Tuberous Sclerosis Complex Behavior Plan

A quick self-help guide for parents and caregivers

Why behavior may change

In tuberous sclerosis complex (TSC), behavior can change because of seizures, poor sleep, pain, illness, constipation, medication effects, sensory overload, or difficulty communicating. Children and teens may also have autism-related differences, attention or impulse-control problems, anxiety, depression, aggression, or self-injury. A sudden change may be medical information, not simply defiance.

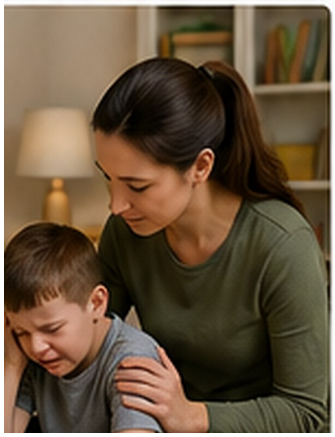
START WITH WHAT IS HAPPENING NOW

Someone may be unsafe, or the change is sudden	Go to Medical & Safety on page 7.
Your child is overwhelmed, shutting down, or losing control	Use Meltdowns, Sensory Overload, or Communication on pages 2-4.
The problem keeps happening during routines, school, or handoffs	Use Daily Routines, School & Households, or Caregiver Communication on pages 5-8.
Your teen is holding it together all day and crashing at home	Go to For Teens on page 9.

USE THE SAME ORDER EACH TIME

1. **Check TSC basics**
   Look for seizure changes, poor sleep, pain, illness, constipation, headache, medication changes, or sensory overload.
2. **Make the moment safer and easier**
   Lower demands, reduce noise and language, move breakable items, and offer one simple choice when your child can still respond.
3. **Teach and practice later**
   After recovery, practice the break signal, communication word or picture, visual routine, or coping step your child can use next time.

When a Meltdown Starts



The first goal is safety

Move breakable items, reduce the number of people nearby, and give your child room. During the peak of a meltdown, long explanations and consequences usually make recovery harder.

DURING THE FIRST FEW MINUTES

- Move other children and unnecessary adults away. A crowd can make the episode last longer.
- Use one calm sentence, such as: “You are safe. I am here.” Then stop talking unless safety requires more.
- Lower lights and noise. Pause questions and demands.
- If touch usually helps, ask before touching. If touch makes things worse, give more space.
- Follow the seizure rescue plan if the episode may be seizure-related.

IF YOUR CHILD CAN STILL RESPOND

- Offer one simple choice: “Couch or quiet room?”
- Offer water, a blanket, headphones, or a familiar comfort item.
- Use a visual timer if waiting is difficult.
- Accept a gesture, picture, or communication-device response. Spoken words are not required.

AVOID DURING THE MELTDOWN

- Do not lecture, argue, demand an apology, or ask repeated “why” questions.
- Do not add consequences while your child is still overwhelmed.
- Do not force eye contact, touch, or a conversation about what happened.

AFTER YOUR CHILD IS CALM

- Reconnect first through quiet attention, a snack, water, or a familiar activity.
- Keep the review short: “That was hard. Next time, use break first.”
- Practice one replacement response, such as a break card, communication word or picture, safe place, or short coping routine.
- Write down what happened before the meltdown and how long recovery took.

GET MEDICAL OR SAFETY HELP

- Call emergency help when you cannot keep your child or other people safe, there is serious self-injury or dangerous aggression, your child runs into danger, or there is loss of consciousness or trouble breathing.
- Contact a medical provider promptly for new or increasing aggression, self-injury, unusual confusion, a change after seizure activity, or a clear change from your child’s usual pattern.
- For repeated self-injury that is not an immediate emergency, remove hazards, follow the safety plan, record what happened before and after, and contact your child’s medical and behavioral providers.

Sensory Overload

COMMON SIGNS

- Covers ears, freezes, cries, shuts down, or tries to leave.
- Avoids clothing, grooming, bathing, food textures, crowds, drills, or bright lights.
- Seeks deep pressure or movement, chews on objects, rocks, spins, or paces.

