

STOMP

Stopping over-medication of people
with a learning disability, autism or both

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Top Tips for Advocates

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VoiceAbility

**HOW YOU CAN HELP TO STOP
THE OVER-MEDICATION OF
PEOPLE WITH A LEARNING
DISABILITY, AUTISM OR BOTH**

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On an average day in England, between 30,000 and 35,000 adults with a learning disability, autism or both are taking a prescribed psychotropic medication when they do not have a diagnosed mental health condition.

Public Health England

The problem of over-medication

STOMP stands for stopping the over-medication of people with a learning disability, autism or both. Specifically, the campaign is about the use of psychotropic medication.

People with a learning disability, autism or both are more likely to be given psychotropic medications than other people. These medications affect how the brain works. They include medications for psychosis, depression, anxiety, sleep problems or epilepsy. Sometimes they are given to people because their behaviour is seen as challenging. The evidence that psychotropic medication can help with challenging behaviour is poor.

Psychotropic medication can cause side effects such as:

- significant weight gain
- feeling tired or 'drugged up'
- severe constipation or bowel obstruction
- serious problems with physical health, including organ failure.

Research by the Learning Disabilities Mortality Review (LeDeR Programme) and others has shown that the inappropriate use of psychotropic medications can be a significant contributory factor, or the cause, of a person's death.

Use of psychotropic medication can be especially concerning if people take them for too long, take too high a dose or take them without good reason. Psychotropic medications are helpful for some people at some times. For many other people and in many circumstances, there are different ways of helping so that the person needs less medication or none at all.

MORE ABOUT THE STOMP CAMPAIGN

Visit [england.nhs.uk/stomp](https://www.england.nhs.uk/stomp) for helpful resources including videos, case studies, pledges for both healthcare and social care providers and an Easy Read overview leaflet.

The solution: you're part of it!

Advocacy can play a critical role in ensuring that people's views about their medication are heard, that their rights are upheld and they are supported to make their own choices and enjoy a good life. This guide explains how you can make a difference.

Top tips: at a glance

1 KNOW YOUR ROLE

Understand your role as an advocate in relation to the use of medication and in supporting people to have a better life.

2 LEARN ABOUT BEST PRACTICE IN SUPPORTING PEOPLE WHOSE BEHAVIOUR CHALLENGES

Understand relevant approaches for supporting people and the guidelines and restrictions on the use of psychotropic medication.

3 FIND OUT WHAT MEDICATION PEOPLE ARE TAKING

Support people to find out what medication they are on, to understand it and to ask questions about it. Do this on the person's behalf when appropriate.

4 LOOK AND LISTEN

Be aware of common side effects of taking psychotropic medication, and look out for these.

5 ASK ABOUT HEALTH AND SENSORY CHECKS

If someone's behaviour has changed, exploring any health and wellbeing issues underlying this could reduce the need for psychotropic medication.

6 GET THE RIGHT INVITATIONS

Be in the right places to support the person you advocate for, if he or she wants you to.

7 SAY SOMETHING!

Support people to raise any concerns about their medication, or do this on the person's behalf when appropriate.

8 SECOND THAT

Support people to ask for a second medical opinion about medication where they want to do so. Do this on the person's behalf when appropriate.

9 THINK SAFEGUARDING

If you think that a misuse of medication constitutes abuse or that a vulnerable person is at risk of abuse, notifying the local authority of a safeguarding concern may be the right thing to do.

10 ASK FOR SUPPORT

Do discuss medication concerns during supervision with your line manager.

Top tips guide

1. KNOW YOUR ROLE

Understand your role as an advocate in relation to the use of medication and in supporting people to have a better life.

Your role in relation to psychotropic medication is the same as in all other areas of advocacy. You are there to enable the person:

- to understand the situation and their rights in it
- to express their views and preferences and ensure that these are fully taken into account in decisions
- to challenge decisions (or where needed do so on the person's behalf)
- to have more choice and control and to live a better life.

Supporting people with medication issues can fall into the role of every advocate – it's not confined to advocates working with inpatients. The majority of people with learning disabilities, autism or both are not in hospital. They are usually prescribed medication by their GP.

In some circumstances, Independent Mental Health Advocates (IMHAs), Independent Mental Capacity Advocates (IMCAs) and Care Act Advocates may have to take action about psychotropic medications in order to fulfil their legal duties.

