Problem Behaviour in Adults with Intellectual Disabilities: International Guide for Using Medication

The World Psychiatric Association (WPA): Section on Psychiatry of Intellectual Disability (SPID)

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About this Guide

This guide is produced to provide advice to people who are considering the prescription of medication to manage problem behaviour among adults with intellectual disabilities. This guide has been adapted for an international audience from a national guideline for the United Kingdom (UK) (www.ld-medication.bham.ac.uk). The original UK guide followed the National Institute for Health and Clinical Excellence, UK (NICE, nice.org.uk) criteria on guideline development methods and was assessed using the internationally accepted 'Appraisal of Guidelines for Research and Evaluation' (AGREE, 2001) criteria for guideline development. The guide is based on the available current scientific and clinical evidence, and clinical consensus.

A working group of members of the Section on Psychiatry of Intellectual Disability (SPID) of the World Psychiatric Association (WPA) (see names on page 2) scrutinized the UK guide and developed the International Guide. The International Guide is written in line with the other international guides and documents produced by the WPA such as the 'Psychiatry for the Person' (Mezzich, 2007) and the 'Consensus statement on the use and usefulness of second generation antipsychotic medication' (www.worldpsychiatricassociation.org/content/consensus.shtml).

This guide neither recommends nor refutes the use of medication for the management of problem behaviour among adults with intellectual disabilities. Such decisions must be taken after careful consideration of all the possible benefits and potential risks involved with the intervention. This guide provides certain safeguards if health professionals consider prescribing medication. Health professionals should take this guide into account when exercising their clinical judgment. The guide does not, however, override the individual responsibility of health professionals to make decisions appropriate to the circumstances of the individual situation.

This guide does not consider in any detail the indications for choosing specific medication to manage problem behaviour among adults with intellectual disabilities. Rather, it provides recommendations for clinical practice surrounding the use of medication to manage problem behaviour among people aged 18 years and over with intellectual disabilities. All relevant medication and related issues are considered.

It is acknowledged that there will be considerable variation in service models, training and resources throughout the world therefore not all recommendations would be achievable all the time in all the places. However, as the recommendations in this guide are quite general, the fundamental principles remain the same. It is hoped that by allowing for the resource limitations, the health professionals will try to follow, as much as possible, the recommendations in this guide in their day to day practice.

The aim of the guide is to facilitate the care process, and improve the way that problem behaviour is managed. This should lead to a better quality of life for adults with intellectual disabilities.

Introduction

Different terms such as 'learning disability', 'learning difficulty' and 'mental retardation' are used in different countries but for the sake of consistency we have used the term 'intellectual disabilities' throughout the text. Some adults with intellectual disabilities may display problem behaviour. Problem behaviour in this context is defined as socially unacceptable behaviour that causes distress, harm or disadvantage to the person or to other people or property, and usually requires some intervention. The term 'problem behaviour' in this context incorporates other terms such as 'challenging behaviour', 'behaviour disorder', 'behaviour problem', and

'behaviour difficulty'. Examples of problem behaviour include verbal aggression, physical aggression to self (self-injurious behaviour; SIB), others or property.

General principles underpinning the prescribing of medication

Assessment and formulation

The primary aim of management should be not to treat the behaviour per se but to identify and address the underlying cause of the behaviour. However, it is not always possible to find a cause for the problem behaviour. When this is the case, the management strategy should be to minimise the impact of the behaviour on the person, the environment around her/ him and other people.

There may be many reasons for problem behaviour, including physical or mental health problems. Many factors internal to the person – such as negative childhood experiences, maladaptive coping strategies etc. – and external to the person – such as understimulating or overstimulating environment etc. – may contribute to problem behaviour. Sometimes behaviour may be used as a means of communication. For example persons with severe intellectual disabilities who cannot speak or use a sign language may scream because they are in pain and they can not communicate this message in any other way. Sometimes persons with intellectual disabilities may use behaviour to communicate their likes and dislikes.

