



Adults with TSC Newsletter



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Understanding Sleep Issues in TSC

By Rita Mason

Add a good night's sleep or, really, lack thereof to the myriad of issues facing people living with tuberous sclerosis complex (TSC). Dr. Tanjala Gipson recently shared some good tips on how to get to sleep and how to sustain it.

Dr. Gipson, Director of the TAND Clinic at Le Bonheur Children's Hospital in Memphis, led the discussion on the January Adults with TSC Informational Call. The key things to keep in mind that can interfere with sleep in TSC patients are epilepsy, mental health issues and physical manifestations.

"It is important to treat the sleep disruption, but

more so to know why the sleep is being disrupted," Dr. Gipson said. "Sleep studies are key."

She explained sleep hygiene, or the routines people must establish for themselves to get to sleep. For example, timing. Some prefer an odd number of sleep hours, while some want more sleep. Others might function better with less hours. Choosing room temperature is another aspect: a colder room or a warmer room? Studies debate the detriment of electronics before bed, but some people do relax with their phone or tablet.

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Adult Resources

Upcoming Adult Topic Calls:

Thursday, February 20, 2020:
"Open Forum" presented by Adult Regional Coordinators.

Thursday, March 26, 2020:
"What is Behavior Intervention?" presented by Gregory Woznicki, M.Ed, BCCS, CCTS-I, Community Options, Inc. of Southeastern PA.

All Adult Topic calls start at 8 pm Eastern, 7 pm Central, 6 pm Mountain, 5 pm Pacific.

To participate simply use the toll-free call-in number: 1-866-613-5223 then enter access code: 4334003#. If you have questions or would like to receive handouts (if available) before each call, contact Dena Hook at dhook@tsalliance.org or (800) 225-6872.

Questions? Contact Dena Hook, Vice President, Support Services, at dhook@tsalliance.org.



TSC Now is the TS Alliance's podcast series!

[Check out the last episode!](#)

Additional Resources

TSC Talks, a podcast hosted by Jill Woodworth, explores tuberous sclerosis complex and other related issues. Each week Jill talks to parents/caregivers, adults affected by TSC, and other professionals about their experiences managing TSC, the challenges they've faced and where they find hope.

[Listen to the latest episode now](#)



TSCMatters

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Bedding is also key, such as the sheets you prefer or the merits of a weighted blanket.

People with TSC must understand their sleep preferences, but once these are understood the underlying cause must be uncovered. For Dr. Gipson, a combined sleep study and EEG are best to rule out some common causes for the disruption during the sleep cycle:

- Seizures are disruptive and will affect sleep patterns, whether they are obvious or hidden.
- Mental-health issues, such as anxiety, worry and depression, can also be a hindrance. Knowing how to quiet the mind is important.
- Physical manifestations, such as headaches, restless leg syndrome or sleep apnea also affect the ability to obtain good sleep.

Dr. Gipson recommends a combined sleep study with an EEG to uncover the cause, then described strategies to get a good night's rest. With the help of dedicated specialists, these strategies may include cognitive behavior therapy to help the person dealing with anxiety or depression. Also look at medications, consider either taking them away, adjusting dosage or perhaps adding one to ease a person to rest. In addition, iron replacement might help deal with restless leg syndrome.

Dr. Gipson was able to answer questions from callers and shared how being able to participate in Adults with TSC Informational Calls "is one of my absolute favorite things to do."

For more information on sleep issues in TSC, visit www.tsalliance.org/individuals-families/adults/ to listen to the recording of the call and view Dr. Gipson's PowerPoint presentation.

For more adult resources including previous issues of the Adults with TSC Newsletter, information on reproductive health and contact information for your Adult Regional Coordinator, check out the Adult page on the TS Alliance website [here](#).

Upcoming TS Alliance Events

SAVE THE DATE!

The TS Alliance will be hosting three Regional TSC & LAM Conferences in partnership with The LAM Foundation in 2020. Here are the dates and locations for these conferences (*tentative and subject to change*):

- Saturday, June 20, 2020 - Memphis, TN
- Saturday, September 26, 2020 - Gainesville, FL
- Saturday, October 24, 2020 - Denver, CO

More information, including a link to register, will be available later this year.



Upcoming Step Forward Walks:
[Arizona Walk - Saturday, April 4, 2020](#)
[Houston Walk - Saturday, April 25, 2020](#)
[Seattle Walk - Sunday, April 26, 2020](#)
To find a walk near you [click here](#).