NICE advice

Psychotropic medicines in people with learning disabilities whose behaviour challenges

Key therapeutic topic
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nice.org.uk/guidance/ktt19

Options for local implementation

- 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.
- 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 guidance 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

Background

The NICE guideline on challenging behaviour and learning disabilities explains that a learning disability is defined 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 the disability. The guideline advises that it is important to treat each person as an individual, with specific strengths and abilities as well as needs, and that a broad and detailed assessment may be needed.

The NICE guideline states that 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. Approximately 5–15% of people with learning disabilities in educational, health or social care services have behaviour that challenges, with higher rates in teenagers and people in their early 20s, and in specific settings. The behaviour may serve a purpose for the person such as creating sensory stimulation, getting help or avoiding demands. Some care environments increase the likelihood of behaviour that challenges. Multiple factors are likely to underlie the behaviour and thorough assessments of the person, their environment and any biological predisposition, together with a functional assessment, are needed to identify these. Interventions depend on the specific triggers for each person and may need to be delivered at multiple levels (including the environmental level). The aim should always be to improve the person's overall quality of life.

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 use of a licensed medicine. The exception to this is risperidone which is licensed for the short-term symptomatic treatment of persistent aggression in conduct disorder in children (aged 5 years or more) and adolescents with learning disability who meet specific criteria. 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 these medicines outside their authorised indications is suitable.

NICE guidance

The NICE guideline on challenging behaviour and learning disabilities, gives recommendations on the care of people with learning disabilities whose behaviour changes, including the use of medicines. The NICE quality standard on learning disabilities describes a concise set of prioritised statements designed to drive measurable quality improvements within these areas. A NICE Pathway on challenging behaviour and learning disabilities brings together all related NICE guidance and associated products on this topic in a set of interactive topic-based diagrams.

The NICE guideline 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. The guidance recommends considering antipsychotic medicines 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).

Antipsychotic medicine should be offered only in combination with psychological or other interventions. Medicine choice should take into account the person's preference (or that of their family member or carer, if appropriate), side effects, response to previous antipsychotic medicine and interactions with other medicine.

The NICE guideline recommends that antipsychotic medicine should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician). 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, start with a low dose and use the minimum effective dose needed. The effectiveness and any side effects of the medicine should be reviewed after 3–4 weeks and it should be stopped if there is no response at 6 weeks. When required 'PRN' medicine should be prescribed 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. A full multidisciplinary review should be conducted after 3 months and then at least every 6 months covering all prescribed medicines (including effectiveness, side effects and plans for stopping). Prescribers should only continue 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.

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 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.

National reports

Three pieces of work have been commissioned following the Department of Health publication Transforming care: a national response to Winterbourne View Hospital. These cover:

- prescribing of psychotropic medicines by GPs for people with learning disabilities
- a pilot improvement project that examined medicines practices and related matters
- medication prescribed for people with learning disabilities detained under the Mental Health Act (1983).

Prescribing of psychotropic medicines by GPs to people with learning disabilities

The largest natural sub-group of people with learning disabilities is those people who are currently not in hospital and who, for the most part, may be assumed to be receiving most or all of their medicines from their GP. Public Health England commissioned a study to examine prescribing of psychotropic medicines for this group of people. The analysis used GP records from the Clinical Practice Research Datalink primary care database (CPRD GOLD) and mainly focused on 5 classes of medicines: hypnotics, anxiolytics, antipsychotics, antidepressants and antiepileptic medicines.

The report on Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England found widespread prescribing of psychotropic medicines, including prescriptions for multiple medicines from the same and different classes. With the exception of antiepileptic medicines, a high proportion of people had no relevant licensed indications recorded for the psychotropic medicines they were prescribed.

The report found that adults with learning disabilities were exposed to 1 or more of the study medicines on 41% of person-days. Antipsychotics were being prescribed on 17% of person-days, medicines used in mania and hypomania on 7% of person-days, antidepressants on 17% of person-days, anxiolytics on 4% of person-days and antiepileptic medicines on 23% of person-days. For most classes of medicine the exposure rates increased through adult life. A large proportion (90% or more) of the prescribing was not short term (prescriptions were followed by at least 1 repeat prescription).

Nearly one-quarter (23%) of adults with learning disabilities receiving an antipsychotic received more than 1 medicine in this class. Only 6% were receiving doses of individual medicines above the recommended maximum, but the analysis did not consider additive dose effects in people prescribed more than 1 medicine in a BNF section or sub-section.

Among adults with learning disabilities a high proportion did not have relevant indications recorded for the psychotropic medicines they were prescribed: 58% for antipsychotics, 32% for antidepressants, 56% for hypnotics and 46% for anxiolytics. The majority of people prescribed an antiepileptic drug (91%) had a relevant indication recorded. The authors estimated that between 30,000 and 35,000 adults with a learning disability in England (approximately 1 in 6) are taking an antipsychotic, an antidepressant or both in the absence of the conditions for which these medicines are indicated.

NHS Improving Quality report

NHS Improving Quality published the Winterbourne medicines programme report, a report on a pilot improvement project which examined medicines practices and related matters in 6 sites across England that provide care for those with learning disabilities. Although many examples of good practice were found, there were also some common themes for improvement. The report made 6 key recommendations intended to maximise improvement outcomes:

- involve people with learning disabilities, their families and carers
- invest in quality improvement training and time-out
- undertake analysis to understand current practice and areas for improvement
- ensure services actively use a care pathway for behaviours that challenge
- employ multidisciplinary/ interdisciplinary approaches
- stop and check at every stage along the pathway of care.

