

Publications Gateway Reference 03689

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Dear colleague

The use of medicines in people with learning disabilities

In December 2012, the Department of Health (DH) publication “Transforming Care: A national response to Winterbourne View Hospital” stated that:

“7.31 We have heard deep concerns about the over-use of antipsychotic and antidepressant medicines. Health professionals caring for people with learning disabilities should assess and keep under review the medicines requirements for each individual to determine the best course of action for that patient, taking into account the views of the person wherever possible and their family and/or carer(s). Services should have systems and policies in place for that patient to ensure that this is done safely and in a timely manner and should carry out regular audits of medication prescribing and management, involving pharmacists, doctors and nurses”

When used appropriately, and where there is a clear diagnosis of, for example, psychosis, these medicines can contribute effectively to the treatment of people, including those with learning disability. Medicines such as anticonvulsants are vital to controlling debilitating seizures. However, all these medicines have powerful effects, often with serious side effects. So when they are used, a careful assessment of the risks and benefits must be undertaken. However, and worse of all, some of these medicines can be used wholly inappropriately, as a “chemical restraint” to control behaviour, in place of other more appropriate treatment options.

Unfortunately there is not much evidence to guide practice in this area. Despite a very recent and thorough analysis of the evidence by NICE it would appear that the limited evidence that does exist around adverse effects of antipsychotic treatment in this population reflect the concerns about use in adults with schizophrenia.

The Maudsley Guideline¹ reports on one very large systematic review which quantified risks and benefits of maintenance antipsychotics. The results described

¹ Taylor D, Paton C, Kapur S. The Maudsley Prescribing Guidelines in Psychiatry - 12th edition. Wiley Blackwell

below equate to the following for every 100 adult patients treated with an antipsychotic agent for schizophrenia:

- six will develop movement disorder;
- 10 will develop anticholinergic effects;
- five will develop sedation; and
- five will develop weight gain.

Close links between the use of antipsychotics, stroke and mortality have been reported in patients with dementia^{2,3}. We do not know the extent to which we can extrapolate the findings of studies into side effects of antipsychotics in people with schizophrenia and people with dementia but they are not without risks and are likely to cause significant harm for some individuals with learning disability.

As a consequence of the deep concerns of inappropriate use of these medicines, NHS England gathered together a group of carers, health professionals, policy makers and others to develop together a programme of work aimed at understanding the scale and appropriateness of the use of antipsychotic, antidepressant, anxiolytic, hypnotic and antiepileptic medicines.

The group commissioned three pieces of work:

1. an examination of prescribing of these medicines in primary care by Public Health England (PHE);
2. partnership working with six project sites in England to further understand process and pathways to test new ways of working by NHS Improving Quality (NHS IQ); and
3. an audit of Second Opinion Authorised Doctor information on use of medicines in people detained under the Mental Health Act by the Care Quality Commission (CQC).

Examination of primary care prescribing

This work has identified a high level of inappropriate use of psychotropic drugs in people with learning disabilities.

The study used GP records from the Clinical Practice Research Datalink. This is a well-established system that collects comprehensive, anonymised, clinical data from a large number of general practices throughout the UK for research studies. It covers roughly 8% of the population of England and the data it provides is considered to give a good representation of practice in England.

Among adults known to their GP to have learning disabilities, 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 2.7%. Nearly one third (29.5%) of

² Banerjee S: *The use of antipsychotic medication for people with dementia: Time for action*. A report for the Minister of State for Care Services: Department of Health; November 2009.

³ Douglas I: *Exposure to antipsychotics and risk of stroke: self-controlled case series study*: BMJ 2008;337:a1227

all adults known to have learning disabilities were receiving one or more of these types of drug.

These figures, particularly those for antipsychotics and antidepressants are much higher than the prevalence of psychotic conditions or affective disorders established from research studies and increase progressively with age.

58% of adults receiving antipsychotics and 32% of those receiving antidepressants had no relevant diagnosis recorded. 22.5% of prescriptions for antipsychotics included more than one drug in this class and 5.5% were for doses exceeding the recommended maximum. Based on these figures the authors 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 disorder). This is 16.2% of the adult population known to their GP as having a learning disability.

Rates of prescribing to adults with autism were also high, though the pattern was less clear as numbers were much smaller. Prescribing of drugs acting on the central nervous system to children and young people with learning disabilities and autism was much less common but also had worrying features.

We recognise that these medicines are typically initiated by specialist doctors and only very rarely by general practitioners. Whilst the responsibility for prescribing lies with the practitioner who signs the prescription, it is critical that GPs and specialists work together, through shared care arrangements, to monitor and regularly review patients taking these powerful medicines.