Therefore, a thorough assessment of the causes of behaviour and their consequences, along with a formulation, is an absolute prerequisite in managing any problem behaviour (see Appendix 1). A proper assessment and formulation (see Appendix 2) may need input from several disciplines and from families and carers. A multi-axial/ multilayered diagnostic formulation (see DC-LD, UK; RCPsych, 2001 and DM-ID, USA; Fletcher et al, 2007) may be useful in this context. The assessment should include personal, psychological, social, environmental, medical and psychiatric issues.

A formulation should be made even in the absence of a medical or psychiatric diagnosis. The psychiatric diagnosis prior to psychotropic treatment may follow the person-centred approach and the idiographic assessment as recommended by the WPA Institutional Programme on Psychiatry for the Persons (Mezzich, 2007).

Input from the person with intellectual disabilities and their families and carers

A proper assessment and formulation will often depend on input from the person with intellectual disabilities and/or their family and carers. This input should continue at every stage of management. It is important to share information with the persons with intellectual disabilities in a way that they can understand. This may require additional time and effort on the part of the health professionals and other members of the multidisciplinary team. It may also involve using innovative methods of information sharing, such as using pictures.

Multidisciplinary input

Multidisciplinary input may also be needed during implementation and monitoring of the management options. This may not always be possible to achieve because of lack of resources. Where relevant and if possible, an attempt should be made to secure multidisciplinary input to the process of managing problem behaviour.

When to consider medication

If there is an obvious medical or psychiatric cause for the behaviour, this should be managed in an appropriate way. If an underlying psychiatric disorder is treated with medication, the relevant guides governing the use of medication in the treatment of psychiatric disorders should be followed (see WPA, Mezzich, 2007; NICE, UK; www.nice.org etc.).

If no medical or psychiatric disorder can be recognised then non-medication based management should be considered depending on the formulation. Sometimes after considering non-medication based management options, medication may be used either on its own or as an adjunct to non-medication based management.

The exact situation under which medication and/ or non-medication based management strategies should be implemented will depend on individual circumstances, and is therefore not within the remit of this guide (see Appendix 3). However, it may be possible to improve the psychological well-being of the person by providing counselling and addressing social and environmental factors by finding more enjoyable activities to do during the day and use medication simultaneously to make the person concerned less anxious. This strategy may be seen as an interim strategy, which then needs to be monitored carefully at regular intervals to assess its effectiveness.

Monitoring the effectiveness of the intervention

The effectiveness of any intervention and possible adverse effects should be monitored at regular intervals. This should include objective assessments with input from the person with intellectual disabilities and/or her/ his family and carers, and members of other relevant disciplines, where necessary and possible. Examples of assessments include behavioural (both problem behaviour and other behaviours) and adverse effects, reports from families and carers, direct examination of physical and mental state, and if necessary relevant investigations such as blood tests, ECG etc..

An attempt should be made at each stage of monitoring to revisit and re-evaluate the formulation and the management plan. The aim is to prescribe medication, if necessary, at the lowest possible dose and for the minimum duration. Non-medication based management strategies and the withdrawal of medication should always be considered at regular intervals.

Prescribing within Person-Centred Planning

The management of behaviour should always be person-centred. It should be influenced by the person her/ himself and/or her/ his carers and should be designed according to the person's best interests. The prescribing should not take place in isolation but should always be part of a much broader person-centred care plan for the person with intellectual disabilities.

Communication issues

The management plan should be communicated clearly to the person with intellectual disabilities and her/ his family and carers. All other relevant professionals that are involved in the care of the person should be told about the management plan on a need-to-know basis. This process should be updated at regular intervals. Special care is needed and innovative approaches may be required when information about the management is shared with the person with intellectual disabilities and their family and carers.

Legal issues/ Capacity and consent

Management options for problem behaviour must comply with the country's legal framework. The health professionals should always document the assessment of the capacity of the person to give informed consent to the proposed intervention. In the absence of capacity, as much as possible a consensus among the multidisciplinary team and the families/carers should be gathered to decide which intervention is in the best interests of the person with intellectual disabilities. In some countries a substitute decision maker is appointed on behalf of the person who does not have capacity.

