

TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

JULY 2026

Summer is officially here! As temperatures rise and calendars fill with vacations, family gatherings, and outdoor activities, we know that living with Tethered Cord Syndrome can bring unique challenges during the warmer months. That's why this issue is dedicated to helping you make the most of the season while prioritizing your health, comfort, and well-being.

Inside this month's newsletter, you'll find practical summer tips for managing TCS symptoms in the heat, staying hydrated, conserving energy, and planning activities that work with your body, not against it. We've also included ideas for summer fun, travel-friendly suggestions, and reminders that it's okay to slow down and listen to what your body needs.

As always, our community continues to inspire us with its resilience, strength, and willingness to support one another. Whether you're enjoying a summer adventure or simply finding ways to stay cool and comfortable at home, we hope this month's newsletter provides helpful resources and encouragement along the way.

Thank you for being part of the TCSA community. We are honored to walk this journey together.

Wishing you a safe, healthy, and enjoyable summer!
Warmly,

The TCSA Team

**ILLUMINATE PATHS TO
COMMUNITY AND
CONNECTION FOR THOSE
WITH TETHERED CORD**



**HELLO
SUMMER!**



Tetheredcord.com



SUMMER SURVIVAL GUIDE

Summer Survival Guide: Tips and Tricks for Navigating Tethered Cord Syndrome in the Heat

Summer brings sunshine, vacations, family gatherings, and outdoor adventures, but for many people living with Tethered Cord Syndrome (TCS), warmer temperatures can also bring unique challenges. Increased pain, fatigue, muscle spasms, bladder concerns, and heat sensitivity can make the season feel more difficult to navigate. The good news? A little planning can go a long way toward helping you stay comfortable and enjoy everything summer has to offer.

1. Stay Ahead of the Heat

Many individuals with TCS report that heat can worsen symptoms such as fatigue, pain, weakness, or dizziness. Instead of waiting until you feel overheated, try to stay cool proactively. Some helpful strategies include:

- Carrying a refillable water bottle everywhere you go
- Using cooling towels, neck wraps, or portable fans
- Seeking shade whenever possible
- Planning outdoor activities during the early morning or evening hours
- Taking regular breaks in air-conditioned spaces

Remember: overheating can happen gradually, so pay attention to your body's signals.

2. Hydration Is More Important Than You Think

Hot weather increases the risk of dehydration, which can contribute to fatigue, headaches, muscle cramps, blood pressure changes and bladder irritation.

Try:

- Drinking water consistently throughout the day
- Adding electrolyte drinks when spending extended time outdoors
- Eating water-rich foods such as watermelon, cucumbers, oranges, and berries
- Limiting excessive caffeine and alcohol, which can contribute to dehydration

A simple rule of thumb: if you're thirsty, you're already behind.

3. Pace Yourself

Summer often comes with pressure to do more: Vacations, family events, festivals, and outdoor activities. But overexertion can lead to symptom flares.

Give yourself permission to:

- Schedule rest breaks
- Split large activities into smaller chunks
- Alternate active and restful days
- Say "no" when your body needs recovery time

Pacing isn't giving up...it's preserving energy for the things that matter most.

4. Choose Summer Activities That Work for You

Summer fun doesn't have to mean pushing through pain.

Some lower-impact options include:

- Swimming or water therapy
- Visiting museums or indoor attractions
- Early morning walks
- Picnics in shaded areas
- Gardening in short sessions
- Family movie nights or backyard gatherings after sunset

The goal isn't to keep up with everyone else, it's to find activities that support your health while bringing joy.

5. Listen to Your Body

One of the most valuable skills for living with TCS is recognizing your personal warning signs.

Pay attention if you notice:

- Increased pain
- New numbness or tingling
- Worsening fatigue
- Muscle spasms
- Changes in bladder or bowel symptoms
- Dizziness or overheating

These signs may be your body's way of asking for rest, hydration, cooling, or medical attention.

7. Give Yourself Grace

Summer often comes with images of endless energy and adventure. But living with Tethered Cord Syndrome means your experience may look different, and that's okay. Celebrate what you can do. Adapt when needed. Rest without guilt. Every small victory matters. This season, focus less on meeting expectations and more on creating moments of comfort, connection, and enjoyment.

