

How to Support Persons with **TOURETTE SYNDROME**

Understanding Tourette Syndrome and
the protection of
Disability Discrimination Ordinance (DDO)



平等機會委員會
EQUAL OPPORTUNITIES COMMISSION

What is **Tourette Syndrome (TS)**?

Tourette Syndrome (TS) is a neurological condition. People with TS may blink, twitch their mouth or make grimaces involuntarily; or clear their throat, sniff, blurt certain words or phrases repeatedly, or have jerking movements. These temporary and repetitive movements or sounds, are considered as tics for TS.¹ Tics symptoms are associated with high dopamine level which leads to abnormal activity in the neuronal circuit connecting the frontal lobe and basal ganglia. The standards for diagnosis of TS were not clear in the past, and TS has been considered a rare disease. Around 30% to 40% people living with TS would have their symptoms disappear as they grow up. However, around 30% of them still have symptoms persist into adulthood.²



Tips on how to communicate with people with Tourette Syndrome (TS)

DOs & DON'Ts when meeting people with TS:³



Dos

If people with TS has a tic of any kind that interrupts speech, please **be patient** and let him/her express their thoughts.

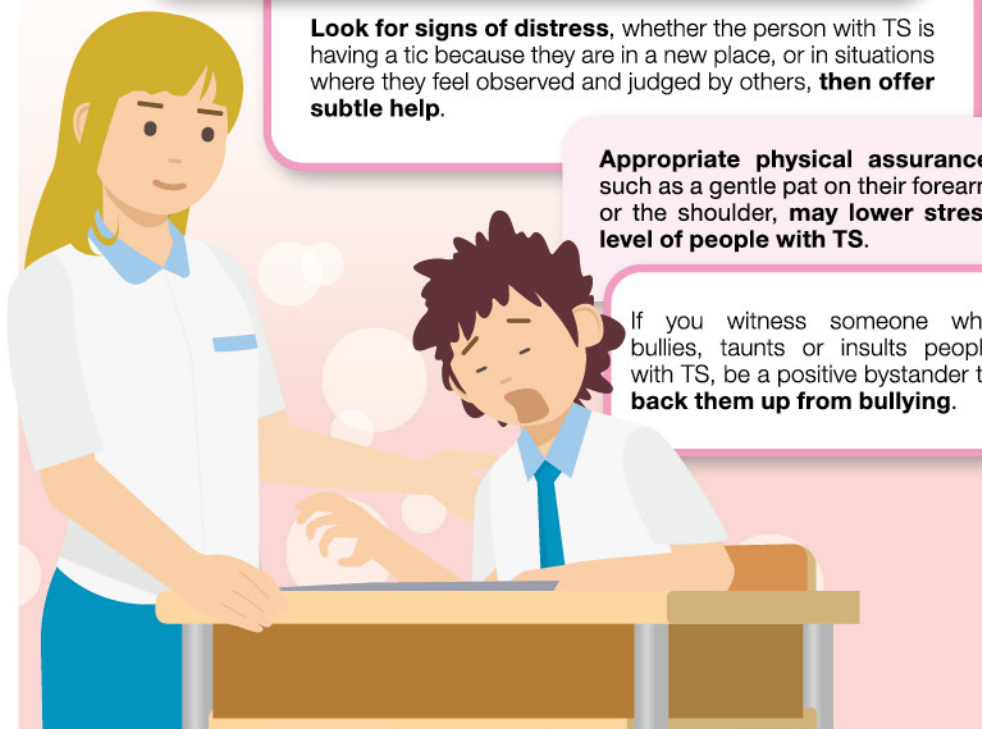
Ignore the tics when having a conversation with person with TS, focus on the content, so that the tics will not increase because the person with TS becomes more nervous.

It's a good idea to **listen, observe and consider the feelings** of the person with TS and his/her personal acceptance level **before asking or showing care about his/her tics**.

Look for signs of distress, whether the person with TS is having a tic because they are in a new place, or in situations where they feel observed and judged by others, **then offer subtle help**.

Appropriate physical assurance, such as a gentle pat on their forearm or the shoulder, **may lower stress level of people with TS**.

