

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

**(STOMP)**

# Reducing inappropriate psychotropic drugs in people with a learning disability, autism or both in general practice and hospitals

**We all need to make it a priority to reduce and stop the use of inappropriate drugs, to reduce adverse side effects and potential drug interactions. This is vital to the person's safety and their quality of care.**

The goal is to improve the quality of life of people with a learning disability, autism or both by reducing the potential harm of inappropriate psychotropic drugs this includes being used wholly inappropriately, as a "chemical restraint" to control challenging behaviour, or in place of other more appropriate treatment options. It is time for action, it is time for you to lead a medication review of all people with a learning disability, autism or both, with a view to implementing a planned supervised dose reduction and stopping of inappropriate psychotropic drugs.

## Aim of this document

Multiple psychotropic drug use often starts at a specialist level which is then passed onto primary care with or without follow up. Many GPs are overseeing the management and prescribing long term. Following the Banerjee report (2009) and the national drive to reduce inappropriate use of antipsychotic drugs in dementia to save lives, confidence has grown amongst GPs and care teams to review prescribing.<sup>1</sup> This document aims to provide support to begin the process of challenging continued use in people with a learning disability, autism or both.

## Why reduce the use of psychotropic drugs in people with a learning disability, autism or both?

Public Health England have estimated that on an average day in England, between 30,000 and 35,000 adults with a learning disability, autism or both are taking a prescribed antipsychotic, an antidepressant or both without appropriate clinical indications (psychosis or affective/anxiety disorder). A substantial proportion of people with a learning disability, autism or both who are prescribed psychotropic drugs for behavioural purposes can safely have their drugs reduced or withdrawn.

This research showed that among adults known to their GP to have a learning disability, (excluding only those in hospital as inpatients) on any average day:

- 17.0% were taking prescribed antipsychotic drugs
- 16.9% antidepressants
- 7.1% drugs used in mania and hypomania
- 4.2% anxiolytics
- 2.7% hypnotics

## Now is the right time to stop prescribing inappropriate psychotropic drugs

Challenging behaviour has been described as behaviour which puts an individual or others at risk in any social situation and limits their access to services. Causes tend to be personal factors such as communication difficulties and physical health issues and/or environmental factors such as abusive or restrictive social environments. Assessment usually requires observation and a physical assessment to exclude physical causes with the development of a behavioural support plan and referral to secondary care services.

National Institute for Health and Social Care Excellence (NICE)<sup>3</sup> advises that specialists consider prescribing antipsychotic medication to manage behaviour that challenges only if:

- Psychological or other interventions alone do not produce change within an agreed time or
- Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
- The risk to the person or others is very severe (for example, because of violence, aggression or self-injury)

Only offer antipsychotic medication in combination with psychological or other interventions.

If there is a positive result the specialist needs to conduct a full multidisciplinary review after three months and then at least every six months covering all prescribed medication (including effectiveness, side effects and plans for stopping).