- **IMHA:** You must support people to raise issues about the use of medication if they are concerned about this. You must also raise concerns yourself on request and for people who do not have the capacity to ask you to do this for them but who would be well served by you doing so.
- **IMCA:** Consider whether a particular use of psychotropic medication constitutes Serious Medical Treatment under the Mental Capacity Act – if so the person is entitled to an IMCA or appropriate adult.
- **Care Act:** If the person wants you to do so, ask about the use of medication in assessments, care plans and reviews. You must also ask about this for people who do not have capacity to ask you to do this for them but who would be well served by you doing so. If the person does not have the capacity to challenge a decision made during an assessment, planning or review of their care, including a decision about medication, you must do so if you think that the decision does not promote the individual's wellbeing.

There is more detail about these legal provisions in the supplement to this guide, available at voiceability.org/for-professionals/stomp

2. LEARN ABOUT BEST PRACTICE IN SUPPORTING PEOPLE WHOSE BEHAVIOUR CHALLENGES

Understand relevant approaches for supporting people and the guidelines and restrictions on the use of psychotropic medication.

The Challenging Behaviour Foundation's Pathway Resource (see inset box) is a clear and well-presented resource, which you can use with people with a learning disability, autism or both, their loved ones and professionals to help address over-medication.

The NICE guidance document 'Challenging behaviour and learning disabilities: prevention and interventions' (see inset box) gives recommendations on the care of people with learning disabilities, autism or both whose behaviour challenges, including the use of medications. The guidance is that psychotropic medication should only be used for challenging behaviour if:

- psychological or other interventions alone do not reduce the challenging behaviour within an agreed time, or
- treatment for any mental or physical health problem has not led to a reduction in the behaviour, or
- the risk to the person or others is severe (for example because of harming others or self-injury).

The guidance also makes it clear that when providing support and interventions for people with a learning disability and behaviour that challenges, independent advocacy must be offered to the person and to their family members or carers, as described in the Care Act, Mental Capacity Act and Mental Health Act.

Positive Behavioural Support (PBS) is one approach that supports many people with learning disabilities whose behaviour challenges. It can reduce or prevent the perceived need for medication. Advocates should have at least a general understanding of PBS so that they can explore the extent to which it may help.

POSITIVE BEHAVIOURAL SUPPORT

Positive Behavioural Support (PBS) is a person-centred framework for providing long-term support to people with a learning disability, and/or autism, including those with mental health conditions, who have, or may be at risk of developing, behaviours that challenge. It is a blend of person-centred values and behavioural science and uses evidence to inform decision-making.

PBS focuses on understanding when and why a person is likely to behave in a certain way, in order to change events, circumstances and support to the individual so that the person can lead a fuller and more enjoyable life.

Find out more:

skillsforcare.org.uk/Topics/Learning-disability/Positive-behavioural-support/Positive-behaviour-support.aspx

RESOURCES RELATED TO CHALLENGING BEHAVIOUR

Challenging Behaviour Foundation Pathway Resource: medication.challengingbehaviour.org.uk

Challenging Behaviour Foundation Family Resources: challengingbehaviour.org.uk/supporting-you/for-families

Challenging behaviour and learning disabilities: prevention and interventions (NICE guidance) nice.org.uk/guidance/ng11

Learning disabilities and behaviour that challenges: service design and delivery (NICE guidance) nice.org.uk/guidance/ng93

Care Management Group STOMP Best Practice Guide: careengland.org.uk/news/stomp-best-practice-guide-cmg

What can I do about challenging behaviour? Learning Disability Professional Senate Guide: www1.bps.org.uk/system/files/user-files/DCP%20The%20Faculty%20for%20People%20with%20Intellectual%20Disabilities/public/STOMPleafletfinal.pdf

3. FIND OUT WHAT MEDICATION PEOPLE ARE TAKING

Support people to find out what medication they are on, to understand it and to ask questions about it. Do this on the person's behalf when appropriate.

Ask people what medication they are on. If the person does not know then support them to get this information if they want to. Support the person to raise any questions that they want to ask. If the person lacks the capacity to tell you whether or not they want you to find out about or ask about medication, then do so if it would be in their best interests to do so and they do not object.

Find out more about particular medication using authoritative websites such as easyhealth.org.uk, and by asking the person's Support Worker or a more senior member of staff. Support Workers or other more senior members of support staff should be asking the person's doctor (GP or Consultant) the following questions. As an advocate, you can encourage this to happen and support the involvement of the person. In some circumstances it may be appropriate for you to support the person directly. This will depend on your particular role and working relationships.

