

# Children with Tourette Syndrome and COVID-19

## What are the unique challenges?

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**Y**oung people with Gilles de la Tourette Syndrome (GTS) may be particularly impacted by COVID-19\* and significant stress may be induced by the social restrictions and lockdowns as those with GTS usually like, and have the need, to release energy and be active. See **Box 1** for what you can do to keep yourself active. See **Box 2** for what you can do in situations where you may cough in a public place which draws attention to you. Other symptoms such as spitting may result in conflict with the law as there are strict guidelines to not spit (and may incur significant fines) and you may wish to carry a "Tourette card" with you if you need to explain to authorities about your condition and that spitting is a symptom (a tic). Similarly the presence of associated features such as *echopraxia* (e.g. imitate the action of others) or '*stimulus induced tics*' (e.g. in response to an external stimulus such as an urge to cough or sniff when observing others cough or sniff), or Non-Obscene Socially Inappropriate Symptoms (NOSIS; e.g. displaying behaviours that are socially not acceptable, provocative or transgressive such as developing new spitting or inappropriate touching tics, with a particular urge to do so in public or in settings where it is totally inappropriate), may be particularly problematic during the time of this pandemic. Tic-related obsessive compulsive behaviours (e.g. forced touching where there is an urge to touch objects or people) in the current context may result in issues as we are expected to maintain social distancing and refrain from physical contact. Awareness and support is therefore critical.

Two most common responses to environmental stress are emotional arousal and impulsivity, which may worsen tics and predispose to an array of disruptive behaviours. The presence of co-morbidities such as Attention Deficit Hyperactivity Disorder (ADHD) with hyperactivity, impulsivity and intrusiveness may pose particular challenges while in social isolation at home without access to outdoor activities, school or therapy services and also families having to negotiate parents "working from home", physical space limitations and in addition caring for the needs of siblings or other

### Box 1: How to keep yourself active

Exercise and sports usually help young people to manage their tics but the social isolation and lock down is impacting this significantly. Being in a constrained space without any opportunity for releasing the excess energy can lead to oppositional and aggressive behaviour especially when attention deficit hyperactivity disorder (ADHD) is present. Use outdoor activities as much as possible and legally allowed. If there is no access to outdoor space, then engage in activities that can be done indoors such as simple work outs or exercises, meditation or yoga, or use a stationary bike, punching bag, bouncing castle (or a similar home-made substitute), or create a "tent" space either in the home or in the backyard to get a "quiet" space for the child to use to calm down etc. There are also freely available online programs as below.

- **PE with Joe:** <https://www.thebodycoach.com/blog/pe-with-joe-1254.html>
- **Jump start Johnny:** <https://www.jumpstartjonny.co.uk/home>
- **Cosmic kids yoga:** <https://www.youtube.com/user/CosmicKidsYoga>

family members with high risk for COVID-19 infection in the household etc., all of which may contribute to the stresses. Obsessive compulsive disorder may also have its own unique impact due to exacerbation of worries about germs and contamination and undue anxiety about contracting the infection. Furthermore, therapeutic measures for OCD such as preventing themselves from excessive cleaning and washing as part of therapies such as response prevention techniques may be harder to enforce during this time when frequent hand washing is recommended.

### Box 2: Strategy for managing difficult conversations

While cough is a common tic, during this time of COVID-19, this may raise questions and you may get questioned by others as to whether it is due to COVID-19 infection. You may find that having a prepared response to provide if you are asked about your cough may be a good strategy. For example you may say that "It is my tic, I have Tourette Syndrome. It is not due to Corona virus". If you find it difficult to respond to such questions and you are worried that your tic symptoms may be misunderstood or cause social conflict, you may wish to carry a card which says you have Tourette Syndrome and on the back of the card write out the common tics that you have that you think may get you into trouble.

### Families and COVID-19 stresses:

For families of children with GTS and other neuro-developmental conditions such as Autism or learning disorders, lack of access to therapy and other services including schools or other educational centres, recreational and sporting activities, contact with extended families and grandparents are all likely to have a significant impact. This is further compounded by the closure of primary care and specialist services particularly to face to face appointments, reluctance of families to attend health facilities for fear of exposure to COVID-19 or due to worry about being a burden to already stretched health services. This may also have unintended consequences such as families increasing the dose of medication or increased use of 'as needed' medication in response to worsening of symptoms or associated challenging behaviours, but without medical input or monitoring. Sleep may also be significantly disrupted during times of stress and see **Box 3** for measures that can be taken to help ease sleep related issues.

### Mental health during COVID-19

Mental health issues such as anxiety and depression may be precipitated or worsened by the stress due to the current pandemic. Also the extensive media coverage of the pandemic may cause undue anxiety.

### Box 3: Helping with sleep

Sleep routine and sleep hygiene are extremely important. The amount of sleep we need depends on our age. On average toddlers need around 12 hours of sleep a night; children aged three to six need around 10-12 hours; seven to 12 year olds need 10-11 hours; and teenagers need around eight to **nine hours**. Some easy to follow steps are provided below.