WHAT TO CHANGE FIRST

- Reduce the input: dim lights, lower sound, clear the room, and pause questions.
- Offer headphones, sunglasses, a hat, a quiet space, movement, a chew item, or a fidget.
- Offer one simple choice between two calming supports: “Would you like your noise-reducing headphones, or would you like to move to a quieter space?”
- Warn before alarms, touch, grooming, crowds, and changes in routine.

MAKE THE PLAN FIT THE SETTING

Store	Go at a quieter time, keep the trip short, use a simple list, and leave before overload.
Clothing	Remove tags, test fabrics at home, and keep a backup outfit.
Meals	Include a familiar food and avoid pressure during overload.
School	Warn before drills, assemblies, substitutes, and schedule changes; identify a quiet recovery space.

WHEN THE FIRST STEPS DO NOT HELP

- Look for the trigger: sound, light, touch, smell, clothing, hunger, fatigue, pain, waiting, or transition.
- Notice whether the sensitivity is long-standing or began after seizure changes, illness, medication changes, or poor sleep.
- Ask an occupational therapist, school contact, or medical provider for help when sensory needs interfere with eating, hygiene, school, sleep, or safety.

Contact a provider for a sudden new pattern

Sensory differences may be part of your child’s usual pattern, especially when autism-related traits are present. A sudden new sensitivity with headache, vomiting, pain, constipation, sleep change, confusion, self-injury, or unsafe attempts to escape may signal a health change.

Communication and AAC

WHEN BEHAVIOR MAY BE THE MESSAGE

Some children have difficulty understanding spoken language, finding words, or explaining pain, fatigue, fear, or sensory overload. Frustration may increase when adults ask many questions or expect a spoken answer.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) STAYS AVAILABLE

AAC includes picture cards, communication books, gestures, signs, and speech-generating devices. Keep the child's communication system within reach throughout the day, and use the same system across home, school, and community settings.

HOW TO SUPPORT COMMUNICATION

- Pair spoken words with a picture schedule, first-then board, choice board, or break card.
- Pause for 5 to 10 seconds before repeating the question or adding a prompt.
- Respond to every clear communication attempt, even when it is incomplete.

USE AAC IN DAILY ROUTINES

Snack	more, different, drink, help, all done
Bath	water, stop, towel, hot, cold, pain
Bedtime	tired, story, light off, wait, finished
Medical visit	hurt, scared, break, yes, no, all done

IF COMMUNICATION IS STILL HARD

- Use one picture, one choice, or one short sentence.
- Check the battery, volume, available words, and whether your child can easily reach and use the device.
- Ask a speech-language pathologist, developmental specialist, or school assistive-technology contact for help when speech or language is delayed, social communication is difficult, or AAC access and vocabulary need improvement.
- Contact a medical provider when communication drops suddenly after seizure activity, illness, poor sleep, pain, headache, or a medication change.

Make Daily Routines Easier

SET UP THE ROUTINE BEFORE YOU ASK

- Put the needed materials where the task starts.
- Use a visual schedule, timer, first-then statement, or short written checklist.
- Give one-step directions and use short work periods when attention, restlessness, or impulse control is difficult.
- Preview changes with pictures or a short written plan when your child depends on routines or becomes distressed by unexpected changes.
- Build in movement or a short break before a difficult task.

EXAMPLE

Instead of “Get ready,” use: “Shoes, backpack, then car.” Point to the pictures or checklist as you speak.

TEACH THE STEPS WHEN YOUR CHILD IS CALM

- Show the first step, do it together, and then let your child try.
- Use the same words and visuals each time.
- Practice when your child is rested and calm, not during a meltdown, seizure recovery, illness, or exhaustion.
- Reduce adult help one step at a time after the routine becomes familiar.

REINFORCE THE SKILL

- Praise the exact behavior: “You started when the timer beeped.”
- Reward effort, safe behavior, and completion rather than perfection.
- Use small, predictable rewards that can be delivered consistently.
- Keep consequences brief and directly related to the behavior.

WHEN THE PLAN IS NOT WORKING

- Make the task smaller before adding more reminders or consequences.
- Check sleep, pain, seizures, medication, sensory load, and whether inattention, restlessness, impulsivity, anxiety, rigid thinking, or trouble shifting is making the routine harder.
- Ask for additional support when routines remain unsafe, your child cannot start or finish despite consistent help, or caregivers are too exhausted to use the plan.

