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

Autism and Mental Health Conference

September 2018

Hazel Griffiths
David Gerrard
Why have STOMP?

- Public Health England says every day about 30,000 to 35,000 adults with a learning disability are being given psychotropic medicines when they do not have a diagnosed mental health condition. This is often to manage behaviour which is seen as challenging.
- It includes medicines used to treat psychosis, depression, anxiety, sleep disorders and epilepsy.
- These medicines are right for some people, but over medication or using them for the wrong reason puts people at risk of weight gain, health problems and even premature death.
Aims

1. Improve the quality of life of children, young people and adults with a learning disability, autism or both, who are prescribed psychotropic medicines.

2. Make sure people are only given them for the right reason, in the right amount, for as short a time as possible.

3. Improve everyone’s understanding of these medicines and give everyone the confidence to ask why they are needed.

4. Make more non-drug treatments and support available.

5. Make sure the person with their family and paid carers are involved in any decisions to start, stop, reduce or continue taking them.

www.england.nhs.uk/stomp
In 2016 the call to action led to a STOMP pledge to stop over medication by:
• Royal Colleges of Nursing, Psychiatrists and GPs
• Royal Pharmaceutical Society
• British Psychological Society
• NHS England
• Then Minister Alistair Burt
Since then, other bodies have signed up including the Learning Disability Senate, Voluntary Organisations Disability Group (VODG), the Royal Colleges and Associations for social workers, speech and language therapists, music, art and drama therapies, dietetics and occupational therapists

www.england.nhs.uk/stomp
New CBF resources for carers

visit medication.challengingbehaviour.org.uk

For information and advice each step of the way

Find out how to order a printed copy of the **Medication Information Pack** from the Challenging Behaviour Foundation at www.challengingbehaviour.org.uk/contact
A pledge for social care providers led by VODG was launched in 2017.

More than 160 providers have signed up who support about 50,000 people. Visit [www.vodg.org.uk/campaigns/stomp campaign](http://www.vodg.org.uk/campaigns/stomp campaign)

A best practice guide produced by the Care Management Group (CMG) was also launched in 2017.
And now a pledge for healthcare providers
• To look for other ways of supporting people, such as PBS training for support staff, talking therapy and doing things that help people feel better

• To make sure people, families and carers know about the medicine and are involved in decisions about the person’s care

• To make sure staff know about the medicine too, such as why it is being used and what the side effects can be
Pledge for healthcare providers

• To make sure people can speak up if they have a question or are worried about the medicine
• To keep good records about the person’s health, wellbeing and behaviour
• To follow all the laws and rules about how the medicine is used
• To work with people with a learning disability, autism or both, their families, care teams, health professionals, commissioners and others to stop over medication

www.england.nhs.uk/stomp
Coming soon – for children and young people

- STOMP-STAMP – supporting treatment and appropriate medication in paediatrics.
- The Royal College of Paediatricians & Child Health and the Academy of Childhood Disability partnering with NHS England, with other pledge partnerships under development.
- STOMP-STAMP is led by the NHS England Children and Young People’s team for learning disability, autism or both.
- Expected launch in the Autumn.

www.england.nhs.uk/stomp
Inspired by Hazel’s son - the brilliant STOMP play from MiXit

Coming soon – a 10 minute film based on this
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?
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
We Support STOMP network for STOMP leaders

A place to find or share resources and advice about making STOMP work in your organisation or group

How to join:
Create an account at www.source4networks.org.uk

Search for #wesupportSTOMP
or email emmastark@nhs.net
who will send you an invite to join the group
Everyone can get involved in some way

Visit [www.england.nhs.uk/stomp](http://www.england.nhs.uk/stomp)

Or email [england.wesupport.stomp@nhs.net](mailto:england.wesupport.stomp@nhs.net)
The NHS England
learning disability programme