1. **A good sleep routine is important including setting a regular time to go to bed and to wake up each day.**
2. **You may follow a bed time routine when you go to bed (e.g. having a warm bath and brushing teeth, as well as doing some quiet, enjoyable activities like reading a book or listening to a story or music or doing breathing/relaxation exercises) and when you wake up (e.g. some gentle exercise or free online workouts).**
3. **Avoid stimulating activity in the hour before bedtime, switch off all gadgets including TV, tablets and game consoles.**
4. **Eat a light, pre-bedtime snack if you're hungry such as a small carbohydrate snack like porridge, toast or biscuit and warm milk but avoid stimulating drinks such as coffee/tea, caffeinated drink, before bed time.**
5. **Make the physical surroundings as comfortable as possible such as the room temperature, and the room to be quiet and dark (except for night lamp if needed).**

Parents' own underlying anxiety about financial difficulties, loss of job, income, fear of acquiring COVID 19, worry about worsening of child's condition and lack of access to health care or supports etc. can negatively influence parenting and impact negatively the parent-child relationship and interactions. See **Box 4** for general strategies for managing during the COVID-19 pandemic.

#### Box 4: General strategies to manage during COVID-19

- Reduce excessive exposure to media coverage to curb anxiety but it is important to share age – appropriate information about COVID-19\*\* and help them understand why there is a change to their routine and why it is important to have that change.
- Limit parental anxiety (or the expression thereof) as much as possible. If parents are experiencing significant stress or anxiety, they need to seek help as parental anxiety can make problems worse for the child.
- Try the “What if... A practical guide to possible problems”\*\*\* which includes scenarios such as What if... My tic is a cough or I have suggestible tics?, What if... I can’t sleep?, What if... I can’t go out to exercise? etc. A “What if” board strategy will help you to identify what your worries are and make plans to manage them. It’s a simple but effective strategy for managing big changes or common problems. Allowing some “worry time” to talk about the anxieties but keeping it limited to that “worry time” could help to contain it.
- In those with contamination fears and fear of catching an illness such as in obsessive compulsive disorder (OCD), seek appropriate psychological support (explore online programs if the regular face to face therapies are no longer available).
- Reduce screen time reasonably, (i.e. without triggering rage attacks and to avoid excessive boredom) but more importantly focus on the content of what is being watched. Instead of focussing on how much screen time, focus on content of what is being watched and ensure that it is age appropriate, engaging/interactive and meaningful (avoid violence and aggression).
- Insist on upholding current rules (hygiene, social distancing) firmly but also gently.
- Children who do not have access to the school routine or access to educational and therapeutic programs or to grandparents etc. due to self isolation may become stressed and challenging behaviours may ensue. This can be addressed at least partly by using face time or skype/whatsapp or similar methods to stay connected, engage in e-health or online options for educational and therapeutic programs (e.g. museums and zoos are making available opportunities for virtual tours).
- The majority of parents who are working from home are also stressed as they spend their days in limited space (small apartments) with children which can increase intrafamilial conflicts and in a few cases domestic violence may worsen. Parents need to immediately seek help from relevant agencies in these situations.
- Access relevant support as applicable (emotional, spiritual, cultural, psychological and social, financial).

#### Select resources:

\* <https://doi.org/10.12688/f1000research.23275.1>

\*\* Corona Virus Explained

\*\*\* <https://www.tourettes-action.org.uk/resource-235-how-to-get-good-sleep.html>

<https://www.unicef.org/coronavirus/covid-19-parenting-tips>

[file:///C:/Users/25138558/Downloads/covid-19-disability-briefing%20\(1\).pdf](file:///C:/Users/25138558/Downloads/covid-19-disability-briefing%20(1).pdf)

[https://www.aacap.org/AACAP/Families\\_and\\_Youth/Resource\\_Libraries/Coronavirus.aspx](https://www.aacap.org/AACAP/Families_and_Youth/Resource_Libraries/Coronavirus.aspx)

<https://www.redcross.org.au/stories/covid-19/talking-to-kids-about-covid-19>

[https://emergingminds.org.uk/wp-content/uploads/2020/03/COVID19\\_advice-for-parents-and-carers\\_20.3\\_.pdf](https://emergingminds.org.uk/wp-content/uploads/2020/03/COVID19_advice-for-parents-and-carers_20.3_.pdf)

[https://www.escap.eu/index/coronavirus-and-mental-health/?utm\\_medium=email&utm\\_campaign=Coronavirus%20-%20Mental%20Health%20Resource%20List&utm\\_content=Coronavirus%20-%20Mental%20Health%20Resource%20List+CID\\_9399deb28932044d4d0e4a502bfbdb2fb&utm\\_source=HTML%20mailing&utm\\_term=list%20of%20resources](https://www.escap.eu/index/coronavirus-and-mental-health/?utm_medium=email&utm_campaign=Coronavirus%20-%20Mental%20Health%20Resource%20List&utm_content=Coronavirus%20-%20Mental%20Health%20Resource%20List+CID_9399deb28932044d4d0e4a502bfbdb2fb&utm_source=HTML%20mailing&utm_term=list%20of%20resources)