

香港妥瑞症協會

The Hong Kong Tourette Association



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The Hong Kong Tourette Association



http://tourette.org.hk

Background

The Hong Kong Tourette Association was established in 2018 by a number of parents of patients affected by Tourette Syndrome (TS), and with the support of Queen Mary Hospital.

Mission

- # Help TS patients and their families cope with the condition by providing them with medical resources and support.
- # Enhance education on TS, both to schools and public, and obtain greater medical resources for Tourette treatment and to reduce discrimination and stigma.
- # Work with relevant authorities to develop policies and services to safeguard the patients' legitimate rights and interests.

Service Groups

- Patients of TS
- Carers / Parents of TS patients
- People who are concerned with TS

What are Tics Disorders / Tourette Syndrome?

Tics are sudden, involuntary and repetitive muscle movements. Tics that produce movement are called 'motor tics', while tics that produce sound are called 'vocal tics'. Tics can occur in nearly any part of the body.

Common Motor and Vocal Tics

Tics can be divided into simple tics and complex tics. Examples of different types of tics may include:

- **Simple motor tics:** eye blinking, eye movements, facial grimacing, nose twitching, mouth movements, head jerks and turns, shoulder shrugaing
- Complex motor tics: slower and seemingly more purposeful movements, facial gestures, self-biting, hand gestures and prolonged gyrating
- **Simple vocal tics:** throat clearing, coughing, sniffing, spitting, grunting, sucking
- Complex vocal tics: apparently more "meaningful" syllables, phrases and words; echolalia (repetition of another person's spoken words), coprolalia (involuntary swearing or utterance of obscene words)

Tourette Syndrome is diagnosed when an individual has multiple motor tics AND at least one vocal tic, that continue for a year or more and can change in form over time.

Cause of Tics Disorder

The onset is usually in childhood. Its clinical presentation is associated with a high dopamine level which leads to abnormal activity in the neuronal circuit connecting the frontal lobe and the basal ganglia.

Co-Occurring Features

Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Depression, Anxiety, Autism Spectrum Disorder (ASD), Specific Learning Difficulties, Sleep and Aggression.

Myth Buster

1. Tourette Syndrom only occurs in childhood and it would disappear gradually. Therefore, we need not be concerned about it?

Around 30-40% of the patients would experience symptom remission as they grow up. However, around 30% of them would have symptoms persist into adulthood.

2: 'Tourette Syndrom is contagious. We should keep a distance from those with it'

Tourette Syndrome is not an infectious disease. It won't spread via any kind of contact. Patients with Tourette Syndrome shouldn't be isolated.

3: "Tics and epilepsy are the same thing."

Tics and epilepsy are two different neurological disorders. Epilepsy is caused by sudden abnormal electrical activities in the brain. It may lead to loss of consciousness or impair the conscious level, whereas for tics, only particular muscle groups are affected and the patients' consciousness is maintained. Moreover, their treatment and prognosis are also different.

4: "Kids with Tourette Syndrome just deliberately produce the sounds and make the moves for fun."

Tics are involuntary movements. Although those affected maybe able to suppress tics for a short while, it is usually followed by a subsequent surge. Children with Tourette Syndrome shouldn't be blamed for the symptoms that they suffer from.

5: "Tourette Syndrome can be cured by medications."

There are currently no specific drugs that can bring about total permanent cessation of tics. Several medications can only reduce the frequency or intensity of tics for a period of time. Additionally, it is possible to reduce tics by practicing behavioural treatment such as habit reversal training (HRT). You should be aware that the effectiveness of HRT and medication varies patient by patient.



- 不自然地眨眼
- 發出"呀" "呀"聲
- 身體不自主地抽動

您可能患有妥瑞症 ...

給妥瑞症患者 多一點關懷 多一點愛 多一點支持

CARE, LOVE and SUPPORT for patients with Tourette Syndrome and Tics Disorder

For patients with Tourette Syndrome

- If you encounter bullies, please remember
- 1. To keep calm
- 2. To talk to your parents, teachers & friends
- 3. You have the right to be safe, and being bullied is not your fault
- Please do advocate for vourselves:
- 1. "Tourette syndrome should not stop me from what I want to do!"
- 2. "I can lead a normal life even with Tourette Syndrome."
- 3. "I have Tourette syndrome, but I have my own mastery."

成立背景

<香港妥瑞症協會> 是一個根據香港法例第151 章《社團條例》註冊成立的非牟利法定團體。 二零一八年由妥瑞症患者,其家屬,聯同瑪麗醫院兒童及青少年精神科的醫護人員的協助下而成立。我們本著關愛之心,透過同路人寶貴的經驗分享,提高士氣,倡導助人自助、互相支持、互信互勉的精神,促進治療及康復。

目標/宗旨

- # 發揮助人自助互相支持之精神,幫助香港妥瑞症及抽動症患者的家庭舒緩壓力;
- # 提升公眾對妥瑞症及抽動症的認識及減低對妥瑞症及抽動症患者的歧視;
- # 透過舉辦活動,講座及教育,加強學校及公眾對妥瑞症 及抽動症的認識和處理方法;
- # 關注及幫助妥瑞症及抽動症患者爭取權益及保障患者的合理權益;
- # 與各醫療機構合作,改善本港妥瑞症及抽動症的治療及病人服務。

服務對象:

妥瑞症/抽動症患者,其家屬 照顧者及關注妥瑞症人仕。

甚麼是妥瑞症?