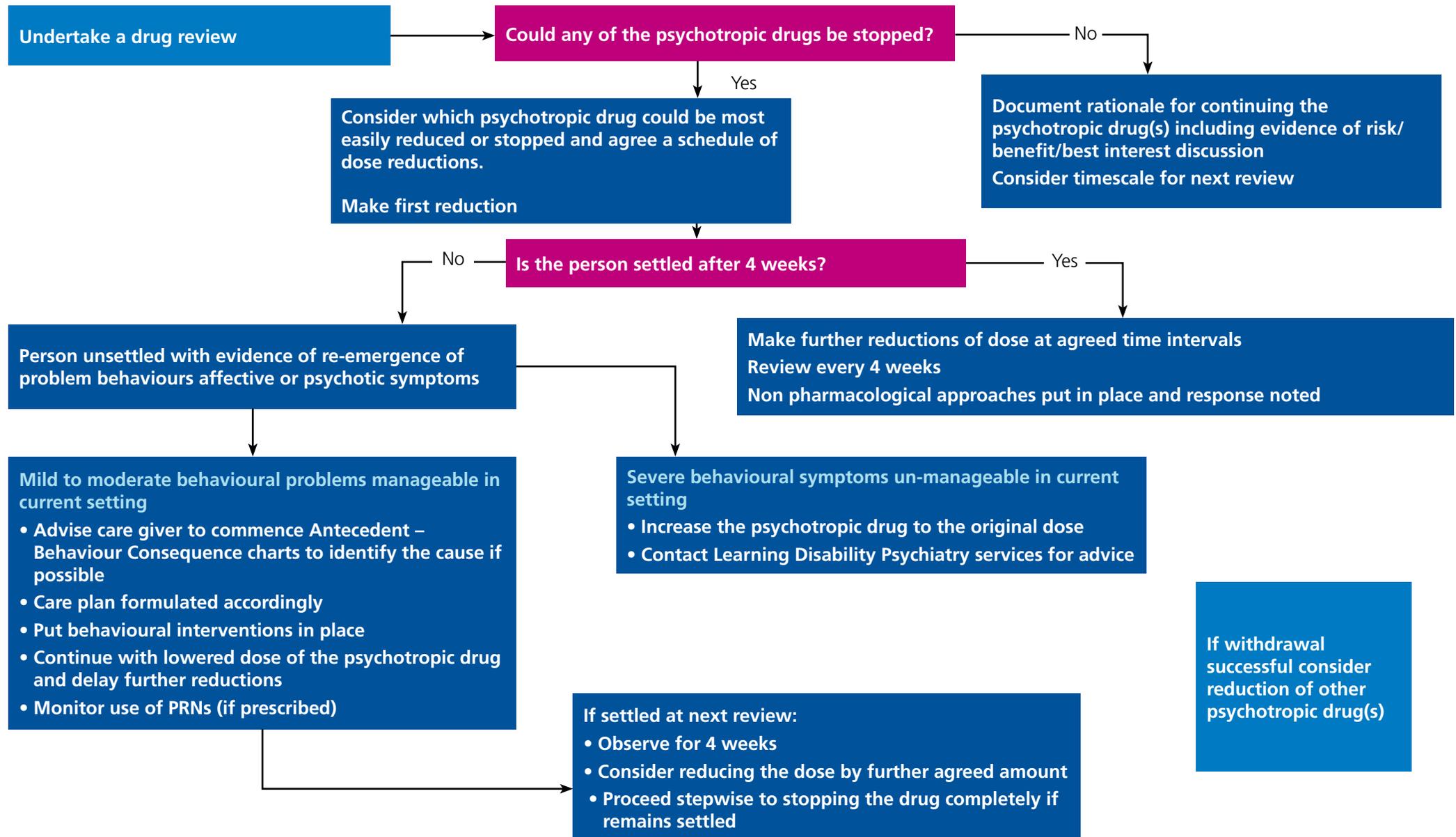
A person-centred approach is necessary when reducing or withdrawing psychotropic drugs. If prescribed for behaviours that challenge there is the expectation that the drugs will stop unless:

- There is evidence that the person with a learning disability, autism or both has gained significant benefit from the use of the psychotropic drug(s) and recent attempts to withdraw the drug(s) has resulted in a deterioration
- The nature of the behaviours experienced prior to prescribing psychotropic drug(s) was so severe that withdrawal is considered clinically inappropriate by the carers and others

If the psychotropic drug is prescribed for a mental illness there is the expectation that the drug treatment will follow the recommendations of the relevant NICE guidance. If the person with a learning disability has been symptom free for some time maintenance may not be the best course and they may need referral to the specialist person with a learning disability team.

# APPENDIX 1

## Algorithm for the review, reduction or stopping of psychotropic drugs in people with a learning disability, autism or both



# APPENDIX 2

## Suggested steps for your GP practice

### Practice-wide steps

1. Have a meeting to discuss the issue and appoint a GP lead.
2. Organise for a practice team member to interrogate the practice prescribing system or work with the CCG Pharmacy team to obtain details of all people with a learning disability, autism or both on psychotropic drugs.
3. Share the results with the practice team, the people with a learning disability specialist and teams and others who can help.
4. Together develop an agreement about a programme of reviews with their named individual GPs and ensure follow up. Make this part of their annual health checks.

### Steps for an individual with a learning disability, autism or both

1. Undertake a drug review and find out when and why each drug was started. Try to find out what were the indications and/or behaviours and concerns that prompted the start of each drug:
  - a. Undertake medicines reconciliation by checking with your GP records and secondary care letters.

- b. Check with the person, family and their carers. Ensure accessible information and any necessary communication support is available<sup>4</sup>.
  - c. If behaviour is part of a mental illness or autistic spectrum disorder/ADHD (Neurodevelopmental Disorder) then discuss with a people with a learning disability psychiatrist.
2. Check whether previous attempts at drug reduction and withdrawal have been tried, how it was undertaken and what was the outcome. Remember:
  - a. Sudden withdrawal of psychotropic drugs may result in discontinuation effects.
  - b. The carers may not give the drugs sometimes. Find out why and what happens.
3. Achieve a consensus amongst carers, family, the person (if possible) and involved professionals that there is scope to reduce or stop psychotropic drug use and it is in the person with a learning disability, autism or both's best interest.