Wherever You Are This Summer

While summer often brings vacations, backyard barbecues, and outdoor adventures, we know that's not everyone's reality.

For some members of our TCS community, summer may look like managing pain from bed, navigating medical appointments, coping with worsening symptoms, or relying on mobility aids just to get through the day. I know, I have been there too. If that's where you find yourself this season, please know that you are not forgotten, and you are not alone.

Your summer does not have to look like anyone else's to be meaningful. Some days, success may mean making it to an appointment, completing a therapy session, getting outside for a few minutes of fresh air, or simply making it through a difficult day. **Those victories matter.**

As a community, we recognize the strength it takes to keep moving forward when your world has become smaller than you ever imagined. Whether you're spending your summer exploring new places or navigating life from home, you remain an important and valued part of the TCSA family. We see you, we support you, and we're cheering you on every step of the way.

From all of us at TCSA, we wish you a safe, healthy, and symptom-managed summer!



July 7th @ 7:00 pm – 8:00 pm CDT

Tethered Tuesday (virtual support group for adults)

- Connect with other adults living with tethered cord syndrome.
- 1st Tuesday of the month at 7pm CST

July 14th @ 12:00 pm – 1:00 pm CDT

Tethered Tuesday (virtual support group for parents/caregivers)

- Connect with other parents/caregivers of children living with tethered cord syndrome.
- 2nd Tuesday of the month at 12pm CST

July 21st @ 12:00 pm – 1:00 pm CDT

Tethered Tuesday (virtual support group for adults)

- Connect with other adults living with tethered cord syndrome.
- 3rd Tuesday of the month at 12pm CST

July 25th @ 7:00 pm – 8:00 pm CDT

Tethered Tuesday (virtual support group for kids)

- Connect with other kids who are living with tethered cord syndrome! Caregivers are always welcome to listen in and help as needed, but the content and discussions in this group are geared toward children (3-17).
- 4th Tuesday of the month at 7pm CST



TETHERED CORD
SUPPORT ALLIANCE



EDUCATIONAL WEBINAR

REHABILITATIVE STRATEGIES FOR TETHERED CORD SYNDROME



PRESENTED BY AN EXPERT
PANEL OF PHYSICAL
THERAPISTS



EXPERT
PANEL



COLLABORATIVE
LEARNING



BETTER SUPPORT.
BETTER OUTCOMES.



JULY 14TH, 2026



7:00 PM CST



REGISTRATION
IS FREE

OPEN TO PROVIDERS,
PATIENTS, CAREGIVERS,
AND THE PUBLIC



REGISTER TODAY!



COLLABORATING
FOR STRONGER
OUTCOMES



TETHERED TUESDAYS UPDATE



We've simplified things! Going forward, all Tethered Tuesdays meetings will use one consistent Zoom link. Be sure to save the link or QR code to your preferred device for easy access to all Tethered Tuesdays support group meetings.



TCSA ANNUAL REPORT

Thank you to everyone who joined us for the TCSA Annual Report! We are grateful for the support of our team members, volunteers, donors, and community partners who took the time to learn about our programs, accomplishments, and goals for the year ahead. Your engagement, encouragement, and commitment to our mission help make our work possible. We look forward to continuing to grow our impact together and are excited for the opportunities and initiatives ahead. Thank you for being part of the TCSA community!

[SEE OUR YEAR IN REVIEW](#)

TCSA PEER SUPPORT PROGRAM

The TCSA Peer Support Program offers one-on-one support to individuals and families affected by tethered cord syndrome. If you would like to meet with a peer support agent or educational advocate, please fill out [this form](#) to be connected with someone who can answer questions and help you navigate your own tethered cord journey.

OUR MISSION IS TO IMPROVE MEDICAL CARE AND QUALITY OF LIFE FOR ALL WITH TETHERED CORD SYNDROME

Founded in 2024, the Tethered Cord Support Alliance is the first ever 501(c)(3) devoted solely to Tethered Cord Syndrome

SUBSCRIBE TO OUR NEWSLETTER TO STAY IN THE LOOP!

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