妥瑞症是一種慢性神經生理疾病,患者會不由自主地反覆抽動 (Tics),不論是身體或聲語上。而抽動的部份有單一或同時多個,或會隨時間有所改變。

常見的抽動例子有:

動作抽動:眨眼、扮鬼臉、撅嘴、搖頭、聳肩、皺眉、肢 體抽搐、腹部緊張等;更甚是拍手、蹲下、觸碰東西、有 猥瑣不雅的動作、模仿他人的動作。

聲語抽動:清喉嚨、咳嗽、擤鼻涕、吹口哨、嘶嘶聲、哼聲等,嚴重的會仿動物的叫聲、仿他人口音、不斷重複詞彙或句子、發出不平常的音調/節奏/聲量、粗言穢語。

如何界定患上妥瑞症?

如發現有不自主的動作及/或聲語抽動,每天多次並持續一年或以上,便極可能患上妥瑞症。需尋求專業醫生確診。

妥瑞症的成因?

妥瑞兒腦部的多巴胺受體過度活躍以致其前額葉與基底核 之間的神經迴路發生問題。

除抽動外,患者還會有其他病狀嗎?

會的!共同出現的症狀可能包括強迫症,注意力不足、過動症、學習或行為障礙。



坊間傳言和事實真相

1.「妥瑞症發生在小孩身上,而且隨著患者年齡漸長而慢 慢消失,因此我們毋須理會。」

大約30%-40%的病人長大後症狀會消失,但仍有30%病人症狀會持續到成人階段。

- 2.「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。
- 3.「抽動即癲癇。」

抽動與癲癇乃兩種不同的腦神經疾病。癲癇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。 至於抽動症病人一般只是個別肌肉受影響,病人的意 識會保持清醒。另外,兩者的治療方式及預後發展亦 大相逕庭。

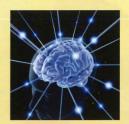
- 4.「妥瑞症小孩純粹因為搗蛋而發出怪聲及擠眉弄眼。」 抽動症是不隨意的,雖然患者可以短暫抑壓抽動,但 後續會更激烈地抽動。因此家長不應責怪孩子,宜應 理解其病患。
- 5.「妥瑞症無法用藥物治療。」 多巴胺拮抗劑可以緩解約50%~60%症狀。

能治癒嗎?

目前尚沒有特定的藥物能治癒妥瑞症並完全停止抽動。數種藥物治療只能在一段時間內減少抽動的頻率或強度。然而,妥瑞兒亦可透過習慣反向訓練 (Habit Reversal Training) 的治療來減少抽動。

病發時如何處理?

有時患者在抽動時,身邊人過分的關注、緊張的詢問會使他們更加難受;可以的話,給他們一個空間和時間讓患者發洩及平靜下來更好。



聆聽及理解患者的感受或有助抒緩他們的負面情緒。病發 後讓患者明白這病不是他們的過錯引起的,其實跟傷風感 冒沒兩樣,最好能教導患者接受自己和與妥瑞症共存!

對妥瑞症患者的話

如果遇到欺負你的人:

- 1. 請保持冷靜
- 2. 向父母,老師或朋友傾訴
- 3. 並記著你擁有安全的權利,被欺負並不是你的錯

為自己發聲:

- . 「我不要讓妥瑞症阻止我想做的事!」
- 2. 「即使有妥瑞症,我仍很正常。」
- 3. 「我有妥瑞症,但妥瑞症並不能控制我。」

家長點滴

如果孩子在病發或情緒較差時得到家人/師長的體諒和關懷,或會容易渡過困境,把身心傷害減至最低! 我們相信:患有妥瑞症的兒童也可以擁有快樂的童年。

家長/照顧者·或可考慮加入香港妥瑞症協會·讓同路人 互勵互勉·一起為妥瑞症患者爭取權益·及創造一個沒有 牆的社會!

入會方法

- 填寫入會申請表,將表格及會費(港幣\$100)以劃線支票郵寄至本會。本會執行幹事委員會將每月定期審核並決定是否接納申請,並通知申請人申請結果。
- 幹事會有權接納或拒絕任何加入本會的申請。

會員申請表 Membership Application

	l/Applicant's Particul		
姓名/Name	e: 中文	_ English	
男/M 女/F	出生日期/D.O.	B: Year/Month_	
聯絡電話/0	Contact Tel		
電郵/Emai	:		
聯絡地址//	Address:		
工作狀況/\	Working Status:		
學生 Student	半職 全職 Part-time Full-time	退休 其他 Retired Oth	ers_
教育程度: Education	小學 Level Primary	中學 大 Secondary U	:學 niversity
患者資料	Patient's Particulars		
姓名/Name	e: <u>************************************</u>		
男/M 女/F	出生日期/D.O.	B: Year/Month_	
病發年齡/月	Age of onset:		
確診日期/0	Date of diagnosis:		
確診醫療機	機構/Diagnosed by:		
會員類別/N	Membership:		
基本會員 Full	附屬會員 Associate		
本人願意成為本會義工 I would like to be a volunteer		是 Yes	否 No
興趣/專長	/Interests:		
本人願意申	請成為<香港妥瑞症協	協會>會員,並同意	意遵守會員規

I wish to apply for membership of "The Hong Kong Tourette Association" and in the event of being accepted, I hereby agree to be bound by the Memorandum & Articles and By-laws of the Hong Kong Tourette Association.

簽名	日期
Signature	Date