

# SHARED CARE GUIDELINE

## Shared Care Guideline for the treatment of Tourette's Syndrome and other tic disorders in children and adolescents.

<b>Scope:</b> Pennine Care NHS Foundation Trust NHS Bury NHS Heywood, Middleton and Rochdale NHS Tameside & Glossop	NHS Oldham NHS Stockport	<b>Version:</b>  Version 1
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<b>Author(s)/Originator(s)</b>	Pennine Care NHS Foundation Trust	
<b>To be read in conjunction with the following documents:</b>	BNF 63 September 2012 BNF for children 2011-2012 Summary of Product Characteristics (SPC) Pharmaceutical company's patient information leaflet (PIL) <b>Pennine Care CL 16</b> The Prescribing, Supply and use of Unlicensed Medicines <b>Pennine Care CL17</b> The use of Licensed Medicines outside the conditions of their Product Licence	
<b>Authorised by:</b>	Drugs and Therapeutics Committee, Pennine Care NHS Foundation Trust	
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### 1. Scope

Pennine Care NHS Foundation Trust and associated Primary Care Trusts (PCTs). Acute Trust Service Level Agreement (SLA) partners.

### 2. Introduction

This shared care guideline covers the prescribing for the treatment of Tourette's Syndrome and other tic disorders in children and young people. It includes licensed medicines, licensed medicines for unlicensed applications, and recommended or accepted use of unlicensed medicines ('off-label' prescribing).

As with many paediatric treatments, some uses of medicines in this age group are with informed use of off-label prescribing.

In 2000, the Royal College of Paediatrics and Child Health issued a policy statement on the use of unlicensed medicines or the use of licensed medicines for unlicensed applications, in children and young people. This states clearly that such use is necessary in paediatric practice and that doctors are legally allowed to prescribe unlicensed medicines where there are no suitable alternatives and where the use is justified by a responsible body of professional opinion. [1]

Tic disorders including Tourette's syndrome are neuropsychiatric disorders characterised by motor and phonic tics. They are commonly associated with comorbid disorders, e.g. obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) [2].

Tics may be defined as sudden, purposeless, repetitive, non-rhythmic, stereotyped movements or vocalisations, e.g. eye twitching or blinking. Examples of phonic tics are throat clearing, grunting and barking.

Tics can result in psychosocial, educational and functional impairment of the patient. CAMHS teams can offer a range of strategies to help patients live with their symptoms, but when tics are causing significant disability or distress medication can be very helpful to relieve symptoms [3].

The SCG recognises there are differences in commissioning of Child and Adolescent Mental Health Services across the Trust for 16 to 18 year olds and that there are differences in the practice of prescribing and supervision for 16 to 18 year olds by working age adult psychiatrists.

### **3. Supporting Information**

Studies looking at the pathology of Tourettes syndrome provide evidence of an imbalance in the neurotransmitters of the frontal and sub-cortical neural pathways. Modulating dopamine by acting on the post-synaptic D2 receptors is the main action of drugs used in the pharmacological treatment of tics. Serotonin imbalance in sufferers of Tourettes syndrome has been identified more recently and it is thought that action on the 5-HT<sub>2</sub> receptors also results in an alleviation of symptoms. [3]

There have been three or more double blind trials supporting the use of haloperidol, risperidone and clonidine. Haloperidol has the most evidence but its use is limited due to adverse effects such as extrapyramidal symptoms (EPS) or tardive dyskinesia (TD).

The efficacy of risperidone has been confirmed in two randomized, double-blind, placebo-controlled trials, randomized double-blind trials and many case studies. Risperidone has shown similar efficacy to haloperidol but with fewer, severe adverse effects.

Further research is needed to provide evidence for the efficacy of other antipsychotics. At present there is one double blind trial and over 150 patient cases published in case series supporting the use of sulpiride and aripiprazole for the treatment of Tourettes. Aripiprazole in particular has been shown to be efficacious in refractory cases. Several case reports and open-label studies

have also suggested efficacy of olanzapine and quetiapine for the treatment of Tourettes. [4,5,6]

Clonidine has been used for almost thirty years in the treatment of Tourettes, but there is a lack of randomized, placebo-controlled trials. Clonidine is mostly used in patients with a combination of ADHD and tics. Many case reports and open-label trials are available but have looked at small patient numbers. However in 2002 a large randomized placebo-controlled trial reported that clonidine reduced tics significantly in children suffering from ADHD and tic disorders. [7]

The European clinical guidelines for Tourette's syndrome and other tic disorders were published in 2011. These up to date guidelines summarise the evidence available and outline the options available for pharmacological management of patients with tic disorders in detail. [3]

#### 4. Prescribing and monitoring

##### 4.1 Summary of indications, dosage & formulations

Drug	Licensing	Formulations	Dose range
<b>Antipsychotics</b>			
Haloperidol	Licensed in ≥5 yrs	Tablets Oral liquid	5-12yrs 12.5-25mcg/kg twice daily*  12-18yrs 1.5mg three times daily*  Adjust doses to response. Max 10mg
Risperidone	Unlicensed	Tablets Oro-dispers. tablets Oral liquid	0.25-6mg (total daily dose) <sup>a</sup>
Sulpride	Unlicensed	Tablets Liquid	2-12yrs 50-400mg twice daily*  12-18yrs 100-400mg twice daily*  Adjust doses to response.
Aripiprazole	Unlicensed	Tablets Oro-dispersable tablets Oral solution	2-25mg (total daily dose) #
<b>Other</b>			
Clonidine	Unlicensed	Tablets	0.05mg-0.3mg (total daily dose) <sup>a</sup>

\*BNFc 2011-2011 recommended doses

<sup>a</sup> Doses used in reported trials [3]

#Doses used in reported trials [5]

##### 4.2 Monitoring

There are concerns that children and young people are more sensitive than adults to the potential adverse effects of antipsychotics, including weight gain, metabolic effects and movement disorders.

