Managing Behavioural Problems in Patients with Learning Disabilities

Some people with a learning disability display behaviour that challenges. Although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating).

Multiple factors are likely to underlie behaviour that challenges. To identify these, thorough assessments of the person, their environment and any biological predisposition are needed, together with a functional assessment.

Although the use of antipsychotic medication in people with learning disabilities (LD) is a relatively common occurrence, there are specific issues relating to this patient group concerning assessment, titration and long-term treatment.

Based on this clinical evidence, the National Institute for Clinical Excellence (NICE) has made clear that antipsychotics should only be used where psychological or other interventions alone do not produce change or where there is the risk of severe harm to the patient or others.

The following is advised when considering treatment:

- When providing support and interventions for people with a learning disability and behaviour that challenges, take into account the severity of the person’s learning disability, their developmental stage, and any communication difficulties or physical or mental health problems.

- For recent-onset behaviour that challenges, or marked changes in patterns of existing behaviours, take into account whether any significant alterations to the person’s environment and physical or psychological health are associated with the development or maintenance of the behaviour.

- It is important to try and identify a cause for the symptoms and manage these using non-pharmalogical measures rather than resorting to drugs to treat the symptoms.

- Consider personalised interventions that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time.

- 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 (for example, because of violence, aggression or self-injury).

- Only offer antipsychotic medication in combination with psychological or other interventions.
## NON PHARMACOLOGICAL TREATMENTS

Many different factors may be associated with behavioural problems in patients with learning difficulties these are outlined in the table below:

<table>
<thead>
<tr>
<th>Personal Factors</th>
<th>Severe Learning Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Autism</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
</tr>
<tr>
<td></td>
<td>Epilepsy</td>
</tr>
<tr>
<td></td>
<td>Communication difficulties (expressive and receptive)</td>
</tr>
<tr>
<td></td>
<td>Visual impairment (which may lead to increased self-injury and stereotypy)</td>
</tr>
<tr>
<td></td>
<td>Physical health problems</td>
</tr>
<tr>
<td></td>
<td>Behavioural phenotypes associated with certain syndromes (for example fragile X syndrome).</td>
</tr>
<tr>
<td></td>
<td>Variations with age (peaking in the teens and twenties)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environmental factors</th>
<th>Social isolation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Environments with little or too much sensory stimulation and those with low engagement levels</td>
</tr>
<tr>
<td></td>
<td>Visual and auditory sensory impairments</td>
</tr>
<tr>
<td></td>
<td>Changes to the person’s environment (for example, significant staff changes or moving to a new care setting).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prescribed medicines</th>
<th>These may cause psychotic symptoms in during use or on withdrawal:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Benzodiazepines</td>
</tr>
<tr>
<td></td>
<td>Anticonvulsants - carbamazepine, phenytoin</td>
</tr>
<tr>
<td></td>
<td>Steroids - prednisolone</td>
</tr>
</tbody>
</table>

- Challenging behaviours may be a way of communicating an unmet need.

- Clinicians will need to be aware of and address the above factors before doing anything else; this should include taking a history of the problem, having the behaviour described by the carer/team and discussing current and past behaviour with the carer/team

- Diagnosis can be difficult in people with limited language skills although this may be easier in those with a mild degree of LD if sufficient allowance is made for their reduced vocabulary. Many individuals with LD may have a concomitant behaviour disorder which may confound diagnosis, particularly where there is major impairment of social interaction.

- Assess and regularly review the following areas of risk during any assessment of behaviour that challenges:
  - suicidal ideation, self-harm (in particular in people with depression) and self-injury
  - harm to others
  - self-neglect
  - breakdown of family or residential support
  - exploitation, abuse or neglect by others
o rapid escalation of the behaviour that challenges.

- Involve the person/carers/staff in developing a written behaviour support plan that is based on a shared understanding about the function of the behaviour. This should:
  o identify proactive strategies designed to improve the person's quality of life and remove the conditions likely to promote behaviour that challenges, including: changing the environment (for example, reducing noise, increasing predictability).
  o identify adaptations to a person's environment and routine
  o identify preventive strategies to calm the person when they begin to show early signs of distress, including individual relaxation techniques or distraction and diversion onto activities they find enjoyable and rewarding.

- Decide and record what symptom/behaviour you are treating, set up a system for monitoring it (e.g. using simple charts completed by nursing staff or carer). Review frequently (fortnightly for the first 2 months and monthly thereafter).

- Consider individual psychological interventions for adults with an anger management problem. These interventions should be based on cognitive-behavioural principles.

