

# Stopping The Over-Medication of People – STOMP:

A resource for autistic people  
and their families



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

**STOMP** stands for stopping over-medication of people with a learning disability, autism or both with psychotropic medicines. It is a national project involving many different organisations, which are helping to stop the over use of these medicines. STOMP is about helping people to stay well and have a good quality of life.

**National Autistic Society** is the UK's leading charity for people on the autism spectrum and their families. Since 1962, it has been providing support, guidance and advice, as well as campaigning for improved rights, services and opportunities to help create a society that works for autistic people.

# Inside this guidebook

## Topic

Who is this guide for?	5
A word on language	5
Introduction to psychotropic medications	6
Why might I be prescribed psychotropic medication?	7-9
How long might I need to take psychotropic medication?	10
Common side effects of medication	11
What to expect when visiting your doctor	12
Medication reviews	13-15
Getting support with psychotropic medication	16
How to monitor your own health	17
Living well	18-19
Useful organisations and helplines	20-21
Further information	22-23
Workbook: Preparing to visit a doctor to talk about psychotropic medication	25-31
About the STOMP and STAMP national project	32-33
What is the main aim of STOMP?	33

## The yellow and blue boxes in this guidebook

### Yellow box

**Key information**

*The information inside a yellow box like this one contains key information.*

### Blue box

**More information**

*The information inside a blue box like this one contains links where you can find more information.*

## Who is this guide for?



This guide and workbook are for you, if you are an autistic adult (aged 18+) and you are prescribed psychotropic medication.

The guide may also be useful to parents and carers of autistic adults and medical professionals who have autistic people in their care.

For information about psychotropic medication, [see page 6](#)

## A word on language

Over the years, different terms have been used for autism. Research from 2015 suggests that there is no single term that everyone prefers. You can read more on the National Autistic Society's [website](#).



Within this guide, we will use the terms 'autistic people' or 'people on the autism spectrum', which includes Asperger syndrome. It's important that you use the language that feels most comfortable to you. For example, some people may have been given a diagnosis of Asperger syndrome, and prefer to use this term when talking about diagnosis.

# Introduction to psychotropic medications

Psychotropic medication is a term for medications that can change your behaviour, mood, thoughts or perception.

There may be times when it is right to take these medications to keep you safe and well. However, they should always be used

at the lowest dose for an appropriate amount of time and be regularly reviewed. If no longer helpful, they should potentially be stopped. As with many medications, they can cause unwanted effects, some of which can impact on your physical wellbeing.



*It is important to note that autistic people should not be prescribed psychotropic medication to address the core features of autism.*



*Do not stop or change how you take your medication without support from your healthcare professional.*



**STOMP:**

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>





# Why might I be prescribed psychotropic medication?



There are many reasons why you might be prescribed this type of medication. Below are some examples.

## Some are related to mental health difficulties, such as:

- **Psychosis:** when people lose some contact with reality. This might involve seeing or hearing things that other people cannot see or hear (hallucinations) and believing things that are not actually true (delusions).
- **Depression:** a mental health condition that results in persistent feelings of sadness and/or hopelessness.
- **Anxiety:** a feeling of unease, such as worry or fear, that can be mild or severe. Signs of anxiety can include problems with sleep or panic attacks.

It is normal to feel anxious or low in mood sometimes. Anxiety helps us to recognise and deal with stressful situations and low mood is a natural reaction to difficult or distressing situations.



For more information on psychosis and its symptoms, visit the NHS website: [www.nhs.uk/mental-health/conditions/psychosis/overview/](https://www.nhs.uk/mental-health/conditions/psychosis/overview/)



For more information on depression, visit the NHS website: <https://www.nhs.uk/mental-health/conditions/clinical-depression/overview/>



For more information on anxiety, visit the NHS website: <https://www.nhs.uk/mental-health/conditions/generalised-anxiety-disorder/symptoms/>



*Sometimes, depression and anxiety get better on their own, after a few days or weeks. But the doctor might prescribe you medication if you are not getting any better or if you have tried other things which have not worked.*

- **Epilepsy** can be another reason someone is prescribed psychotropic medication. Epilepsy is a condition that causes a person to have seizures. Many types of seizure can happen and epilepsy can affect anyone at any age. About [one in every 100](#) people have epilepsy. Autistic people are at heightened risk, with between 20% and 40% having epilepsy. This rate increases steadily with age.