A report of the study is published by PHE on the Learning Disabilities Team website (www.ihal.org.uk).

Pilot improvement project

This project examined medicines practices and related matters in six sites across England which provide care for people with learning disabilities. The staff at each site worked with experts from NHS IQ, carrying out a “deep dive” into their practice. Whilst many examples of good practice were found, there were also some common themes for improvement. For example, patients, carers or families did not always know why medicines had been prescribed and there was evidence of inadequate communication. On the other hand, there was evidence of the benefits, for example multidisciplinary working, and in particular the deployment of clinical pharmacy expertise. The full report has been published by NHS IQ and can be found at www.nhsiq.nhs.uk/winterbourne.

Second Opinion Authorised Doctor information

The CQC has access to data on medication prescribed to people with learning disabilities detained under the Mental Health Act (1983) and who require a second opinion for treatment with medication for mental health, under the provisions of that Act. The data arise from the work of Second Opinion Appointed Doctors (SOADs) who provide a statutory safeguard for such patients. SOADs visit the patient and explore the current and proposed treatment, certifying what is considered to be appropriate and reasonable in circumstances where the patient cannot or does not

consent to it, discussing it with team members and the patient before reaching their conclusions.

The treatment plan is submitted to the CQC when the Second Opinion request is made by the provider clinician. These plans, comprising the types and doses of medication and the reasons given by the doctor for the prescription, together with information provided about the patient's diagnosis, were compared with information and guidelines in the British National Formulary (BNF). It must be recognised that the BNF is a guide, and may be departed from if there are sound reasons. Similarly, many of the medications used in learning disability and considered professionally appropriate may not be specifically licensed for this population and the indications described in the BNF may not cover applicability in this field. This is because the research is relatively limited, and medication manufacturers do not commonly submit information on Learning Disability usage in their product licence application. As a consequence such use may not be cited in the BNF. As an example, autism is not a BNF-recognised indication for prescribing antidepressants, however it is one for which they are widely used according to the literature, though evidence of efficacy is limited. In this survey autism appeared to be a distinct reason for antidepressant use.

The survey identified 945 requests representing 796 individual patients across a 10 month period – some 10% of the total Second Opinion requests submitted in that period. 2/3 were male, mean age 34 yrs. 53% were being treated by an NHS provider, 47% by an independent.

Over half of the prescriptions did not overtly match the accepted indications by reference to the diagnosis. There is published work from specialists in learning disability giving detailed suggestions on medication applicability, however matching these against the data was outside the scope of this survey.

Private hospitals had a higher proportion of patients' prescriptions featuring multiple simultaneous medications of similar type, and in higher doses, compared with NHS hospitals; it is not yet apparent whether this relates to differences in practice, or arises from commissioners referring different diagnostic and prognostic patient groups to different provider types.

In a significant number of cases medication appeared to be prescribed primarily to manage behaviour that was perceived as challenging rather than for symptoms of mental illness.

While the provider's treatment rationale provided some clarification for medication use by expanding on the patient's presentation, in general there was limited rationale offered for the entirety of the treatment plan, particularly when polypharmacy and high dosage was used.

The intervention of the SOAD made changes to the overall treatment plan in some 25% of cases, commonly by restricting the dose total or number of preparations permitted to be used.

The full report will be published by CQC in September.

Next steps

These three reports provide robust evidence of inappropriate use of powerful medicines in people with learning disabilities. This is not acceptable practice and must improve.

To address this we intend to build on the success of a call to action to reduce antipsychotics in dementia by applying a similar collaborative approach to reducing inappropriate use of these and other powerful medicines in people with Learning Disability.

This process begins on 17 July 2015. We have called an urgent action summit to bring together carers and family representatives, professionals, improvement experts and other key interested parties to agree the steps that need to be taken to reduce the inappropriate use of these medicines and improve this aspect of care in people with learning disabilities who are some of the most vulnerable people in our society. We will issue regular updates on this work and call upon your support in addressing this serious issue.

NICE guidance (NG11) <http://www.nice.org.uk/guidance/NG11> published in May 2015, offers guidance on appropriate alternative strategies and interventions.

We have published guidance for those patients and their families and/or carers who may be worried about the medicines they or their loved one is receiving which can be found [here](#).

Yours faithfully



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National Clinical Director for Learning Disability



Dr Keith Ridge CBE
Chief Pharmaceutical Officer

This letter is supported by the following organisations:

