

Kidney Tumor Discussion Guide

Tips on talking with your doctor about your kidneys

If you have kidney issues related to tuberous sclerosis complex (TSC), the most important thing you can do is keep appointments with your doctor. This tool will help you talk with your doctor at your visits, so you can become partners in managing your condition and treatment. Review it before you go. And bring it with you. This discussion guide is not comprehensive, so please be sure to talk to your doctor about any questions or concerns that you have about your disease.

Your doctor visit is a chance to learn more about your health

Date: _____

Questions to ask your doctor

The better prepared you are, the more you will get out of the doctor visit. Asking your doctor the questions below will help you stay informed and involved in your treatment plan.

Remember to tell your doctor if you have had any pain in your side or your back or if you have had any blood in your urine.

Based on my most recent medical tests:

1. What is my kidney (renal) function? _____
Has it changed since my last visit? _____
If so, do you recommend any changes to my care? _____
2. What is my blood pressure? _____
Has it changed since my last visit? _____
If so, do you recommend any changes to my care? _____
3. How many TSC kidney tumors (renal angiomyolipomas) do I have? _____
Do I have more than at my last visit? _____
Are they in both kidneys or just one? _____
4. How big is my largest tumor? _____
Do I have any tumors over 4 cm or larger in diameter? _____
If your doctor says yes, you might want to say: "I understand that kidney tumors are more likely to rupture when they are about 4 cm or larger. Can we talk about a plan of action?"
5. The TSC guidelines recommend a scan of your kidneys every 1 to 3 years. If you are not getting scans this often, ask: "Should I get a scan every 1 to 3 years?" _____
6. Are there any tumors that have grown since my last scan? _____
If your doctor answers yes, you might want to ask: "Should I get more frequent scans to monitor the tumors?" _____
"Should we talk about treatment of these tumors?" _____

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7. Check any signs or symptoms that you have had since your last appointment. These symptoms can also be associated with TSC. If you are concerned that you may have other symptoms of TSC besides kidney tumors, ask your doctor. He or she can recommend a plan of action.

Leave this section blank if you haven't had any of these signs or symptoms.

- | | |
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| <input type="checkbox"/> Seizures (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.) | <input type="checkbox"/> Skin tags or growths |
| <input type="checkbox"/> Brain tumors (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.) | <input type="checkbox"/> Shortness of breath |
| <input type="checkbox"/> TAND, also known as TSC-associated neuropsychiatric disorders (Includes behavior, psychiatric, and intellectual problems; difficulty in school; and social concerns.) | <input type="checkbox"/> Wheezing |
| <input type="checkbox"/> Facial bumps | <input type="checkbox"/> Frequent cough |
| <input type="checkbox"/> Bumps on lower back | <input type="checkbox"/> Chest pain |
| <input type="checkbox"/> Light-colored spots on skin | <input type="checkbox"/> Sleep problems |
| | <input type="checkbox"/> Indents in your teeth or bumps on gums |
| | <input type="checkbox"/> Problems with your vision |
| | <input type="checkbox"/> Other _____ |

8. I know that TSC is a lifelong condition that can affect different parts of the body. Do you think I should be managing my TSC any differently than I am now?

9. Can you help me coordinate a team of specialists to monitor my other organs that might be affected by TSC?

Ask for names and phone numbers of doctors who are familiar with TSC and its signs and symptoms. Such doctors may include a dermatologist, pulmonologist, neurologist, primary care physician, and geneticist.

10. Should I see a geneticist to understand more about my TSC and to know if there is a family connection to my disease?

Ask for the name and phone number of a genetic counselor.

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!

