

Tourette syndrome poster – What is Tourette syndrome?

Pedersen KA¹, Skaraberget HH ², Lande HL³, Thorstensen AG⁴, Nøstvik LI⁵

¹Regional Resource Center for Autism, ADHD and Tourette Syndrome, South Eastern Norway Regional Health Authority, Oslo University Hospital, Norway, ²Child and Adolescent Psychiatric Services, Akershus University Hospital, Kongsvinger, Norway, ³Child and Adolescent Psychiatric Services, Vestre Viken Hospital Trust, Drammen, Norway, ⁴Child and Adolescent Psychiatric Services, Oslo University Hospital, Oslo Nord, Norway, ⁵Norwegian Tourette Association

Background:

European clinical guidelines for Tourette syndrome and other tic disorders – version 2.0 Part II: psychological interventions recommend psychoeducation as an initial intervention for all individuals diagnosed with Tourette syndrome (TS). Based on previous created and designed materials at Regional Resource Center for Autism, ADHD and Tourette Syndrome (RRC) to be used in communication when the diagnosis Autism spectrum disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD) is concluded, we wanted to design similar material for individuals diagnosed with TS. The purpose of the former materials regarding ASD and ADHD were to provide visual and written support for a review of relevant areas when the diagnose has been confirmed. The aim with the materials in this project is to simplify and standardise communication of the findings and conclusions of an Tourettes diagnosis assessment. The materials contain a « package » including a written introduction to the materials, posters with illustrations and text divided into main areas affected in people with the diagnoses and co-occuring challenges, and further communication/discussion cards belonging to the different areas correponding with the poster. The illustrations in the materials are irrespective of language and cultural background, and the entire material is also produced in several language versions. The former material is free for everyone to use, and has been printed and distributed to all relevant clinics belonging to the South Eastern Regional Health Authority in Norway.

Methods:

The materials concerning ASD and ADHD have been 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, and a working group was established consisted of representatives from Child and Adolescent Psychiatric Services at Oslo University Hospital, Vestre Viken Hospital Trust and Akershus University Hospital, Norwegian Tourette Association and Melkeveien Design office. A group of adolescence with Tourette syndrome from the Norwegian Tourette Association has also been involved in the work, and gave valuable suggestions.

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 to prioritize and elaborate the best illustrations and describing text. The graphic designer involved, was the same person who had designed the previous ASD and ADHD materials. This became very helpful since she knew the background of earlier work.

Results and Conclusions:

ESSTS

The result of the project is 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. It is evaluated to make it easier to convey and understand findings – irrespective of language and cultural background.

The material is however not intended to replace a structured psycho-educative approach, but rather be a visual support and supplemental tool in psychoeducation. The materials contain two posters. One poster shows illustrations and short text about motor and vocal tics. The other poster presenting common co-occurring conditions and challenges prevalent for those with Tourette syndrome. Each illustration and belonging text is also to be found in the cards, called conversation/discussion cards. The cards give the clinicians an opportunity to tailor the communication to each patient, and help the patient to recognize his/her individual symptoms and challenges. The cards are intended to provide a starting point for discussion about the content depicted in each card. The material will be printed in a limited number of copies and distributed to relevant clinics in the region. The materials will also be translated to several languages. The material is free for everyone to use, and can be downloaded from the RCC webpage and www.touretteplakaten.no.