

STOMP

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

NHS
England

The Autism Professional
Annual Conference

March 2018
Hazel Griffiths



Hazel's story



- How my son ended up in an ATU and overmedicated
- How it felt to me as a nurse and a mum
- Finding alternatives to medication
- How my son is now
- Sharing the learning
- What am I doing about it now as part of the STOMP work?

The Goals of STOMP



1. **STOMP** is a health campaign to stop the over use of psychotropic drugs and manage people's behaviour.
2. Improve the quality of life of children, young people and adults with a learning disability, autism or both who are prescribed **psychotropic** drugs.
3. Make sure people only receive these drugs for the right reasons and in the right amount.
4. Improve understanding of these drugs and when they should, or should not be used
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 when making any changes to treatment.
7. Make sure people have regular medication reviews.

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!

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
Deb S et al ,World Psychiatry. 2009 Oct; 8(3): 181–186

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 From Pledge to Action

- STOMP is part of transforming care programme and came about after the Winterbourne review which raised deep concerns around overuse of psychotropic medicines.
- STOMP is supported by royal colleges, organisations in social care and NAS have all signed up to the STOMP pledge.
- So far 150 social care organisations have signed up supporting over 50,000 people
- Signing a pledge document is all well and good.
What does this mean in practice?
Commitment
Actions
- STOMP is currently working on a Healthcare provider pledge which will officially be launched in April 2018

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.

Hazel Watson

NHS
England

[Signature]



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Psychological Society
Promoting excellence in psychology

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ROYAL
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Royal College of
General Practitioners

[Signature]

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

[Signature]



Royal College of Nursing
Shaping nursing since 1916

[Signature]



Supported by the Challenging Behaviour Foundation

Aim For Providers

- To develop a PLEDGE specific to all healthcare providers (NHS + Independent sector)
- To develop commitments linked to the pledge
- To develop measureable outcomes that can demonstrate that the pledge commitments make a difference
- To pilot the pledge, commitments and outcomes in selected organisations
- To launch the pledge to all providers
- To monitor the pledge commitment and make STOMP everyone's business
- To appoint a STOMP champion within each organisation

Challenges

- For example 2000 people may need a STOMP review across the NE region – many in primary care
- Awareness of STOMP is low among patients, carers, families and primary care teams
- GP confidence to review medication is low – this may result in multiple referrals
- Information sharing with primary care is poor
- We do not always adhere to the NICE NG11 principles when starting and reviewing medication
- Monitoring rates are variable (less than 50% in some areas)
- Awareness of alternatives to medication is poor (PBS)
- Social care providers are being trained to challenge for a STOMP review – patient power to force the agenda

What can YOU do?



- Check
- Use Psychotropic medicines wisely, only when needed, review, remove when no longer of any benefit.
- Information for people and families.
- Work together
- Alternatives to medication (PBS)
- Raise awareness-organisation/individual action

Social Care Toolkit



Preparing to visit a doctor

To talk about psychotropic medication

Resources and websites



- Websites about STOMP
- VODG <https://www.vodg.org.uk/>
- NHS E
<https://www.england.nhs.uk/learning-disabilities/stomp/>



England

- Available resources
- VODG, preparing to visit doctors leaflet.
- VODG Social care pledge tool and guidance.
- NHS England GP prescribing guidance leaflet
- NHS England antipsychotics leaflet
- NHS England Overview leaflet