Psychotropic medicines in people with learning disabilities whose behaviour challenges

Key therapeutic topic
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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 only be considered to manage behaviour that challenges in people with learning disabilities 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.


- 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 the 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 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.

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 only be considered 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 preference (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. When required PRN medicine (medicine taken as needed) should be prescribed for as short a time as possible and the specialist should ensure that its use is recorded and reviewed. 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 only continuing medicines that have shown a benefit. The guidance also includes recommendations on appropriate detailed documentation in relation to prescribing and the requirements when prescribing is transferred from the specialist to primary or community care, or between services. This should include relevant information such as 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.

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 disabilities: challenging behaviour and learning disabilities: identifying and managing mental health problems 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, care and support of people growing older with learning disabilities and dementia bring together all related NICE guidance and associated products on these topics in a set of interactive flowcharts.

National resources

Following the publication of Transforming care: a national response to Winterbourne View Hospital the Department of Health and Social Care set out a programme of action to transform services so that vulnerable people no longer live inappropriately in hospitals and are cared for in line with best practice. The programme of work included a Public Health England review of prescribing of psychotropic medicines by GPs for people with learning disabilities and a review by
the Care Quality Commission of medication prescribed for people with learning disabilities
detained under the Mental Health Act. NHS Improving Quality also produced Winterbourne –
Time for change and made recommendations for a national commissioning framework under which
local commissioners would secure community-based support for people with learning disabilities.
NHS England concluded from this research 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.

Subsequently, in July 2015 NHS England pledged urgent action on over-medication of people with
learning disabilities.

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

The national project on Stopping over medication of people with a learning disability, autism or
both 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 (see figure 1).
A summary of medicine advice for patients 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.

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.

A separate medicines optimisation: key therapeutic topic is available on antipsychotics in people 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.

[^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.

Prescribing data, metrics or supporting resources

The selection of metrics to support key therapeutic topics is oversees 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

March 2019: This topic was retained for the 2019 update of medicines optimisation: key therapeutic topics. The evidence context has been updated in the light of new guidance and important new evidence where appropriate.

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.

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

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