Useful questions include:

- Why is this medication prescribed - does the person have a confirmed diagnosis and if not, what is the rationale and evidence for using the medication? How is it meant to help?
- What side effects are common and uncommon?
- How do you measure if it is working? What monitoring and review arrangements should there be and what is actually in place?
- Is the use of this medication the least restrictive option? What other options are there? There should be documentation to say that alternative options have been properly explored.
- Has the person had a physical health check for other issues that could be contributing to any behaviour which challenges (e.g. dental checks, sensory checks etc.)? See Tip 5 below for more suggestions about this.

Review what you have learned against the Challenging Behaviour Foundation's Pathway Resource to make sure the right checks and processes are in place – or will be.

Remember, some uses of psychotropic medications to manage challenging behaviour in people with a learning disability are 'off-label' for a licensed medication. This means it is being given for something other than the purposes authorised for that medication.

4. LOOK AND LISTEN

Be aware of common side effects of taking psychotropic medication, and look out for these.

Psychotropic medications can cause side effects including:

- significant weight gain
- feeling tired or 'drugged up'
- severe constipation or bowel obstruction
- serious problems with physical health, including organ failure.

Professionals assessing whether someone's psychotropic medication is causing unacceptable side effects might talk about

their GASS scale rating (see ncbi.nlm.nih.gov/pubmed/18541624) which is determined following a self-assessment questionnaire – make sure you have seen this where relevant and agree with the approach used to complete it. Help the person to understand and be fully involved in the assessment whenever possible and to ask how unwanted side effects can be minimised.

Psychotropic medication, like physical intervention and seclusion, can be a restrictive practice. This is because it can limit someone's freedom. For example, if someone experiences sedation as a side effect, this impacts on their ability to go out and do the things they enjoy. Therefore, when medication is suggested, less restrictive options should also be considered.

5. ASK ABOUT HEALTH AND SENSORY CHECKS

If someone's behaviour has changed, exploring any health and wellbeing issues underlying this could reduce the need for psychotropic medication.

Think about people's health and wellbeing in general. If someone has an undiagnosed or untreated health condition that is painful or uncomfortable, this might be the reason why his or her behaviour has changed or is challenging. Dealing with an underlying issue could reduce the need for psychotropic medication.

You may need to consider:

- Have health professionals considered all possible general health checks and health screenings? Have health checks been taking place annually as a minimum?
- Have health professionals considered all possible sensory issues?
- Does the person have a health action plan?
- Is the person getting support with diet and exercise?
- Is the person getting any support they need in relation to mental health?
- Is there a restrictive practice in place that could be affecting the person's behaviour?

6. GET THE RIGHT INVITATIONS

Be in the right places to support the person you advocate for, if he or she wants you to.

Think about how you can work best with the person and with their family and professional networks. For example, make sure that you are invited to attend Care and Treatment Reviews and other meetings that focus on the health and wellbeing of the person. Raise medication issues when relevant.

Although it is part of your role to challenge professionals, you want them to see you as someone who makes a constructive and useful contribution and therefore someone they need to invite to meetings about the person.

A key part of your role at meetings is making sure that the person understands decisions taken at these meetings, and are as fully involved in the decisions as they are able to be. The Challenging Behaviour Foundation's Pathway Resource will help you with this.

7. SAY SOMETHING!

Support people to raise any concerns about their medication, or do this on the person's behalf when appropriate.

Support the person to say something about their medication if they are concerned and do so on the person's behalf when they want you to. Do so if you believe you should in order to support the person's wellbeing but they lack capacity to tell you to do so and do not object.

It is important to understand as much as you can about the situation, the given reason for the medication and any relevant related issues. But just as you don't need to be a weather forecaster to know which way the wind blows, you don't need clinical training to ask questions when someone appears to have rapidly put on weight or their speech has become slurred. Be respectful but don't be bamboozled or silent.

