Emotional Overload: Understanding Non-Tic Related Behaviors in Tourette Syndrome

A Guide for Families Living with Tourette Syndrome and other Tic Disorders



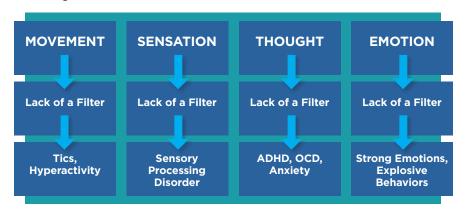
Emotional overload is a common feature of Tourette Syndrome (TS) and can also be referred to as rage attacks, intermittent explosive disorder (IED), emotional dysregulation, sensory dysregulation, and emotional outbursts. Emotional overload occurs when an emotional response does not fit the situation and overwhelms the child's ability to use age-appropriate coping strategies. The emotional response of the child is not equal to the situation to which the child is responding. For example, a parent asks a child to move their shoes from the doorway and this causes a screaming fit. Another example is a class earns a reward and the child with Tourette cannot contain her happiness and continues to be disruptive after being asked to stop several times.

The child's ability to regulate varies by day and situation and therefore these events can be unpredictable yet common. Emotional overload can occur in about half of children with TS (Budman et al., 2000; Ashurova et al., 2021).

Emotional Overload and Tourette Syndrome

Most individuals with TS have at least one neuropsychiatric or co-occurring condition such as ADHD, anxiety, OCD, (Hirchtritt et al., 2015) which contributes to having difficulty managing stressful and overwhelming situations, both positive and negative.

Children with Tourette Syndrome and co-occurring conditions often cannot filter sensations, thoughts, emotions, or movements effectively. This lack of ability to filter is neurobiological in nature and not a conscious choice for the child.



Like TS, there is still no clear scientific explanation for what causes explosive outbursts. Some studies have found that they are more likely to occur in people who had earlier age of onset of tics, as well as greater tic severity (Chen et al., 2013). More recent work (Atkinson-Clement et al., 2020) has shown that explosive outbursts are not related to tic severity. Multiple studies indicate that they are more likely to occur in people with TS who also have attention deficit/hyperactivity disorder (ADHD) (Chen et al., 2013, Atkinson-Clement et al., 2020, Hagstrom et al., 2020).

New research is helping us understand the explosive outbursts in people with TS. Researchers found that people who have TS and explosive outbursts might have differences in underlying brain function and that explosive behavioral outbursts may be a separate condition from TS and not part of TS. Researchers found that people who have TS and explosive outbursts have less efficient brain control, difficulties with regulation of emotion, and aggressive behavior (Atkinson-Clement et al., 2020).

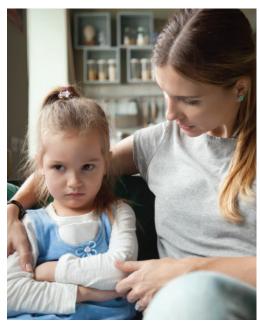
Commonly Seen Behaviors

With an increased understanding of why children lack emotional regulation ability, let's focus on some of the environments and activities where you may see the outbursts and other challenging behaviors. This chart is not meant to be exhaustive but rather illustrates a few examples of everyday issues youth with Tourette and their families manage.

