STopping over-Medication of People with Learning Disabilities

(STOMPwLD) 2016
We all need to make it a priority to reduce and stop the use of inappropriate drugs, to reduce adverse side effects and potential drug interactions. This is vital to our patients’ safety and their quality of care.

The goal is to improve the quality of life of people with a learning disability by reducing the potential harm of inappropriate psychotropic drugs that may be used wholly inappropriately, as a “chemical restraint” to control challenging behaviour, in place of other more appropriate treatment options. It is time for action, it is time for you to lead a medication review of all people with a learning disability, with a view to implementing a planned supervised dose reduction and stopping of inappropriate psychotropic drugs.

Aim of this document

Multiple psychotropic drug use often starts at a specialist level which is then passed onto primary care with or without follow up. Many GPs are overseeing the management and prescribing long term. Following the Banerjee report (2009) and the national drive to reduce inappropriate use of antipsychotic drugs in dementia to save lives, confidence has grown amongst GPs and care teams to review prescribing. This document aims to provide support to begin the process of challenging continued need in people with a learning disability.

Why reduce the use of psychotropic drugs in people with a learning disability?

Glover et al. (2015) has shown that among adults known to their GP to have a learning disability, (excluding only those in hospital as inpatients) on any average day:
- 17.0% were being prescribed antipsychotic drugs,
- 16.9% antidepressants,
- 7.1% drugs used in mania and hypomania,
- 4.2% anxiolytics, and
- 2.7% hypnotics.

It is estimated that on an average day in England, between 30,000 and 35,000 adults with a learning disability are being prescribed an antipsychotic, an antidepressant or both without appropriate clinical indications (psychosis or affective/anxiety disorder). A substantial proportion of people with a learning disability who are prescribed psychotropic drugs for behavioural purposes can safely have their drugs reduced or withdrawn.
Now is the right time to stop prescribing inappropriate psychotropic drugs

Challenging behaviour has been described as behaviour which puts an individual or others at risk in any social situation and limits their access to services. Causes tend to be personal factors such as communication difficulties and physical health issues and/or environmental factors such as abusive or restrictive social environments. Assessment usually requires observation and a physical assessment to exclude physical causes with the development of a behavioural support plan and referral to secondary care services.

National Institute for Health and Social Care Excellence advises that specialists consider prescribing 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.

If there is a positive result the specialist needs to conduct a full multidisciplinary review after three months and then at least every six months covering all prescribed medication (including effectiveness, side effects and plans for stopping).

A person centred individually patient centric approach is necessary when reducing or withdrawing psychotropic drugs. If prescribed for behaviours that challenge there is the expectation that the drugs will stop unless:

• There is evidence that the person with a learning disability has gained significant benefit from the use of the psychotropic drug(s) and recent attempts to withdraw the drug(s) has resulted in a deterioration
• The nature of the behaviours experienced prior to prescribing psychotropic drug(s) was so severe that withdrawal is considered clinically inappropriate by the carers and others.

If the psychotropic drug is prescribed for a mental illness there is the expectation that the drug treatment will follow the recommendations of the relevant NICE guidance. If the person with a learning disability has been symptom free for some time maintenance may not be the best course and may need referral to the specialist person with a learning disability team.

APPENDIX 1

Algorithm for the review, reduction or stopping of psychotropic drugs in People with a Learning Disability

Undertake a drug review

Could any of the psychotropic drugs be stopped?

Consider which psychotropic drug could be most easily reduced or stopped and agree a schedule of dose reductions.

Make first reduction

Is the person settled after 4 weeks?

