



Understanding Tourette from the Outside

What Tics Don't Tell Those Who Watch

An illustrated guide for parents, caregivers and families

Ticcami | La Tourette e Me
www.latouretteeme.it

Understanding Tourette from the Outside

For family members, teachers, partners and anyone who cares



This is not only for people who live with tics. It is also for anyone who wants to understand what Tourette syndrome really is and how to support someone without causing harm.



When tics seem voluntary

Why a coordinated behaviour does not always mean it is voluntary

- Not every tic is completely sudden or immediate.
- A person can feel a build-up or premonitory urge before the tic.
- It is possible to temporarily suppress tics, but it takes effort and should not be mistaken for full control.
- After holding tics back, they may rebound and come out more strongly.
- Before judging, it helps to understand the difference between urge, suppression and true intention.



Why saying “stop it” doesn’t help

Telling a person with Tourette to stop does not solve the tic.



A reproach does not stop a tic.



It can increase tension or self-consciousness.



It may turn the moment into something more difficult.



Embarrassment and pressure can worsen the situation.



It often makes the person feel judged rather than supported.



Why tics increase at important moments

Stress, emotion and pressure can make tics more noticeable



Stress does not only mean negative pressure



School, tests or new situations can influence tics



Even positive emotions can increase activation



Tension before important moments can amplify symptoms



Preparing the environment and expectations can help reduce overload



Why it looks fine outside and chaotic at home

Apparent calm in public does not mean the person is not struggling

- ✓ Self-control that is visible outside can cost a lot of energy
- ✓ When a person feels safe, tics or exhaustion may emerge more openly
- ✓ Home is often where the built-up pressure comes out
- ✓ This rebound is not manipulation or bad behaviour
- ✓ Understanding the contrast helps families respond with less blame



Tics and attention: moving does not mean not listening

Movement is not a measure of listening

- ✓ Immobility is not the only sign of listening
- ✓ Moving or vocalising does not always mean being distracted
- ✓ Looking away can sometimes help with processing
- ✓ Eye contact is not always a reliable proof of attention
- ✓ The best way to know is to verify comprehension, not just posture



How to behave during intense tics

Calm, safety and less pressure are possible



First create safety and a calm environment



If there is no danger, avoid dramatizing the moment



Offer help only if requested or clearly needed



In public, protect the person's privacy and dignity



Simple shared strategies can be agreed in advance



What really helps: less control, more listening

The best support starts with respect



Do not replace the person or take over unnecessarily



Asking how to help is better than guessing



Respect timing, limits and autonomy



Use language that reduces shame and pressure



The strongest ally is respect, listening and normality





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