If you witness someone who bullies, taunts or insults people with TS, be a positive bystander to **back them up from bullying**.



Don'ts

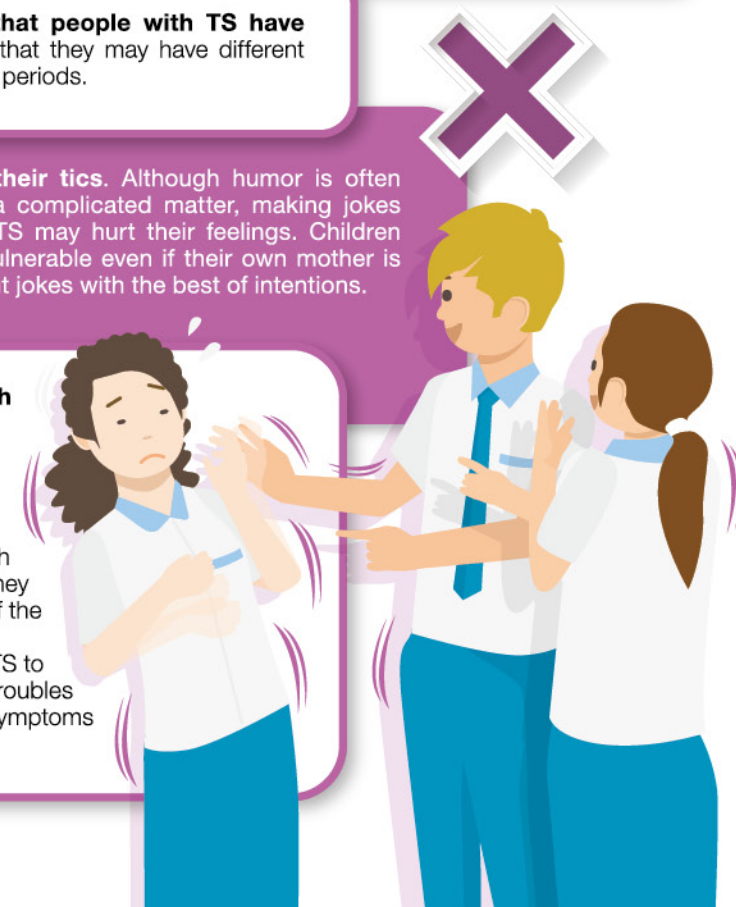
Don't stare if people with TS have a tic, no matter how exaggerated the tics may be, try to act natural.

Don't try to fix them. People with TS often do not have control over their tics and feel bad about it. Try to understand and accept them.

Don't be surprised that people with TS have new tics, understand that they may have different types of tics at different periods.

Don't joke about their tics. Although humor is often used to downplay a complicated matter, making jokes about people with TS may hurt their feelings. Children with TS are more vulnerable even if their own mother is only making innocent jokes with the best of intentions.

Don't blame people with TS for being rude with their tics. Many children with TS go through very unpleasant experiences at school, not only with other children but also with teachers, who, because they are completely unaware of the condition, attribute the behavior of children with TS to bad manners or causing troubles since they interpret their symptoms as purposeful behaviors.




¹ 香港瑪麗醫院 - 妥瑞症及抽動症診所 https://www3.ha.org.hk/hkwc/ppi/InfoPam/docs/PSY/psy_22.pdf

² ibid


³ 12 ways to support your friend with Tourette's (February 2, 2021) by NeuronUP
<https://neuronup.us/category/cognitive-stimulation-news/neurodevelopmental-disorders/tourette-syndrome/>

Myths & Truths about Tourette Syndrome (TS)



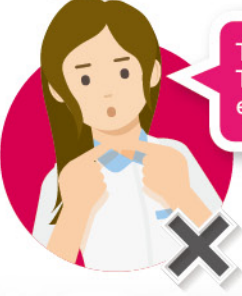
Tourette Syndrome is a kind of mental condition. People with TS are aggressive.

TS is not a mental condition. It is a neurological condition. The tics may cause distress to people with TS, or even depression. Counseling and psychotherapy may help them manage the symptoms and grasp better coping skills.