### Additional actions for consideration

4. Agree a regular review with consistency about the source and format of information about the impact of the reduction in psychotropic drugs from family or carers that know the person well.
5. Ensure there is a plan for dealing with re-emergent behaviours and liaise with the local community people with a learning disability team.
6. When acting or making decisions on behalf of someone who lacks capacity to make a decision for themselves, you should be able to explain and record how you have had regard to the Mental Capacity Act Code of Practice by acting in their 'Best Interest' and still discussed the medication with them.<sup>5</sup> The Royal College of General Practitioners has a mental capacity toolkit to help you.<sup>6</sup>

## Principles of dose reduction and drug discontinuation

1. Make reductions stepwise and realistic, keeping specialists involved. Generally withdraw or reduce one drug at time. Choose the drug with the least evidence of benefit first.
2. The rate of reduction should depend on an agreement between the carers, and if possible the person and the prescriber. This should be informed by the level of concern of the carers, the history of the behaviours associated with the introduction of the drugs, the duration of exposure, dose of drug, half-life of drug, previous response to such reduction / discontinuation and the availability of other strategies and support for the carers to deal with re-emergent behaviours.
3. For drugs with a long half-life (e.g. fluoxetine) or delivered as long acting injections withdrawal will take longer. For drugs with significant drug-drug interactions (carbamazepine) withdrawal may impact on the effects of the other drugs.

## Some potential problems

Accept that the reduction may take some time and will be difficult from time to time.

- a. Sometimes if behaviours deteriorate it can be difficult to judge whether it is a withdrawal effect (usually occurs within the first week), the person adapting to the absence of the drug (usually in the first month), a return of the behaviours for which the drug(s) was prescribed. Sometimes the person may

just be more alert and the carers may have difficulties with the impact of this on their usual working practice. Observe PRN usage in these circumstances.

- b. It is better to slow down the rate of reduction rather than sticking to a rigid plan if there are concerns about the person's behaviours.

Be aware of drug discontinuation effects (see table below). These are usually mild and self-limiting but may be difficult to elicit in people with a learning disability, autism or both.

Psychotropic drug class	Discontinuation effects	Management
Antipsychotics	No consensus about whether there are discontinuation problems. Some older antipsychotics worsen tardive dyskinesia	Slow down rate of reduction
Antidepressants	Most SSRI and other antidepressants are associated with discontinuation effects. Flu-like symptoms, dizziness, insomnia and irritability are common	If mild – reassurance If severe – reintroduce antidepressant
Benzodiazepines and Z drugs	At least 1/3 of long term users suffer discontinuation problems – stiffness, weakness and flu-like symptoms	Minimal intervention and reduce slowly Consider switch to diazepam
Mood stabilisers	Rapid withdrawal of anticonvulsants has been associated with seizures	Slow down rate of reduction

# APPENDIX 3

## Practice Examples

**Trafford Clinical Commissioning Group (CCG)** has employed a clinical pharmacist from the Greater Manchester West Mental Health NHS Foundation Trust to assist with the identification of potential cases for the 'Call to Action'.

Following a request from the CCG Medicines Management Lead the five biggest (in terms of catchment / number of people with a learning disability on register) practices agreed to participate. There was an average of 50 people per practice with a learning disability diagnosis, obtained through READ codes.

Working with the practice managers and staff the clinical pharmacist set up the search criteria on Egton Medical Information System (EMIS) using the general term of 'Learning Disability'. He then worked through each person with a learning disability case to identify any prescribing of psychotropic drugs. Once that cohort of people was identified, the list was examined to find any instances of prescribing for challenging behaviour. A pro-forma was imported into EMIS to record the review and any recommendations made.

**In Salford** they are reviewing 150 people who are seen by the people with a learning disability psychiatry team and are prescribed PRN psychotropic drugs. This review will involve either face to face review or telephone review.

They are firstly exploring the frequency of use of PRN psychotropic drugs, and then devising a plan to reduce any that have not been used for a number of months. This reduction will be done in partnership with the individual and a responsive action plan devised if for some reason a deterioration is reported. They are also updating the local policy for staff teams administering PRN drugs as part of the wider Positive Behaviour Support Policy.

**NHS Newcastle Gateshead Clinical Commissioning Group (CCG) and NHS North Tyneside CCG** are collaborating with Northumberland, Tyne and Wear NHS Foundation Trust on a psychotropic drug review pilot. The overall aim of the pilot is to provide high quality, evidence based services for people with a learning disability and to understand the resources needed to keep people and their carers involved and safe while psychotropic drugs and alternative therapies are considered in the community. A key principle in this work is that people with complex needs must have a review led by specialists.

