INTRODUCTION TO

TARLOV CYSTS

FOR HEALTHCARE PROVIDERS

People living with Tarlov Cyst Disease need providers who listen and provide compassionate care, including an accurate diagnosis and symptom management.

Also called a perineural cyst, a Tarlov cyst is **a type of meningeal cyst that is abnormal expansion of a spinal nerve root** caused by cerebrospinal fluid (CSF) accumulation *within* the nerve's outer sheath. As the fluid accumulates, it enlarges the nerve and forms a cyst, which can compress adjacent nerves and cause debilitating symptoms. Tarlov cysts can form anywhere along the spine where nerve roots are present, but occur most commonly in the sacrum.

Know the Symptoms

- Pain and or numbness in sacral area, buttocks, hips, down the back of the legs, and into the feet
- Weakness and/or cramping in legs and feet
- Pain with sitting, standing for even short periods of time, having to move around frequently when sitting or use a cushion. Some patients describe the sensation of sitting on a rock
- Bladder and bowel-related symptoms: urinary urgency or frequency, urinary retention with the need to push to empty, and constipation requiring laxative or enema use
- Pain with sexual intercourse
- Persistent genital arousal disorder
- Pain or numbness in the perineum, vagina, or rectum

Your Role Matters

- Misdiagnoses can lead to patients enduring unnecessary and ineffective procedures
- Persistent pressure from the cyst(s) can cause permanent nerve damage
- People with Tarlov cysts frequently report feeling frustrated and dismissed

~16% of Tarlov cysts are symptomatic

contrary to the original belief that they are always "insignificant." Tarlov cysts are an often overlooked source of chronic pain. *

*https://pubmed.ncbi.nlm.nih.gov/33452905/

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How To Diagnose

The gold standard for identifying Tarlov cysts is an MRI, and the best specifications for an MRI order are **"Non contrast MRI of the sacrum with T2 weighted images of sagittal and axial views of the entire sacrum"**.

Scan to learn more about Tarlov cysts

Who Is Affected

The global pooled prevalence of Tarlov cysts is 4.18%*, and they are **found most commonly in women**. The exact cause is unknown, but in many cases, the Tarlov cysts may have been present for years before the symptoms started spontaneously or were triggered by a traumatic event. There is an association between Tarlov cysts and collagen disorders such as Marfan syndrome and Ehlers-Danlos syndrome.

How To Help Patients With Suspected Tarlov Cysts

Take their pain seriously. People with Tarlov cysts frequently report feeling frustrated and dismissed. Debilitating pain can cause them to miss work and social activities.

Reconsider "incidental" MRI findings. It is not unusual for the MRI report to not to mention Tarlov cysts or to state that they are an incidental finding of no clinical significance. But if a patient is experiencing symptoms associated with Tarlov cysts, it may be worth a closer consideration.

Write a letter for workplace accommodations or disability claims. A patient's ability to work could be affected by sitting intolerance, a need to lie down, an unpredictable bowel and bladder, cognitive side effects of medication, or inability to concentrate due to pain. Ensure medical records reflect relevant symptoms including severity, frequency, and impact on daily functioning.

Refer them to a neurosurgeon who specializes in Tarlov cysts.

Refer them to a pain management specialist, urologist, or gynecologist, as appropriate, to manage symptoms.

Improving the lives of people affected by Tarlov cyst disease by accelerating research, educating the medical community, and providing evidence-based information and support.

TARLOV CYST DISEASE FOUNDATION

Find resources for providers and patients at tarlovcystfoundation.org