Introduction

The use of medication is but one potential intervention that may, when appropriately used, help to reduce the frequency and severity of challenging behaviour affecting people with learning disabilities. However, given the complexity of, and multiple possible reasons for such behaviours, this information sheet should be read in conjunction with other information sheets in this pack.

Challenging behaviours may occur for multiple reasons and effective intervention is dependent on being able to identify the developmental, biological, psychological, and social factors that may have predisposed to, precipitated, or be maintaining the challenging behaviour in any individual. It is this understanding that informs intervention and this is particularly true when it comes to the use of medication. Superficially similar behaviours may arise for different reasons and therefore intervention is only likely to be effective if the particular reasons in the individual and his/her environment have been identified and interventions tailored for that individual. **Medication should only be prescribed following a proper assessment and where a clear rationale for medication use has been identified.**

There is a long history of excessive and inappropriate use of usually major tranquillising medication (referred to as neuroleptic medication), such as chlorpromazine, for “treating” challenging behaviour. On these occasions the logic appears to have been that someone has been aggressive or self-injurious and therefore needs “tranquillising” and therefore “major tranquillisers” should be used. This is a serious misunderstanding of how medications should be used. The inappropriateness of this type of approach has been confirmed in a recent publication by Tyrer and colleagues in the Lancet. They reported that the routine use of such medication in the management of challenging behaviour brings no additional benefit.

The diagnostic process as a guide to prescribing

Medications used in psychiatric and neurological practice have been developed and tested for the treatment of specific illnesses. For example, this includes anti-depressant medications in the case of depression, anti-psychotic medications for the treatment of psychosis, and anti-convulsants to reduce seizures in the case of epilepsy.

In all of these examples, the efficacy of the particular medications concerned will have been tested using what are referred to as “double-blind placebo-controlled trials” for the...
treatment of the respective illnesses in the general population. They will have been found to be either as or more effective than existing treatments or more effective than a placebo. These medications therefore have been licensed for the treatment of those particular disorders. The list of such medications, the recommended doses and reported side effects are given in the “British National Formulary“, which is updated on a yearly basis.

**Risk benefit analysis**

Given the above, the prescribing of medication requires both a diagnostic assessment and a “risk benefit” analysis. The doctor concerned needs to make a judgement as to whether the likely benefits of the medication outweigh any likely disadvantages with respect to the potential side effects. This is no different from the instigation of any other form of intervention, such as behavioural strategies, where the benefits must be judged to outweigh the potential disadvantages. This always requires a judgement to be made and there will be times when that judgement turns out to be incorrect but such a possibility is minimised if the right procedure is followed.

**Site of action of medication**

The medications used in the context of challenging behaviour affecting people with learning disabilities almost invariably will have their actions on the brain. Oral medications are absorbed through the gut and into the bloodstream. They travel with the blood and those that are able to do so cross over what is referred to as “the blood-brain barrier” and thereby enter the brain.

In the brain, medications will have particular actions, for example, in terms of stabilising brain activity (in the case of anticonvulsants) or by acting on specific receptors that are part of one of many different “neurotransmitter systems”. For example, it is thought that anti-psychotic medication may act on the dopamine systems in the brain and anti-depressants on the 5-hydroxytryptamine (serotonin) systems in the brain.

One of the significant advances in psychiatric practise is that new medications are being developed that have very specific actions on particular neurotransmitter systems that are thought to be dysfunctional in the context of psychiatric illnesses such as depression, schizophrenia, etc.

Given the fact that people with learning disabilities have an increased risk of epilepsy, one concern with some of this medication whose action is on the brain is the possibility that seizure control may deteriorate, or people who previously did not have seizures might have their “seizure threshold“ reduced and therefore increase the risk that seizures might occur for the first time.

In considering whether to use such medication, such factors have to be balanced against the potential benefits, and specific antidepressant medications are thought to be better where epilepsy is a possibility (see risk benefit analysis).

**Length and course of treatment**

In addition to determining what medication to give, it is necessary to determine for what length of time the medication should be given. In practice there are three common situations:
First, medication may be given on a one off basis, for example, in a crisis situation (often referred to as on “a prn” basis). This is the use of medication in the short term to help manage a particular problem and it is only given when that problem occurs. Examples include the use of rectal diazepam or buccal midazolam for the treatment of repeat seizures in a short space of time (“status epilepticus”) or the use of sedative medication when a person is extremely distressed or anxious.

Secondly, medication can be given for a specific period of time to treat an identified illness. The best example of this is outside the field of psychiatry and is the use of antibiotics to treat an infection. In psychiatric practice the use of anti-depressants will usually be time limited depending on response to treatment.