Main recommendations

Anyone prescribing medication to manage problem behaviour among adults with intellectual disabilities should follow this good practice.

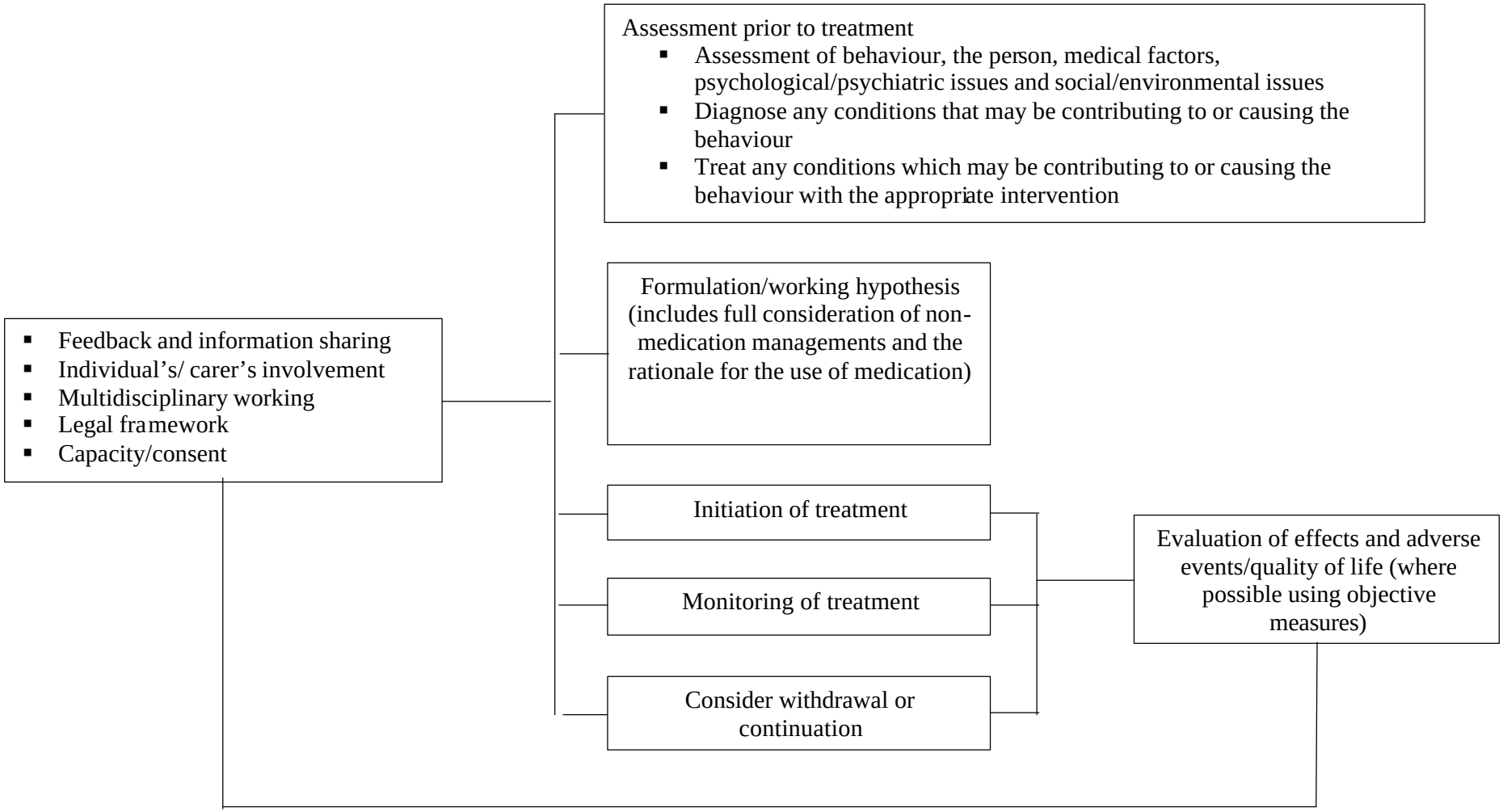
- Medication should be used only in the best interests of the person.
- All non-medication management options should have been considered and medication should be seen as necessary under the circumstances, or alongside non-medication management.
- If possible, evidence to show that the medication is cost-effective should be taken into account.
- Information about which interventions worked before and which did not should be noted.
- If previously interventions produced unacceptable adverse effects, the details should be noted.
- The effect of availability or non-availability of certain services and therapies on the treatment plan should be considered.
- Relevant local and national protocols and guidelines should be followed.

