



Preparing to visit a doctor

To talk about psychotropic medication

.....

This leaflet is for a **support worker** who is accompanying a person with a learning disability, autism or both to a GP or consultant appointment.

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Preparing to visit a doctor

To talk about psychotropic medication

Introduction

This leaflet is for a support worker who is accompanying a person with a learning disability, autism or both to a GP or consultant appointment to review medication that has been prescribed to manage their behaviour.

The leaflet aims to help you:

- Work with the person to prepare for their appointment.
- Remember to take all the information you need.
- Compile a list of questions to ask during the appointment.
- Summarise key information at the end of the appointment.

There are two forms. The first is a checklist to help you make sure you have all the information you need. The second is designed for you to work through with the person, helping them think about what is important to them in relation to their medical appointment.

Getting started

It is suggested that you start by:

- Asking whether the person wants to involve anyone else, such as a relative, friend or advocate, in preparing for or attending the appointment and, if so, facilitate this.
- Checking the person's care record for any recent changes in their health, behaviour, care plan, personal circumstances (such as a change in staff, levels of activity or bereavement), use of 'as required' (PRN) medication or experience of side effects.
- Informing a senior member of staff that the appointment concerns medication that has been prescribed to manage the person's behaviour.

It is important that you set aside sufficient time for the person to be fully involved in preparing for their appointment and completing the form with you. If you and the person have different opinions about their health, record both opinions and share both with the doctor.

Reasonable adjustments

If the person requires any reasonable adjustments in order to be fully involved in the appointment, these should be requested beforehand.

Examples of common reasonable adjustments include:

- An extended appointment time
- Use of communication tools
- Visiting the clinic or surgery prior to the appointment
- An independent advocate

Previously agreed actions

It is recommended that you check if any actions have been agreed at previous health appointments and whether these have been implemented.

If any of the care provider's actions cannot be completed, it is suggested that you inform a senior member of staff before the appointment.

You could also refer to the person's health action plan and check whether it contains any information or actions relevant to this appointment.

Symptoms

Symptoms tell you when someone is unwell. Ask the person about how they are feeling, both physically and emotionally. Ask the person about when any symptoms started and what makes them better or worse.

Check the person's records for any signs of unmet health needs.

Communication

If someone has difficulty expressing themselves, a change in their behaviour may help you understand how they feel. For instance, this may indicate that they are unwell or in pain. Check their health records for instances when they appeared to be in pain or distress, what may have been the cause and what worked to help manage their pain and distress.

If their behaviour has resulted in any serious risk to them or someone else you should note this and talk to a senior member of staff prior to the appointment. If your organisation has someone with responsibility for positive behaviour support, you may also find it helpful to talk to them.

The person will need to take along any communication tools they usually use so they can be fully involved in the appointment. Where a person lacks mental capacity to make a decision about their medication, they should still be as involved as possible in a way that is meaningful to them.

Medication

Before you accompany someone to an appointment, you will need some basic information about the medication they take, the reason it has been prescribed and when it was last reviewed. You should find this information in the person's care record and on their medication administration record (MAR) sheet.

Some people with a learning disability, autism or both are prescribed psychotropic medication. 'Psychotropic' means any medication which results in changes to perception, mood or consciousness. This can be prescribed for a variety of reasons. For instance, a person may be taking medication because they have a health need, such as epilepsy or a mental health condition.

Some people are prescribed psychotropic medication to manage their behaviour. Where this is the case you may find it helpful to take the current prescribing guidance for GP's to discuss at the appointment.

This can be found at www.vodg.org.uk/wp-content/uploads/STOMP-GP-Prescribing-v17-ONLINE-SELF-PRINT.pdf

People who are prescribed psychotropic medication to manage their behaviour should receive a multi-disciplinary review three months after their medication was initially prescribed and at least every six months thereafter. A multi-disciplinary review should involve all relevant professionals and either a relative or advocate who can speak on behalf of the person. If a multi-disciplinary review is overdue, you should request one.

In addition, alternatives to medication (such as active support, intensive interaction or positive behaviour support) should be explored. If this has not happened you should request advice and, if needed, a referral to a specialist.

Side effects

Medicines have benefits and they also have side effects. Psychotropic medication can have serious side effects, including feeling sluggish and sleepy, weight gain, constipation and organ failure. Side effects can have a significant impact on the person's quality of life and common side effects, such as constipation, can become life-threatening if untreated.

This means it is especially important to make sure that psychotropic medicines are needed, are working and that their side effects are weighed against their benefits on a regular basis. You can find out more about side effects in the patient information leaflet for each medication. Easy read information about a wide range of medication and its side effects can be found at [**www.easyhealth.org.uk/categories/medicines-\(leaflets\)**](http://www.easyhealth.org.uk/categories/medicines-(leaflets))

If you are monitoring the side effects the person is experiencing, then it is helpful to take copies of these records to the appointment with you.

Questions

List any questions which you or the person you are supporting want to ask during the appointment. For more ideas about what questions to ask, see: Questions to ask when you go to the doctor or to a hospital www.easyhealth.org.uk/sites/default/files/questions_to_ask_visiting_the_doctor_or_hospital.pdf

Summary

Before you leave the appointment, make sure that you both understand what the doctor is saying about what is wrong, what needs to happen next and what the health outcomes are to be achieved.