#### About epilepsy



For information on epilepsy, its symptoms and treatment, the NHS website can be very useful:

<https://www.nhs.uk/conditions/epilepsy/>



*It is common for people to take psychotropic medication and some may take more than one type. If none of the examples mentioned above apply to you, you should ask your doctor why they have suggested you take psychotropic medication.*

#### About co-occurring conditions



Autism is often diagnosed alongside other conditions. The National Autistic Society offers information on various co-occurring conditions and their impact on autistic people:

<https://www.autism.org.uk/advice-and-guidance/topics/related-conditions/related-conditions/all-audiences>



- **Behaviour** – often psychotropic medications are given to people whose behaviour is thought to be ‘challenging’. This kind of use is called “off-label” because behaviour is not a condition the medication would usually be used for. However, psychotropic medications have been used in this way for many years and have been found to help some people. This may be prescribed for some people at certain times but needs to be regularly reviewed.

Autistic people and their parents or carers need to be consulted and listened to, to make sure the medication is not having a negative impact on the person it is prescribed for. The medication should be stopped as soon as it is no longer needed.



#### NHS behaviour case study



<https://www.england.nhs.uk/learning-disabilities/about/resources/caretransformed/stopping-andrews-psychotropic-medication-in-hertfordshire/#:~:text=He%20was%20taking%20olanzapine%2C%20as,side%20effects%20of%20these%20drugs>

#### About mental health conditions



The National Autistic Society provides information and resources about autism and different mental health conditions:

<https://www.autism.org.uk/advice-and-guidance/topics/mental-health>

#### Mind - a mental health charity



[https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/treatment-options/?gclid=EAlaIQobChMli8LTi-ui7QIVDNPtCh21bgINEAAYAiAAEgK93vD\\_BwE](https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/treatment-options/?gclid=EAlaIQobChMli8LTi-ui7QIVDNPtCh21bgINEAAYAiAAEgK93vD_BwE)

# How long might I need to take psychotropic medication?

It will depend on how you respond to the medication and the condition it is treating. It might take several weeks for the medication to have its full effect and you may feel worse before you start to feel better.

Your doctor should review your medication at least once a year but you can ask for a review at any time. If the medication is not helping you or is causing too many side effects, the doctor may suggest trying a different medication.



*Ask your doctor or pharmacist how long you will need to keep taking your medication for.*

Hazel Griffiths (2020) has put together a set of eight questions that you or your family can ask prescribers:



- What is the medication prescribed for?
- How do you know it is working?
- How long will it be needed for?
- How do you evaluate the impact or effect of the medication?
- What happens if it does not work or seems to stop working?
- Can it be stopped, and how?
- How will side effects be monitored and how often?
- What other treatments, support or interventions can be used?

Source: Griffiths, H. (2020). As a mum, I despaired at how difficult it was to challenge clinicians. *Your Autism*, Spring 2020, 10-11

# Common side effects of medication

Side effects can happen with any medication. Some people may not experience side effects.



## Different medications have different side effects.

These are some side effects you might get from psychotropic medications:

- feeling tired or sleepy
- feeling unwell, for example feeling sick
- putting weight on or losing it
- change in appetite
- constipation (finding it hard to poo) or an upset stomach
- feeling stiff or shaky or feeling dizzy when you stand up
- blurred eyesight or a dry mouth.



