

Psychotropic medicines in people with learning disabilities whose behaviour challenges

Key therapeutic topic

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www.nice.org.uk/guidance/ktt19

Key points

- There is evidence of widespread prescribing of psychotropic medicines (antipsychotics, antidepressants and hypnotics) for people with learning disabilities, many of whom do not have relevant indications recorded for the psychotropic medicines they are prescribed. The use of most psychotropic medicines to manage challenging behaviour in people with learning disabilities is an off-label^[1] use of a licensed medicine.
- People with learning disabilities may benefit from referral to a learning disability team for specialist review to minimise the use of psychotropic medicines.
- Antipsychotic medication should be considered to manage behaviour that challenges in people with learning disabilities only when other interventions have not been helpful and when the risk to the person or others is very severe. They should only be offered in combination with psychological or other interventions to help manage challenging behaviour.
- Learning disability features in the [NHS Long Term Plan](#) published in January 2019.
- Options for local implementation:
 - Review and, if appropriate, optimise prescribing and local policies relating to the treatment of challenging behaviour in people with learning disabilities to ensure these are in line with the NICE guideline on [challenging behaviour and learning disabilities](#).

^[1] In line with the guidance from the [General Medical Council \(GMC\) on prescribing unlicensed](#)

medicines, the prescriber should take full responsibility for determining the needs of the patient and whether using a medicine outside its authorised indications is suitable.

Evidence context

NICE guidance

The NICE guideline on challenging behaviour and learning disabilities covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges. It highlights the importance of understanding the cause of challenging behaviour and performing thorough assessments so that steps can be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers.

NICE defines a learning disability by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. The guideline notes that the amount of everyday support a person with a learning disability needs will depend mostly on the severity of their disability. NICE emphasises the importance of treating each person as an individual, with specific strengths and abilities as well as needs. NICE recommends working in partnership with children, young people and adults who have a learning disability and behaviour that challenges, and their family members or carers and involving them in decisions in their care. The guideline outlines general principles of care including supporting self-management and encouraging the person to be independent.

It is relatively common for people with a learning disability to develop behaviours that challenge, and more common in people with more severe disability. This behaviour can include aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system.

The full guideline states that many types of psychotropic medicines have been used to manage behaviour that challenges, including antipsychotics, antidepressants, mood stabilisers and sedatives. Medicines are mostly used to reduce excitation and aggression, despite the limited evidence for efficacy in people with learning disability. Antipsychotics are the most frequently used class of psychotropic medicine, prescribed for as many as two-thirds of people with learning disability who are receiving any type of psychotropic medicine. The use of most psychotropic medicines to manage challenging behaviour in people with learning disabilities is an off-label^[2] use of a licensed medicine. The exception to this is risperidone, which is licensed for the short-term

symptomatic treatment (up to 6 weeks) of persistent aggression in conduct disorder in children and young people aged 5 years and older who have a learning disability, in specified circumstances. The [summary of product characteristics](#) recommends that risperidone is prescribed by a specialist in child neurology and child and adolescent psychiatry or physicians well familiar with the treatment of conduct disorder in children and young people.

NICE recommends considering medicines, or optimising existing medicines, for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges. Antipsychotic medication to manage behaviour that challenges should be considered 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).

Antipsychotic medication should be offered only in combination with psychological or other interventions and the reason for prescribing should be explained to the person with a learning disability and to everyone involved in their care. Medicine choice should take into account the person's preferences (or that of their family member or carer, if appropriate), side effects, response to previous antipsychotic medicine and interactions with other medicine. Antipsychotic medicine should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician). NICE recommends that the specialist is responsible for identifying the target behaviour and monitoring the effectiveness of treatment, including the frequency and severity of the behaviour and its impact on functioning. Prescribers should prescribe only a single antipsychotic, starting with a low dose and using the minimum effective dose needed. The effectiveness and any side effects of the medicine should be reviewed after 3 to 4 weeks and it should be stopped if there is no response at 6 weeks. If a 'when required or PRN medicine' is prescribed, this should be for as short a time as possible and the specialist should ensure that its use is recorded and reviewed.

