

In this Spotlight series, Tourettes Action speaks with professionals across the health and education sector about their role in supporting someone with TS

SPOTLIGHT

on...speech and language therapists



Q&A with Jenni Lindinger, Speech and Language Therapist

Tourettes Action interviewed Jenni Lindinger to find out how a Speech and Language therapist could be of support to someone with Tourette Syndrome.

Can you give us an overview of what Speech and Language Therapy (SLT) is, and what contribution can speech and language therapists make in treating Tourette Syndrome (TS)?

Communication is a human right, and the role of a speech and language therapist (SLT) is to break down barriers in communication, whatever the cause, to ensure this right is always protected. There are many reasons why people might struggle to communicate; some people have a stammer, some have tics, others develop a speech phobia that means they are unable to speak in certain situations, some have articulation problems and find it hard to say certain sounds, and others have condition such as autism, developmental language disorder or verbal dyspraxia to name a few. SLTs make a unique contribution in working with people who experience anything that stops them being able to communicate as fully and equally as they want to, and we do this by providing intervention across three important areas.

Firstly, a therapist will assess the nature of the difficulty getting in the way of communication, and what can be done to change the nature and severity of the communication difficulty. This might involve therapy to develop language, to produce clear speech sounds, to increase fluency, or to reduce the frequency and severity of tics.

Secondly, an SLT will investigate a client's communication skills to ensure they interact effectively with other people, so when their difficulty starts to affect their communication, our clients have a specialist toolkit of communication skills to draw on. When communication is going smoothly, simple communication skills, such as taking conversational turns, making eye contact, reading body language, showing empathy and contributing to a topic appropriately, come naturally to many of us. But these skills come less naturally to us when tics increase, or a stammer gets worse, or the right words just won't come to mind, which can make communicating feel less comfortable and increase anxiety, which then



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often exacerbates the original problem. We then sometimes find our clients begin avoiding social situations to avoid this happening. But when we help our clients to explicitly learn communication skills, this helps increase their sense of control and empowers them in social situations, therefore reducing anxiety and pressure, so breaking this cycle.

Finally, an SLT will consider the well-being of our clients, for example, assessing if the communication difficulty is affecting their confidence, self-esteem, identity, achievements, friendships and happiness. Sometimes we put in preventative support, for example, by training schools, clubs and peer groups in how to ensure our clients are included, understood and supported appropriately. Sometimes we deal with the consequences of experiencing their communication difficulty over many years, and work with them on increasing their confidence, assertiveness, self-care, resilience, positive self-talk and self-acceptance of themselves.

So what would a SLT do with a client with tics or Tourette Syndrome?

An SLT, with specialist behavioural therapy training (CBITS - Comprehensive Behavioural Intervention for Tics), such as that offered by Tourettes Action, would provide the same treatment for the verbal and motor tics themselves as an OT (Occupational Therapist) or psychologist with similar training may do. They would also supplement this with their specialist knowledge of verbal and non-verbal communication skills to enhance their treatment. At present, few SLTs are trained in how to provide this treatment, despite the fact that they have the clinical skills to do so.

Currently, the majority of SLTs work within the traditional remit of SLT, for example, they focus on Autistic Spectrum Disorder, stammering, speech sound difficulties and issues with their language development. However, during my personal experience as an SLT it was not uncommon for me to see children coming to therapy who also have tics, and either had to access two different professionals, or only had treatment for one condition despite the fact that their tics were a factor in their communication difficulties. By having the additional behavioural therapy training (CBITS) from Tourettes Action it meant that I was able to tackle both aspects of their difficulty, making it easier for children and their families.

At present it is unclear how many SLT's there are in the UK who have trained to deliver CBITS for people with TS. Tourettes Action (TA) is hoping to train more clinicians including SLTs to deliver this therapy.

SLTs are definitely in a position to contribute to the body of professionals that TA are looking to train to offer this therapy. It might be that, in the future, services for TS consider taking on a trained SLT into their department, in order to have someone who can both provide treatment for tics as well as provide specialist knowledge in communication.

If an adult or a child has TS do they automatically qualify for a SLT referral?

You would not typically get a NHS referral for SLT because you have TS. However if you have cooccurring conditions, which affects your speech, language and communication, such as Autistic Spectrum Disorder (ASD), a stammer or a language disorder, then you can be referred for SLT, and this is done through a GP, school or directly by parents to the local service. SLTs are trained to work with the co-occurring condition but currently, families will often have to see an additional professional for their tics.

