

In this Spotlight series, Tourettes Action is shining a light on not-yet validated treatments and emerging research in the field of TS

SPOTLIGHT

ON... MINDFULNESS



Tourettes Action Research Manager, Dr Seonaid Anderson discusses the concept of Mindfulness and it's potential role in supporting people with TS

Mindfulness is a very popular topic in current psychology. In this article, Dr Anderson looks closer at the concept of mindfulness and how it might support people with movement disorders like Tourette Syndrome.

What is mindfulness?

Mindfulness comes from philosophical and religious traditions, particularly Buddhism. It has been described as a way of learning to pay attention to the present moment. Giving full attention to physical sensations, thoughts, emotions and behaviour. Mindfulness trains us to be 'in the moment' and respond - not react - to what is happening now, rather than worrying about what has happened or what might happen in the future.

Our mind is often disconnected from our body and so we are unaware of the potentially valuable information that the body can give us, such as stress warning signs, or clues about the emotions that are driving our behaviour. Mindfulness training involves learning how to make awareness a more accessible and sustainable experience. It involves breathing and meditation exercises. Some definitions vary

slightly and The [Oxford Mindfulness Centre](#), uses the definition that "Mindfulness is the awareness that emerges through paying attention on purpose, in the present moment, with compassion, and open-hearted curiosity."

Positives

Research would seem to suggest that there are some benefits that can be gained from practising mindfulness. A review of research evidence from 2011 reported reduced anxiety and greater feelings of life having meaning.

Features of mindfulness meditation are being integrated into forms of therapy. Research reviews have found that mindfulness-based cognitive therapy has helped [prevent depression relapse](#) for some people. However some of the research evidence is poor and not as rigorous as would be desirable, and therefore there is lower confidence in the results.

Higher quality research is needed.

Mindfulness can be adapted to meet the needs of different groups, it is a non-pharmacological intervention and therefore non-invasive, and it's secular approach makes it suitable for people from a diverse range of backgrounds and beliefs.

How does it help?

It has been suggested that mindfulness might help people have more control over their minds and ignore distractions; they may feel more aware of their own body; being able to regulate their emotions more easily, and by changing their perspective of themselves. Mindfulness would also hope to encourage greater compassion for the self and help people to adopt more of a non-judgemental attitude, which can help to address self-critical thinking commonly seen in anxiety and depression.

Some researchers using MRI or fMRI brain imaging [found brain changes](#), in terms of activity levels and volume and connectivity changes, which may provide some support for the idea that mindfulness helps your brain regulate your emotions. However this existing evidence is of variable quality and difficult to interpret without clearer results from research.

A cautious approach

In practicing mindfulness an issue which could be important to consider is having realistic expectations, as some people may find it difficult to practice, and find it takes a considerable amount of active effort. It may be that an individual finds mindfulness very useful but as yet there are no 'formally recognised qualifications to teach mindfulness, and training pathways are not yet accredited' (Williams, 2015). Those teaching mindfulness 'should at the very least have their own established personal practice of mindfulness' (Williams, 2015). Also when seeking a mindfulness course it would be a good idea to check if the teachers are following UK mindfulness teacher guidelines (Kuyken et al 2012).

There may be reasons people don't want to do it – it's not their 'thing', people may find it difficult and frustrating.

What about mindfulness for people with movement disorders such as Tourette Syndrome?

Mindfulness and meditation is potentially a real challenge for people with movement disorders but there seems little reason as to why it should not be beneficial for people with TS. However, adhering to strict guidelines of mindfulness training which require someone to sit still and meditate can be challenging, especially for someone with a movement disorder. Many people with movement disorders also have co-occurring conditions such as ADHD which would increase the difficulty of adhering to some forms of mindfulness training.

Reese et al (2014) and her colleagues have done some [research into looking at this aspect in relation to tics and TS](#). The researchers 'sought to develop and test a modified form of mindfulness-based stress reduction (MBSR-tics) for the treatment of Tourette Syndrome (TS) and Chronic Tic Disorder (CTD)'. Hannah Reese commented to me that the researchers 'applied the principles of mindfulness to tics and especially the premonitory urge to tic. Participants were encouraged to become more aware of the urges to tic and to then explore the possibility that they could ride the wave of the urge to tic without engaging in the tic itself. Much of the practice doing this occurred in a sitting meditation called "Riding the Wave."' (Personal communication, 2016). They concluded that 'this small open pilot study provides preliminary support for the feasibility, acceptability, and efficacy of MBSR-tics for individuals 16 or older with TS or CTD. A larger randomized controlled trial with blind assessment is necessary to confirm these initial, promising findings'.