School and Across Households

WHAT SHOULD STAY THE SAME

- The safety response and the words adults use during escalation.
- The break signal, AAC words or pictures, and recovery space.
- Medication and seizure information, including when to call a caregiver or provider.
- A short handoff routine between settings.

WHAT CAN BE DIFFERENT

- Bedtime, chores, screen limits, rewards, and household routines may differ.
- Do not argue about those differences in front of the child.
- When a routine changes, explain it clearly and keep the safety steps familiar.

SCHOOL SUPPORTS

- Predictable schedules, visual directions, shorter assignments, movement breaks, and a quiet recovery space.
- If attention, hyperactivity, impulsivity, communication, repetitive behavior, or distress with change affects learning, request a school evaluation and specific supports.
- When behavior interferes with learning or safety, ask about a functional behavior assessment (FBA), a behavior intervention plan (BIP) that teaches replacement skills, and needed supports in the IEP or Section 504 plan.

USE A BRIEF DAILY HANDOFF

Share sleep, medication, seizure concerns, pain or illness, sensory load, what your child used to communicate, and what helped.

GREEN	YELLOW	RED
Typical day; usual supports are enough.	Extra stress, poor sleep, seizures, or overload; lower demands.	Safety concern or major medical change; follow the safety plan and call for help as needed.

Medical and Safety Decisions

CHECK FOR THESE CHANGES

Seizures	New type, increased frequency, unusual recovery, staring, or confusion.
Sleep	New insomnia, night waking, daytime fatigue, loud snoring, or several nights of poor sleep followed by a clear behavior change.
Pain or illness	Headache, vomiting, stomach pain, constipation, dental pain, infection, or injury.
Medication	Missed dose, double dose, new medication, dose change, or side effect.

CHOOSE THE NEXT STEP

Call emergency help now

You cannot keep your child, teen, or other people safe; there is serious self-injury, dangerous aggression, running into danger, loss of consciousness, trouble breathing, or severe illness or injury; or the seizure rescue plan says to call emergency services.

Contact a provider soon

Contact a provider promptly for sudden changes in behavior, mood, sleep, communication, appetite, or energy; new or increasing self-injury; changes after seizure activity, medication, illness, injury, or loss of skills; severe confusion, hearing or seeing things others do not, extreme suspiciousness, or a major personality change.

Track for the next visit

The concern is mild, stable, and does not create a safety risk. Record the pattern so it can be reviewed at the next TSC visit.

WHAT TO RECORD

- Date and time, what happened before, and sleep the night before.
- Medication timing, seizure concerns, pain or illness signs, and recovery time.
- What helped and whether the same pattern occurred at home, school, or another setting.
- At least yearly, review behavior, mood, attention, learning, sleep, communication, and daily living with a provider familiar with TSC. Request developmental, behavioral, psychological, or neuropsychological evaluation when concerns persist or skills are lost.

Keep Caregivers and School Connected

WHAT TO SHARE

- What happened before the behavior, what the behavior looked like, what helped, and how long recovery took.
- Sleep, medication, seizure concerns, pain or illness, sensory triggers, and communication changes.
- The same break phrase, AAC words, visuals, and safety response.

HOW TO SHARE IT

- Use a one-page handoff sheet, shared note, patient portal, or a photo stored in each caregiver's phone.
- Keep notes factual and brief. Avoid labels such as "manipulative," "lazy," or "attention-seeking."
- Review the plan after a medication change, seizure change, school break, new caregiver, or major stressor.

WHEN SUPPORT IS LIMITED

- Keep the plan to the essentials: safety, medication and seizure information, communication, sensory supports, and who to call.
- Caregiver exhaustion can make a safety plan hard to follow. Ask relatives, school staff, social work, behavioral health, or respite services for specific help.
- Use the TSC Alliance clinic finder when local providers are unfamiliar with TSC or when concerns span seizures, behavior, learning, sleep, and mental health.