Once the decision to prescribe is taken the following recommendations should be followed.

- Ensure that appropriate physical examinations and investigations have been carried out.
- Ensure that the appropriate investigations such as blood tests and ECG etc. have been carried out at regular intervals and the results are available to the appropriate people.
- Clarify to the person and/or her/his family or carers if the medication is being recommended outside its licensed indication. If this is the case, they should be told about the type and quality of evidence that is available to demonstrate its effectiveness.
- Identify a key person who will ensure that medication is administered appropriately and communicate all changes to the relevant parties.
- If possible, provide the person and/or her/his family or carers with a copy of the agreed recommended treatment plan at the time of prescribing.
- As far as possible, there should be an objective way to assess outcomes including adverse effects (where possible the use of standardised scales or the monitoring of the severity and frequency of the target behaviour is recommended).
- Ensure arrangements for appropriate follow-up assessments have been made and that they take place.
- As far as possible, one medication for the problem behaviour should be prescribed at a time.

- As a general rule, the medication should be used within the standard recommended dose range.
- Above the maximum recommended dose of medication should only be used in exceptional circumstances after full discussion with all the relevant stakeholders under appropriate safeguards and regular reviews.
- Start with a low dose and titrate the dose up slowly.
- Medication should be used at the lowest required dose for the minimum period of time necessary.
- Consideration for withdrawing medication and exploring non-medication management options should be ongoing.

Key processes associated with using medication to manage problem behaviour in adults with intellectual disabilities



Evidence of the risks associated with prescribing medication in adults with intellectual disabilities and problem behaviour

Most medications carry a potential risk associated with adverse events. However, evidence is largely gathered from studies among patients with psychoses who do not have intellectual disabilities. For example, current evidence shows that atypical antipsychotics carry a certain amount of risk relating to weight gain, cardiac abnormalities, and various metabolic abnormalities, including impaired glucose tolerance, lipid metabolism and prolactin metabolism.

There is no good-quality evidence to either support or refute concerns that people with intellectual disabilities may be at greater risk of the adverse effects of medication than people from the general population.

The shortage of good-quality evidence does not mean that medication is associated with an unacceptable risk specifically for adults with intellectual disabilities.

In view of the above, the following general recommendations are proposed.

Adverse events

- Discuss with the person and/or her/his family, carers common and serious adverse events related to the treatment (where possible provide accessible information in writing).
- Also advise what action to take if a serious adverse event takes place.
- All adverse events should be recorded properly.

