

Section 5 - Effective conversations at a medication review

This section looks at how and when reviews should happen, who they might be with, and the aim and structure of the conversation.

A medication review - sometimes called a structured medication review - is an important opportunity to make sure medication is working effectively, and discuss whether changes should be made. NICE guidance says a medication review should be considered for children with long term conditions and children taking multiple medications. This means if your child is autistic and or/has a learning disability and is taking psychotropic medication then you can ask for a medication review. Ask the doctors and health professionals involved in your child's care.

Effective medication reviews are part of an ongoing relationship between the family and the professional team, not a one-off event. Sometimes care will be delivered by a multi-disciplinary team (MDT) – a team with different professionals working together, and the person who reviews medication may not be the same person who prescribes it initially. Reviews may happen with a range of professionals including specialists such as Consultants as well as more general staff including GPs and pharmacists. It is important the reviewer is the most appropriate person to carry out the review based on the needs of the child or young person.

The medication review is an important point to formally review the medication, but if there are any concerns about whether or not the medication is working, or about side effects, there should always be a point of contact for the family to raise this with. If in doubt contact your GP, or out of hours, 111. In an emergency, contact 999.

Annual Health Check

In response to health inequalities experienced by people with a learning disability, Annual Health Checks were introduced in 2008 for anyone aged 14 or over who is on their GP's learning disability register. They should be carried out by doctors and nurses who work at GPs surgeries, and are designed to pick up any unmet health needs early on. Plans are also underway to implement a specific health check for autistic people, who similarly experience poorer physical health outcomes.

If your child is over 14 and has a learning disability, they can be offered an annual health check, and this should include a discussion about their medication. If there are any concerns picked up in the Annual Check it should trigger further action, including a medication review.

Checklist C sits alongside this section and sets out what needs to be considered at a medication review, including when continuing, changing or stopping medication.

Like this guide, the checklists have been co-produced with parents, carers and professionals.

Checklist C: What do parents and carers and professionals need to discuss in a medication review?

Checklist C - editable version

The four key areas of questions to think about in conversations at a medication review are below. They relate directly to the headings in checklist C.

Is the medication working?

The medication review is a chance to reflect on the specific impact the medication is having on the health issue it was prescribed for. At the point of prescription, it should have been made clear what changes the medication was intended to make. Is it making those changes? What improvements have been noticed?

It can be helpful to collect key information for use at a medication review, to specify the impact of the medication. This includes benefits as well as side effects. We have links to tools including a sleep diary in the resource section, but professionals and families should explore which tools will be most helpful for each specific child.

The important thing is to be realistic about what information should be collected, and only collect it for a very definite purpose. Parents and carers sometimes report being asked to collect a lot of information, which takes time and adds pressure, which they are then unsure is used. Agree in advance what the information will be used for, and only collect the essentials.

"When they say 'keep a diary' – keep a diary of what?! There's so much going on in her life at the moment. Yes, she's not sleeping, yes, she's not eating, she's challenging when we're getting her ready. So I'm trying to keep a diary, but then it feels like I'm keeping too much information! They didn't specify what to record – or how, or how much. That feels like a very big responsibility for the parent to record that. If they'd have given me a form where I could put the specific information they wanted, that would have been much easier."

This is also a chance to discuss the way the medication is being taken. Is it easy to take and remember? Are there some conditions in which it seems to work better? Does the balance between how it works across school and home feel right? Based on these discussions, parents and carers and professionals might decide to try adapting dosage or timings.

What is the overall impact on the child or young person's health and well-being?

It is critical to discuss any side effects that might be of concern, for example, unwanted changes in mood, sleep, weight, or other health measures. There might be monitoring information that is important, for example, through blood tests.

Family members will have a good sense of how their young person usually is when they are healthy, and should be supported to report any concerns they have about the overall well-being of their young person since starting the medication.

If side effects are identified, it is important to discuss their impact on the young person, and any practical measures that could minimise the impact, especially if the medication is felt to be effective.

Are any transitions approaching that we need to plan for?

A range of different professionals can prescribe medication, and the prescribing individual might change over time, for example, from a paediatrician to a GP. When a child or young person is nearing adulthood, be clear about how and when they will be referred to adult services, and the steps that will be taken to ensure this is a smooth transition. It might be that different support is available post 18, or that pathways of care are different, or that types or doses of medication change.

Make sure everyone is prepared well in advance for any changes in the individual prescribing or reviewing the medication, and any other shifts in medication or support. It can help for parents and carers to have a written note of the transition plan and any new contacts, so that there is continuity in their supply of medication, as well as in their care and support.

There might be wider changes approaching in the child or young person's life, like moving school or changing where they live. Good conversations at a medication review will create space to consider how these might affect health, well-being or medication needs in advance, so that a proactive plan can be agreed.

What is the outcome of the review?

Following a careful review of the young person's health, any benefits noticed from the medication, and the wider impact on their well-being, a joint decision can be made about whether taking the medication is still in the child or young person's best interests. The type, dosage, or timing of the medication may be adjusted, or the medication may be stopped.

A review is also a good point to consider what alternative interventions or support could be helpful instead of, or alongside, medication.

Is there a plan for eventual reduction or withdrawal of the medication, or is it likely to be needed long-term? If there are any risks around becoming 'reliant' on the medication and losing underlying skills, it can be helpful to discuss the best way to manage those risks, and continue to build skills.

How will the outcome of the review be shared across all the people that need to know about it? That might include different health professionals, teachers at school or college, or colleagues from social care, as well as parents and carers if for any reason they were not at the review. Is there a health passport, or other systematic way to share the relevant information?

Finally, discuss when the next medication review will be. Book in a date in to give people certainty if possible, and think about any specific information that should be brought to the review.

Tools and Resources

Tools and resources to measure impact on quality of life

Links

Scope have developed a Sleep Diary- Link

<https://www.scope.org.uk/advice-and-support/keeping-sleep-diary/>

Resources

[Glasgow Antipsychotic Side Effect Scale](#)

[Disability Distress tool](#)

[Carer's Concerns Quality of Life Questionnaire](#)

[Psychotropic Medication Review Document](#)

[MENCAP Pharmacy Project](#)- MENCAP has produced a resource booklet for pharmacists, people with learning disabilities, family members and carers Information on Medication Use