For families able and willing to access private therapy, there are SLTs who have a specialist interest in TS/tics and have the training to be able to offer therapy for this, and these therapists can be found by contacting ASLTIP (Association of Speech and Language Therapists in Independent Practice) – see details below.



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So it may be that the co-occurring conditions cause the TS patient to be seen by an SLT?

I'm not aware of any NHS SLT paediatric services that offers treatment for TS when it occurs in isolation (and I only work with children, so I can only comment on this), but there are children who have TS alongside other difficulties such as ASD, stammering, language disorders etc, who would be seen. However, their TS would not typically be treated by an SLT, and they would typically be seen by another professional. However, if SLTs were trained to deliver this, then clients could see one therapist rather than multiple professionals to receive treatment, especially since there may be an overlap in some aspects of the treatment.

So SLT's could treat someone with tics but it's not the usual pathway?

Broadly speaking, someone would not typically be referred to SLT for TS as it is not a condition that SLTs typically treat, and would definitely not be likely to fall within the NHS remit. However, SLTs do have the clinical skills to treat this, when given additional training from specialists.

As an SLT is concerned with communication would they treat only the vocal tics?

SLTs would not just treat vocal tics – once trained, we'd treat motor and vocal. That's because we deal with communication, both verbal and non-verbal, and motor tics may have just as much as an impact on confident communication as verbal tics. In a similar way, stammering is not just verbal, but has motor components

How can we empower patients and give them knowledge about what is available, what should patients be asking for when asking to be referred to SLT?

So, I guess the best response to this is for an NHS service would be for someone to ask their healthcare

professional 'I would like a referral to SLT as I think it would help with my child's social communication skills, which are affected by their ASD and TS combined'.

However, the rationale for seeing a private therapist trained in treatment for TS would be 'I would like an appointment with an SLT to help dealing with both the tics resulting from TS as well as the resulting impact on their ability to communicate confidently and express themselves fully, and to develop their social skills, confidence and resilience.'

How does someone access SLT?

SLT services for children can be accessed directly by parents contacting their local NHS service. Parents can also go through their GP and through their school for a referral. Access to adult services should be discussed with your GP.

How long does a referral take?

This varies by area, but most NHS services will see a child within 5 weeks. This may be an initial assessment session with clients then another wait before therapy can start, however, this depends on each individual service. Questions relating to waiting lists and timeframes should be asked to the NHS service manager. In private practice, clients can often be seen within 1-2 weeks for assessment and therapy.

Where would someone see an SLT?

Generally, therapists work wherever there are clients - in clinic, hospital, school, homes, nurseries etc. Privately, SLTs generally offer school/nursery and home visits. Some private therapists may have a therapy centre where they also offer appointments from.

How would someone find a registered private SLT therapist?

ASLTIP (Association of Speech and Language Therapists in Independent Practice) have a directory



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'www.helpwithtalking.com' which has a list of all therapists working privately, and can be filtered by area and speciality.

About Jenni Lindinger

Jenni is the founder and clinical director of the <u>The</u> <u>Expressive Child</u> – a private therapy practice in Surrey. She is a registered Speech and Language Therapist and has worked in the NHS, hospitals, clinics, speech and language units and in schools. Jenni is on Tourettes Action's list of behavioural therapists which is an informal list of psychological therapists in the UK offering behavioural therapy and cognitive behavioural therapy for the treatment of tics & Tourette Syndrome.

If you would like a copy of the Tourettes Action behavioural list please contact the helpdesk.

Tourettes Action would like to thank Jenni for her very helpful explanations to our questions

USEFUL ORGANISATIONS/ FURTHER READING

Royal College of Speech & Language Therapists RCSLT - professional body for people working in or studying speech and language therapy in the UK.

<u>helpwithtalking.com</u> - Association for speech and language therapists in independent practice here you can find independent SLTs

afasic.org.uk - parent-led organisation who provide information and training for parents – and professionals – and produce a range of publications.

specialneedsjungle.com - resources, articles and information for parents and carers of children with special needs, disabilities and health conditions to better enable them to navigate the special needs system.

If you have questions or comments please contact us:

Helpdesk phone: 0300 777 8427 Helpdesk email: <u>help@tourettes-action.org.uk</u>