Make further reductions of dose at agreed time intervals

Review every 4 weeks

Non pharmacological approaches put in place and response noted

Person unsettled with evidence of re-emergence of problem behaviours affective or psychotic symptoms

Mild to moderate behavioural problems manageable in current setting

• Advise care giver to commence Antecedent Behaviour Consequence charts to identify the cause if possible
• Care plan formulated accordingly
• Put behavioural interventions in place
• Continue with lowered dose of the psychotropic drug and delay further reductions
• Monitor use of PRNs (if prescribed)

Severe behavioural symptoms un-manageable in current setting

• Increase the psychotropic drug to the original dose
• Contact LD Psychiatry services for advice

If withdrawal successful consider reduction of other psychotropic drug(s)

If settled at next review:

• Observe for 4 weeks
• Consider reducing the dose by further agreed amount
• Proceed stepwise to stopping the drug completely if remains settled

Document rationale for continuing the psychotropic drug(s) including evidence of risk/benefit/best interest discussion

Consider time scale for next review

If withdrawal unsuccessful

If withdrawal successful consider reduction of other psychotropic drug(s)
Suggested steps for your GP practice

1. Have a meeting to discuss the issue and appoint a GP lead.
2. Organise for a practice team member to interrograde the practice prescribing system or work with the CCG Pharmacy team to obtain details of all people with a learning disability on psychotropic drugs.
3. Share the results with the practice team, the people with a learning disability specialist and teams and others who can help.
4. Together develop an agreement about a programme of reviews with their named individual GPs and ensure follow up. Make this part of your annual health checks.

Three first steps for reducing and/or stopping psychotropic drug use in an individual with a learning disability:

a. Undertake medicines reconciliation
   - Check with the person, family and their carers. Ensure accessible information and any necessary communication support is available.
   - If behaviour is part of a mental illness or autistic spectrum disorder/AADD (Neurodevelopmental Disorder) then discuss with a person with a learning disability psychiatrist.
   - Check whether previous attempts at drug reduction and withdrawal have been tried, how it was undertaken and what was the outcome. Remember:
     - Sudden withdrawal of psychotropic drugs may result in discontinuation effects
     - The carers may not give the drugs sometimes. Find out why and what happens
     - Achieve a consensus amongst carers, family, the patient (if possible) and involved professionals that there is scope to reduce or stop psychotropic drug use and it is in the person with a learning disability's best interest.
   - Undertake a drug review and find out when psychotropic drugs in an individual with a learning disability in General Practice.

Additional actions for consideration
4. Agree a regular review with consistency about the source and format of information about the impact of the reduction in psychotropic drugs from family or carers that know the person well.
5. Ensure there is a plan for dealing with re-emergent behaviours and liaise with the local community people with a learning disability team.
6. When acting or making decisions on behalf of someone who lacks capacity to make a decision for themselves, you should be able to explain and record how you have had the concerns about the behaviours.
7. For drugs with a long half-life (fluoxetine) or antidepressants that are withdrawn slowly, be aware of drug discontinuation effects (see table below). These are usually mild and self-limiting but may be difficult to elicit in people with a learning disability.

Principles of dose reduction and drug discontinuation
1. Make reductions stepwise and realistic, keeping specialists involved. Generally withdraw or reduce one drug at a time. Choose the drug with the least evidence of benefit first.
2. The rate of reduction should depend on an agreement between the carers, and if possible the patient and the prescriber. This should be informed by the level of concern of the carers, the history of the behaviours associated with the introduction of the drugs, the duration of exposure, dose of drug, half-life of drug, previous response to such reduction / discontinuation and the availability of other strategies and support for the carers to deal with re-emergent behaviours.
3. For drugs with a long half-life (fluoxetine) or on long acting injections withdrawal will take longer. For drugs with significant drug-drug interactions (carbamazepine) withdrawal may impact on the effects of the other drugs.

Some potential problems
Accept that the reduction may take some time and will be difficult from time to time. Sometimes if behaviours deteriorate it can be difficult to judge whether it is a withdrawal effect (usually occurs within the first week) the person adapting to the absence of the drug (usually in the first month) or a return of the behaviours for which the drug(s) was prescribed or the person is just more alert and
the carers have difficulty with this impacting on their working practice. Observe PRN usage in these circumstances.

b. It is better to slow down the rate of reduction rather than sticking to a rigid plan if there are concerns about the behaviours.