*Ask your healthcare professional or care team about possible side effects of the medicine you are taking. Tell them if you think you have a side effect.*



For more information on antidepressants and antipsychotics and their side effects, visit the NHS website:

<https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/medicines-and-psychiatry/antidepressants/overview/>

<https://www.nhs.uk/mental-health/conditions/psychosis/treatment/>

# What to expect when visiting your doctor



When you book your appointment you can tell the receptionist about the things that might help you and ask for them to make these adjustments.

## Reasonable adjustments

Under the *Equality Act 2010*, you are entitled to reasonable adjustments that can make your appointment with your doctor more comfortable and easier.

### Examples of reasonable adjustments:

- to wait somewhere other than in the main waiting room
  - in a quiet room, outside etc
- some flexibility around the time of your appointment
  - a less busy time of day for example
- extending the length of time of your appointment so that you feel less rushed
- being told if appointments are running to time or running late
- being told if you will be seeing a different doctor, so you know in advance
- to be able to write or draw your thoughts or feelings
- having a low sensory environment, for example turning off bright overhead lights.



There are further examples given in the workbook on [page 29](#) but you can ask about other things that work for you.



The NHS has a guide to reasonable adjustments in healthcare:  
<https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

# Medication reviews

A medication review is a check-up to make sure your medication is working well for you. If it is not working well, your healthcare professional may adjust the dosage or even change the medication.

They should make regular appointments for you to have medication reviews or you can ask for a review at any time. You can have family, carers, staff, a friend or an advocate there if you want someone to support you.

- You can tell the healthcare professional how you are feeling and if anything is worrying you, for example any side effects you may be experiencing.
- You can ask questions about your medication and what else might help.

## These are the sort of questions you might want to ask:

1. What is the medication called and what is it for?
2. Why do I need this medication?
3. What are the possible side effects?



The above are especially relevant if new medication is introduced during the review.

4. Am I taking the right amount at the right time?
5. How long will I need to take it for?
6. What else or who else can help?
7. Is there a plan for stopping or reducing the medication?

You might think of other questions too. There is a workbook at the end of this guide, where you can record them.

## Talking to your doctor

You may find it helpful to plan what you want to say before your meeting with your GP or talk it through with someone you trust, who can come in with you. Advocacy services may be helpful for you if it is difficult for you to have conversations with the people who are providing you with medication.

You have a right to be involved in decision making around your care and treatment and to ask about different sorts of treatment. Your doctor needs to understand how you are feeling, anything you are worried about, and what helps you feel better.

## Make sure your doctor knows if you are:

- in pain or ill
- lonely, worried, or unhappy
- afraid of someone or something
- angry or frustrated about what you can or can't do
- hearing or seeing things that upset you
- noticing changes in the way your body feels
- having thoughts that you want to hurt or harm yourself or other people.

If other people you trust tell you they are noticing changes in you, tell your doctor about this.



*Everyone feels worried or unhappy sometimes. Often the thoughts and feelings go away on their own, but if it happens a lot or is a big problem, ask for help. Ask your doctor or pharmacist about different things that can help you.*



**“Your doctor needs to understand how you are feeling, anything you are worried about, and what helps you feel better.”**



## My Health Passport

You could download and fill out a health passport (pictured right). Showing this to medical professionals looking after you can help them to understand your communication style, other needs you may have and how to make adaptations to your appointment.



For a health passport, visit the National Autistic Society website:  
<https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport>

## My Health Passport For autistic people



Healthcare staff, please consult this passport before you assess me or carry out any interventions.  
 Hospital staff, please keep this passport with my notes at the end of my bed and return to me when I am discharged.

Please look at the guidance notes before filling out your health passport the notes are at [www.autism.org.uk/health-passport](http://www.autism.org.uk/health-passport)

### Personal information

Name:   
 I like to be called:   
 Date of birth:   
 NHS number:

If I am admitted to hospital, I would like the following person to be contacted:

Name:   
 Relationship:   
 Phone number:

Other people I would like you to contact in connection with my treatment and care:

Name:  Relationship:  Phone:   
 Name:  Relationship:  Phone:

I have an Advance Directive: Yes ☐ No ☐

A really important thing to know about me is:

The guidance notes have examples of what to put here, please see [www.autism.org.uk/health-passport](http://www.autism.org.uk/health-passport) for the guidance notes. It may help if you fill this out after completing the rest of the form.