Choice of medication

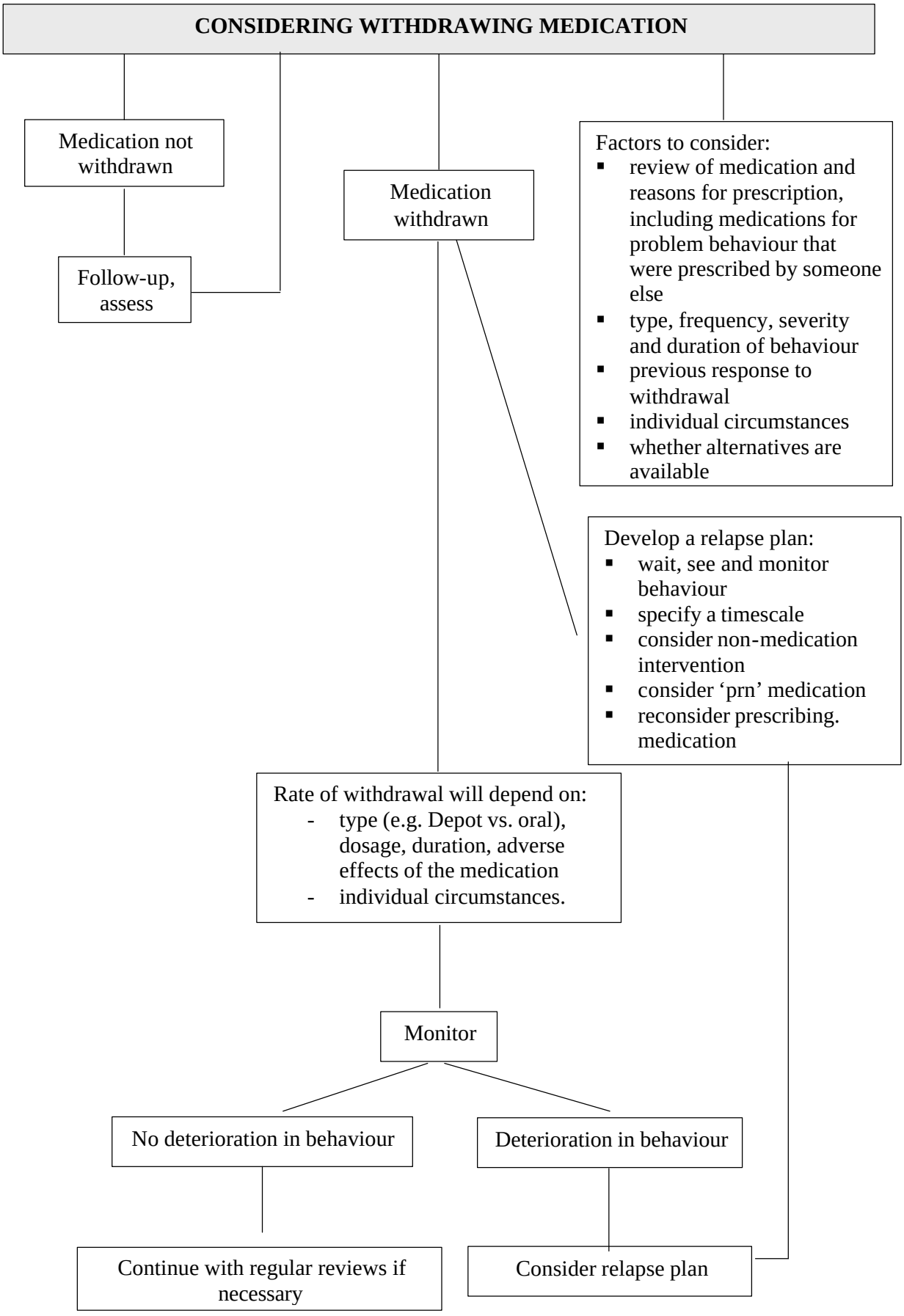
It is not possible to recommend currently specific medication for the treatment of specific problem behaviour because there is no evidence to support such recommendations. However, we have provided in Appendix 4 a list of medication that are used for the management of problem behaviour in adults with intellectual disabilities with their common adverse effects (also see Unwin & Deb, 2008 for a consensus survey in the UK).

Discontinuation of treatment

- Once a medication is prescribed, the risk-benefit profile should continue to be evaluated regularly, with particular emphasis on the person's and her/his family carers' quality of life.
- Consideration of a reduction in the dose or withdrawing the medication and exploring non-medication management options should be ongoing.

In instances where the behaviour re-emerges after reducing the dose or withdrawing the medication

- There should be a relapse management plan in place when considering medication withdrawal (see flow chart on page 10).
- Be aware of the withdrawal effect of certain medication and allow adequate time for that to settle before reconsidering the use of medication.
- Always consider non-medication based interventions and re-assess the initial formulation and rationale for using the medication.