Tourette Syndrome is contagious. We should not play with children with TS.


Tourette Syndrome is not an infectious disease. It is not contagious from any kind of contact. People with TS should not be isolated.



Tics associated with TS are the same as epilepsy.

Tourette Syndrome and epilepsy are two different neurological conditions.

Epilepsy is caused by a sudden burst of electrical activity in the brain. It may or may not lead to changes of conscious level. Whereas for tics associated with people with TS affect particular muscle groups, and the consciousness of people with TS is maintained.



Be assured, teacher will help you!

Don't worry!

What kind of accommodation should be considered

for Children with TS in school setting?

The mental and cognitive development of children with TS are no different from other ordinary children. However, they often encounter learning or social barriers in school due to the tic symptoms. For example, they may experience ridicule and rejection from classmates, or teachers may mistakenly believe that they deliberately cause trouble in class. Schools should provide accommodation for children with TS, for instance:

Formulate intervention and counseling strategies for children with TS

Separate areas during the exam, allow extra time to complete (if applicable), etc.

Teachers should understand TS properly

Educate other students about TS

Adjust homework and learning modules into small units (if applicable)

Adopt positive behaviour management in class

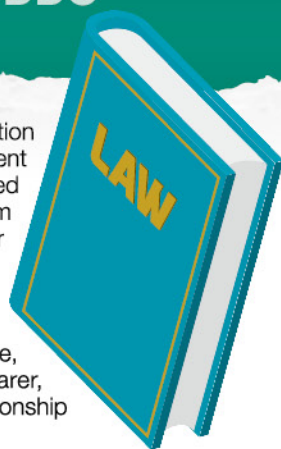
Assist students with TS to develop interpersonal relationships with their classmates

Some children with TS may also have other learning difficulties, such as ADHD, etc. These children need special assistance in learning. Schools should provide reasonable accommodations in class management and learning for children with TS.

What is the protection under the DDO for people with TS or their associates?

The definition of 'disability' under section 6 of the Disability Discrimination Ordinance (DDO) consists of 'malfunction, malformation or disfigurement of the body'. The involuntary tics for people with TS can be considered as a disability covered under the DDO. They will be protected from discrimination and harassment within applicable fields of the DDO, for instance, employment fields, education settings, goods and service provision, etc.

The associates of people living with TS are also protected by the DDO. Under section 2 of the DDO, an associate includes a spouse, another person living with a person with a disability (PWD), relative, carer, another person who is in a business, sporting or recreational relationship with the PWD.



What is Disability Discrimination?

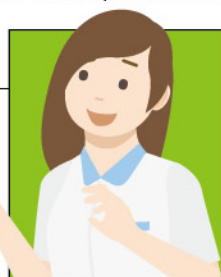
There are two forms of disability discrimination which is direct discrimination and indirect discrimination. Direct Discrimination means treating an employee with a disability less favourably on the ground of the person's disability in comparable circumstances. For example, an employer gives an employee a lower salary because of the employee's TS, but the job nature and workload of the employee is the same as other employees who do not have this condition.

Indirect discrimination involves imposing a seemingly neutral condition or requirement on everyone, but such condition or requirement has a disproportionate adverse effect on persons with disability, and applying such condition or requirement is not

justified in practice. For example, a student with TS needs to go to the hospital for treatment regularly, and he/she cannot comply with the usual school attendance rate, and has been given a lower grade in conduct. In addition, the school cannot show that the requirement is justified.

What is Disability Harassment?

Disability Harassment is an unwelcome conduct on account of a person's disability where a reasonable person, having regard to all the circumstances, would have anticipated that that person with disability would be offended, humiliated or intimidated. For example, insulting remarks or offensive jokes about a person with TS, name calling and mimicking gesture of person with TS. These may be unlawful disability harassment acts.



Acknowledgement

The EOC would like to extend our special thanks to Hong Kong Tourette Association for their valuable advice given for this leaflet.