Care Quality Commission report

The Care Quality Commission (CQC) has access to data on medicines prescribed to people with learning disabilities detained under the Mental Health Act (1983) and who require a second opinion for treatment with medicines for mental health, under the provisions of that Act. Second Opinion Appointed Doctors (SOADs) provide a statutory safeguard for such people. SOADs visit the person and explore the current and proposed treatment, certifying what is considered to be appropriate and reasonable in circumstances where the person cannot or does not consent to it, discussing it with team members and the person before reaching their conclusions. A treatment plan is submitted to the CQC when the second opinion request is made by the provider clinician. These plans include information on medicines and the reasons given by the doctor for the prescription, together with information provided about the person's diagnosis.

The CQC conducted a survey of this information which is available in the report Survey of medication for detained patients with a learning disability. The survey identified 945 requests representing 796 individual patients across a 10 month period; the mean age was 34 years and two-thirds were male. Over half of the medicines did not have a recorded diagnosis that matched the recognised indications for that medicine. Antipsychotics were the most commonly used class of medicine, prescribed in 91% of requests, of which 44% were prescribed more than 1 antipsychotic at a time. The CQC report notes that we do not know the extent to which medicine was prescribed as an attempt to manage behaviour as opposed to treat a mental disorder. If at least some of the

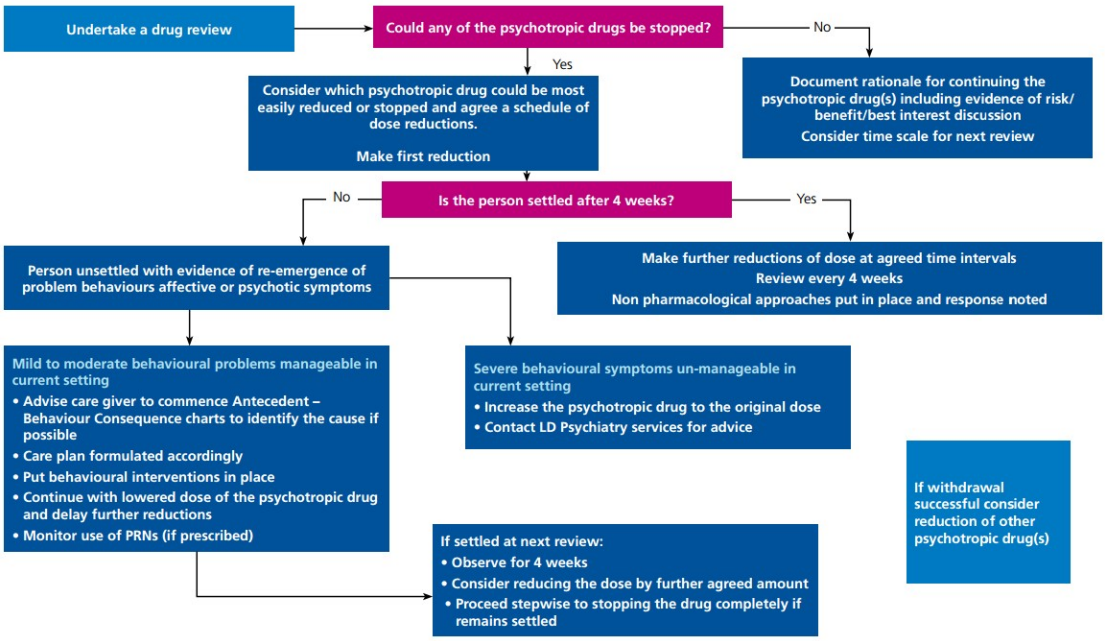
prescribing was to control behaviour, this might be because staff either lacked the resources or skills to manage in other ways behaviour that they found challenging. In general there was limited rationale offered for the entirety of the treatment plan, particularly when polypharmacy and high doses were used. The SOAD made changes to the overall treatment plan in around one-quarter of cases, commonly by restricting the total dose or number of preparations permitted to be used. However, many certified treatment plans still permitted the administration of multiple psychotropic medicines and of high doses of antipsychotic medicines.

Reviewing, reducing or stopping psychotropic medicines in people with learning disabilities

In July 2015 NHS England pledged urgent action on over-medication of people with learning disabilities. The NHS England publication Stopping over-medication of people with learning disabilities (STOMP) provides support to begin the process of challenging the continued need for psychotropic medication in people with a learning disability.

The toolkit includes suggested steps to reduce inappropriate prescribing for GP practices, examples of good practice from NHS organisations and example case studies of psychotropic medicine reduction. The publication also includes an algorithm for the review, reduction or stopping of psychotropic medicines in people with a learning disability (see figure 1).

Figure 1 Algorithm for the review, reduction or stopping of psychotropic drugs in people with a learning disability (NHS England: Stopping over-medication of people with learning disabilities)



A summary of Medicine advice for patients is available on the NHS England website, including guidance for patients, families and cares, a list of useful telephone numbers and a set of frequently asked questions.

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.

A separate key therapeutic topic is available on antipsychotics in people with dementia.

Practice examples and shared learning

There is a NICE shared learning example relating to psychotropic medicines in people with learning disabilities on 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. The medication clinic focused on adherence to the NICE guideline on challenging behaviour and learning disabilities, to ensure that use of antipsychotic medication is only considered for challenging behaviour once non-pharmacological methods have been tried and do not fully remove the behaviour.

Prescribing data, metrics or supporting resources

The selection of metrics to support key therapeutic topics is overseen by the NHS England Medicines Optimisation Intelligence Group, and work is ongoing in this area. At this point, no metrics have been identified by this group to support this topic.

Update information

February 2018: This topic was retained for the 2018 update of medicines optimisation: key therapeutic topics. The evidence context has been updated in the light of new guidance and important new evidence.

About this key therapeutic topic

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

For information about the process used to develop the key therapeutic topics, see the integrated process statement.

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