## Feedback, comments and complaints

If you are unhappy about how anyone treats you, you have a right to say so. Talk to a member of staff or a doctor or ask for a complaints form you can fill in. If they do not sort out your problem, there are other things you can do.



**Ask Listen Do** is a project about making feedback, concerns and complaints easier. You can find out more about this at:  
[www.england.nhs.uk/asklistendo/people](http://www.england.nhs.uk/asklistendo/people)

**“If you are unhappy about how anyone treats you, it is your right to say so.”**



# Getting support with psychotropic medication



- Do not stop or change how you take your medication without support from your doctor or psychiatrist.
- Everyone involved in your care should listen to how you feel and what helps you feel better.
- Family, friends, staff, advocates and other health professionals can support you.
- Your doctor, psychiatrist, nurse or pharmacist can give you information and advice about your medication.
- Your doctor, psychiatrist, nurse or pharmacist can help you find other ways to make you feel better too.
- Ask for reasonable adjustments, such as easy read information or anything else that will make your appointment with health professionals easier for you.



**“Do not stop or change how you take your medication without support from your doctor or psychiatrist.”**

# How to monitor your own health



It is important, if you are experiencing mental health difficulties and you are prescribed psychotropic medication, that your mental and physical health is checked. This means that any problems you are having need to be noticed by someone, not just you, and should be passed on to the person who currently prescribes your medication.

Monitoring your health might include having regular blood tests ie once a year, depending on the psychotropic medication you are taking.

It might also help to keep a diary of how you feel each day and whether you experience changes in your body (physical changes, such as weight or pain).



*It's not always easy to monitor our own health. Sometimes, other people who know us well may notice a change in our mental or physical health. Therefore, talking to another person can help. This includes your doctor too.*

*Remember, everyone is different so not everything will work for you.*



This is a toolkit designed by and for young autistic people and can be helpful:

<https://www.ambitiousaboutautism.org.uk/what-we-do/youth-participation/youth-led-toolkits/know-your-normal#:~:text=The%20Know%20Your%20Normal%20campaign,understand%20what%20their%20normal%20is>

# Living well

It is important that people are able to access some kind of non-medical therapy alongside their medication. It helps to talk to your health and social care team about getting extra support or talking to other professionals about alternative therapies to enable you to take less medication, or eventually stop taking it. Alternative

therapies include talking therapies, seeing a speech and language therapist to help you to self-advocate your views and feelings, yoga, mindfulness or art therapy.



## For more information about therapies:



### British Association of Art Therapists

<https://www.baat.org/About-Art-Therapy>



### National Autistic Society

<https://www.autism.org.uk/advice-and-guidance/topics/strategies-and-interventions/strategies-and-interventions/counselling>



### Mind

<https://www.mind.org.uk/information-support/drugs-and-treatments/arts-and-creative-therapies/about-arts-and-creative-therapies/>



### NHS

<https://www.nhs.uk/live-well/eat-well/>

<https://www.nhs.uk/live-well/>

There are things that we can possibly do to maintain our individual, good level of mental and physical health. These include:



Spending time doing things we enjoy (for example, knitting, reading, visiting places we enjoy)



Spending time with a friend, or a family member



Trying to have a regular sleeping routine



Spending time with animals. Some people find this relaxing. If you don't have a pet you could offer to join any friends who do have dogs to walk or volunteer at a local animal rescue shelter



Eating well - for example including fruits and vegetables in our diet and avoiding too many sugary foods



Exercise, such as walking, swimming or running. Choose the exercise you enjoy

### Mind

There is lots of information on Mind's website about how exercise can improve your mental health, including ideas of how to get started if you are feeling nervous about taking up a new activity.

