

Your child's stereotypies

This leaflet explains more about stereotypies. It will give more information than your child's doctor has already given you, and includes a section for support and more information. If you have any questions, please speak to a member of the team caring for your child.

Stereotypies

Stereotypies are repetitive movements or sounds. These might include simple movements such as body-rocking, head-nodding, and finger-tapping, or more complex movements, such as arm and hand-flapping, waving or pacing. Stereotypies form a normal part of development (especially between the ages of 2 and 5), but for some children they continue into adolescence (teenage years).

Stereotypies are often present on their own, but can also be seen with other medical conditions to do with brain development, such as autism spectrum disorder, dyspraxia and Tourette's syndrome. Some brain conditions that present with a range of problems can also have stereotypies as a feature of the whole presentation, such as with childhood stroke. Blind children can also engage in stereotypies.

Stereotypies do not cause any damage to the brain, but it is not yet known exactly what causes them or why some children do these movements and sounds and others don't. It is thought that stereotypies may reflect:

- learned patterns of behaviour
- some children's way of soothing or stimulating themselves
- the brain maturing at different rates
- genes affecting the structure and chemistry of the brain - stereotypies might be hereditary (run in families).

It is likely that stereotypies in children might be caused due to a combination of these factors.

Signs and symptoms of stereotypies

Stereotypies often start before 2 years of age and happen more commonly in boys than girls. They can last from a few seconds to a few hours, and can appear many times a day. Stereotypies often happen when children are excited, engrossed in activities, thinking about things they like, bored, anxious/worried or tired.

Common places to see stereotypies are in the car, at mealtimes, while watching television, and playing computer games. Stereotypies will often stay the same across development and may improve without treatment as children get older.

Children typically report 'enjoying' the stereotypies and they use words such as 'wobbles', 'bouncing', 'fiddles', 'shakes', 'relaxation' or 'pacing' to describe them. Parents might be very concerned about the stereotypies, as children can appear to be 'in world of their own' during them. Parents often have worries about:

- the unusual nature of the movements or sounds
- whether they reflect an epileptic event or seizure
- whether doctors are missing a serious condition that needs attention
- the potential impact on friendships, and possible bullying
- interfering with learning at school and activities at home

Treatments options

Most children respond well to self-help strategies and do not require specific treatments, as stereotypies usually reduce with age. However, if the stereotypies do interfere with school, friendships or everyday life, treatment might be needed.

A form of behavioural therapy called habit reversal therapy (HRT) has been shown to be effective for the management of stereotypies. Cognitive behavioural therapy (CBT) can also be useful to help manage thoughts and emotional feelings that trigger the stereotypies. Medicines are also available, although these are rarely used. Some children might also need support if a co-occurring a problem, such as autism, is identified.

Self-help

There are some simple things you and your child can do that might improve stereotypies at home and school, such as:

- **Talk** to your child about the stereotypies to help reassure them that the movements are nothing to worry about. Encourage them to tell you if they have any problems.
- **Name the stereotypies** to help your child realise that they and the stereotypies are not the same thing ('externalise' the problem).
- **Monitor/observe** when your child performs the stereotypies to help identify when they are happening, in case they need extra support at these times. They might happen when your child is at school when bored, when they don't understand the work, or are trying something new.
- **Support** your child by encouraging them to perform the stereotypies at home, in their own bedroom, in the bathroom. This strategy in psychological therapy is called promotion of privatisation, as we are encouraging the child to do the movements in private only. Children naturally adopt this strategy as they get older and more aware of social norms.
- **Increase awareness** to help your child learn when they are performing the movements by discretely pointing it out to them (for example, have a special signal or name for them, or give a gentle tap on the shoulder) and re-engaging them with their work, activity or task.
- **Minimise the stereotypies** by helping your child to develop a movement or sound that is 'smaller' and 'less socially noticeable' than the stereotypy (for example, standing up on tip toes, rather than jumping).
- **Practice stereotypy suppression** by selecting a time or situation when your child will try to 'hold in' the stereotypies, with short practice sessions to begin with (perhaps 3 to 5 minutes) that are slowly increased as your child successfully holds them in.
- **Praise and rewards** should be given to help keep your child motivated to practice controlling stereotypies, and at any other time when you notice they have stopped.

Habit reversal therapy

This involves helping your child gain greater control over the stereotypies by increasing awareness of when they are performing them, and teaching them a new response when they feel the urge to do the stereotypy. Over time, children get used to not performing the stereotypy, which helps the movements or sounds to lessen. This technique is more likely to be successful if practiced regularly, and if the child is aware of their inner bodily sensations, and wants to stop performing the stereotypies.

Cognitive behavioural therapy

This is a talking therapy that involves helping children gain an understanding of how thoughts, feelings and behaviours are connected. CBT can help children who perform stereotypies when they are worried or upset, by teaching them other ways to cope with their emotions. CBT is often more suitable for older children who are experiencing problems controlling the stereotypies due to feelings of anxiety or low mood affecting their daily life.

Medicines

Medicines are usually only considered to treat the stereotypies if behavioural strategies have been ineffective or difficult to engage with due to other factors (for example, learning difficulties). The choice of medicine will depend on several things, such as:

- the type of symptoms that are causing concern
- how severe the symptoms are
- the possible risk of side effects

Referral for further assessment might be required and your managing team will discuss this.

Extra information for schools

How to support a child with stereotypies at school

Stereotypies might not interfere with a child's school life so may not need any intervention. If they are affecting engagement in school life, these are some strategies that teachers can do to improve stereotypies in school, working in tandem with the parents' management at home:

- **Talk** to the pupil about their stereotypies to help reassure them that the movements are nothing to worry about. Encourage them to tell you if they have any problems.
- **Monitor/Observe** when the pupil performs the stereotypies to help identify when the stereotypies are happening in case they need extra support at these times (for example, at school when they are bored or don't understand the work, when trying something new, or during transitions)
- **Increase awareness** to help the child learn when they are performing the movements by discretely pointing it out to them (have a special signal or name) and re-engaging them with their work, activity or task.
- **Encourage** the child to respect other people's space and feelings (and using positive reinforcement for doing so using praise and rewards).
- **Discuss ideas** of 'acceptable' and 'unacceptable' behaviours in the classroom. For example, they can't sing loudly in class.
- **Minimising the stereotypies** by encouraging the child to use a movement or sound that is 'smaller' and 'less socially noticeable' than the stereotypy (for example standing up on tip toes, rather than jumping), and use positive reinforcement for doing so using praise and rewards.

- **Support to privatise or minimise** by encouraging the pupil to perform the stereotypies at break time or quiet time. This strategy in psychological therapy is called promotion of privatisation, as we are encouraging the child to do the movements in private only. Children naturally adopt this strategy as they get older and become more aware of social norms.
- **Discuss importance** of engaging in school sequences and transitions, and not to get 'caught up' in their stereotypies.
- **Minimise visual displays in classroom** if the pupil also engages in daydreaming. Try to have fewer distractions where the child sits.

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm **email** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone** 020 7188 3514 **email** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please contact the department your appointment is with.

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **phone** 111 **web** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web** www.nhs.uk

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