RESOURCES TO HELP WITH DISCUSSIONS WITH CLINICIANS

VoiceAbility's Challenge Guidance explains options for challenging professionals' decisions with or on behalf of people: voiceability.org/for-professionals/challenge-guidance

STOMP resources for professionals who make or are involved in prescribing decisions: england.nhs.uk/learning-disabilities/improving-health/stomp/professionals/

Step-by-step guide for support workers on discussing medication with a GP: vodg.org.uk/publications/preparing-to-visit-a-doctor-to-talk-about-psychotropic-medication/

Information about commonly prescribed medication, their use and side effects: [easyhealth.org.uk/categories/medicines-\(leaflets\)](https://easyhealth.org.uk/categories/medicines-(leaflets))

Leaflet on alternatives to medication (produced by British Psychological Society): bps.org.uk/search/google/stomp%20leaflet

Description of 'diagnostic overshadowing': when symptoms of physical illness are attributed to someone's mental illness: journals.rcni.com/mental-health-practice/diagnostic-overshadowing-a-potential-barrier-to-physical-health-care-for-mental-health-service-users-mhp2013.12.17.4.22.e862

TV clip about the impact of medication and the STOMP programme (from BBC Breakfast): youtube.com/watch?v=pewyD6Z6czU

STOMP videos (produced by Derbyshire Healthcare NHS Foundation Trust with support from NHS England): youtube.com/playlist?list=PL4shZXQ9YqmIFPJX02IWJvhHqdrMf_EkO

8. SECOND THAT

Support people to ask for a second medical opinion about medication where they may want to do so. Do this on the person's behalf when appropriate.

If you are at all uncomfortable about the decisions that are being made or the approach

that professionals are taking, do think about obtaining an alternative view. There is not a right to a second opinion, but it is good practice for a clinician who has taken a decision to agree to seeking a second opinion.

9. THINK SAFEGUARDING

If you think that a particular misuse of medication constitutes abuse or that a vulnerable person is at risk of abuse, notifying the Local Authority of a safeguarding concern may be the right thing to do.

There may be situations where an advocate witnesses the frequent use of psychotropic medications to 'calm' residents. This sedation could impact on the person's ability to go out and do the things they enjoy and could

deprive someone of their liberty. It could be an indicator of poor care, if more appropriate care options and sufficient suitably skilled staff are not apparent. In such situations, as well as requesting a review of the individual's care plans, you might in some circumstances also need to raise a safeguarding alert and a concern with CQC. You should discuss these issues with your manager.

There is further information about safeguarding in the supplement to this guide provided at voiceability.org/for-professionals/stomp

10. ASK FOR SUPPORT

Do discuss medication concerns during supervision with your line manager.

Supporting people in relation to medication can be difficult and all treatment decisions can be emotional for those involved. It is important to get practical advice and opportunities to reflect on the situation and develop your own practice.

HOW ADVOCACY CAN MAKE A DIFFERENCE: AN ILLUSTRATIVE STORY

Sati was a lively young person who loved meals out, dancing and horses. Sati became increasingly distressed over a period of months, culminating in her banging her head against the wall several times a day. Though Sati communicated using a variety of sounds and a small number of Makaton signs, no-one could work out what was causing her to be so upset.

Deeply concerned, the staff at her supported living service helped Sati to see first a GP and then a psychiatrist. The psychiatrist prescribed Sati Risperidone to take daily and Diazepam to be given as and when needed. She did not diagnose a mental health disorder but was clear that it would be cruel to Sati to let the situation go unchecked. Over the months ahead, Sati's head-banging became far less frequent. However, she seemed to have lost her joy for life, was reluctant to do the things she used to love and put on an unhealthy amount of weight.

Two years later and still on the medication, Sati was assigned an advocate to help her participate in a review of her care plan. Learning about the changes in Sati's life, the advocate asked questions about why the medication was being prescribed, if it was working and what other less restrictive approaches might be taken to support her. This triggered the Care Manager to make a referral to the Community Learning Disability Team.

Over the following four months, that team carried out an assessment of Sati's behaviour to understand why it might be happening. They developed a Positive Behavioural Support plan with Sati and worked with the staff team on its implementation. This was aided by the information that the advocate had helped Sati and others to communicate about what she enjoyed now and in the past.

The team liaised with the psychiatrist, who reviewed her medication and agreed a reduction plan, confident in the knowledge that Sati had support from other less restrictive approaches.

This booklet was written by VoiceAbility, with support from NHS England.

It is intended to assist both advocates and health and social care professionals. It may also be helpful to people who are being prescribed psychotropic medication and their families.

There is further information in the supplement to this document, which is available at voiceability.org/for-professionals/stomp

This booklet and accompanying documents are intended to provide helpful tips. They ought not to be relied upon as a statement of the law or as advice on health or medical matters.



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