

## Tourette Syndrome (TS) in Queensland

### The Problem:

- Tourette Syndrome is a complex neuropsychiatric illness with a high co-morbidity rate, and significant psychosocial and physical distress and disability, for sufferers in the moderate to severe range of illness severity. It is best seen as an impulse control disorder which results in waxing and waning of disinhibited movements (tics) and socially taboo compulsions and emotional dysregulation, which can greatly affect social and emotional functioning, and commonly leads to social ostracism and stigma.
- It is a common and widely misunderstood illness which predominately affects children and adolescents in the critical period of self esteem and identity formation.
- Currently there are no coordinated specialist treatment programs for TS in the public health system. Clinicians have a low literacy rate for assessing and managing the condition with a tendency towards unnecessary and expensive imaging investigations (MRI brain scans and EEG, often requiring sedation and hospitalization), and over prescribing of antipsychotic medications with under-utilisation of non-medication options (support groups, educational adjustments, specific psychological and social interventions, sensory strategies). Currently, Child Psychiatrists in the community are unable to refer to Paediatric Neurologists in the public system, without referrals going through General Paediatric clinics first. This is unusual, given both Specialists have spent many years specializing in childrens' brains. As a result of this, children with severe TS who require intervention from both, may have their treatment delayed by many months, or even years.
- There appears to be general confusion over whom to refer these children to, with both paediatric and mental health services under-resourced and over-stretched with long waiting times. Most clinicians see TS as a neurological illness, but it is often the psychiatric comorbidity that incurs the most distress and disability. As a result, children often fall through the cracks between both departments.
- The public education system in Queensland is currently grossly inadequate in catering to the unique educational needs of children with TS, resulting in misdiagnosis of autistic spectrum disorder in many to access much needed educational funding support, and high rates of educational disengagement and home-schooling due to under-resourcing and low levels of education on how to manage TS children in the classroom. TS children are frequently excluded and punished for their symptoms in many classroom settings, resulting in widespread systemic neglect and additional, preventable, psychological harm to children.
- The TS community is desperate to access primary, secondary, and tertiary services with knowledgeable and experienced clinicians who can provide appropriate diagnostic assessment, and administer specialist treatment programs, including Comprehensive Behavioural Intervention for Tics (CBIT), wraparound educational packages, social support and skills

training, and appropriate psychological, social, and sensory strategies to support the children's development and minimize long-term sequelae. There is also a paucity of services available for the 10 to 15% of sufferers who experience a severe and protracted illness into adulthood.

#### Prevalence rates:

- Lifetime prevalence for tics in the population is 20%
- TS: Mean rate 1% (Zoey, Shaw & Coffey, 2014)
- 37% of those with TS have the moderate to severe form (Bitsko et al 2014)
- Special education settings in Australia: 65% have tics, 24% have TS (Eapen et al.), yet there is currently no TS category for additional learning support funding in Queensland.
- Based on ABS statistics for June 2014, there are approximately 47 000 people estimated to be living with TS in Queensland, and 17 390 with moderate to severe TS state-wide. In greater Brisbane (excluding the Sunshine and Gold Coasts), according to ABS statistics for June 2014, we would anticipate 22 700 sufferers of TS, and 8399 sufferers in the moderate to severe category of illness.
- These estimates are significantly higher than other disorders which currently have dedicated multidisciplinary specialist services and treatment programmes (e.g. Prader Willi syndrome which has a multidisciplinary clinic with a prevalence of only 4 per 100000, and Autistic Spectrum Disorder which has a host of public and private medical and educational services at both state and federal levels, and has a prevalence of 0.5% according to the ABS).

#### Comorbidities:

- 80% of TS sufferers will have multiple diagnoses
- 60-80% will have Attention Deficit Hyperactivity Disorder, many have comorbid Oppositional Defiant Disorder (ODD)
- 25-70% will suffer "rage attacks" which may be classified as either Disruptive Mood Dysregulation Disorder (DMDD) or Intermittent Explosive Disorder (IED)
- 40-60% will have Obsessive Compulsive Disorder/other anxiety disorders
- 35% will have Autistic Spectrum Disorder, of those that don't reach the criteria for this diagnosis, many will have problems with theory of mind, executive functioning, and social skills (often mood dependent and related to emotional dysregulation)
- 30% will have Bipolar Spectrum Disorders
- 25% will suffer Major Depressive Disorder
- 65% will suffer Sleep Disorders
- 40% will suffer comorbid chronic physical health conditions
- 40-50% will suffer significant learning disorders
- A significant proportion suffer Sensory Processing Disorders

#### Proposed Solutions:

- Increase awareness and understanding of the illness amongst clinicians:
  - Include easily accessible information about Tourette Syndrome, and support services such as the Tourette Syndrome Association of Australia (TSAA), on Queensland Health IT Databases.
  - Establish a state-wide database of clinicians with training, knowledge, and experience in treating TS and clear and appropriate referral pathways.
  - Fund education and training programs for clinicians (particularly medical staff e.g. General Practitioners, Emergency Department staff, Paediatric and Psychiatric Registrars and Consultants, psychologists for CBIT, and OTs).
  - Provide a space and support for the National Tourette Syndrome Conference to be held in Brisbane in May 2016.
- Establish a multidisciplinary tertiary referral clinic for the most severe cases. Currently Child Psychiatrist Dr Shannon Morton and Paediatric Neurologist Dr Kate Sinclair are planning to collaborate with the assistance of experienced Psychologists, Occupational Therapists, and hopefully a representative from Education Queensland, to form such a clinic. Dr Morton is happy to donate free appropriate space in the community for the clinic to operate, and to bulk-bill under a private practice model. However, in order to offer such a service to regional areas, assistance with funding videoconferencing equipment would be helpful, as well as funding a state-wide coordinator as the contact for the multi-disciplinary clinic to triage referrals, coordinate assessments, provide educational resources to clinicians and patients, and conduct research and evaluations of the program.
- Use the Bubble and Squeak Support Group at The Kooky Kid Clinic as a template to set up similar support groups in other districts and regions.
- Provide Funding for a yearly camp for young people and families living with TS in Queensland. A weekend camp is proposed incorporating therapeutic support activities and respite, including a pilot trial of "Tourettes the Musical" to raise community awareness and build self esteem and confidence in the children participating.
- Queensland Health to petition Education Queensland to offer a Tourette Syndrome category of verification for additional learning support.
- Queensland Health and Education Queensland to work collaboratively to provide intensive educational options for the severe cases of TS, such as creating greater availability of Day School Programs.

#### References:

- Zoey, A., Shaw, B.A., Coffey, B. J. (2014). Tics and Tourette Syndrome. *Clinical Key*. 37(3) pp: 269-286.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Centre of Disease and Prevention (US): Bitsko, R., Holbrook, J.R., Visser, S, N., Mink, J.M., Zinner, S.H., Ghandour, R.M., & Blumberg, S.J. (2014). A National Profile of Tourette Syndrome, 2011–2012. *J Dev Behav Pediatr* 35(5), pp :317–322.