The NICE guideline highlights the importance of appropriate documentation when starting an antipsychotic, including a rationale for the medicine (which should be explained to the person with learning disability and everyone involved in their care), how long the medicine should be taken for and how the treatment should be reviewed and stopped. If there is a positive response to an antipsychotic medicine the extent of the response should be recorded, including how the behaviour

has changed and any side effects or adverse events. NICE recommends conducting a full multidisciplinary review covering all prescribed medicines, after 3 months and then at least every 6 months along with the recommendation of continuing only those medicines that have shown a benefit. When prescribing is transferred to primary or community care, or between services, the specialist should give clear guidance to the practitioner responsible for continued prescribing about the behaviours to target, monitoring of beneficial and side effects, taking the lowest effective dose, how long the medicine should be taken for and plans for stopping it.

A large US retrospective cohort study that was discussed in NICE's medicines evidence commentary on [antipsychotic treatment and risk of unexpected death in children and young people](#), suggests that the prescribing of high-dose antipsychotics in children and young people who do not have schizophrenia or related psychosis, is associated with an increased risk of unexpected death. There was an increased risk in deaths from cardiovascular and metabolic causes but not from suicide and injury compared with the control group. Despite some limitations with this study, it reinforces NICE recommendations for safe prescribing of antipsychotics in this age group.

The NICE guideline on [mental health problems in people with learning disabilities](#) makes recommendations for people with learning disabilities who are taking antipsychotic medicines and not experiencing psychotic symptoms. The guideline recommends that the prescriber should:

- consider reducing or discontinuing long-term prescriptions of antipsychotic medicines
- review the person's condition after reducing or discontinuing a prescription
- consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems, and
- annually document the reasons for continuing the prescription if it is not reduced or discontinued.

NICE also provides guidance on [service design and delivery for people with learning disabilities and behaviour that challenges](#) with the aim of promoting a lifelong approach to supporting people and their families and carers by focusing on prevention and early intervention and minimising inpatient admissions.

In April 2018 NICE published a guideline on [care and support of people growing older with learning disabilities](#) covering care and support for adults with learning disabilities as they grow older. This includes identifying changing needs, planning for the future, and delivering services including health, social care and housing. It aims to support people to access the services they need such as recommending annual health checks to help them manage conditions that can quickly affect them

as they grow older. The NICE guideline on [dementia](#) may also be relevant to the care of people with learning disabilities as they grow older.

The NICE quality standards on [learning disability: behaviour that challenges](#), [learning disabilities: identifying and managing mental health problems](#) and [care and support for people growing old with a learning disability](#) describe a concise set of prioritised statements designed to drive measurable quality improvements within these areas. NICE's Pathways on [learning disabilities and behaviour that challenges](#), [mental health problems in people with learning disabilities](#), and [care and support of people growing older with learning disabilities](#) bring together all related NICE guidance and associated products on these topics in a set of interactive flowcharts.