You can learn more about Tourette Syndrome from the following organizations:

The Hong Kong
Tourette Association

Taiwan Tourette
Family Association

Tourettes Action

The Tourette
Association of America

Tourette Syndrome
Association of Australia

You can contact these organizations for help:

The Hong Kong Tourette Association
Tel: (852) 2794-3010

Queen Mary Hospital,
Tourette Syndrome and Tics Disorder Clinic
Tel: (852) 2255 3111 / 2255 3106

How to contact the EOC?

EOC hotline: (852) 2511 8211

SMS service: 6972566616538 (For people with hearing impairment/speech difficulties)

Fax: (852) 2511 8142

Address: 16/F, 41 Heung Yip Road, Wong Chuk Hang, Hong Kong



QR code for this leaflet

如何支援 妥瑞症患者

認識妥瑞症及《殘疾歧視條例》
的有關保障



平等機會委員會
EQUAL OPPORTUNITIES COMMISSION

認識 妥瑞症

妥瑞症是一種腦神經疾病。患者常不自主地眨眼、嘴角抽動、擠眉弄眼；或不停地清喉嚨、發出嗤鼻聲、重複某些單詞片語或肢體抽動，這些短暫及重複的動作或聲音，都是妥瑞症的抽動情況。¹ 妥瑞症的抽動病徵是由於患者腦部的多巴胺過度活躍，以致腦部前額葉與基底核之間的神經迴路發生問題。妥瑞症早期的診斷標準不明確，被認為是一種罕見疾病。大約30%至40%妥瑞症患者長大後症狀會消失，但30% 的患者的症狀持續到成人階段。²



與妥瑞症患者溝通的小秘訣

當遇到妥瑞症患者時：³



應該

如果患者在說話時出現抽動，打斷了講話，請**耐心等待**，讓他/她表達自己的想法。

談話時**直接忽視**患者的抽動，將焦點放在談話內容，使患者的抽動不會因緊張而增加。

最好**先聆聽、觀察和考慮患者的感受**和個人接受程度，才**詢問或關注**有關他/她抽動的情況。

留意到患者的壓力跡象，如患者的抽動是否因為置身在陌生的地方，或感到別人的觀察和批判，並**低調地提供協助**。

恰當的身體接觸，例如：輕拍手臂或肩膀，可以**緩和患者的焦慮情緒**。

如遇到有人欺負、嘲諷或侮辱妥瑞症患者，伸出援手，**支援妥瑞症患者免受欺凌**。



避免

若抽動發作，**不要盯著妥瑞症患者**，無論抽動有多誇張，你可以盡量表現得自然。

不要試圖糾正患者的抽動，妥瑞症患者通常無法控制自己的抽動，並且對此感覺很糟糕。你可以嘗試了解及接受他們。

不要對患者新的抽動作感到驚訝，明白患者在不同時期有不同抽動。

不要拿患者的抽動開玩笑。雖然幽默經常被人用來淡化複雜的情況，但拿妥瑞症患者來開玩笑，可能會傷害他們的感情。尤其是患有妥瑞症的兒童，更容易受到傷害，即使是其母親善意地開玩笑，也可能使孩子情感上受到傷害。

不要責怪妥瑞症患者的抽動是故意無禮。許多患有妥瑞症的兒童在學校都經歷過非常不愉快的經歷，不僅是同學，有時老師也沒有意識到他們患有這種疾病，以為症狀是故意的行為，所以把他們的抽動行為視為不禮貌或製造麻煩。



¹ 香港瑪麗醫院 - 妥瑞症及抽動症診所 https://www3.ha.org.hk/hkwc/ppi/InfoPam/docs/PSY/psy_22.pdf

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妥瑞症的謎思與真相



妥瑞症是精神病，
他們有攻擊性。

妥瑞症不是精神病，這是一種神經系統的疾病。抽動症狀可能讓妥瑞症患者帶來情緒困擾，甚至抑鬱。心理輔導有助他們作出相應調適，及掌握應對的技巧。




妥瑞症會傳染，我們不應該與
妥瑞症的小朋友玩。

妥瑞症並非傳染病，並不具有傳染性。
所以，妥瑞症患者不應被孤立。



妥瑞症的抽動是與
腦痙症一樣。

妥瑞症的抽動與腦痙症乃是兩種不同的神經系統疾病。腦痙源於腦部電波活動異常，且有機會引致昏迷或影響意識程度。至於妥瑞症患者一般只是個別肌肉受影響，患者的意識會保持清醒。