Thirdly, medication may be used over the longer term and sometimes for life. In these cases medication does not ‘cure’ the illness but whilst it is being taken effectively controls it. This may include the use of anticonvulsant medications for treating epilepsy or the long-term use of antipsychotic medication for treating psychotic illness. In these cases, any judgement about the long-term use of medication needs to be made over time and the decision to continue will largely depend on how individuals have responded to medication and whether there is evidence of a relapse when such medication is reduced.

**Medication and challenging behaviour: some general principles**

The prescribing of medication in the context of challenging behaviour affecting a person with a learning disability therefore is a process with specific stages as follows:

1. There should be a detailed analysis of the reasons for a person’s challenging behaviour. This will often require the skills of different disciplines and the collecting of data over time.

2. The bringing together of evidence from the history, often given by an informant, and the examination of a person’s physical and mental state in order to identify whether the person’s challenging behaviour might be occurring in the context of a psychiatric illness, such as that of depression, mania, psychotic illness, or dementia. In addition, physical disorders must also be excluded and such illness, if identified, may also require use of medication, for example, antibiotics to treat infections or the use of painkillers if someone is in discomfort.

3. If a diagnosed psychiatric or neurological disorder is present, then medication may be prescribed that is known to be effective in treating such a disorder. In the case of people with the learning disability who already are likely to have an abnormality of brain function and development, the prescribing of medication whose action is on the brain, needs to be undertaken with care. Starting doses are usually less and have to be increased carefully depending on observations of the person and information from informants.

4. The continued prescribing of medication will depend on the response to treatment and any concerns about the occurrence of possible side-effects. A further ‘risk benefit analysis’ should again be carried out having started medication. In the case of anti-convulsants, outcome measures would include frequency and severity of seizures and in the case of depression, mania, or
psychotic illness whether the person’s mood and mental state had improved. Where the underlying problem (e.g., epilepsy, depression etc.) is thought to be a factor in the cause of the person’s challenging behaviour the relationship between any improvements in the above and the frequency and severity of the challenging behaviour should also be monitored.

5. The regular use of medication should be with the person’s consent (or in the case of a child the parent’s or guardian’s consent) or, if the person lacks the capacity to consent, the medication should be given in line with the legislation of the country where the person is living. In England and Wales this is the Mental Capacity Act 2005 (MCA) and in Scotland the Adults with Incapacity (Scotland) Act 2000. In the case of the former, treatment can be given to a person unable to consent to that treatment if it is considered to be in his/her ‘best interests’*. The MCA 2005 and its Code of Practice sets out how best interests should be determined. In some cases, where the medical treatment is considered to be serious and there are no family or friends to consult, an Independent Mental Capacity Advocate (IMCA) should be appointed. In Scotland and Northern Ireland and in other legislation the conditions set down in common law or in statute should be met.

*Note (from the Mencap heath factsheet – used with permission): ‘Best interests’ is not just what the treating health professional thinks is best for the person, but is about what that person would want if they were able to make their own decision. This should be based on the values, wishes and beliefs of the person with a learning disability, and the treating health professional should consult with relatives and carers about this.

The use of medication to treat ‘specific behaviours’ and in situations of uncertainty

With developments in neuroscience and as our understanding of challenging behaviour improves then there may be the possibility of the use of specific medications under very particular circumstances for the treatment of ‘behaviours’ such as self-injurious behaviour. Already neuroleptic medications and medications that affect pain pathways (naloxone) have been used in the case of severe self-injurious behaviour. This is a complex area and is likely to develop further in the future.

Whilst the diagnostic process should guide prescribing in the field of learning disability this can be problematic. Obtaining the necessary information can be more difficult if the person has limited language and cannot easily describe how they are feeling. It may therefore, on certain occasions, be acceptable to prescribe medication in situations of some uncertainty, providing the rationale is clearly established and the monitoring of outcomes is in place.

The key questions that should always be asked are:

1. For what reasons is the medication being prescribed?
2. What underlying disorder is thought to be present and is it known to respond to medication?
3. What are the potential risks and benefits of such treatment?
4. How will the outcome of the intervention be monitored?
5. For how long and at what dose will the medication be given and what reviews will be undertaken?
6. Has the person given consent, or does he/she lack the capacity to consent and if so is its use in that person’s best interest? Where medication is given, particularly in an emergency, what is the legal justification for such an intervention?

**Common medications in psychiatric and neurological practice**

a) **Antipsychotic medication**

One of the first effective psychiatric medications to be developed was chlorpromazine (Largactil). This medication was shown to reduce the hallucinations and delusions that were known to occur in those affected by major psychotic illness, such as schizophrenia. This and the subsequent “neuroleptic medications” became known as major tranquillisers or antipsychotic medication. There is now a new generation of such medication including, for example, risperidone, olanzapine and quetiapine.