CONSIDERING WITHDRAWING MEDICATION
Medication not withdrawn
Follow-up, assess
Medication withdrawn
Factors to consider:
review of medication and reasons for prescription, including medications for problem behaviour that were prescribed by someone else
type, frequency, severity and duration of behaviour
previous response to withdrawal
individual circumstances
whether alternatives are available
Develop a relapse plan:
wait, see and monitor behaviour
specify a timescale
consider non-medication intervention
consider 'prn' medication
reconsider prescribing. medication
Rate of withdrawal will depend on:
- type (e.g. Depot vs. oral), dosage, duration, adverse effects of the medication
- individual circumstances.
Monitor
No deterioration in behaviour
Deterioration in behaviour
Continue with regular reviews if necessary
Consider relapse plan

Poly prescribing

It is not uncommon for people with intellectual disabilities to take medication for a wide variety of disorders and illnesses. However, the term poly prescribing in this document is used to describe the prescribing of more than one medication for a particular indication, in this case problem behaviour.

Evidence to support poly prescribing

There is a lack of studies of combinations of psychotropic medications to manage problem behaviour among adults with intellectual disabilities. Therefore, it is not possible to recommend any combination of medication as enhancing the efficacy of medications prescribed on their own. However, the evidence based on observational studies suggests that the reduction in poly prescribing not only improves behaviour but also the quality of life of the person for whom medication is prescribed.

In the light of this, the following recommendations are made.

If an add-on medication is indicated, the recommendations include

- If the add-on medication is ineffective, reassess the situation.
- If the first medication is to be continued, the reasons for continuing to use more than one medication simultaneously for the same indication must be recorded.
- The use of an add-on medication from the same medication category is not recommended (the exception is anti-epileptic medications for the treatment of epilepsy).
- If the combination is effective, try to withdraw or at least reduce the dose of one of the medications at a future date.
- Always consider the option of either a non-medication intervention or using such an intervention in combination with the medication.
- Try to return to monotherapy as soon as possible.
- Avoid using more than two medications simultaneously for the same indication.
- More than two medications should only be used under exceptional circumstances.
- Try to secure another clinician's opinion if more than two medications are to be used simultaneously.
- The use of more than three medications simultaneously is difficult to justify unless they are used for other indications, such as simultaneous epilepsy or psychiatric disorder.

Evidence to support withdrawing medication that has been prescribed for a long period

Studies of withdrawing medication show that, in a proportion of cases, the medication can be successfully withdrawn after a long period of use. In a proportion of cases, the dose can be reduced, although total withdrawal is not possible, and in some cases, it is difficult to even reduce the dose of medication after a long period of use. Many factors affect the success of withdrawal of medication, including non-medical factors such as the training and the attitude of care staff. However, on the basis of such evidence it is not possible to recommend which medication to withdraw and how, but the following general recommendations are proposed.

The person on one or more medication for a long period of time to manage problem behaviour

- Try to stabilise the person's problem behaviour on a minimum number of medications prescribed at the lowest possible dose, or no medication.
- Follow the recommendations given in the 'Discontinuation of treatment' section of this guide.
- Withdraw one medication at a time.
- Withdraw medication slowly.
- If necessary, allow time (sometimes a few weeks) after withdrawing one medication and before starting to withdraw another.

Appendix 1: The assessment

(This list is not a comprehensive but a broad scheme. Not all assessments will be required in all circumstances)

An assessment should address

- The behaviour of concern.
- The person.
- Medical and organic factors.
- Psychological factors.
- Psychiatric factors.
- Social factors.
- Environmental factors.

Assessment of the problem behaviour should take the following factors into account

- The type and nature of the problem behaviour(s).
- Past history of problem behaviour.
- Baseline behaviour prior to the onset of problem behaviour.
- The onset of the problem behaviour(s).
- The frequency, severity and duration of the problem behaviour(s).
- Associated problem behaviours and other behaviours.
- The impact of the problem behaviour(s) on the person's life, other's lives and the environment.
- Reaction to the problem behaviour by the person/ others/ services.
- Function of the problem behaviour.

Risk assessment

- The type and the nature of risks:
    - risk to others
    - risk to the individual
    - risk to the environment
    - other risks including offending history
- Methods of risk assessment such as use of rating scales etc.
- Previous risk assessment.
- Review record of risks assessment at a regular interval.