同學可以放心，
老師會幫助你的！

不用擔心！

學校應為患有妥瑞症的學童 提供怎樣的調適？

患有妥瑞症的兒童在心智方面的發展與一般兒童沒有分別，但由於抽動症狀往往令他們在學校裡遇到學業或社交上的困難，例如：同學的嘲諷和排斥，或者有老師可能誤以為他們故意在課堂上搗蛋。因此，學校應為患有妥瑞症的學童提供適當的調適，例如：

為有關學童制訂
介入與輔導策略

教育其他同學
關於妥瑞症

考試時分開區
域，允許額外時
間完成
(如適用)

老師應該先對
妥瑞症有
正確的了解

採取正面
行為管理

調整作業
和教材為小單元
形式學習
(如適用)

協助妥瑞症學童
與同學發展人際
關係

一些患有妥瑞症的學童亦可能同樣有其他的學習障礙，例如注意力不足/過度活躍症(ADHD)等，這些學童在學習方面需要特殊的協助，學校應在課堂管理方面和學習方面，為患有妥瑞症的學童提供適當的調適。

《殘疾歧視條例》 對妥瑞症患者有何保障？



根據《殘疾歧視條例》第6條，「殘疾」的定義包括身體的「機能失常、畸形或毀損」，妥瑞症患者不自主的抽動情況屬於受《殘疾歧視條例》保障的殘疾。《殘疾歧視條例》保障妥瑞症患者在適用範疇內免受歧視及騷擾，例如僱傭、教育、貨品及服務的提供等。

妥瑞症患者的有聯繫人士同樣受到《殘疾歧視條例》的保障。根據《殘疾歧視條例》第2條，「有聯繫人士」的定義包括配偶、共同生活的另一人、親屬、照料者及在業務、體育或消閒上有關係的另一人。



甚麼是殘疾歧視？

殘疾歧視可分為直接歧視和間接歧視。直接歧視是指在可比較的相類似情況下，殘疾人士因其殘疾而受到較非殘疾人士為差的待遇。例如：僱主基於僱員患有妥瑞症，給予他/她較低的工資，但該員工的工作性質和工作量與非殘疾員工相同。

間接歧視是指向所有人一律施以劃一的條件或要求，而這樣做亦對殘疾人士做成不利，而不能顯示施加該等條件或要求是有理由支持的。例如：一名患有妥瑞症的學生需定期到醫院接受治療，但因而未達校方的一般出席率要求，學校因此在操行分方面給予他較差的等級，而學校不能顯示施加該項要求是有理由支持的。

甚麼是殘疾騷擾？

殘疾騷擾是指因某人的殘疾，對他/她作出不受歡迎的行徑。而在有關情況下，一名合理的人在顧及所有情況後，也會預期該行為有冒犯、侮辱或威嚇成分。例如：針對妥瑞症患者出言侮辱或說冒犯的笑話、取笑患者的稱呼，及模仿妥瑞症患者的抽動姿勢作為笑話，皆有可能屬違法殘疾騷擾行為。



鳴謝 平等機會委員會特別感謝香港妥瑞症協會就本小冊子給予寶貴意見。

你可以到以下組織了解更多有關妥瑞症的資訊：

香港
妥瑞症協會

台灣
妥瑞症協會

英國
妥瑞症組織

美國
妥瑞症協會

澳洲
妥瑞症協會

你亦可聯絡相關機構尋求協助：

香港妥瑞症協會：

電話：(852) 2794-3010

瑪麗醫院 - 妥瑞症及抽動症診所：

電話：(852) 2255 3111 / 2255 3106

怎樣聯絡平機會？

平機會熱線：(852) 2511 8211

短訊：6972566616538（供聽障或有語言障礙人士查詢使用）

傳真：(852) 2511 8142

地址：香港黃竹坑香葉道41號16樓



本小冊子的詳情