НОМЕ	SCHOOL	SOCIAL SITUATIONS	PUBLIC/COMMUNITY
When asked to stop a preferred task or to do a non-preferred task the child may not stop or may refuse to do the task.	When transitioning between classes the child may be loud, get out of line, or refuse to follow classroom rules.	When playing with peers, the child may be seen to be "bossy," always having to be right.	When unexpectedly going out to a store, restaurant or social activity, the child may demonstrate unfavorable behaviors such as acting out, lethargy or refusal.
When asked to leave the house to go elsewhere (even if it has been enjoyable in the past), the child may refuse to leave.	When asked to do a non-preferred task, the child may refuse to begin work.	When playing games with peers, the child may make up new rules to benefit themselves.	When running errands, the child may be inflex- ible, and the adult may not be able to complete the errands.
When asked to make transitions from video games, the child may refuse or meltdown.	After an active activity like lunch, recess or PE, the child may have difficulty calming down and working.	When interacting with peers, the child may demonstrate awkward social skills, especially when meeting new friends.	At a restaurant or birth- day party, the child may become overwhelmed and vocalize "I can't eat here, it's too loud, I don't want to be here, I just want to go home."
When upset during interactions with pets or siblings, the child may lash out verbally or physically.	Academic stressors like a math test, oral presentation, difficult work, or sitting for too long, may cause the child to become loud, socially awkward and/or unable to engage.	The child may misinterpret others' attention as 'liking them' or 'hating them.'	At a crowded or loud venue, the child may engage in inappropriate touching or talk to self and/or others.
When the child is stressed or angry, he/she/ they may damage items or parts of the home.	In large social situation with peers, the child may not have the ability to gage the interaction of others. The child may misinterpret the reactions or statements of peers.	When interacting with peers, the child may be bullied or may be the one doing the bullying without realizing it.	When the child cannot leave a situation right away, he/she/they may experience what appears to be an over exaggeration of emotion/behavior.
During family dinners, the child refuses to come sit or acts inappropriately at the dinner table.	When playing a game, the child may have difficulty waiting for a turn, following rules, accepting responsibility for their part, or may feel they are always the one to blame.	When playing sports, the child may think others have cheated, or are following the rules incorrectly.	It may be difficult to stand or wait in line, and the child may become demanding and demonstrate large emotions of frustration and impatience.
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Self-Regulation for Parent or Caregiver and Child

Self-regulation is the ability to manage emotions, behaviors, and movements appropriate to the situation in both positive and negative situations (Davis et al., 2020). Self-regulation is a very complex skill that starts to develop in early childhood and continues to develop into adulthood. Many factors influence how well people can manage self-regulation such as one's personality, biology, cultural beliefs, social factors, parenting, or healthcare styles and even health conditions, such as Tourette Syndrome (Davis et al., 2020). Being able to self-regulate is critical in having emotional control, being able to pay attention, and being able to manage behavior. Differences in the brain, including the "lack of a filter" in the basal ganglia, make self-regulation for individuals



with tics challenging and make it more likely for children to exhibit interfering non-tic behaviors. Additionally, co-occurring conditions, such as ADHD, anxiety, and autism spectrum disorder, if present, can make self-regulation more challenging due to the brain differences in the autonomic nervous system (Davis et al., 2020). Known deficits with executive functioning in some children with Tourette Syndrome can also make regulating emotions difficult (Romero-Ayuso et al., 2020).

Children with tics experience many factors that can have an impact on their emotions and behaviors. Dealing with internal urges of tics, obsessive thoughts, and filtering out sensory overload can all lead to explosions of emotions throughout the day. In fact, when children with tics suppress emotions or tics throughout the day, it is common to see an explosive outburst towards the end of the day. They may also resist doing their homework, which may become a nightly battle between the child and their parents or caregivers. Because the child suppressed tics and compulsions and was able to function - despite their sensory overload - during the school day, by the time they arrive at home they experience an overload or explosion of their tics which is difficult to manage. Essentially, their "cup" of emotions filled up and overflowed to the point where they could no longer self-regulate.

Challenges with self-regulation are not unique to children with tics. Parents and caregivers can have experiences throughout the day that lead to feeling overwhelmed with emotion. Caring for kids, running errands, managing a job, and functioning on limited sleep all can cause an overload of emotions and at times result in explosive responses towards family members. Simply put, we all have a "cup" that overflows when we cannot handle any more and we are not able to regulate appropriately.

Teaching Self-Regulation

Developing self-regulation skills can be difficult for many children with TS. These skills not only are critical in helping manage unwanted non-tic behaviors as a child, but self-regulation skills have been shown to be crucial for later life success (Montroy et al., 2016). The good news is that therapy and behavioral interventions have been shown to be highly effective for teaching and improving self-regulation.