Assessment of the person

- Strengths – abilities, opportunities, resources.
- Needs – impact of disabilities, service and resource gaps in their lives, mental and physical health needs.
- Likes, dislikes and preferences and how these are expressed.
- Personal history – social, developmental, psychological.
- History of use of services.
- Difficulties in developing fulfilling relationships, lives or interests.

In this context, it is helpful to have a description of the individual's current and past weekly routine.

Medical and organic factors

- Acute medical/ dental problem (tooth ache).
- Chronic physical conditions (Chronic bronchitis).
- Medical conditions (heart disease).
- Epilepsy.
- Other neurological conditions (spasticity).
- Genetic conditions (Lesch Nyhan syndrome).
- Sensory impairment (visual and hearing impairment).
- Communication problems (speech and communication).
- Physical disabilities (paralysis).
- Illicit drug and alcohol-related factors.
- Prescribed medications (adverse effects of prescribed medication).
- Relevant developmental and medical history.

Psychological/psychiatric factors

- Psychiatric disorders (depression).
- Relevant history of psychological development (maladaptive coping strategy).
- Psychological/ emotional issues, such as bereavement, relationship, abuse etc..
- New/ongoing/recurrent stress.
- Difficulty in developing fulfilling relationships.
- Developmental disorders, like Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD), including impulsivity.
- Neuropsychological factors.
    - impaired intelligence
    - impaired memory
    - impaired attention
    - impaired or abnormal communication skills
    - impaired executive function
    - impaired frontal lobe function, such as lack of initiative and apathy
    - lower threshold of stress tolerance.

Social and environmental factors

- Description and assessment of the environment (living condition such as an inappropriate accommodation) and daily activities.
- Factors relating to other people around the person, including staff/carers.
- Change in the environment.
- Influence of life events.
- Relationship with peer group, friends, family members and care staff (including any changes).
- Effect of the daily activities (including any changes).
- Effect of (or lack of) leisure and day activities (including any changes).
- The organisational setting – systems and procedures (system to monitor care within an organisation, training for the care staff etc.).
- Absence of appropriate/adequate support for the person and their family or carers.
- Under or over stimulating environment.
- Lack of (or opportunity for) appropriate social exposures.
- Issues relating to integration within the wider society, stigmatisation and discrimination.
- Carer issues, including levels of stress and lack of support for carers.

Appendix 2

As a general rule the formulation should consist of the following

- A list of the target problem behaviour(s) to be managed.
- A clear description of the problem behaviour, including frequency and severity.
- An assessment of the problem behaviour(s) and its causes.
- A differential diagnosis of causes giving rise to the problem behaviour.
- A record of reactions to and outcomes of the behaviour.
- An assessment of predisposing, precipitating and perpetuating risk factors.
- Consideration of all management options and their outcome.
- The rationale for the proposed management option.
- A risk assessment.
- Possible adverse effects from the proposed intervention(s).
- The likely effect of the proposed intervention(s) on the person's quality of life.

Appendix 3

Below are some of the situations under which the clinicians may consider using medications

- Failure of non-medication based interventions.
- Risk/ evidence of harm/distress to self.
- Risk/ evidence of harm/distress to others or property.
- High frequency/severity of problem behaviour.
- To treat an underlying psychiatric disorder or anxiety.
- To calm the person to enable implementation of non-medication based interventions.
- Risk of breakdown to the person's placement.

- Good previous response to medication.
- Person/carer choice.

The guide does not recommend the lack of adequate or available non-medication based interventions should be the reason for using medication but acknowledges that in practice this may happen. The guide recommends as much as possible this practice should be stopped or at least minimised. Under these circumstances the medication should be used for as short a period as possible.

Appendix 4

Commonly used psychotropic medications, their dosage, adverse effects and necessary investigations.

Antipsychotics

Commonly used *Typical antipsychotics* are chlorpromazine (more sedating), haloperidol (more extrapyramidal adverse effects), thioridazine (restricted use in the UK).

