Specialist Pharmacy Service

NICE Bites

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A summary of prescribing recommendations from NICE guidance

Mental health problems in people with learning disabilities

NICE NG54; 2016

This guideline covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings and should be used in conjunction with NICE guidelines on specific mental health problems.

Organisation and delivery of care and support – see NICE pathway

- A designated leadership team of healthcare professionals, educational staff, social care practitioners and health and local authority commissioners should develop and implement service delivery systems in partnership with people with learning disabilities and mental health problems and their family members/carers/care workers (as appropriate).

General principles of care

Communication

- Take into account the person's communication needs and level of understanding throughout assessments and treatment:
  - speak to the person directly rather than talking about or over them,
  - use clear, straightforward and unambiguous language,
  - assess whether communication aids, an advocate or someone familiar with the person's communication methods are needed,
  - make adjustments to accommodate sensory impairments (including sight and hearing impairments),
  - explain the content and purpose of every meeting/session,
  - use concrete examples, visual imagery, practical demonstrations and role play to explain concepts,
  - communicate at a pace that is comfortable for the person, and arrange longer or additional meetings or treatment sessions if needed,
  - use different methods and formats for communication (written, signing, visual, verbal, or a combination of these), depending on the person's preferences,
  - regularly check the person's understanding,
  - summarise and explain the conclusions of every meeting/session,
  - check that the person has communicated what they wanted.

Consent, capacity and decision-making – see NICE pathway

Annual health check

- GPs should offer an annual health check using a standardised template to all adults with learning disabilities, and all children and young people with learning disabilities who are not having annual health checks with a paediatrician.
- Involve a family member/carer/care worker, or a healthcare professional or social care practitioner who knows the person well. Take into account that more time may be needed to complete health checks.
- Include the following in annual health checks:
  - a mental health review, including any known or suspected mental health problems and how they may be linked to any physical health problems,
  - a physical health review, including assessment for conditions and impairments which are common in people with learning disabilities,
  - a review of all current interventions, including medication, related side effects, interactions and adherence,
  - an agreed and shared care plan for managing any physical health problems (including pain).
- During annual health checks with adults with Down's syndrome, ask them and their family members/carers/care workers about any changes that might suggest the need for an assessment of dementia, such as:
  - any change in the person's behaviour,
  - any loss of skills (including self-care),
  - a need for more prompting in the past few months.

Identification and referral for assessment

- Staff and other carers should consider a mental health problem if a person with learning disabilities shows any changes in behaviour, such as loss of skills or needing more prompting to use skills, social withdrawal, irritability, avoidance, agitation, or loss of interest in activities they usually enjoy.
- Consider using identification questions (adjusted as needed) as recommended in NICE pathways on specific mental health problems to identify common mental health problems.
- Paediatricians should explain to parents that mental health problems are common in children with learning disabilities, and may present in different ways.
- If a mental health problem is suspected in a person with learning disabilities, conduct a triage assessment. Include:
  - a description of the problem, including its nature, severity and duration,
  - an action plan including possible referral for further assessment and interventions.
- Refer people who have a suspected serious mental illness or suspected dementia to a psychiatrist with expertise in assessing and treating mental health problems in people with learning disabilities.
- See also NICE pathway: Dementia.

Assessment – see NICE pathway

- A professional with expertise in mental health problems in people with learning disabilities should coordinate the mental health assessment, and conduct it with:
  - the person in a place familiar to them if possible, and help them to prepare for it if needed,
  - the family members/carers/care workers and others that the person wants involved in their assessment,
  - other professionals (if needed) who are competent in using a range of assessment tools and methods with people with learning disabilities and mental health problems.
- Speak to the person alone to find out if they have any concerns (including safeguarding concerns) that they don't want to talk about in front of family members/carers/care workers.

Before assessments

- Agree a clear objective, and explain it to the person, their family members/carers/care workers (as appropriate), and all professionals involved,
- Explain the nature and duration of the assessment to everyone.
- Explain the need to ask certain sensitive questions.

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- Address any queries or concerns the person may have about the assessment process.