Through a data sharing agreement, the CCGs identified the number of people with a learning disability on psychotropic drugs and those on the GP register of people with a learning disability but without a serious mental health diagnosis.

A sample of GP practices then carried out a desk-top case review of people in this group using a multi-professional agreed questionnaire. The questionnaire included the duration of psychotropic drugs prescribed, associated diagnosis or indication and whether other non-pharmacological interventions have been implemented. The findings of this case review will guide the priority with which the person with a learning disability will receive a multi-disciplinary review, and the resources that may be needed long term.

# APPENDIX 4

## Examples of psychotropic drug reduction

**A man with a learning disability was treated for 2 years with risperidone 2mg (challenging behaviour) and mirtazapine 30mg (depression).** He was monitored by the care home for 3 months post admission. Then risperidone was reduced by 0.5mg every 3-4 weeks until stopped. Final reduction from 0.5mg to zero lasted for 6 weeks at the person with a learning disability's request. Withdrawal totally successful. Mirtazapine was then withdrawn reducing by 50% for two weeks then stopped.

Lessons learnt: The person with a learning disability dictated the pace and was involved in all decision making; good observation from trained staff to monitor for behavioural worsening; slow but steady reduction planned and implemented.

**A seventy-two year old man with a mild learning disability who had lived in an institution since childhood.** Returned to the community when in his sixties. Staff reported that he was often 'restless', not able to sit still, legs always moving. Difficult for staff to reassure him and to take part in activities. Prescribed sulpiride 800mg daily and trifluoperazine 30mg daily commenced in the hospital, but prescriptions issued by the GP. Psychiatrist reviewed the psychotropic drugs. Evidence of akathisia secondary to antipsychotic. No signs of psychosis. Challenging behaviour in attempting to hit people when he thought staff were not listening to him. Habit of touching the breasts of female workers. Trifluoperazine reduced and withdrawn over six months by Psychiatrist supported by GP. Sulpiride reduced thereafter to 100mg but a resurgence of challenging behaviour. Period of reduction was twelve months. Currently using 200mg daily only. No signs of akathisia. Placement is secure and no longer in jeopardy since the re-instatement of sulpiride 200mg. Good support in the community from support staff.

**A lady with a learning disability (aged 42)** was prescribed zuclopenthixol decanoate injection 200mg every 4 weeks for approximately 14 years but the clinical reason for this was unclear from the clinical notes. As part of the people with a learning disability health check, the GP felt this could be reviewed. Following a review by the learning disability psychiatry team, there were no signs of current mental illness nor mention in the available notes. Although the lady had not experienced side effects from the injection, there was no clear benefit from using this. A reduction/stop was discussed with the lady. She was reluctant to stop the injection initially, but agreed to try reducing it slowly with support. The dose was reduced to 100mg every 4 weeks for 3 months. No deterioration in behaviour has been observed and the plan is for the GP to stop the drug and monitor the situation.

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### References

- 1 Department of Health. The use of antipsychotic medication for people with dementia: Time for action. A report for the Minister of State for Care Services by Professor Sube Banerjee. October 2009 [webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_108302.pdf](http://www.webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf)
- 2 Public Health England /CPRD (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England. [http://www.improvinghealthandlives.org.uk/securefiles/160419\\_1226/psychotropic%20medication%20and%20people%20with%20learning%20disabilities%20or%20autism.pdf](http://www.improvinghealthandlives.org.uk/securefiles/160419_1226/psychotropic%20medication%20and%20people%20with%20learning%20disabilities%20or%20autism.pdf)
- 3 NICE. [NG11] 2015 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' [www.nice.org.uk/guidance/ng11](http://www.nice.org.uk/guidance/ng11)
- 4 In line with the Accessible Information Standard (SCC11605 Accessible Information), see [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)
- 5 Office of the Public Guardian (2005) Mental Capacity Act Code of Practice <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>
- 6 RCGP Mental Capacity toolkit [www.rcgp.org.uk/~media/Files/CIRC/CIRC-76-80/CIRC-Mental-Capacity-Act-Toolkit-2011.ashx](http://www.rcgp.org.uk/~media/Files/CIRC/CIRC-76-80/CIRC-Mental-Capacity-Act-Toolkit-2011.ashx)

**Notes:**

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This document has been endorsed by the Royal College of General Practitioners, the Royal Pharmaceutical Society, the Royal College of Nursing, the Royal College of Psychiatrists, and the British Psychological Society and the Challenging Behaviour Foundation.



Further information is available at: [www.england.nhs.uk](http://www.england.nhs.uk)