

Tourette syndrome poster - What is Tourette Syndrome?

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Posters and accompanying communication cards presenting core symptoms in Tourette syndrome and common co – occurring challenges

AIM:

- Visual support in communication with patients and family when a Tourette syndrome diagnosis is confirmed
- Materials containing illustrations and short text presenting core symptoms in Tourette syndrome – irrespective of language and cultural background

Background: Psychoeducation is recommended as an initial intervention for all individuals diagnosed with Tourette syndrome (Andrén P. et al., 2022). Regional Resource Center for Autism, ADHD and Tourette Syndrome (RRC) has previously designed materials to be used in communication when the diagnosis Autism Spectrum disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD) is concluded. Accordingly we wanted to design similar material for individuals diagnosed with Tourette Syndrome.

Methods: The materials concerning ASD and ADHD are used as a precursor in this project, with the aim to create similar materials adapted to Tourette syndrome. The work has been led by RRC. A working group were established, consisted of clinicians from Child and Adolescent Psychiatric services and Norwegian Tourette Association. The work was based on the diagnostic criteria described by the ICD-10. Experiences from participating clinicians and representative from the Norwegian Tourette association were important and valuable in elaborating the best illustrations and describing text.



Results: The results are qualitative materials developed to be a support and supplement in psychoeducation and communication with patients and family members, presenting the core challenges in Tourette syndrome following a diagnostic assessment.

The materials contain:

- An introduction to the materials
- Two posters. One shows illustrations and short text about motor and vocal tics, the core symptoms of Tourette syndrome. The other poster presenting common co-occurring conditions and challenges prevalent for those with Tourette syndrome
- Conversation/discussion cards containing each illustration and text from the poster

The materials are evaluated to make it easier to convey and understand findings from a Tourette syndrome assessment – irrespective of language and cultural background. The primary target group for the materials is clinicians responsible for assessment and offering psychoeducation to children and adolescence with Tourette syndrome.

The entire material will be translated and produced in several language versions, is free for use and can be downloaded from www.touretteplakaten.no

Reference: Andrén P., et al., 2022. European clinical guidelines for Tourette syndrome and other tic disorders – version 2.0 Part II: psychological interventions. European Child and Adolescent Psychiatry Journal 2022



What is Tourette syndrome?

Motor tics – involuntary movements

- Many have facial tics
 - Eye blinking
 - Eye rolling
 - Sticking the tongue out
 - Head shaking
 - Licking the lips
 - Nose scrunching
- Motor tics may involve different parts of the body
 - Hand twisting/finger spasms
 - Movement of muscle right of the body (right-left, left-right)
 - Head shaking
 - Eye rolling
 - Head shaking
- Vocal tics - involuntary sounds
 - Breathing sounds
 - Sniffing
 - Coughing
 - Howling
 - Squawking
 - Sighs
 - Whining
 - Humming
 - Throat clearing
- Tics
 - Premotor sensations preceding tics
 - Many will have a distinct, uncomfortable sensation before the tic occurs
 - Ticking/tingling
 - Burning/heatting
 - Aching/sore (‘have to do it’)
 - After the tic
 - The discomfort is relieved

Common secondary problems

- Pain
 - Pain in muscles and joints
 - Headaches and neck pain
 - Headaches and neck pain
- Sleep disturbance
 - Trouble falling asleep at night
 - Frequent waking during the night
- Mood swings
 - May quickly feel sad or upset
 - May quickly feel happy
 - May quickly feel angry
- Obsessions or compulsions
 - ‘Have to’ do things
 - Troubling thoughts that keep repeating
 - Counting
 - Systematic patterns
 - Things need to feel right
- Learning and attention may be affected
 - Focusing on tics demands attention
 - Hearing tics
 - Head shaking/biting back tics
 - Compulsive tics
 - Difficult to concentrate
 - May experience inner turmoil
 - May also have ADHD
- Mood swings
 - May quickly feel sad or upset
 - May quickly feel happy
 - May quickly feel angry

Illustrations and short text about motor and vocal tics

Illustrations and short text presenting common co-occurring conditions and challenges prevalent for those with Tourette syndrome

Fatigue/tiredness

- From having tics
- From holding back tics
- After school

Motor tics may involve different parts of the body

Common secondary problems

- Motor tics – involuntary movements
- Many have facial tics
 - Eye blinking
 - Eye rolling
 - Sticking the tongue out
 - Mouth opening
 - Licking the lips
 - Nose scrunching
- Motor tics - involuntary movements
 - Head shaking
 - Head shaking
 - Head shaking
- Obsessions or compulsions
 - ‘Have to’ do things
 - Troubling thoughts that keep repeating
 - Counting
 - Systematic patterns
 - Things need to feel right
- Learning and attention may be affected
 - Focusing on tics demands attention
 - Hearing tics
 - Head shaking/biting back tics
 - Compulsive tics
 - Difficult to concentrate
 - May experience inner turmoil
 - May also have ADHD

Illustrations and short text about motor and vocal tics

Communication cards intended to give the clinicians an opportunity to tailor the communication to each patient, and help the patient to recognize his/her individual symptoms and challenges