



STOMP

Guidance for Social Care

Stopping Over-Medication
of People with a Learning
Disability, Autism or Both

Supported by NHS England



The aim of this guidance is to support the implementation of the STOMP pledge.

Introduction

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It is estimated that on an average day in England between 30,000 and 35,000 people with a learning disability, autism or both are taking prescribed psychotropic¹ medication without appropriate clinical justification. Long-term use of these medicines puts people at unnecessary risk of a wide range of side effects including weight gain, organ failure and even premature death.

STOMP aims to:

- Improve the quality of life of people with a learning disability, autism or both
- Make sure people only receive psychotropic medication for the right reasons and in the right amount
- Improve understanding of psychotropic medicines and when they should or should not be given
- Improve understanding of alternatives to medication
- Make sure that people with a learning disability, autism or both are involved in decisions about their health and treatment.

People may be prescribed medication as a way of controlling their behaviour, even though there are alternative evidence-based approaches available. NICE guidance² states that the use of psychotropic medication should be the last resort for managing behaviour which challenges and should only be considered if:

- Psychology or other therapies do not help within an agreed timeframe
- Treatment for a mental or physical health condition has not improved the behaviour
- The risk of harm to the person or others is very severe

Psychotropic medication should only be prescribed for managing behaviour which challenges when it is used in combination with psychology or other therapies.

While the final responsibility for prescribing always sits with a doctor, there is much that social care providers can do to reduce the risk of people taking more psychotropic medication than they need. The STOMP pledge aims to help providers to think about their role in supporting people to reduce the amount of inappropriate psychotropic medication they take and delivering the right support at the right time.

1. The term "psychotropic" refers to medication which results in alterations to perception, mood or consciousness.

2. National Institute for Health and Care Excellence (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Accessed: <https://www.nice.org.uk/guidance/ng11>

Who should sign the STOMP pledge?

We are inviting social care provider organisations to sign up to the pledge and support their staff teams to implement it.

The STOMP pledge

We pledge to act in the best interests of the people we support at all times by:

- Actively promoting alternatives to medication such as active support, intensive interaction or positive behaviour support.
- Ensuring the people we support, and their circle of support, are involved in decisions about their care, including their medication.
- Ensuring all staff have an understanding of psychotropic medication, including its main uses and side effects.
- Encouraging staff to speak up if they have a concern that a person we support may be over-medicated.
- Maintaining accurate records about the health, wellbeing and behaviour of the people we support.
- Supporting people to have regular reviews of their medication.
- Monitoring the use of psychotropic medication.
- Working with people with a learning disability, autism or both, their families, health professionals, commissioners and others to stop over-medication. This includes working closely with prescribers.

We will set out the actions we will take and report annually on the progress we have made.

Implementing the pledge

We are asking each signatory of the STOMP pledge for social care to identify a lead person who will champion STOMP in their organisation. Each signatory is asked to complete a self-assessment and develop an organisational action plan identifying the steps they will take to stop the over-medication of people with a learning disability, autism or both.

We have provided a series of prompts to help providers think about how the pledge commitments apply to them. We hope the prompts will inspire fresh thinking. They are not intended to be exhaustive. The prompts and action plan template are designed to be used at an organisational or a local level. This is to assist providers in cascading their commitment to STOMP throughout their organisation.

Signatories should send their signed pledge and completed organisational STOMP action plan to stomp@vodg.org.uk

We will periodically ask providers to review progress and refresh their action plan. We will provide a suggested format for this. Within the review we will ask providers to share information on:

- The number of people who have reduced or stopped their psychotropic medication: this may be a reduction in the dosage, the number of medications or the amount of PRN/as required medication taken.
- The number of people who, following a multi-disciplinary review, remain on all their psychotropic medication.

This information will help us develop a national picture of the impact STOMP is making.

What support do staff teams need to implement the pledge?

Staff will need clear communication about why your organisation is signing up to STOMP and the positive differences that stopping over-medication can bring to the lives of the people they support.

It is likely that staff will need to receive training and support which reflects any changes you are asking them to make in their ways of working, for instance concerning communication, active support or positive behaviour support. Providers should take this into account when developing their implementation plan.

Who else should we involve?

It is important that providers talk to the people they support and family carers about the pledge. Accessible information on STOMP can be found <https://www.england.nhs.uk/learning-disabilities/stomp>.

Providers should also talk to their commissioners and healthcare colleagues about their commitment to STOMP. In particular, they should talk to prescribers (both GP's and psychiatrists) and community learning disability healthcare teams. It may be helpful to do this before getting into conversations about potential changes to an individual's medication, so that the prescriber understands the organisation's commitment to working in partnership to stop overmedication. Information for prescribers can be found <https://www.england.nhs.uk/learning-disabilities/stomp>.

COMPLETING THE SELF-ASSESSMENT AND ACTION PLAN TEMPLATE

Things to think about at an organisational level:

Is your approach to challenging behaviour evidence-based?

What staff training and information do you provide on:

- Person-centred approaches?
- Supporting people with challenging behaviour?
- Supporting people with autism?
- Involving people in decision-making?
- Psychotropic medication?

Is this training and information specific to the needs of the people you support?

What systems are in place to monitor the quality of record keeping about health, wellbeing and behaviour? What are these systems telling you?

How do you know the extent to which psychotropic medication is used in your organisation (both regular use and PRN/as required medication)?

Are psychotropic interventions given the same degree of scrutiny as physical interventions? What monitoring systems do you use?

Suggested steps you might take at an organisational level:

Make your commitment to STOMP known to staff, the people you support, their families and allied health and social care professionals, including commissioners.

Undertake a review of all relevant staff training.

Involve people with a learning disability, autism or both in the delivery of training, such as training about autism or challenging behaviour.

Undertake an audit of the use of psychotropic medication in your organisation.

Introduce a system for monitoring trends in the use of PRN medication.

Review your medication policy to reflect your commitment to STOMP.

Consider upfront what resources you need in place to support people well should their behaviour become more challenging.

Share your learning and good practice concerning stopping over-medication with the social care sector as a whole.

Things to think about at a local level:

Are people who may present behaviour which challenges always supported by someone who knows them well, understands their communication and knows how to respond if they are upset?

Can staff describe how the people they support present when they are experiencing the side-effects of medication?

Do staff have the skills and confidence to support people to be involved in decisions about their medication? Can you give recent examples of where staff have involved people in these decisions?

How do staff support people to prepare for their annual health check?

What do the people you support, family carers (if they are involved) and advocates say about their involvement in decisions about medication?

How do you ensure that staff are confident and comfortable in raising a concern?

How do you ensure that the information you supply to a prescriber is complete and accurate?

Can you give recent examples of working in partnership to reduce over-medication?

Suggested steps you might take at a local level:

Discuss your commitment to STOMP with staff, the people you support, their families and allied health and social care professionals.

Develop person-centred plans and resources which support people to take part in decisions about their medication and their annual health check.

Support people to involve other people of their choice such as family members, and/or an advocate in decisions about their health and medication.

Work closely with prescribers and allied professionals in supporting people to reduce the amount of inappropriate psychotropic medication they take.

Offer a range of activities that support a medication reduction programme, such as talking therapies, support with social interaction and developing a structured day.

Work closely with the person's wider circle of community contacts, such as their landlord, community services and local police, to promote their safety during a medication reduction programme.

Ensure that people taking psychotropic medication receive a multi-disciplinary review three months after it was initially prescribed and at least every six months thereafter. If this does not happen, you can request it.

Ensure people's health checks always include a review of their medication. Again, if this does not happen, you can request it.

Resources

NHS England has developed:

- Guidance for prescribers on Stopping Over-medication of People With Learning Disabilities
 - Accessible advice for patients, families and carers about STOMP
 - These documents are on: <https://www.england.nhs.uk/learning-disabilities/stomp>
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The Learning Disability Health Charter complements the STOMP pledge. It is designed to support social care providers and their staff teams to promote the health and wellbeing of people with learning disabilities, including enabling them to access primary health services.

<https://www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities/>

The National Institute for Health and Care Excellence issues advice, guidance and standards on a wide range of topics relevant to health and social care. You may find the following resources particularly helpful:

- <https://www.nice.org.uk/>
 - Psychotropic medicines in people with learning disabilities whose behaviour challenges <https://www.nice.org.uk/advice/ktt19>
 - Challenging behaviour and learning disabilities; prevention and interventions for people with learning disabilities whose behaviour challenges <https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005>
 - Autistic spectrum disorder in adults: diagnosis and management <https://www.nice.org.uk/guidance/cg142>
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BILD provides resources, training and consultancy on active support and positive behaviour support.

www.bild.org.uk/

Easy Health provides a range of accessible resources and information about health.

<http://www.easyhealth.org.uk/>

The Royal College of Psychiatrists has produced practice guidelines on Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge

https://www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf

Notes

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