Psychotic illness is generally considered to be a disorder that usually occurs for the first time in adult life and is characterised by a change in the person’s mental experiences, such as the onset of hallucinations or delusions, and/or a deterioration in a person’s ability to think. This can be difficult to diagnose in people with a more severe learning disability but a good history makes it possible to diagnose such illnesses, if they occur, in people with spoken language and less severe learning disabilities.

If there is evidence that a person’s challenging behaviour has developed for the first time in the context of a developing psychotic illness, then the use of such medication is appropriate and is likely to be effective in reducing the abnormal experiences suffered by the person concerned and the associated challenging behaviours.

This group of medications are associated with short and longer-term side effects often affecting the motor systems of the body and leading to some rigidity or tremor. Such risks can be minimised by keeping to the lowest dose and careful monitoring of how much medication is needed.

b) **Anti-depressant medication**

Like the neuroleptic medications, these medications have developed over time and are now generally very effective in the treatment of depression. The most commonly prescribed antidepressants are from the group referred to as the selective serotonin reuptake inhibitors (SSRIs).

Depression is something that can occur during life, and is usually characterised not only by a deterioration in a person’s mood, sometimes with associated tearfulness, but also in a change in sleep pattern, often a loss of appetite (or occasionally an increase of appetite), and a loss in concentration and in general interest. Sometimes there is a diurnal variation whereby someone tends to be worse at a particular time of the day. Depression, particularly in people with learning disabilities, can be associated with increasing irritability and poor concentration and therefore may present with the onset of, or deterioration in, pre-existing challenging behaviours.
Some of the new anti-depressants are also helpful in those with significant anxiety or obsessive behaviours. In choosing which anti-depressant to use, consideration needs to be given to the exact characteristic of the depressive illness, and if anxiety or obsessional features are a key feature, then certain anti-depressant medications may be more helpful than others.

c) Mood-stabilizing medication

A well-recognized psychiatric illness is referred to as bi-polar disorder or manic-depressive illness. Such illnesses are characterised by extreme fluctuations in mood including periods of depression to episodes of ‘hypomania’ or ‘mania’. In the case of hypomania (a lesser form of mania) or mania a person can become very over-active, disinhibited, and irritable.

Treatment of bipolar disorder may include the use of both anti-depressant and major tranquillising medications depending on the person’s mental state. Longer-term treatment could also include the use of specific anti-convulsant medications that have also been shown to be effective in the stabilisation of abnormal mood states and are in this context referred to as “mood stabilisers” (e.g., carbamazepine, sodium valproate and lamotrigine). The medication lithium can also be used.

The use of this medication has to be monitored regularly through the use of blood tests to check levels of the medication in the blood. The reason for this is that, unlike many other medications, the therapeutic level and the toxic levels are close to each other. Also kidney function and the function of the thyroid gland should be monitored where lithium is used as the kidney and thyroid gland can be adversely affected by lithium use.

d) Sedative and anti-anxiety medications

This is potentially a more problematic area for the prescription of medication. As described above some anti-depressant medications can reduce anxiety and may be of considerable value.

The main group of sedative medications are referred to as the ‘benzodiazepines’ and include medications such as diazepam (valium). Their long-term use is not recommended because of the risk of becoming dependent but they are used occasionally in acute situations on a ‘prn’ basis. Where a person has become highly aroused and frightened such medication may be of value as part of an established plan that includes a range of strategies aimed at preventing challenging behaviour arising and managing it when it does occur.

The use of medication under these circumstances must be monitored very carefully and issues of consent or the legal justification for its use carefully addressed.

e) Anti-convulsant and other medications

As described above anti-convulsant medication may also be used as “mood stabilising” medication. However, occasionally challenging behaviour may occur in relationship to seizures. Under these circumstances the treatment of the epilepsy may result in a reduction in the challenging behaviour. Careful observations are required to disentangle the role of epilepsy in such situations but if such a relationship was found to exist, the treatment of epilepsy with anti-convulsants may be useful in reducing challenging
behaviour. There are an increasing number of anti-convulsants and the choice of what to use largely depends on the exact type of epilepsy.

Particularly in older people with Down’s syndrome the onset of the memory and cognitive problems associated with dementia may result in changes in behaviour. Increasingly medications are being developed that may temporarily improve functioning and thereby behaviour. The best known of such ‘anti-dementia’ medication is that of donepezil.

Conclusions

Medication may have a role to play in the treatment/management of challenging behaviour. If it is used it should be for clearly defined reasons and in the context of a specific treatment plan. Special care needs to be taken as people with learning disabilities (or possibly with specific syndromes) may be more at risk for adverse effects. Where challenging behaviour may be due to an underlying psychiatric illness, such as depression, the effective treatment of the depression is likely to be of considerable benefit. Future research in this area is likely to result in the development of further medications that will be of significant benefit in the future in the management of challenging behaviour where there are clearly biological factors that are contributing to such behaviours.

Suggested reading


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We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

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