<https://www.mind.org.uk/about-us/our-policy-work/sport-physical-activity-and-mental-health/>



# Useful organisations and helplines



## Mental health enquiries and support:



**NHS A-Z of Mental Health charities:** <https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>

Provides a list of charities and what they can offer.



**Mind:** <https://www.mind.org.uk/information-support/helplines/>

**Tel:** 0300 123 3393 | **Text:** 86463 | **Email:** [info@mind.org.uk](mailto:info@mind.org.uk)

Provides advice and support to empower anyone experiencing a mental health problem.



**Rethink Mental Illness:** <https://www.rethink.org/advice-and-information/living-with-mental-illness/medications/>

Provides services, local groups and advice and guidance about mental health to individuals and their families or carers.



**SANEline:** [http://www.sane.org.uk/what\\_we\\_do/support/](http://www.sane.org.uk/what_we_do/support/)

**Tel:** 07984 967 708 | **Email:** [support@sane.org.uk](mailto:support@sane.org.uk)

Provides support and advice.



**The Samaritans:** <https://www.samaritans.org/how-we-can-help/contact-samaritan/talk-us-phone/>

**Tel:** 116 123

Provides a confidential and safe space for people who want to talk and be listened to.





## Epilepsy advice and support:



**Epilepsy Action:** <https://www.epilepsy.org.uk/info>

Provides advice and information on epilepsy and related topics.

## Information about talking therapies:



**British Association of Counselling and Psychotherapy:**

<https://www.bacp.co.uk/>

Provides information about talking therapies.





## Further information



Citizens Advice provides information on the *Equality Act 2010* and the types of reasonable adjustments that should be available:  
<https://www.citizensadvice.org.uk/law-and-courts/discrimination/what-are-the-different-types-of-discrimination/duty-to-make-reasonable-adjustments-for-disabled-people/>



There is an Easy Read guide to the Equality Act on the Government's website:  
<https://www.gov.uk/government/publications/easy-read-the-equality-act-making-equality-real>



You can find information about seeking help for mental health on the National Autistic Society website:  
<https://www.autism.org.uk/advice-and-guidance/topics/mental-health/seeking-help>



Mind has information about reasonable adjustments:  
<https://www.mind.org.uk/information-support/legal-rights/discrimination-in-everyday-life/reasonable-adjustments/>



The Mind website also has information about your legal rights in relation to the Mental Health Act, Mental Capacity Act and Human Rights Act in England and Wales:  
<https://www.mind.org.uk/information-support/legal-rights/>



The workbook '*Preparing to visit a doctor*' might help you at an appointment. You can download a copy from the Voluntary Organisations Disability Group's website:

<https://www.vodg.org.uk/publications/preparing-to-visit-a-doctor-to-talk-about-psychotropic-medication/>



The NHS has an easy read guide to the Mental Health Act, a law that tells people with a "mental health disorder" what their rights are and how they can be treated:

<https://www.nhs.uk/mental-health/social-care-and-your-rights/mental-health-and-the-law/mental-health-act-easy-read/>



For more information on medication reviews, visit the National Institute for Health and Care Excellence:

<https://pathways.nice.org.uk/pathways/medicines-optimisation/medication-review>



# Workbook:

## Preparing to visit a doctor to talk about psychotropic medication



There is also a STOMP workbook in easy read format:

<https://www.vodg.org.uk/publications/preparing-to-visit-a-doctor-to-talk-about-psychotropic-medication/>

This workbook can be used to help prepare for a medication review.

You could ask someone you trust to help you fill it in.



## My details:

My name:

My doctor's (GP's) name:

My doctor's surgery address:

My doctor's surgery phone number:

## Health professional I am visiting:

Their name:

Type of health professional:

(GP, psychiatrist, community  
psychiatric nurse)

Do I want someone with me?

Yes

No

If yes, who?