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<table>
<thead>
<tr>
<th>Psychotropic drug class</th>
<th>Discontinuation effects</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotics</td>
<td>No consensus about whether there are discontinuation problems</td>
<td>Slow down rate of reduction</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>Most SSRI and other antidepressants are associated with discontinuation effects</td>
<td>If mild – reassurance</td>
</tr>
<tr>
<td></td>
<td>Flu-like symptoms, dizziness, insomnia and irritability are common</td>
<td>If severe – reintroduce antidepressant</td>
</tr>
<tr>
<td>Benzodiazepines and Z drugs</td>
<td>At least 1/3 of long term users suffer discontinuation problems – stiffness, weakness and flu-like symptoms</td>
<td>Minimal intervention and reduce slowly</td>
</tr>
<tr>
<td>Mood stabilisers</td>
<td>Rapid withdrawal of anticonvulsants has been associated with seizures</td>
<td>Consider switch to diazepam</td>
</tr>
</tbody>
</table>

If severe – reintroduce antidepressant

Consider switch to diazepam
APPENDIX 3

Practice Examples

Trafford Clinical Commissioning Group (CCG) has employed a clinical pharmacist from the Greater Manchester West Mental Health Foundation Trust to assist with the identification of potential cases for the ‘Call to Action’.

Following a request from the CCG Medicines Management lead the five biggest lists (i.e. terms of catchment / number of people with a learning disability on register) practices agreed to participate. There was an average of 50 people per practice with a learning disability diagnosis, per practice with a learning disability diagnosis, participate. There was an average of 50 people (register) practices agreed to participate.

Egton Medical Information System (EMIS) using a pro-forma was imported into EMIS to record instances of prescribing for challenging behaviour. When a case was identified, the list was examined to find any non-pharmacological interventions that were part of the wider Positive Behaviour Support Policy.

APPENDIX 4

Examples of psychotropic drug reduction

A man with a learning disability was treated for 2 years with risperidone 2mg (challenging behaviour) and mirtazapine 30mg (depression). He was monitored by the home care for 3 months post admission. Then risperidone was reduced by 0.5mg every 3-4 weeks until final reduction from 5mg to zero lasted for 6 weeks at the person with a learning disability’s request. Withdrawal totally successful. Mirtazapine was then withdrawn by reducing by 50% for 2 weeks then stopped.

Lessons learnt: The person with a learning disability dictated the pace and was involved in all decisions. Good observation from treatment allowed the staff to monitor for behavioural worsening; slow but steady reduction planned and implemented.

A seventy-two year old man with a mild learning disability in Salford Mental Health Foundation Trust on a psychotropic drug review pilot. The overall aim of the pilot is to provide high quality, evidence based services for people with a learning disability and to understand the resources needed to keep patients and carers involved and safe while psychotropic drugs and alternative therapies are considered in the community. A key principle in this work is that people with complex needs are involved in a review led by staff themselves.

Through a data sharing agreement, the CCGs identified the number of people with a learning disability on registers and those on the GP’s with a learning disability register but without a serious mental health diagnosis. A sample of GP practices then carried out a desk-top case review of people in this group using a multi-professional agreed questionnaire.

The questionnaire included the duration of psychotropic drugs prescribed, associated diagnosis or indication and whether other non-pharmacological interventions have been implemented. The findings of this case review will guide the priority with which the person with a learning disability will receive a multi-disciplinary review and the resources that may be needed long term.

A lady with a learning disability (aged 42) was prescribed zuclopenthixol decanoate injection 200mg every 4 weeks for approximately 14 years but the indication for this was unclear from the clinical notes. As part of the people with a learning disability health check, the GP felt this was not needed. Following a review by the learning disability psychiatry team, there were no signs of current mental illness nor mention in the available notes. Although the lady had not experienced side effects on the injection, there was no clear benefit from using this. A review/stop discussion was discussed with the lady. She was reluctant to stop the injection initially, but felt she would give it a try. Following a review, the dose was reduced to 100mg every 4 weeks for 3 months. No deterioration in behaviour has been observed and the plan is for the GP to stop the drug and monitor the situation.

References

This document has been endorsed by the Royal College of General Practitioners, the Royal Pharmaceutical Society, the Royal College of Nursing, the Royal College of Psychiatrists and the Challenging Behaviour Foundation.

This document can be made available in alternative formats such as large print, and may be available in alternative languages, upon request. Please contact Joanne Coleman at joanne.coleman6@nhs.net. Other resources are available for people with a learning disability, their family or carer.