Some specialist centres for Tourette Syndrome in hospitals, and therapists offer mindfulness as part of their treatment package. At St Thomas Hospital (as part of the TaNDEM service) a mindfulness group for children with TS was trialled, with the aim to teach some mindfulness techniques. This was based on a well-recognised programme that is run in many schools across the country called '.b'. It was partly funded by a charity grant from [Roald Dahl's Marvellous Children's Charity](#)

The TaNDEM clinic has also piloted a Mindful Parenting group for parents of children with neuro-

disabilities, and they provide ad hoc individual mindfulness work as and when needed

Here we gain a parent's perspective on these mindfulness sessions:

'My daughter Lilly* is 9 years old and was diagnosed with a Chronic Tic Disorder last September. Whilst Lilly's condition was described as mild it was acknowledged that she did not like having tics; Lilly hated making noises and the thought of making noises at school or out and about made her anxious and stressed which in turn led to more tics. There were times when Lilly was very unhappy.

As a way of helping Lilly we were offered the chance to join the mindfulness programme run by the hospital. Initially Lilly did not understand what she was participating in or why; but very quickly it all seemed to make sense to her. Each week she would learn a different mindfulness exercise and then be expected to practice it at home. By about the third week Lilly had discovered that she could use her 7:11 breathing technique at school when she felt stressed and anxious. She would say, "Mummy I used my 7:11 breathing today when I started making noises, and my noises stopped". Lilly still experienced tics but she had gained some control over her situation and seemed much happier and more confident. One of the benefits of the 7:11 breathing technique for Lilly was that she could use it without drawing any attention to herself.

Lilly often experienced a worsening of her tics in the early evening and at bed time. Her evening tics have been so bad at times that she has struggled to get to sleep and become very frustrated and upset. The mindfulness programme taught Lilly how to 'Beditate' – a meditation exercise in bed. Lilly practices her 'beditation' exercise every evening before bed, she has learnt to relax fully and control her breathing which in turn has enabled her to manage her tics. There have even been times when she has fallen asleep! The 'beditation' exercise has been especially useful to us as a family as it has provided us with a way of directly helping and supporting Lilly as more often than not my husband and I practice it with her. Mindfulness has not cured Lilly of her tics and she still gets frustrated and upset at times, however it has

enabled Lilly to help herself and manage her condition better'.

Lilly * is a pseudonym.

These programmes seem to have been useful and there seems little reason as to why it should not be beneficial for people with TS. Tourettes Action wanted to help people with Tourette Syndrome overcome barriers to practicing mindfulness which is why we have created the first [guided relaxation](#) for people with tics. The script for the relaxation was guided by the work of Dr Tamara Russell, a clinical psychologist and neuroscientist who had written a book in 2016 called [Mindfulness in Motion](#). Two of the concepts described in her book were incorporated into the guided relaxation script: setting 'intention' and exploring neural pathways from within the body during meditation. You can [read more](#) about how the relaxation was created.

An important aspect of this guided relaxation is that there is a [feedback form](#) that we ask people to complete after listening to the relaxation. Gathering information from people who have used the guided relaxation will be essential to finding out if people find it effective. The feedback survey asks about changes during and after the relaxation in terms of frequency and intensity of tics, as well as any changes in the urge to tic. Please take the time to complete the survey if you use our Guided Meditation.

Other information

If you feel concerned about your mental well-being please speak to your medical professional. If you have questions or concerns about Tourette Syndrome and want to speak to someone who understands the issues, then please contact our helpdesk-details below.

If you have any questions about this article or research, or would like to share your experiences of mindfulness please contact Dr Seonaid Anderson, research manager at Tourettes Action.

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RESOURCES

Tourettes Action Mindfulness resources

- [Guided Relaxation for Tics MP3](#)
- [Article on Mindfulness, Tourette Syndrome and developing the Guided Relaxation for tics](#)

USEFUL ORGANISATIONS/ FURTHER READING

[Mindfulness Centre of Excellence](#) is a virtual organization dedicated to enabling and nurturing the next wave of mindfulness. MCoE is a secular hub for training, research and exploring new ways of disseminating mindfulness understanding and awareness.

Mindfulness and Mental Well-being

[Five steps to mental wellbeing](#)

[Can mindfulness improve pupils' concentration?](#)

[Mindfulness in Schools Project \(MiSP\)](#)

Research papers

[Effects of mindfulness on psychological health: A review of empirical studies](#)

[8-week Mindfulness Based Stress Reduction induces brain changes similar to traditional long-term meditation practice – A systematic review](#)

[Effects of school-based mindfulness training on emotion processing and well-being in adolescents: evidence from event-related potentials](#)

[How does mindfulness modulate self-regulation in pre-adolescent children? An integrative neurocognitive review](#)

[Developing mindfulness with children and young people: a review of the evidence and policy context](#)

[Mindfulness at school reduces \(likelihood of\) depression-related symptoms in adolescents](#)

[Mindfulness-based interventions in schools—a systematic review and meta-analysis](#)

[The Effectiveness of Mindfulness Training for Children with ADHD and Mindful Parenting for their Parents](#)

[Mindfulness Interventions with Youth: A Meta-Analysis](#)

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