Visit www.england.nhs.uk/learningdisabilities

- Ask Listen Do
- STOMP – stopping over medication with psychotropic drugs
- Care (Education) and Treatment Reviews
- Annual health checks
- Summary care records
- Right Care for people with epilepsy, heart disease and swallowing difficulties
- Quality Checkers
- Transforming Care
- Always events
- Mortality reviews
- and more
Background

- Reason for medication
- Past attempts to reduce
- Physical health information
- Target behaviours with outcome measures
- Availability of alternatives (PBS)
Opinions + Concerns

• Person taking medication
• Carers and family
• Explore fear of challenge
• Advice and reassurance
• STOMP literature and case studies
• Link to CBF
STOMP

PROCESS

Medication(s)

Just list psychotropic medications and their length of use if known together with known changes in dose etc.

Indication/behaviours

Specific behaviours (if known) – frequency, severity and triggers
Explore if any behavioural support plan in place – list interventions

Patient Opinion (useful to have meds in the review to show specific tablets by colour/shape)

Is their medication working?
What do they take it for?
Check for taste and swallowing issues
Side effects – consider GASS if antipsychotic – see form
About changes to medication – what do they want to happen
Past attempts at medication changes - outcome

Care/Carer Family Opinion

How well is the patient – known issues and changes in presentation
Opinion of how well the medication appears to control behaviour
Side effect burden
Specific behaviours that are witnessed – frequency and severity

Care Setting – Environment-Stability

Staff turnover
Client turnover
Unsettled clients
Building works etc.
Specific times – Christmas etc.

Carer Expertise

PBS trained
Staff knowledge of individual clients
Staffs awareness of support plans for behaviours

MSE - Appearance, Speech, Mood, Risk, Perceptions, Thoughts, Insight

Monitoring

Antipsychotics – FBC, U+Es, LFT, TFT, Lipids, Glucose/HbA1c, Prolactin, BP, Weight, Pulse and ECG if cardiovascular issue (or concomitant QTc prolonging meds)

Plan

Capture changes to medication with reasons
ISSUES OF NOTE

**CHOLINERGIC REBOUND**
- Flu-like illness
- Abdominal cramps
- Runny nose
- Excessive lacrimation
- Hypersalivation
- Dyspepsia

**OTHER**
- Prolactin normalisation
- Sexual drive
- Need for contraception

**DISCONTINUATION EFFECT**
- Rebound dyskinesia
- Rebound akathisia
- Rebound dystonia
- Relapse in behavioural control
- Emergence of undiagnosed mental illness
STOMPM

RESULTS TO DATE

- Each client has 4.7 reviews on average
- 47% completely free of medication
- 37% undergoing reduction without incident
- 15% needed to be restarted/increased
- Average in research to date 45% (our figure 84%)
- The difference is PBS
RESULTS TO DATE

TYPES OF MEDICATION

- Risperidone 48%
- Quetiapine 9%
- Olanzapine 5%
- Aripiprazole 26%
- Amisulpride 4%
- Antidepressant 4%
- Benzodiazepine 4%
- Antidepressant 4%

REDUCTION IN SIDE EFFECTS

- Weight: Pre reduction 38, Post reduction 20
- Sedation: Pre reduction 24, Post reduction 15
- EPSE: Pre reduction 12, Post reduction 8
- Dizziness: Pre reduction 28, Post reduction 20
- GI: Pre reduction 20, Post reduction 4
- Prolactin: Pre reduction 20, Post reduction 4
Eddie is 34 and has cerebral Palsy and severe learning disability

- Taken risperidone for 15 years 1mg BD – no mental health diagnosis
- Prolactin 3000+ - no attempt at dose reduction
- No tolerance of physical health monitoring
- Behaviours grabbing at others causing superficial injury and moaning
- NO support plan and staff fixated on medication
- Referred to PBS then to STOMP
Graph showing incidents of behaviour occurring between June 16 and July 17 alongside reduction of Risperidone