ONE-PAGE HANDOFF

Sleep and medication	_____
Seizure, pain, illness, or sensory concerns	_____
What the child used to communicate	_____
What helped / what to avoid	_____
Who should be called if the plan is not enough	_____

WHEN ADULTS DISAGREE

Agree first on safety, medication and seizure information, the break signal, and when to call for help. Discuss other differences away from the child. Try one change for a set amount of time, then review together whether it helped.

For Teens

SCHOOL-HOME CRASH

- Start with food, water, quiet, movement, and time to recover.
- Use one short homework plan after the teen has settled.
- Before calling it disrespect, check sleep, seizures, medication, pain, anxiety, and sensory overload.
- Ask the school what demands or social situations use the most energy.

HOW TO WORK WITH YOUR TEEN

- Ask what feels difficult before offering solutions.
- Let the teen choose one goal and one support to try first.
- Use private check-ins. Ask about persistent worry, irritability, loss of interest, low mood, withdrawal, sleep, appetite, and energy without assuming the behavior is disrespect.
- Contact a medical or mental health provider when these changes persist, worsen, or interfere with school, relationships, or daily life.
- Do not discuss behavior in front of siblings, relatives, or peers without permission.

PLANNING FOR INDEPENDENCE

- Teach the teen to describe medications, seizure safety, communication needs, and helpful supports.
- Practice scheduling appointments, using reminders, asking for breaks, and carrying needed information.
- Prepare gradually for work, driving, relationships, privacy, and adult medical care.
- Except during an immediate safety concern, do not expect a teen to follow a plan they had no part in creating.

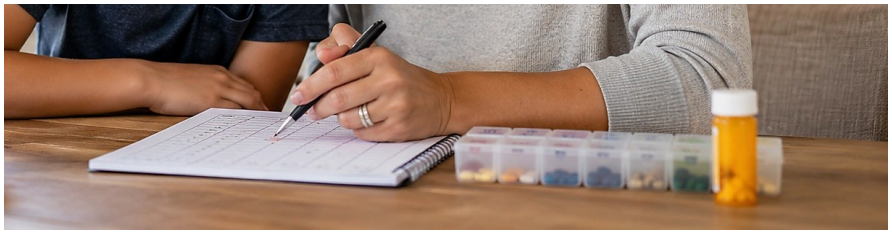
GET URGENT HELP

- Seek immediate help for self-injury, talk of not wanting to live, dangerous aggression, running into danger, or another immediate safety risk.
- Contact a medical or mental health provider for sudden personality change, withdrawal, hopelessness, major sleep or energy change, loss of skills, hearing or seeing things others do not, extreme suspiciousness, severe confusion, or a sharp drop in school functioning.

A plan teens can carry

Medication list | seizure rescue information | who to call | helpful break or sensory supports | communication needs | school or work accommodations

References



Dawson, P., & Guare, R. (2009). *Smart but scattered: The revolutionary "executive skills" approach to helping kids reach their potential*. Guilford Press.

Greene, R. W. (2021). *The explosive child: A new approach for understanding and parenting easily frustrated, chronically inflexible children* (6th ed.). Harper.

Guare, R., Dawson, P., & Guare, C. (2013). *Smart but scattered teens: The "executive skills" program for helping teens reach their potential*. Guilford Press.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 et seq. (2004).

Northrup, H., Aronow, M. E., Bebin, E. M., Bissler, J., Darling, T. N., de Vries, P. J., Frost, M. D., Fuchs, Z., Gosnell, E. S., Gupta, N., Jansen, A. C., Jóźwiak, S., Kingswood, J. C., Knilans, T. K., McCormack, F. X., Pounders, A., Roberds, S. L., Rodriguez-Buritica, D., Roth, J., ... Krueger, D. A. (2021). Updated international tuberous sclerosis complex diagnostic criteria and surveillance and management recommendations. *Pediatric Neurology, 123*, 50-66. https://doi.org/10.1016/j.pediatrneurol.2021.07.011

TSC Alliance. (n.d.). *Clinical manifestations*. https://www.tscalliance.org/understanding-tsc/clinical-manifestations/

TSC Alliance. (n.d.). *Find a TSC clinic*. https://www.tscalliance.org/find-support/tsc-clinics/

Tuberous Sclerosis Complex International. (n.d.). *International TSC consensus guidelines*. https://www.tscinternational.org/international-tsc-consensus-guidelines/