STOMP
Stopping Over Medication of People with Learning Disabilities, Autism or both

Presentation for CBNSG Getting it right, whose responsibility?

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June 16. 2017
The Goals of STOMP

1. Improve the quality of life of children, young people and adults with a learning disability, autism or both, who are prescribed psychotropic drugs.
2. Make sure people only receive these drugs for the right reasons.
3. And in the right amount.
4. Improve understanding of these drugs and when they should, or should not.
5. Improve understanding of non-drug treatments and support which may help.
6. Make sure that people work with their doctor and the people who support them in making any changes to treatment.
Medicines Project Core Message

Public Health England estimates that every day 30,000 to 35,000 adults with a learning disability are being wrongly prescribed an antipsychotic, antidepressant or both. These are psychotropic drugs.

Unnecessary use of these drugs, puts people at risk of significant weight gain, organ failure and even premature death.
A human rights issue

- If you are drugged up, you can’t communicate with people properly
- The world passes you by
- It’s a way of restraining people
- It can make your behaviour more challenging in the long run
- It doesn’t help you learn or change
- It doesn’t help you get out of hospital, the opposite in fact
- People shouldn’t be living like that
STOMP – It’s time to change

• This is about improving people’s lives
• This is about helping people live longer and giving families more time with their loved ones
• This is about stopping the use of these drugs to manage people’s behaviour

Stop Over Medicating People with learning disabilities, autism or both – STOMP it out!

www.england.nhs.uk/learningdisabilities
Make psychotropic drugs the last resort for managing behaviour that challenges

They should only be considered for managing behaviour if -

• psychology or other therapies do not help within an agreed time or
• treatment for a mental or physical health problem has not improved the behaviour or
• the risk of harm to the person or others is very severe

Psychotropic drugs are only used in combination with psychology or other therapies.

Adapted from the NICE guideline [NG11] Published date: May 2015 ‘Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges’

www.england.nhs.uk/learningdisabilities
Reducing the use of psychotropic drugs

- Psychotropic drugs should always be prescribed at the lowest possible dose, for as short a time as possible.
- Non-drug treatments and the withdrawal of psychotropic drugs should be considered regularly at treatment reviews.
- If the person’s condition does not improve, the choice and use of medicines should be managed to avoid adding more drugs on top of existing ones.

Adapted from the International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities


www.england.nhs.uk/learningdisabilities
Are these good enough reasons to leave people over medicated?

- ‘He has just been admitted’
- ‘We have just got her stable’
- ‘We are just getting him ready to move on’
- ‘We need to give her time to adapt to the community’
- ‘Everything is currently going well - don’t rock the boat’
The time to start reducing the use of psychotropic drugs is now

You can do it

- A study in 2014 looked at the effects of controlled withdrawal of antipsychotics used for challenging behaviour
- 98 people took part
- 43 people were successful in stopping completely
- At follow-up only 7 people had been put back on antipsychotics

Effects of controlled discontinuation of long-term used antipsychotics for behavioural symptoms in individuals with intellectual disability

www.england.nhs.uk/learningdisabilities
The STOMP Pledge

The STOMP pledge was signed at a summit in London on 1 June by

- Royal Colleges of Nursing, Psychiatrists and GPs
- Royal Pharmaceutical Society
- British Psychological Society
- The Minister Alistair Burt

And supported by the Challenging Behaviour Foundation

They have pledged to work together and with people with a learning disability autism or both and their families, to take real and measurable steps to stop over medication
Royal Colleges/Societies Pledge

Stopping over medication of people with learning disabilities (STOMPLD)

Over-medication, and then lack of review, is a historic problem, but one that nobody knew the true scale of until recently.

It is estimated that on an average day in England, between 30,000 and 35,000 people with a learning disability are being prescribed powerful drugs, with serious potential side effects, without clinical justification and for too long. This is often despite evidence-based alternative interventions being available.

This inequality in care is unacceptable, and it is incumbent on clinicians and every other professional involved in an individual’s care to make sure they are acting in their patient’s best interest at all times.

We, the undersigned, representing professionals from across the NHS, therefore pledge to work together, and with people with a learning disability and their loved ones, to take real and measurable steps to stop over-medication.

We will each set out the actions our individual organisations will take towards this shared aim, and report regularly on the progress we have made – ensuring that we can be held to account.

Endorsed by

The British Psychological Society
Promoting excellence in psychology

The Rt Hon Alistair Burt MP
Minister of State for Community and Social Care

Supported by the Challenging Behaviour Foundation

www.england.nhs.uk/learningdisabilities
Guidance to GPs - STOMP GP advice flyer

STOPPING OVER-MEDICATION OF PEOPLE WITH LEARNING DISABILITIES

(STOMPwLD) 2016
Social Care Provider Pledge

STOMP

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

“If you help people to take the right medication, then their quality of life will be closer to how they want it to be.”

Carl Shaw, Learning Disability Advisor, NHS England

Providers are signing the STOMP campaign at https://www.vodg.org.uk/campaigns/stompcampaign/
Pledge for Social Care today.

Supported by NHS England
STOMP pledge for social care

We pledge to act in the best interests of the people we support at all times by:

• Actively promoting alternatives to medication such as active support, intensive interaction or positive behaviour support.
• Ensuring the people we support, and their circle of support, are involved in decisions about their care, including their medication.
• Ensuring all staff have an understanding of psychotropic medication, including its main uses and side effects.
• Encouraging staff to speak up if they have a concern that a person we support may be overmedicated.
• Maintaining accurate records about the health, wellbeing and behaviour of the people we support.
• Supporting people to have regular reviews of their medication.
• Monitoring the use of psychotropic medication.
• Working with people with a learning disability, autism or both, their families, health professionals, commissioners and others to stop overmedication. This includes working closely with prescribers.

We will set out the actions we will take and report annually on the progress we have made.

www.england.nhs.uk/learningdisabilities
Steps providers might take

• Make your commitment to STOMP known
• Review all relevant staff training
• Involve people with a learning disability, autism or both in the delivery of training
• Audit the use of psychotropic medication
• Monitor trends in the use of PRN medication
• Review your medication policy
• Consider what resources you need to keep everyone safe through a medication reduction programme
• Share your learning and good practice
Workshop

• a. Discuss your organisation and the roles associated with psychotropic medication

• b. Discuss potential ways you or your organisation could further the aims of STOMP

• c. Agree Actions (10 minutes) (NB these will be recorded - two specific actions for the plenary session, who will do them and when)
Why are psychotropic drugs used in learning disabilities and in autism?

• Antidepressants use to treat depression and anxiety
  • Depression and anxiety are common however some antidepressants were thought to be useful in autism

• Antipsychotics used to manage psychosis and schizophrenia
  • Widely used to manage aggressive and other challenging behaviours

• Anxiolytics used to manage anxiety
  • Widely used for short term management of aggressive behaviours

• Mood stabilisers (also called antimanic drugs) use to manage mood and Bipolar illness
  • Widely used to manage mood swings and challenging behaviours

• Stimulants used to manage attention deficit hyperactivity disorder (ADHD)
  • Hyperactivity is common in children with learning disabilities and autism

• Hypnotics used to manage sleep
  • Sleep problems common in children with learning disabilities and autism