

Your child's stereotypies

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

What are stereotypies and why does my child have them?

Stereotypies are repetitive movements or sounds. These may include simple movements such as body-rocking, head-nodding, 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 2-5), but for some children they continue into adolescence (teenage years).

Stereotypies are often present on their own, but may 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 one feature of the whole presentation, for example, childhood stroke which is a very rare condition seen by paediatric neurologists. 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 perform these movements/sounds and others do not. 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 may be genetic (run in families).

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

What are the signs and symptoms?

Stereotypies often start before two 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 may use words such as 'wobbles', 'bouncing', 'fiddles', 'shakes', 'relaxation' or 'pacing' to describe them. Parents may 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/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/or activities at home.

What treatments are available? Are treatments necessary?

Most children respond well to self-help strategies and do not require specific treatments, as stereotypies typically reduce with age and over time. However, if the stereotypies do interfere with school, friendships or everyday life then treatment may 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) may also be useful to help manage thoughts and emotional feelings that may trigger the stereotypies. Medications are also available, although these are rarely used. Some children may 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 may 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, and encourage them to come and 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 the stereotypies are happening in case they need extra support at these times (for example, at school when bored, don't understand the work, 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 privatization, 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, special signal/name, a gentle tap on the shoulder) and re-engaging them with their work/activity/task.
- **Minimise the stereotypies** by helping your child to develop a movement/sound that is 'smaller' and 'less socially noticeable' than the stereotypy (for example, standing up/down/on tip toes, rather than jumping).
- **Practice stereotypy suppression** by selecting a time/situation when your child will try to 'hold in' the stereotypies, with short practice sessions to begin with (perhaps 3-5 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 therapy involves helping children gain greater control over the stereotypies by increasing awareness of when they are performing the movements/sounds and teaching them to perform a new response when they feel the urge to perform the stereotypy. Over time, children get used to not performing the stereotypy, which helps the movements/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.

Medication

Medication is normally 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 medication 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 may be required and your managing team will discuss this.

Contact us

If you have any questions or concerns about stereotypies, please call us, **t:** 020 7188 3997, Monday to Friday, 9am-5pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

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.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

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