Possible adverse effects are extrapyramidal symptoms such as acute dystonia (acute opisthotonous-arching of body backwards), Parkinsonian symptoms (tremor, stiffness etc.), akathisia (external and internal restlessness), dystonia (slow movement), and tardive dyskinesia (TD; long term adverse effect; abnormal movements starting with oro-facial muscles but may also affect limbs and shoulders). Also dry mouth, blurred vision and constipation. Other adverse effects are cardiac and sexual dysfunction, and metabolic such as raised prolactin level. Serious adverse effect is neuroleptic malignant syndrome (NMS; primarily autonomic disturbance such as high temperature, high blood pressure, muscle stiffness; confirmatory investigation includes raised muscle CPK level; treatment involves immediate withdrawal of antipsychotics and symptomatic treatment).

Atypical antipsychotics are risperidone, olanzapine, quetiapine, clozapine, aripiprazole, piperidone, amisulpride, zotepine and sertindole (restricted use in the UK). These drugs affect D2/4, 5HT, also alpha, H1, histamine etc. receptors.

Possible adverse effects are extrapyramidal symptoms, NMS, metabolic syndrome, such as glucose intolerance (leading to diabetes mellitus), hyperprolactinaemia, hyperlipidaemia, and weight gain. Other adverse effects are drowsiness, agranulocytosis (particularly associated with clozapine), cardiac arrhythmia (prolonged QT interval) and sexual dysfunction. Most antipsychotics are epileptogenic (clozapine in high doses is particularly bad for this) but atypicals are probably slightly better than the typicals in this respect.

Common investigation necessary for these medications are BP, weight, Full Blood Count/ Total Blood Count (FBC/TBC), Liver Function Test (LFT), Renal Function Test (RFT), serum electrolytes, lipid profile, blood glucose, Electrocardiogramme (ECG/EKG), serum prolactin level etc..

Antidepressants

Old generation of antidepressants are amitriptyline, clomipramine, imipramine etc..

Possible adverse effects are dry mouth, constipation, blurred vision, hypotension, (cholinergic adverse effects), cardiac failure and fatality associated with overdose.

Common investigations necessary for prescribing these medications are FBC/TBC, RFT, serum electrolytes, LFT and ECG/EKG.

New generation antidepressants are Selective Serotonin Reuptake Inhibitors (SSRIs) such as fluoxetine, fluvoxamine, sertraline, citalopram, escitalopram, paroxetine, mirtazapine and venlafaxine, which is a Serotonin and Nor-adrenaline (nor-epinephrine) Reuptake Inhibitor (SNRI). Others are duloxetine, flupentixol, reboxetine and tryptophan.

Possible adverse effects of these medications are agitation, sleep problem, sexual dysfunction, withdrawal problem, serotonin syndrome (associated with SSRIs), increased risk of suicidal ideas.

Common investigations necessary are FBC/TBC, LFT, RFT, serum electrolytes and ECG/EKG (for venlafaxine).

Mood stabilisers

Lithium

Possible adverse effects are tremor, renal failure, thyroid dysfunction, confusion in toxicity.

Common investigations necessary are serum lithium level (in order to adjust the dose and detect toxicity), FBC/TBC, RFT, serum electrolytes and Thyroid Function Test (TFT).

Antiepileptics

Carbamazepine

Possible adverse effects are drowsiness, double vision, ataxia, hyponatraemia and skin rash (may lead to Stevens-Johnson syndrome).

Investigations necessary are FBC/TBC, LFT, serum electrolytes and RFT.

Sodium valproate (valproic acid/semisodium valproate)

Possible adverse effects are drowsiness, weight gain, hair loss, skin rash, ataxia and liver function failure in rare cases. Teratogenecity should be kept in mind if used in women in childbearing age.

Investigations necessary are FBC/TBC, LFT, serum electrolytes and RFT.

Beta blockers such as atenolol and propranolol in high doses as well as anti-anxiety drugs such as diazepam have been used for problem behaviour. The use of benzodiazepine such as the diazepam is restricted for short period of use (6 to 8 week). Opioid antagonists such as naloxone (intramuscular or intravenous preparations) and naltrexone (oral preparations) have been used particularly to treat severe self-injurious behaviour (SIB). However, evidence for their efficacy is equivocal.

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