## My appointment details:

Date of appointment:

Time of appointment:

Venue:

Why I am seeing the  
health professional:



# Have I experienced any of these common side effects?

## My physical health:



Nauseous (feeling sick)

Dizzy

Constipated

My weight has changed since taking the medication

I have headaches

My body feels stiff

My body feels shaky

My mouth is dry

My appetite has changed:

I eat more

I eat less

My sleep has changed:

I sleep more

I sleep less

Other changes I have noticed:

## My mental health: How I feel in my mind



I haven't noticed any changes

I feel better

Confused

Disorientated

I am having thoughts that are sad or hopeless

I am worrying more than usual

I feel afraid or more anxious than is usual for me

I think about ending my own life

How often?

If I am worried - what  
am I worried about?

Do I feel safe?

Yes

No

What will help me to  
feel safe and keep  
others safe?

## Sensory experience



My processing of information and/or sensory experience has changed:

My responses to:

sounds

balance

visual information

my body awareness, for example, how my body is moving in relation to other people or objects

smell

touch

taste

are increasingly over-sensitive or under-sensitive compared to my usual experience.

## Questions to consider:



Is there anything that will make my appointment easier?

What reasonable adjustments do I need?

appointment times and locations written down (text or emails)

an early or late appointment when clinics are quieter

a longer appointment

extra time to think between questions

extra time to explain

natural light (bright lights turned off)

to wait somewhere other than the waiting room

the opportunity to write things down

## The doctor can help you write on this page at the end of the appointment.

This will help you remember what you and your doctor talked about. If you need more help to understand, ask your doctor.



### **My appointment summary:**

How is my health?

Advice from the  
doctor:

Recommended  
treatment:

Why this treatment  
is recommended:

How will this help me  
to get better?

How long might I need  
the treatment for?

How long before my  
next review?

How will I hear about  
my review?

Who do I contact in  
an emergency?

What to do if I need  
to speak to a health  
professional before  
my review?

**Extra notes page:** Use this page to write down any questions you have, or anything else your doctor said.



**Information:**

# About the STOMP and STAMP national project

The STOMP programme was launched in 2016, following an enquiry in 2012 by the Department of Health and Social Care into the care of autistic people. The enquiry led to concerns around the over-prescribing of psychotropic medication to people with a learning disability, autism or both.



STAMP – Supporting Treatment Appropriate Medication in Paediatrics – is specifically for children and young people with a learning disability, autism or both. It is about children and young people getting access to medication when they need it.

STOMP and STAMP is about everyone working together. This includes:

- people being prescribed medications and their families
- health professionals
- social care providers
- education professionals.



For background information about the STOMP and STAMP programme:  
[www.england.nhs.uk/stomp](http://www.england.nhs.uk/stomp)

# What is the main aim of STOMP?

STOMP and STAMP aims to promote everyone working together to support the safe and appropriate use of psychotropic medications, and to reduce over-prescribing. STOMP is not anti-medication.

What we do ask is for prescribers to use medications for the right reasons, and to monitor, review, and remove if side effects outweigh the benefits or the medication is not making a difference.



*It is vitally important to ask what the autistic person's preferences are, and listen. Prescribers should strive to understand how every individual autistic person manages their autism and what they can do to help.*



Ask your health team and support staff to find out more about STOMP  
[www.england.nhs.uk/wesupportstomp](http://www.england.nhs.uk/wesupportstomp)

For more information visit: [www.england.nhs.uk/stomp](http://www.england.nhs.uk/stomp)



For health and medications information in easy words and pictures, ask your doctor or pharmacist or visit [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

## Acknowledgement

Thank you to everyone who has helped with this guidebook and for their support with STOMP and STAMP.

**Published** May 2021



# About the National Autistic Society

The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people.

We transform lives by providing support, guidance and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work.

We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

We have come a long way but it is not good enough. There is still so much to do to increase opportunities, reduce social isolation and build a brighter future for people on the spectrum. With your help, we can make it happen.



**National  
Autistic  
Society**

The National Autistic Society is a charity registered in England and Wales (269425) and in Scotland (SC039427) and a company limited by guarantee registered in England (No.1205298), registered office 393 City Road, London EC1V 1NG.