When conducting assessments

- Take into account the person's: level of distress, understanding of the problem, living arrangements and settings where they receive care, strengths and needs.
- Be aware that:
  - an underlying physical health condition may be causing the problem,
  - a physical health condition, sensory or cognitive impairment may mask an underlying mental health problem,
  - mental health problems can present differently in people with more severe learning disabilities.
- During mental health assessments:
  - establish specific areas of need to focus on,
  - assess all potential psychopathology, and not just the symptoms and signs that the person and their family members, carers or care workers first report,
  - describe the nature, duration and severity of the presenting mental health problem,
  - take into account cultural, ethnic and religious background,
  - review psychiatric and medical history, past treatments and response, physical health problems and any current medication. Refer to other specialists for review if needed,
  - review the nature and degree of the learning disabilities, and if relevant the person's developmental history,
  - assess for problems that may be associated with particular behavioural phenotypes (e.g. anxiety in people with autism and psychosis in people with Prader–Willi syndrome), so that they can be treated,
  - assess the person's family and social circumstances and environment, and recent life events,
  - assess the level of drug or alcohol use as a potential problem in itself and as a factor contributing to other mental health problems (see NICE pathways: Alcohol-use disorders and drug misuse),
  - establish or review a diagnosis; using a classification system such as DSM-5 or ICD-10, or those adapted for learning disabilities (e.g. Diagnostic Manual – Intellectual Disability [DM-ID] or Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation [DC-LD]); or problem specification,
  - assess whether a risk assessment is needed.
- Assess recent changes in behaviour using information from family members/carers/staff or others as well as from relevant records and previous assessments. Take into account the nature, quality and length of their relationship with the person.
- Use results of the mental health assessment to develop a written statement (formulation) of the mental health problem, which should form the basis of the care plan. See NICE pathway.

Assessment tools - see NICE pathway

Initial assessment during a crisis – see NICE pathway

Psychological interventions

Principles for delivering psychological interventions – see NICE pathway

Interventions adapted for people with learning disabilities

- Consider cognitive behavioural therapy, adapted for people with learning disabilities, to treat depression or subthreshold depressive symptoms in people with milder learning disabilities.
- Consider relaxation therapy to treat anxiety symptoms in people with learning disabilities.
- Consider using graded exposure techniques to treat anxiety symptoms or phobias in people with learning disabilities.

Pharmacological interventions

- Only specialists with expertise in treating mental health problems in people with learning disabilities should start medication to treat a mental health problem in:
  - adults with more severe learning disabilities (unless there are locally agreed protocols for shared care),
  - children and young people with any learning disabilities.
- Before starting medication for a mental health problem in children, young people or adults with learning disabilities take account of potential:
  - drug interactions,
  - impact of medication on other health conditions,
  - impact of other health conditions on the medication.
- When necessary consult with specialists to minimise possible interactions e.g. neurologists if prescribing antipsychotic medication that may lower the seizure threshold.
- Assess risk of non-adherence or any necessary monitoring e.g. blood tests, and implications for treatment.
- Establish a review schedule to reduce polypharmacy.
- Provide support to improve adherence. See NICE pathway: Medicines optimisation.
- Assess whether support from community and learning disabilities nurses is needed for physical investigations (such as blood tests),
- Agree monitoring responsibilities between primary and secondary care including who will carry out blood tests and other investigations.
- Monitor and review benefits and possible harms or side effects, using agreed outcome measures. If stated in the relevant NICE guideline, use timescales given for the specific disorder, and adjust it to the person's needs.
- When deciding initial dose and subsequent increases, aim for the lowest effective dose. Take account of both potential side effects and difficulties the person may have in reporting them, and the need to avoid sub-therapeutic doses.
- Prescribers should record:
  - a summary of information provided to the person and their family members/carers/care workers about medication prescribed, including side effects, and any discussions,
  - when medication will be reviewed,
  - plans for reducing or discontinuing the medication, if appropriate,
  - full details of all medication the person is taking, including doses, frequency and purpose.
- For people with learning disabilities taking antipsychotic drugs and not experiencing psychotic symptoms:
  - consider reducing or discontinuing long-term prescriptions of antipsychotic drugs,
  - 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,
  - annually document the reasons for continuing the prescription if it is not reduced or discontinued.
- When switching medication, pay particular attention to discontinuation or interaction effects that may occur during titration. Only change one drug at a time, to make it easier to identify these effects.

