

STOMP and STAMP

A leaflet for families of children and young people with a learning disability, autism or both who may be prescribed (or are prescribed) psychotropic medication



STOMP stands for
Stopping The Over-Medication of children and young
People with a learning disability, autism or both

STAMP stands for
Supporting Treatment and Appropriate Medication
in Paediatrics

What are STOMP and STAMP?

The **STOMP** and **STAMP** programme of work is about making sure children and young people with a learning disability, autism or both are only prescribed the **right medication**, at the **right time** and for the **right reason**.

What do I need to know?

Psychotropic medications affect how a person's brain works. They can be used to treat conditions such as anxiety, depression, sleep problems, epilepsy and psychosis. They may sometimes be given to support a person with autism, learning disability or both who may display behaviours that challenge.

Psychotropic medication can cause problems if taken for the wrong reasons, in high doses or for long periods of time. Side effects may include putting on weight, feeling tired or 'drugged up'. There may also be a possibility of serious problems with physical health.

These medicines can be right for some children and young people to help them live a good life. However, other therapies and types of support can mean psychotropic medications can be reduced or not used at all.

"We've been really lucky because we have had lots of support and help from a wide range of people. But the thing that really made the difference for us was a doctor who was prepared to explore medication and explore how medication could support and contribute to all the other help we were receiving."

Sarah, Owen's mother.

STOMP and **STAMP** are about ensuring there are the right therapeutic interventions available for children and young people. Depending on the child's needs, these could include input from speech and language therapy, occupational therapy, positive behaviour support or other approaches. Ensuring reasonable adjustments at school and in other settings will also be important. Psychotropic medication should not be given instead of these. Therapeutic options and support should always be available.

"Over the last two years, Josh's medication has been reduced to none gradually. He has improved both physically and emotionally since not receiving medication. His general well-being, appetite, sleeping pattern are better, as is his concentration and ability to forward plan."

Phil, Josh's father

Why is this important to me?

STOMP and **STAMP** is about protecting the right of children and young people with autism, learning disabilities or both, and their parents and carers to make decisions about their own care and treatment.

You have a vital role to play in making sure your child only receives the right medication, at the right time, for the right reason. It is important to remember that you have the right to ask questions before decisions are made about medications. Sometimes psychotropic medications are not reviewed or stopped when they are no longer needed, so it is also important to ask questions after they have been prescribed too.

What questions can I ask?

Please remember:

If your child is prescribed psychotropic medication(s), it is not safe to stop or change the dose without the support of a doctor.

If psychotropic medications are being considered for your child

You may want to think about and ask the following questions:

- What therapeutic and support alternatives to psychotropic medication are there?
- How long will the psychotropic medication be prescribed for?
- How often and by whom will the psychotropic medication be reviewed?
- What possible side effects are there to the psychotropic medication?
- Have you discussed all alternatives with a health care professional? For example, your child's paediatrician, speech and language therapist, occupational therapist, community learning disability nurse.

If your child is currently taking psychotropic medication:

You may want to think about the following questions:

- Is it clear why the psychotropic medication was prescribed?
- Has the medication been reviewed regularly by the doctor?
- Is the medication making a positive difference to your child and your family?
- Are there any side effects as a result of taking the medicine?
- Are other therapies or support still being offered to you and your child?

Where can I go for more information?

You may also want to discuss this with your doctor or other health care professional. These website links may also be useful:

STOMP-STAMP:

<https://www.england.nhs.uk/learning-disabilities/improving-health/stamp/>

STOMP (post-18 years):

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

Resource for families of people with learning disabilities, autism or both, who are prescribed (or may be prescribed) psychotropic medication:

<https://medication.challengingbehaviour.org.uk/>

Positive Behaviour Support:

<https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/positive-behaviour-support.html>

Education advice (reasonable adjustments, appropriate provision):

<https://www.ipsea.org.uk/advice-line>

<https://www.autism.org.uk/services/helplines.aspx>

<https://www.mencap.org.uk/advice-and-support/learning-disability-helpline>