on lower back</p> <p>_____</p> <p>_____</p> | <p><input type="checkbox"/> Chest pain</p> <p>_____</p> <p>_____</p> |
| | <p><input type="checkbox"/> Sleep problems</p> <p>_____</p> <p>_____</p> |
| | <p><input type="checkbox"/> Indents in your teeth or bumps on gums</p> <p>_____</p> <p>_____</p> |
| | <p><input type="checkbox"/> Problems with your vision</p> <p>_____</p> <p>_____</p> |
| | <p><input type="checkbox"/> Other</p> <p>_____</p> <p>_____</p> |

2. Ask your doctor: “What changes in my treatment do you recommend based on my signs and symptoms?”

3. It is important to get body areas scanned and monitored often in case new tumors begin to form. The larger tumors grow, the more complications they can cause—especially those in the brain and in the kidneys.

Ask your doctor: “When should I have scans done?”

4. Because TSC affects different parts of the body, you may have to see different doctors, called specialists.

Ask your doctor: “How often should I see other specialists?”

Check the doctors you should see, and then fill in the blank with the date of your visit.

Neurologist (brain doctor) _____

Neurosurgeon (brain surgeon) _____

Nephrologist (kidney doctor) _____

Dermatologist (skin doctor) _____

Pulmonologist (lung doctor) _____

Pediatric cardiologist (heart doctor for children) _____

Ophthalmologist (eye doctor) _____

Dentist _____

Geneticist (gene specialist) _____

Primary care physician _____

5. Ask your doctor to help you coordinate the team to monitor every part of your body that is affected by TSC.

Ask your doctor: “Can you refer me to the other specialists I should be seeing?”

Specialist's name	Phone number	Will monitor my

Notes: _____

Remember, taking charge of your TSC health means asking questions, learning about TSC, and seeing the right specialists based on your signs and symptoms.

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