- For further support consider discussion with the local Disability Advisor (Peterborough and Stamford Hospitals NHS Foundation Trust)

**APPROPRIATE USE OF ANTIPSYCHOTICS IN PEOPLE WITH LEARNING DIFFICULTIES**

**Considerations for New Prescriptions**

- Consider medication, or optimise existing medication (in line with the NICE guideline on medicines optimisation), for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges.

- 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 (for example, because of violence, aggression or self-injury).

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

- When prescribing an antipsychotic start with a low dose and aim to use the minimum effective dose needed. Only prescribe a single drug.
• Review the effectiveness and any side effects of the medication after 3–4 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.

• If there is a positive response to antipsychotic medication:
  o record the extent of the response, how the behaviour has changed and any side effects or adverse events
  o review after 3 months and then at least every 6 months covering all prescribed medication (including effectiveness, side effects and plans for stopping)
  o only continue to prescribe medication that has proven benefit.

• Prior to initiation discuss risks and benefits with the patient/relative/carer, the indication for the prescription, alternatives considered and plans for review, reduction and cessation. If use is unlicensed then consent should be obtained. All discussions about risks and benefits of use must be clearly documented

• Where possible a multidisciplinary discussion should be held to demonstrate this is in the patient’s best interest, e.g. when considering the use of risperidone in children.

• If the original reason for prescribing the antipsychotics returns then go through the above points. If initiated in secondary care then specialists should give clear instructions of when to review and stop medication.

• People with LD maybe more likely to develop side effects with antipsychotics due to their underlying brain damage. The most common side effects are neurological, particularly extrapyramidal side effects such as Parkinsonism, dystonia, akathisia and tardive dyskinesia.

• People with LD are also likely to experience other side effects such as QT interval prolongation, hepatic impairment and blood dyscrasias, due to their multisystem impairment. There is good evidence in adults with normal intelligence that antipsychotics may cause sedation, psychomotor impairment and decreased ability to concentrate. These effects may be compounded in adults with LD because of the underlying organic condition.

Reviewing patients already prescribed an antipsychotic

As there are already people with LD on antipsychotics in primary care, GPs have a key role to play in reviewing these patients with a view to stopping treatment if appropriate. Where antipsychotics are already prescribed to manage behaviour that challenges, all healthcare professionals should question the need for long-term use.

• All patients with LD currently on antipsychotics to manage behaviour that challenges who have not had a trial discontinuation in the last 3 - 6 months
should have the antipsychotic reviewed and stopped to assess the risks and benefits of continued treatment unless:
- The antipsychotic was prescribed for a co-existing condition e.g. bipolar disorder or psychotic depression.
- The patient is under regular review by a specialist for behavioural problems.
- There is a detailed care plan in place for ongoing antipsychotic use.

- If the patient is under regular review by secondary care for behavioural problems then responsibility for reviewing and reducing or stopping the antipsychotic lies with secondary care, otherwise this should be undertaken by the patient’s GP.

- If a decision is made to reduce or stop an antipsychotic carers, should be involved in the decision and supported through the process.
  - Reduce to half dose for two weeks
  - GP review at two weeks
  - Discontinue after a further two weeks

- Review every stage of dose reduction to evaluate patient response.

- The risk of recurrence of challenging behaviour after discontinuation is more likely if:
  - Previous discontinuation has caused symptoms to return
  - The person currently has severe symptoms

- In some cases it may be necessary to withdraw the drug more slowly, particularly if symptoms reappear.
  - Implement small decreases in dose (ensure dose reduction is possible with strengths available), one step down at a time.
  - Where the anti-psychotic is given more than once daily, decrease only one dose to start with, choosing the dose where patient is likely to be least affected.
  - Allow sufficient time for the patient to adapt to the new dose (usually 1-2 weeks) before considering the next small reduction in dose.
  - When the lowest dose has been achieved on a daily basis then administer on alternate days before stopping completely.

- If the behaviour that challenges is severe or complex, or does not respond to the behaviour support plan, review the plan and carry out further assessment that is multidisciplinary and draws on skills from specialist services.

Interventions for coexisting health problems

- Offer children, young people and adults with a learning disability and behaviour that challenges interventions for any suspected or coexisting mental or physical health problems in line with the relevant local or national guidance.
• Consider behavioural interventions for sleep problems in patients with LD. Do not offer medication to aid sleep unless the sleep problem persists after a behavioural intervention, such as establishing good sleep hygiene, and then only:
  o after consultation with a psychiatrist with expertise in its use in people with a learning disability
  o together with non-pharmacological interventions and regular reviews (to evaluate continuing need and ensure that the benefits continue to outweigh the risks).

PATIENT INFORMATION

• A leaflet for patients / carer’s and a guide for health and social care professionals can be found at
  http://www.rcpsych.ac.uk/healthadvice/problemsgroup/learningdisabilities.aspx