What can I do about challenging behaviour?

This leaflet is for anyone supporting a person with a learning disability who is engaging in behaviour that is challenging.

STOMP

Stopping the overmedication of people with a learning disability, autism or both

February 2018
Introduction

What is this leaflet about?

This leaflet is for anyone supporting a person with a learning disability who engages in behaviour that is seen as challenging. It outlines five key areas to check as a first step to giving help.

NHS England has found that many people with learning disabilities are sometimes inappropriately prescribed medication for behaviours seen as challenging. For many people the medication does not work and can lead to serious side-effects such as sedation, weight gain and difficulty moving. We need to change this situation and review the use of medication if it is not working.

One of the reasons for this overmedication seems to be that people do not know what else they can do to help. This leaflet explains more about some of these other things that we know can work to reduce challenging behaviour.

What can I do about behaviours that challenge?

We have outlined five key areas to check as a first step to helping with behaviour seen as challenging. These areas are:

1. Support for physical health
2. Communication
3. Activities
4. Support for mental wellbeing
5. Positive Behaviour Support

If you already have plans for helping someone in these areas then you should review them to make sure they are up to date and are still being used. If you do not have plans for any of these areas then you should develop them. In each area there are links to resources to help you do this.

If you need help reviewing, developing or implementing these plans then your local learning disability team should be able to give you advice. Your GP, other health
professional or social worker should be able to put you in touch with your local learning disability team.

**Don’t stop taking medication without advice**

It is important that you do not stop or change any medicines without getting professional medical advice first because this could be dangerous. Some medicines can be very effective in treating some people with learning disabilities when used appropriately.

If you are worried about your medication then ask for a review from the person responsible for prescribing it. This will usually be a GP, psychiatrist, specialist doctor, pharmacist or nurse prescriber.

There is a leaflet available from the Voluntary Organisations Disability Group (VODG) website to help you prepare for a visit to the doctor to discuss your medication.

**NHS England’s STOMP Programme**

NHS England has developed a programme called STOMP. This stands for “Stopping overmedication of people with a learning disability, autism or both”.

STOMP is about making sure people get the right help for challenging behavior. This means getting psychological and other interventions first or at the same time as medicine. It is about encouraging people to have regular medication reviews if they are given medicine, supporting health professionals to involve people in decisions and showing how families and social care providers can be involved.

Medications that are often given for challenging behaviour include antipsychotics, antidepressants, anti-anxiety medications, sleeping medications and antiepileptics (when they are used purely for a person’s mood). When used with people who engage in behaviours that challenge they need to be used cautiously, for the shortest time possible and reviewed regularly.

More information about STOMP and a number of helpful resources can be found on NHS England’s website.
1. Support for physical health

In general, people with a learning disability have poorer physical health than other people and often live shorter lives. Many of the powerful medications prescribed for behaviour that challenges can often make this ill health worse. If someone feels ill, is in pain, cannot do things the way they usually do or feels uncomfortable then they are more likely to engage in behaviour that is seen as challenging.

Health Action Plans and Annual Health Checks with a GP are two ways of helping people maintain and improve their physical health.

Some questions to consider:

- How confident are you that the person's health needs are being met?

- Are there any signs the person is in pain or ill?

- Do they have an up to date Health Action Plan?

- Have they had an annual health check with their GP?

- Do they need an eye or hearing test?

- Are there any signs of poor dental health or do they have a history of dental problems? Has the person had a dental check-up?

Some useful resources:

Mencap information on Health Action Plans

NHS information on Annual Health Checks
2. Communication

Most people with learning disabilities have some communication difficulties. These can often be hidden or overlooked. If people are having difficulty understanding others or making themselves understood, they are more likely to be confused and anxious. This makes them more likely to engage in behaviour that challenges.

Implementing good communication is proactive and ethical as it reduces the need for reactive and restrictive interventions.

Some questions to consider:

- How confident is everyone supporting the person about being able to communicate with them?
- Does everyone understand what the person is trying to say?
- Is everyone able to adapt their communication so the person understands them?

Some useful resources:

- Mencap information on communicating with someone with a learning disability
- British Institute for Learning Disabilities resources on communication
- Royal College of Speech and Language Therapists good communication standards
3. Activities

Keeping busy with meaningful activities is an important part of life for most people. People with learning disabilities often need to find, access and take part in activities they would like to do. If they are not given support to do this, they can feel anxious, frustrated and confused, which may make it more likely that they will engage in behaviours that can be seen as challenging.

Supporting someone with activities can seem very difficult – people often feel unsure about what help to give and what to say. There are tools that can help with this, for example Active Support. Active Support is one way of enabling people with learning disabilities to engage more in their daily lives. Active Support changes the style of support from ‘caring for’ to ‘working with’. It promotes independence and supports people to take part in their own lives.

Some questions to consider:

- What sorts of things is the person getting to do day to day?
- Do you know what things they like to do? Are they getting to do them?
- What sort of help can be given to best help engage someone?
- Does the person have a person-centred plan to help people know how to engage them?
- Is routine important to the person and do they have a routine that they like? Has the routine changed at all?

Some useful resources:

ARC information on Active Support

United Response resources on Active Support

British Institute for Learning Disabilities leaflet on Active Support
4. Support for mental wellbeing

Mental wellbeing is important for everyone. If a person with a learning disability also has poor mental health, they may be more likely to engage in behaviours seen as challenging. Some of the ways you can support someone with their mental wellbeing are by helping them:

- Connect with others and spend time developing relationships.
- Be active in any ways they can
- Learn new skills

This means that it is important to focus on the key areas outlined in this leaflet (physical health, communication, activities) all the time, not just when someone is engaging in behaviours that challenge. This will help with their mental wellbeing and protect against the development of challenging behaviour.

If someone has a known specific mental health problem, such as depression or psychosis, it is important they get the right sort of help. For longer term mental health difficulties, this help will be through a care plan for the person or those supporting them. Sometimes people need additional help from their GP or a mental health professional.

Some questions to consider:

- Are you helping someone with their mental wellbeing all the time, not only when they are engaging in behaviours seen as challenging?
- Does the person have a known specific mental health difficulty?
- Do you have a care plan for how to help them with this?
- Do they need to be reviewed by their GP or a mental health professional to help with this?

Some useful resources:

- [NHS information on improving mental well-being](#)
- [British Psychological Society report on psychological therapies for people with learning disabilities](#)
5. Positive behaviour support

Positive Behaviour Support (PBS) is recommended in a range of guidance as the best way of helping with behaviours that challenge. PBS should be used before any medication is considered.

The overall aim of PBS is to improve the quality of a person's life and that of the people around them. PBS involves someone having their behaviour thoroughly assessed to understand why it happens. This is usually carried out by a specialist in a care provider organisation or by a health professional (e.g. someone in the Community Learning Disability Team).

A ‘formulation’ (this is an overview of the why the challenging behaviour happens) is developed from the assessment. This is then turned into a Positive Behaviour Support Plan. This outlines all the things that can be done by the person with a learning disability, and the people supporting them, to make the challenging behaviours less likely to happen. It also says what to do if the behaviours that challenge do occur.

All the key areas covered in this leaflet should be part of a Positive Behaviour Support Plan.

Some questions to consider:

- Does the person have a Positive Behaviour Support Plan? If so, is it up to date?
- Is everyone involved in helping the person still using the Positive Behaviour Support Plan?
- If the person does not have a Positive Behaviour Support Plan, have you asked whether one can be developed?

Some useful resources:

- British Institute for Learning Disabilities resources on Positive Behaviour Support (this includes a short video that introduces PBS)
- United Response guidance on Positive Behaviour Support
- Information on Positive Behaviour Support from Skills for Care
- A brief guide to what the Care Quality Commission (CQC) look for in Positive Behaviour Support