Most behavioral therapy and regulation therapy programs utilize similar strategies to help teach children how to self-regulate. Some potential strategies that parents and caregivers can use to help children with tics learn to self-regulate include:

- Help your child understand and accept that it is okay to have difficult feelings and express difficult emotions.
- Sit with your child through difficult emotions and talk about the feelings the child is experiencing.
- Notice triggers or things that fill your cup and share with your child to help your child be aware of triggers and what fills his/her/their cup.

Many children simply lack the neurodevelopmental foundation upon which successful self-regulation is built. Asking them to self-regulate is like expecting a teenager to drive a car without any driver-training classes.

- Mona Delahooke, PhD

- Remind your child that sometimes his/her/their cup fills more quickly than others.
- Work with your child to manage emotions PREVENTATIVELY to avoid overload. See examples of preventative strategies that follow.
- Reassure your child that everyone needs to learn strategies to help make sure their cup doesn't overflow.

- Establish awareness that your emotions impact others. This can be done by
 working with your child on how others make them feel. You can also make them
 aware of what they say and do and how that may make others feel.
- Model healthy self-regulation strategies and share moments where you have had to implement them.

Examples of preventative strategies:

- Using fidgets
- Exercising
- · Relaxation breathing
- Progressive Muscle Relaxation
- Grounding exercises
- Using a calming corner or sensory pod
- · Playing music

- Drawing
- · Practicing mindfulness
- · Staying hydrated
- · Eating a healthy diet
- Sleeping and resting
- Taking a walk

Co-regulation

When one member of the family is feeling overwhelmed or emotionally overloaded, it can impact the rest of the family. This influence of family members on one another can be explained by the family systems theory (White & Klein, 2008). The family systems theory explains that everyone in the family is part of an interconnected system, in which each person is a unique individual with unique views and personalities. As a visual image, think of this like a baby mobile, in which the core family values are the top part of the mobile holding the unit together, but the individual pieces are each member of the family. And when the individual pieces of that mobile [or individual persons] become disjointed by unwanted emotions or behaviors, it can throw the whole mobile [family] off. Meaning, when a child is having difficulty with self-regulation and showing excessive emotional overload, it can impact a parent's own self-regulation.



HOW TO CO-REGULATE

Provide Constructive. Responsive Family Relationships (Including warmth, compassion, communication, listening, recognizing, and honoring feelings) **Provide Structure Model and Teach** in the Home Environment **Self-regulation Skills** (Including having meals (Including mindfulness, together, healthy diet, breathing exercises, meditation, taking a break) exercise, regular sleep schedule, predictability)

Research has shown that from a young age, parents and children tend to co-regulate each other (Bridgett et al. 2020). Parents can soothe or calm a child by simply being calm themselves or using some of their own calming strategies. For this reason, it is critical, as a parent of a child with tics, to learn how to manage your own self-regulation and emotions. By learning how to regulate your emotions, you can help co-regulate your child's emotions (Lobo, 2020). By modeling healthy self-regulation behaviors, such as eating a healthy diet, exercising, getting appropriate sleep, practicing mindfulness, and taking time for yourself when you feel overwhelmed, you can demonstrate healthy regulation strategies to your child. Individual therapy, support groups such as TAA Online Support Groups, mindfulness and meditation apps (many are free), and taking time to exercise alone or with a friend as well as scheduling time to spend with supportive friends can all be helpful.

In conclusion, self-regulation is hard. Parenting a child with tics, who has difficulty with self-regulation, can be especially hard and emotional. It is critical to teach a child with tics to learn how to prevent and manage unwanted emotions and non-tic behaviors through self-regulation programming and modeling behaviors.