Recommendations – wording used such as 'offer' and 'consider' denote the strength of the recommendation.

Drug recommendations – the guideline assumes that prescribers will use a drug's Summary of Product Characteristics (SPC) to inform treatment decisions.

Challenging behaviour and learning disabilities

NICE NG11; 2015

General principles

- Work in partnership with children, young people and adults who have a learning disability and behaviour that challenges, and their family members/carers, and:
  - involve them in decisions about care,
  - support self-management and encourage the person to be independent,
  - build and maintain a continuing, trusting and non-judgemental relationship,
  - develop a shared understanding about the function of the behaviour,
  - help family members and carers to provide the level of support they feel able to.
- Provide information:
  - about the nature of the person's needs, and the range of interventions (e.g. environmental, psychological and pharmacological interventions) and services available to them,
  - in a format and language appropriate to the person's cognitive and developmental level (including spoken and picture formats, and written versions in Easy Read style and different colours and fonts).
- When providing support and interventions for people with a learning disability and behaviour that challenges, and their family members/carers:
  - take into account the severity of the person's learning disability, their developmental stage, and any communication difficulties or physical or mental health problems,
  - aim to prevent, reduce or stop the development of future episodes of behaviour that challenges,
  - aim to improve quality of life,
  - offer support and interventions respectfully,
  - ensure that the focus is on improving the person's support and increasing their skills rather than changing the person,
  - ensure that they know who to contact if they are concerned about care or interventions, including the right to a second opinion,
  - offer independent advocacy to the person and to their family members or carers.
- Aim to provide support and interventions:
  - in the least restrictive setting, such as the person's home, or as close to their home as possible, **AND**
  - in other places where the person regularly spends time (e.g. school or residential care).
- Everyone involved in commissioning or delivering support and interventions for people with a learning disability and behaviour that challenges (including family members and carers) should understand:
  - the nature and development of learning disabilities,
  - personal and environmental factors related to the development and maintenance of behaviour that challenges,
  - that behaviour that challenges often indicates an unmet need,
  - the effect of learning disabilities and behaviour that challenges on the person's personal, social, educational and occupational functioning,
  - the effect of the social and physical environment on learning disabilities and behaviour that challenges (and vice versa), including how staff and carer responses to the behaviour may maintain it.

Organising care – see NICE pathway

Annual health check – as per page 1

Early identification

- Everyone involved in caring for and supporting children, young people and adults with a learning disability (including family members/carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record personal and environmental factors that may increase this risk.
- **Personal factors** - such as:
  - a severe learning disability,
  - autism,
  - dementia (see NICE pathway: Dementia),
  - communication difficulties (expressive and receptive),
  - visual impairment (which may lead to increased self-injury and stereotypy),
  - physical health problems,
  - variations with age (peaking in the teens and twenties).
- **Environmental factors** - such as:
  - abusive or restrictive social environments,
  - environments with little or too much sensory stimulation and those with low engagement levels (e.g.little interaction with staff),
  - developmentally inappropriate environments (e.g. a curriculum that makes too many demands on a child or young person),
  - environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs,
  - changes to the person's environment (e.g. significant staff changes or moving to a new care setting).
- Consider using direct observation and recording or formal rating scales (e.g. Adaptive Behavior Scale or Aberrant Behavior Checklist) to monitor the development of behaviour that challenges.

Initial assessment

- If behaviour that challenges is emerging or apparent, or a family member, carer or member of staff (e.g. teacher or care worker), has concerns about behaviour, carry out initial assessment that includes:
  - a description of the behaviour (including its severity, frequency, duration and impact on the person and others) from the person (if possible) and a family member/carer/member of staff,
  - an explanation of personal and environmental factors involved in developing or maintaining the behaviour from the person (if possible) and a family member/carer/member of staff,
  - the role of the service, staff, family members or carers in developing or maintaining the behaviour.
- Consider using a formal rating scale (e.g. Aberrant Behavior Checklist or Adaptive Behavior Scale) to provide baseline levels for the behaviour and a scale (such as the Functional Analysis Screening Tool) to help understand its function.
- As part of initial assessment of behaviour that challenges, take into account:
  - the person's abilities and needs (in particular, their expressive and receptive communication),
  - any physical or mental health problems, and the effect of medication, including side effects,
  - developmental history, including neurodevelopmental problems (including severity of the learning disability and the presence of autism or other behavioural phenotypes),
  - response to any previous interventions for behaviour that challenges,

Challenging behaviour and learning disabilities continued …….