You can use the summary section to go over the appointment with the person, record what the doctor has said and what will happen next. Ideally this is done in the appointment when the doctor is present. It is recommended that you inform a senior member of staff about the outcome of the appointment, regardless of whether or not the doctor intends to change the prescription.

Jargon buster

Health action plan: a personal plan for adults with a learning disability about how to stay healthy and what help they may need to look after their health.

Multi-disciplinary review: a meeting between the person with a learning disability, autism or both and the people in their life to discuss whether the services and treatment they are receiving meet their needs.

Psychotropic medication: any medication which results in changes to perception, mood or consciousness.

Reasonable adjustments: changes that services (or employers) make so that disabled people can access them.

Further information

Social care providers can sign up to the STOMP (Stopping the Over-Medication of People with a learning disability, autism or both) campaign and access a range of resources at: www.vodg.org.uk/campaigns/stompcampaign/

Prescribing guidance for GP's can be found at: www.vodg.org.uk/wp-content/uploads/STOMP-GP-Prescribing-v17-ONLINE-SELF-PRINT.pdf

Further information about STOMP can also be found at: www.england.nhs.uk

The Royal College of Psychiatrists has produced practice guidelines on: Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf

Easy read information about a wide range of medications, including their uses and side effects, is available at: [www.easyhealth.org.uk/categories/medicines-\(leaflets\)](http://www.easyhealth.org.uk/categories/medicines-(leaflets))

Information about managing and preventing constipation in people with learning disabilities can be found at: www.improvinghealthandlives.org.uk/securefiles/170404_1050//Constipation%20briefing%20sheet%20final.pdf



Information & Action Checklist

To be completed before the appointment

Appointment Details

.....
Name of person supported

.....
Name of person who made the appointment

.....
Name of the staff member who will attend the appointment

.....
Name of doctor

.....
Role of doctor (eg GP/consultant)

.....
Date of appointment

.....
Time of appointment

.....
Reason for appointment

.....



Information & Action Checklist

To be completed before the appointment

Further Details

	Yes	No
..... Family, friend or advocate invited (if required)
..... Reasonable adjustments requested (if required)
..... Care record checked for recent changes such as:		
..... • Physical health, including unmet needs
..... • Mental health, including unmet needs
..... • Personal circumstances (such as a change of staff)
..... • Behaviour
..... • Care plan (anything that may have impacted on the person's behaviour)
..... • Use of 'as required' (PRN) medication
..... Copies of the following documents ready to take to the appointment:		
..... • Relevant sections of the care plan
..... • MAR (Medication Administration Record) sheets since last appointment
..... • Record of behavioural incidents
..... • Records of side effects, such as weight gain or constipation
..... • Health action plan checked: are there any actions relevant to this appointment?
..... • Communication tools ready to take to appointment
..... • Copy of prescribing guidance for GP's printed
..... • Senior member of staff informed about appointment



Information & Action Checklist

To be completed before the appointment

Multidisciplinary review

.....
Date of last multidisciplinary review
.....

Was this:

Yes

No

- More than 3 months ago (for newly prescribed psychotropic medication)? or
- More than 6 months ago (for all other psychotropic medication)?

.....
If yes, add 'Request a multidisciplinary review' to your list of questions to raise at this appointment.
.....

Alternatives to medication

Yes

No

- Are alternatives to medication in place?
Alternatives are planned approaches such as active support, intensive interaction or positive behaviour support.

.....
If no, add 'Seek advice about alternatives to medication' to your list of questions to raise at this appointment.
.....



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This kind of medication might make me **think differently, feel differently or behave differently**



My appointment



My name



Who is going with me



My Doctors name



Date of appointment



Time of appointment



Why I am seeing the doctor



Things agreed at previous appointments



What people **said they would do**

What **happened**



What people **said they would do**

What **happened**



What people **said they would do**

What **happened**



What people **said they would do**

What **happened**



Symptoms: how am I feeling?

My physical health



My mental health



My concerns: I am worried about...



Behaviour

Recent changes in **my behaviour**,
including when these first started





These are common side effects that some people feel. How am I feeling?

Yes No



I feel **poorly**

More details for the doctor

--	--



I am **putting on weight**

More details for the doctor

--	--



I feel **sleepy** or **sluggish**

More details for the doctor

--	--



I feel **stiff** or **shaky**

More details for the doctor

--	--



I am **constipated**

More details for the doctor

--	--



Questions

1

2

3

4

5

6



The doctor should help you write on this page at the end of the appointment. This is to record what you talked about at the appointment. The doctor needs to explain things so you understand. If you need more help to understand, tell the doctor.

Appointment Summary 1

My Condition



Advice from the doctor



Recommended treatment



How this will help me feel better





The doctor should help you write on this page at the end of the appointment. This is to record what you talked about at the appointment. The doctor needs to explain things so you understand. If you need more help to understand, tell the doctor.

Appointment Summary 2



What I **need to do**



What the **doctor will do**



What my **support staff will do**



Date of next review

If you would like to provide feedback on this document,
please contact VODG at **STOMP@vodg.org.uk**




Voluntary Organisations Disability Group

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