

So...no medication...what now?

- The doctor should be planning to talk to other professionals in the Learning Disability team about what they can do to help. This should lead to a detailed assessment of the challenging behaviour to identify any health, psychological, environmental, communication and social factors that could be contributing to the behaviour. Getting a full understanding of the reasons behind the behaviour is the key to changing it.
- The assessment should result in the development of a **Behaviour Support Plan**.

Behaviour Support Plan

A Behaviour Support Plan details all the things everyone can do to reduce the cause and impact of the challenging behaviour.

- You can ask about referring directly to the wider Learning Disability team for a Behaviour Support Plan if you do not think the doctor is doing this.

If medication forms part of this plan, it should be used for the shortest possible time with clear agreement about what specific areas are being targeted (eg sleep or restlessness).

In the meantime...

It may feel like things are taking a long time to change. There are things that you can do in the meantime to help speed the process up.

Think about whether the person you care for could be physically unwell in any way. Are there signs of pain or infection or seizure changes? It is worth asking the GP to help you check for this. Sometimes there are 'hidden' problems such as urine, ear or dental problems.

Keep monitoring sheets to record the behaviours. Ask the doctor for some of these and make sure everyone is filling them in. The more details that you can give the team about the behaviours, the more likely and quickly the right help can be given. Keeping a sleep chart and detailed seizure records can also be helpful.

Think about whether there are things going on around the person you care for that could be upsetting or confusing them. Have there been any changes recently? Talk to other people who spend time with the person and prepare a list of any of these changes (however small) to help speed up the assessment.

Has the person you care for had any input from any of the Learning Disability professionals before? Look for any previous assessments, reports, training notes and recommendations. These may include a communication, psychology, nursing or Occupational Therapy report. These could have some useful ideas to try which may have been forgotten over time.

Think about whether there have been any medication changes recently. Take a list of all medication to all doctor appointments, including the use of any extra medication you have needed to use. (PRN or as required)

Take any incident forms, care plans and risk assessments (if you complete them) to all appointments with professionals.

Contact the psychiatrist, Learning Disability team or GP in between appointments if there is a serious incident that puts the person you care for, or others, at serious risk.

Look after yourself. Remember that you will be seen as an essential part of the team that can help improve the current problems. Sharing information and constantly trying out different ways of caring for and working with someone can be tiring.

Not everything will work straight away. Sometimes a lot of effort is needed to only produce a small change in behaviour.

Share your frustrations and concerns with the doctor or Learning Disability team. There may be training or carer support that could help you to help others.

Further reading and support:

www.england.nhs.uk/learning-disabilities/stomp

Psychotropic drug prescribing for people with an Intellectual Disability.

www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf

Preparing for a visit to the doctor to talk about psychotropic medication. VODG. Sept 2017.

www.vodg.org.uk

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No Medication...? Why...?

Medication might not be the best thing to help people with learning disabilities or autism who are showing challenging behaviours



Introduction

- When someone we care about is showing behaviours that are worrying and difficult to manage (challenging behaviours) we want an answer. We want the behaviours to change or stop as soon as possible.
- You may have been waiting to see the doctor for a while and now you are told that medication, at this stage, is not the answer you were hoping for.

Carers in this position often feel or say the following:



This leaflet is to help you understand why medication hasn't been given at this stage and to give ideas on what else could help instead.

Medication or not?

- Just because you haven't come away with a prescription, doesn't mean that the doctor thinks the problem is any less serious.
- There are a lot of serious symptoms, conditions and behaviours for which there isn't a medication cure but that still need treatment in different ways.
- The decision not to prescribe medication is not based on cost. Most medication used is not expensive.
- Each person showing behaviour changes will be doing so for different reasons. Unlike some other conditions, there is not one standard medication type that treats challenging behaviour.

What's the problem with giving medication?

- There is a concern that sometimes doctors are prescribing too much medication for challenging behaviours in the same way that they sometimes prescribe too many antibiotics.

Have I wasted my time?

- No. You will have given the doctor a lot of useful information that they will be considering to decide on the best way of helping. You have not wasted your time or the doctor's time and you are a step closer to getting the right help.

When should medication be used?

- If challenging behaviour is being caused by mental illness (eg depression, anxiety, psychosis, mania,) there is likely to be an effective medication to help treat this illness.

- If the behaviour is thought to be linked to epilepsy or physical health problems, it is appropriate to prescribe medication to treat these conditions (eg antiepileptics, pain killers, antibiotics.)
- However, often the challenging behaviour is not a symptom of one of these illnesses, but a person's way of showing that something else is wrong.

Could the medication do harm?

- Medication that is used to treat a person's mind or mental state is called PSYCHOTROPIC medication. This includes antidepressants and antipsychotics.
- All psychotropic medication has side effects.
- Antipsychotics have some serious side effects which people with a learning disability or autism may be especially sensitive to. These include sleepiness, weight gain, movement problems and blood pressure / heart problems.
- Sometimes the use of psychotropic medication can do more harm than good if it is not used for the right reasons.

Recent studies have shown that...

- Medication is being given to 'treat' challenging behaviours even when the cause of the behaviour is not clear.
- In most cases of inappropriate prescribing, the drugs are just acting as a sedative (making the person sleepy) rather than actually doing anything to sort out the underlying problems.
- There is no evidence that the routine use of medication in the management of challenging behaviours brings additional benefits.

- Public Health England¹ estimates that every day 30,000 to 35,000 adults with a learning disability are being prescribed a psychotropic medication without an appropriate clinical reason.

What do guidelines say?

- A recent project by NHS England called STOMP² (Stopping the Overmedication of People with Learning Disabilities, Autism or both) is focussing on trying get a reduction in the inappropriate and sometimes harmful use of psychotropic medication.
- NICE (National Institute for Health and Care Excellence)³ produced some clear guidance in 2015. This was based on looking at all the research evidence. They recommend that antipsychotics should only be considered if;
 - Psychological or other interventions alone do not produce change, or
 - Treating any underlying physical or mental illness has not improved the symptoms, or
 - The risk to the person or others is very severe (e.g. extreme aggression or self injury.)
- NICE also emphasise that if medication is used, it should only be done so in combination with psychological or social interventions.
- This means that we shouldn't be looking for a 'quick fix' or a 'magic bullet' for managing challenging behaviours, but should be looking at much wider, longer term ways of helping.

References

¹ Public Health England Report 2015. Follow the link for full report at www.gov.uk/government/news/people-with-learning-disabilities-over-prescribed-psychiatric-drugs

² NHS England www.england.nhs.uk/learning-disabilities/stomp

³ NICE www.nice.org.uk/guidance/ng11