Clonidine may cause orthostatic hypotension so blood pressure and pulse should be measured at baseline and then monitored after each dose adjustment.

The Specialist Team will monitor response to treatment, and adverse effects. This includes 3-6 monthly weight measurements, six monthly blood glucose levels measurements, and baseline and annual cholesterol and triglycerides checks. Suitable action will be taken if these give cause for concern and will be communicated to the GP.

The GP should refer any queries regarding treatment or adverse effects to the Specialist Team.

## **5. Regimen Management**

Aspects of care for which the Specialist is responsible. The term Specialist includes Child and Adolescent Psychiatrist, Paediatrician, or nominated Advanced Practitioner/ Non Medical Prescriber (in agreement with their medical supervisor):

- Direct assessment or supervision of specialist team assessment, evaluation of prior treatment, and rationalisation of treatment.
- Informing patient/ carer of diagnosis, care plan, treatment including side effects and use of unlicensed product. Use of Patient Information Leaflets (PILs), user-friendly information leaflets for children/ adolescents.
- Treatment decisions should be shared between patient, carer and the Specialist.
- Informing young person/ carers of the latest regulatory advice.
- Ascertaining patient/ family's commitment to safe storage and handling of medication.
- Asking General Practitioners (GP) if they are willing to participate in shared care.
- Initiation and titration of medication to a suitable dose or provide instructions/directions to the GP for initiation and/or titration of medication to a suitable dose where this has been agreed.

- Written correspondence to GP from Specialist Team, summarising progress and recommendations for continued treatment.
- Ensure clear arrangements for GP back up, advice and support.
- To inform young person/ carer of the risk of physical side effects, particularly around initiation of treatment.
- Monitoring response to treatment, and adverse effects.
- Ensuring concurrent psychological therapy is offered.
- Promoting access to any appropriate supporting therapies, carer education, and appropriate school liaison.
- Minimum 6 monthly Specialist review appointments once treatment is established.
- Reporting suspected adverse events to the GP and the MHRA via the Yellow Card scheme to [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard)
- Discontinuation of treatment, (or transfer if appropriate).

Aspects of care for which the GP is responsible:

- Replying to requests for shared care as soon as possible.
- Initiation and titration of medication where there is agreement/ Continued prescribing of medication in the community under guidance of Consultant/ Specialist Team
- To undertake appropriate investigations, during treatment if requested to do so by the Consultant.
- Refer to the Consultant/Specialist Team for queries regarding treatment/side effects, and concerns about compliance or suspected drug misuse.
- Ensure compatibility of medication with concomitant prescribed medication.
- Stopping treatment on the advice of the Consultant/Specialist team.
- Continuation without specialist review is not recommended.
- Reporting suspected adverse events to the Specialist team and the MHRA via the Yellow Card scheme to [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard)

## **6. Summary of cautions, contra indications, side effects & interactions**

Please refer to the current edition of the BNF and BNF for Children and Summary of Product Characteristics (SPCs) of the individual drugs for the latest list of contraindication, cautions, side effects and interactions.

**7. Special Considerations**

Handover for shared care largely by written agreement. Individual consideration of patients to occur when issues of tolerance, inconsistent response to treatment, pre-existing medical conditions or issues of patient compliance.

**8. Back-up care available to GP from Hospital, including emergency contact procedures and help line numbers.**

Written correspondence following Consultant/ Specialist Team appointments, specifically detailing the next review date and any dose adjustments.

Telephone advice/ information from the Consultant / Specialist Team during office hours, and plans for earlier review by team if necessary.

Dr [insert text here]\_\_\_\_\_

Contact number: [insert text here] \_\_\_\_\_

Hospital: [insert text here]\_\_\_\_\_

Out of hours on call/ emergency mental health service contactable through hospital switchboards.

**9. Statement of Agreement between GP and Consultant**

This document outlines the suggested care pathway of your patient. If you are unable to agree to the sharing of care and prescribing the suggested medication, please make this known to the Consultant within 14 days stating the nature of your concern.

**10. Written information provided to patient**

- Pennine Care NHS Foundation Trust Patient Information Leaflet
- Patient information leaflet

**11 Supporting references**

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5. Robertson MM 2011., Gilles de la Tourette Syndrome: the complexities of phenotype and treatment. *British Journal of Medicine*. 2011; 72(2): 100-7
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9. Current issues in child and adolescent psychopharmacology. Part 2: Anxiety and obsessive–compulsive disorders, autism, Tourette's and schizophrenia APT July 2003; 9:289-299
10. BNF 62 September 2011 and BNF for Children 2011- 2012
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12. James AC., Prescribing antipsychotics for children and adolescents. *Advances in psychiatric treatment*. 2010;16:63-75.
13. Lavenstein BL., Treatment approaches for children with Tourette's syndrome. *Current Neurological Neuroscience Rep*. 2003;3(2):143-8.