Managing Challenging Behaviors

Prevention Strategies for Challenging Behaviors

Strategies to use prior to an outburst:

- Caregivers need to take time to discuss with their child what is known, observed, or felt prior to an outburst:
 - Schedule a time when the caregivers and the child are free and when all are in the mindset to talk.
 - Show compassion, share observations with the child while carefully considering the observations and feelings of the child. Listen carefully as the child may have insight that the parent or caregiver is unaware of.
 - · Work carefully with the child using some of
 - the prevention strategies mentioned above. • Consult school professionals who work closely with the child, to work on identifying what is known, observed, or felt before an outburst. NOTE: School professionals also can work with the child on prevention strategies.

Be mindful of triggers like transitions or stressors, such as loud or crowded places. You do not need to avoid all situations that may trigger the child, but be vigilant to see what is filling the emotional cup. For example, the family may still be able to go out to dinner, but might choose an earlier time when it isn't so loud. Or a caregiver may be able to bring a child to a quiet space or home earlier from a crowded or loud event.

Once there is an agreement regarding the 'signs' of an impending outburst, that is the time to discuss what the child will do instead. This will look differently when the child is out in the community than when at home, so having plans for different situations will help with success.

Be vigilant on warning signs such as excessive restlessness, boredom, loudness, or statements that they want to go home. Don't wait until it is too late.

Explore having regular family meetings where everyone comes to the table to talk about the week and needs of the family. Everyone in the home participates. Family

Challenging behavior occurs when the demands being placed upon a child outstrip the skills he had to respond adaptively to those demands. ""

Dr. Ross Greene

meetings can be a time to check-in with how everyone is doing, share information, or celebrate achievements. Be sure that family meetings do not always only focus on difficult behaviors and emotions. Including positive topics and opportunities for celebration will help everyone come back with positive feelings.

Strategies to use in the moment of an outburst:

Consider the use of visual aids for designated 'go to location.' Often, in the moment of an outburst, the child having the outburst does not want the caregiver to talk to them. A picture of the go-to space as well as a picture of any sensory tools or techniques that have been previously agreed upon and used can be shown to him/her/them. Space, tools, and techniques should be planned with the child ahead of time.

Allow the child to carry out the plan. It can look like moving to another location, using breathing techniques, or practicing other calming or self-regulating strategies.



Stay calm. Use your own calming strategies if necessary.

Ensure safety:

- · Recognize warning signs
- · Keep breakables away
- Stay calm
- · Leave the room if needed

Strategies to use after an outburst:

- Debriefing is imperative. This needs to happen within a timeframe where everyone
 involved can recall the outburst with clarity and a level of detail (one hour to no
 more than one day), while also allowing space and time to process the experience
 and the triggering event.
- Praise the child for the noted efforts and success observed FIRST.
- Discuss what actions can be further strengthened from all involved.
- Try to remember that it isn't personal.
- Help to collaboratively problem solve.
- Work with a therapy team, if you have one, on emotional regulation and relaxation strategies to use in prevention.





In Conclusion

Helping children and teens with TS, other Tic Disorders and co-occurring conditions manage challenging behaviors and big emotions at home, school, and in the community takes thoughtful work and practice. It also takes time and a great deal of energy. Success comes slowly and with all family members working towards the same goal.

Please visit www.tourette.org for additional educational toolkits. The Tourette Association of America can provide schools and educators with information on Tourette Syndrome and co-occurring conditions by giving an in-service presentation. Reach out to support@tourette.org for help or for more information.

Resources

The Explosive Child - Ross Greene
Beyond Behaviors - Mona Delahooke
Tourette Association of America YouTube Channel

Leaky Brakes

Recommended videos to help with self-management and emotional regulation:

Step 1: Awareness

Step 2: What Fills My Beaker

Step 3: Warning Signs that Beaker is Filling

Step 4: Empty Beaker

Visit their website for more information

Zones of Regulation

The Zones of Regulation: A concept to foster self-regulation and emotional control. This website contains:

- Apps on Zones
- Downloadable forms/sheets
- School applications for various settings (class, assemblies, etc.)
- Webinars

Visit their website for more information.

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