Number of incidents of behaviours

Date

Jun-16 | Jul-16 | Aug-16 | Sep-16 | Oct-16 | Nov-16 | Dec-16 | Jan-17 | Feb-17 | Mar-17 | Apr-17 | May-17 | Jun-17 | Jul-17

Moaning | Grabbing | Pulling hair | Moaning - sensory | Grabbing - communication | Dose of Risperidone

0 | 50 | 100 | 150 | 200 | 250

0 | 0.25 | 0.5 | 0.75 | 1 | 1.5 | 2

Moaning | Grabbing | Pulling hair | Moaning - sensory | Grabbing - communication | Dose of Risperidone
CASE STUDY 2

- Sam is 28 and has taken Risperidone for 4 years.
- Challenging behaviour – verbal and physical aggression together with self injury – head banging and skin picking and anxiety with noted forensic history
- Lives in a specialist autism provider
- TD linked to zuclopenthixol?
- Family anti-medication challenge
- Good physical health – no issues of note
- Medication
  - Risperidone 0.5mg daily
CASE STUDY 2

Behavioural change with medication reduction

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Baseline</th>
<th>Stopping</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self hitting</td>
<td>25</td>
<td>34</td>
<td>4</td>
</tr>
<tr>
<td>Slapping</td>
<td>10</td>
<td>23</td>
<td>2</td>
</tr>
<tr>
<td>Nipping</td>
<td>17</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Screaming</td>
<td>91</td>
<td>99</td>
<td>54</td>
</tr>
</tbody>
</table>
STOMP

LESSONS

- It can be done!
- Use of alternatives
- Data driven - behaviours can increase or decrease
- Engagement of staff and family
- Levers to overcome anxiety - PHM
- Quality of life improvements

- Time
- Environmental changes
  - Service users
  - Staff change
  - Staff reluctance
- Availability of full MDT
- Initial fear and lack of awareness
- Primary care reluctance
- Scale of the issue
<table>
<thead>
<tr>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rc Psych Prescribing Guidance</strong></td>
</tr>
<tr>
<td><a href="http://www.rcpsych.ac.uk/systempages/gsearch.aspx?cx=005217297982068972824%3aqhx0tmhjcsy&amp;cof=FORID%3a9&amp;q=stomp">http://www.rcpsych.ac.uk/systempages/gsearch.aspx?cx=005217297982068972824%3aqhx0tmhjcsy&amp;cof=FORID%3a9&amp;q=stomp</a></td>
</tr>
<tr>
<td><strong>VODG Website</strong></td>
</tr>
<tr>
<td><a href="https://www.vodg.org.uk/campaigns/stompcampaign/">https://www.vodg.org.uk/campaigns/stompcampaign/</a></td>
</tr>
<tr>
<td><strong>British Psychological Society</strong></td>
</tr>
<tr>
<td><strong>BILD PBS Video</strong></td>
</tr>
<tr>
<td><strong>NHS ENGLAND STOMP PAGE</strong></td>
</tr>
<tr>
<td><strong>Challenging Behaviour Foundation</strong></td>
</tr>
<tr>
<td><a href="http://www.challengingbehaviour.org.uk">http://www.challengingbehaviour.org.uk</a></td>
</tr>
<tr>
<td><strong>You Tube STOMP Videos</strong></td>
</tr>
<tr>
<td><a href="https://www.youtube.com/playlist?list=PL4shZXQ9YqmiFPJX02lWJvhHqdrMf_EkO">https://www.youtube.com/playlist?list=PL4shZXQ9YqmiFPJX02lWJvhHqdrMf_EkO</a></td>
</tr>
<tr>
<td><strong>GP Guidance document</strong></td>
</tr>
<tr>
<td><strong>Frith prescribing guidelines</strong></td>
</tr>
<tr>
<td><strong>Maudsley Prescribing Guidelines</strong></td>
</tr>
</tbody>
</table>
STOMP

THANK YOU