NICE NG11; 2016

- the impact of the behaviour that challenges on the person's quality of life and that of their family members or carers, and the person's independent living skills, and educational or occupational abilities,
- social and interpersonal history, including relationships with family members, carers, staff (such as teachers) or other people with a learning disability (such as those the person lives with),
- aspects of the person's culture that could be relevant to the behaviour that challenges,
- life history, including any history of trauma or abuse,
- recent life events and changes to routine,
- the person's sensory profile, preferences and needs,
- the physical environment, including heat, light, noise and smell,
- the care environment, including the range of activities available, how it engages people and promotes choice, and how well structured it is.

♦ After initial assessment, develop a written statement (formulation) that sets out an understanding of what has led to the behaviour that challenges and the function of the behaviour. Use this to develop a behaviour support plan.

Psychological and environmental interventions – see NICE pathway

Pharmacological treatment

♦ Consider medication, or optimise existing medication (see NICE pathway; Medicines optimisation), for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges shown by children, young people and adults with a learning disability.

♦ Consider 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 (e.g. because of violence, aggression or self-injury).

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

♦ When choosing which antipsychotic medication to offer, take into account the person's preference (or that of their family member/carer, if appropriate), side effects, response to previous antipsychotic medication and interactions with other medication.

♦ Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician) who should:
- identify the target behaviour,
- decide on a measure to monitor effectiveness (e.g. direct observations, the Aberrant Behavior Checklist or the Adaptive Behavior Scale), including frequency and severity of the behaviour and impact on functioning,
- start with a low dose and use the minimum effective dose needed,
- only prescribe a single drug,
- monitor side effects as recommended in NICE pathway; Psychosis and schizophrenia,
- review the effectiveness and any side effects of the medication after 3 to 4 weeks,
- stop the medication if there is no indication of a response at 6 weeks, reassess the behaviour that challenges and consider further psychological or environmental interventions,
- only prescribe prn (as-needed) medication for as short a time as possible and ensure that its use is recorded and reviewed,
- review the medication if there are changes to the person's environment (e.g. significant staff changes or moving to a new care setting) or their physical or mental health.

♦ Ensure that the following are documented:
- a rationale for medication (explained to the person with a learning disability and everyone involved in their care, including their family members and carers),
- how long the medication should be taken for,
- a strategy for reviewing the prescription and stopping the medication.

♦ If there is a positive response to antipsychotic medication:
- record the extent of the response, how the behaviour has changed and any side effects or adverse events,
- conduct a full multidisciplinary review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping),
- only continue to prescribe medication that has proven 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:
- which behaviours to target,
- monitoring of beneficial and side effects,
- taking the lowest effective dose,
- how long the medication should be taken for,
- plans for stopping the medication.

♦ For the use of rapid tranquillisation, follow the NICE pathway on violence and aggression.

Reactive strategies – see NICE pathway

Interventions for sleep problems

♦ Consider behavioural interventions for sleep problems in children, young people and adults with a learning disability and behaviour that challenges that consist of:
- a functional analysis of the problem sleep behaviour to inform the intervention (e.g. not reinforcing non-sleep behaviours),
- structured bedtime routines.

♦ **Do NOT** offer medication to aid sleep unless the sleep problem persists after a behavioural intervention, and then only:
- after consultation with a psychiatrist (or a specialist paediatrician for a child /young person) with expertise in its use in people with a learning disability,
- together with non-pharmacological interventions and regular reviews (to evaluate continuing need and ensure that benefits continue to outweigh the risks).

♦ If medication is needed to aid sleep, consider melatonin**U.**

Recommendations – wording used such as 'offer' and 'consider' denote the strength of the recommendation.

Drug recommendations – the guideline assumes that prescribers will use a drug's Summary of Product Characteristics (SPC) to inform treatment decisions.

U Unlicensed indication in people aged <55 years