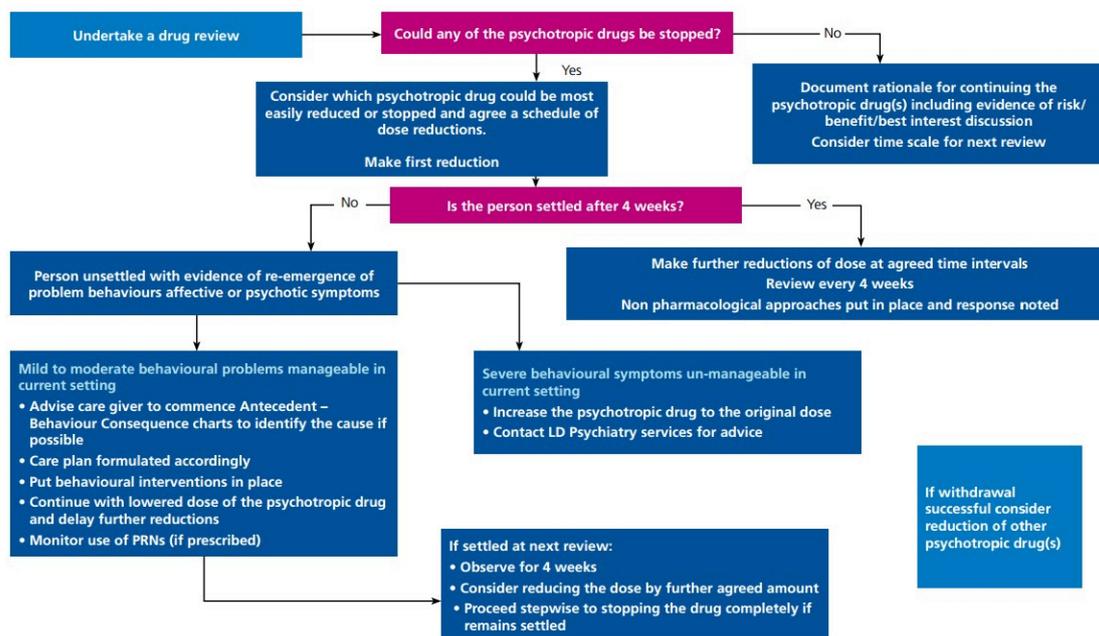
National resources

In July 2015 NHS England [pledged urgent action on over-medication of people with learning disabilities](#). This was in response to research that concluded that:

- there is a much higher rate of prescribing of medicines associated with mental illness among people with learning disabilities than the general population, often more than 1 medicine in the same class, and in most cases with no clear justification
- medicines are often used for long periods without adequate review and
- there is poor communication with parents and carers, and between different healthcare providers.

The national project on [Stopping over medication of people with a learning disability, autism or both](#) (STOMP) provides support to begin the process of challenging the continued need for psychotropic medication in people with a learning disability. There are suggested steps to reduce inappropriate prescribing for GP practices, examples of good practice from NHS organisations and example case studies of psychotropic medicine reduction. There is also [an algorithm](#) for the review, reduction or stopping of psychotropic medicines in people with a learning disability, autism or both (see figure 1).

Figure 1 Algorithm for the review, reduction or stopping of psychotropic drugs in people with a learning disability, autism or both



An [easy read leaflet](#) about STOMP is available, as is a [medication pathway](#), which provides guidance for patients, families and carers of people with learning disabilities who are prescribed or may be prescribed psychotropic medication. A systematic review of mainly observational studies, which was discussed in NICE's medicines evidence commentary on [stopping or reducing antipsychotics in people with learning disabilities who have challenging behaviour](#), found that antipsychotics can be reduced or discontinued in a substantial proportion of adults with learning disabilities who use them for challenging behaviour. The findings were in line with the current NICE guidance that antipsychotic medication used for behaviour should be reviewed regularly with an individualised approach taken to treatment.

STOMP and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) was launched in December 2018 by NHS England and The Royal College of Paediatrics and Child Health. NHS England have published a series of [pledge resources](#) for organisations and individuals that work with children and young people with a learning disability, autism or both to show their commitment to STOMP-STAMP. There is also a [STOMP-STAMP patient leaflet](#) for families of children and young people with a learning disability, autism or both who may be prescribed (or are prescribed) psychotropic medication, to help them ask questions about their care and be more involved in discussion.

Public Health England have published an [audit tool](#) to support annual health checks in people with learning disabilities and also [resources](#) and information on the importance of meeting the needs of

people with dementia and learning disabilities. Public Health England have also published a [study on the extent and trends in the use of psychotropic drugs](#) between January 2010 and December 2017. The methods used in this study could be used to monitor the trends in prescribing rates and patterns of psychotropic drugs prescribed by GPs for people with learning disabilities, autism or both.

A separate medicines optimisation: key therapeutic topic is available on [antipsychotics in people with living with dementia](#).

Practice examples and shared learning

There are several [shared learning case studies](#) relating to this key therapeutic topic showing how NICE guidance and standards have been put into practice by some health and care organisations:

- [Challenging assumptions and improving people's quality of life within a large social care provider organisation.](#)
- [Adhering to the NICE guidance for initiating and reviewing antipsychotic medications in people with a learning disability for the prevention and intervention of challenging behaviours.](#)
- [Transforming care in Lincolnshire.](#)
- [A safe home is still a home.](#)
- [Our Medicines – Our Way: A person centred approach to supporting adults with a learning disability to manage their medicines.](#)
- [Stop-look-care.](#)

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Prescribing data, metrics or supporting resources

At this point, no metrics have been identified to support this topic.

Update information

September 2019: This topic was retained for the 2019 rapid update of medicines optimisation: key therapeutic topics. Editorial amendments have been completed. New shared learning examples, a link to a NICE quality standard, a medicines evidence commentary, and links to some STOMP-STAMP resources have been added.

About this key therapeutic topic

This document summarises the evidence base on this key therapeutic topic that has been identified to support medicines optimisation. **It is not formal NICE guidance.**

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