

Section 4 -Effective conversations when medicine is being prescribed

This section, and checklist B which sits alongside it, looks at conversations when a specific medication is being prescribed for a child or young person who is autistic or who has a learning disability.

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

[CHECKLIST B: What do parents and carers and professionals need to be clear about when medication is being prescribed for autistic children and young people or those with a learning disability?](#)

[CHECKLIST B – editable version](#)

The three key topics to discuss in conversations where a specific medication is being prescribed are below. They relate directly to the headings in checklist B.

What is the medication and what to expect

It is vital parents and carers know exactly what medication is being considered and why. This includes what effect the medication should have, and how long it will be before effects are seen. Some medication can take effect quickly, and for others it may take weeks before the young person notices any change. Understanding the expected timescales can help manage expectations and anxiety.

"Some show effects within three days, with others it's three months! We were given no indication that it would take three months to work. That length of time in which it can take effect is really scary for parents... and kids. There are skills children need to have in order to cope with feeling different as they transition onto a medication."

Parents and carers of autistic young people and those with learning disability say that being able to prepare the young person for what changes they might notice – including effects and side effects – helps their young person manage the transition on to the medication, and keep them safe by ensuring they are alert to any worrying side effects.

"My son is on melatonin and since taking this has had a decreased appetite. They have never told me of any side effects, but speaking to a few moms of special needs children they have told me it is a side effect of the medication. [It] would have been great if this snippet of information had been given at the time of prescribing or at annual reviews where I mentioned my sons weight loss and was told there was nothing to worry about. Apparently, a stone weight loss in 6 months in a 5-year-old is normal?"

Knowing who to contact in an emergency situation with regards to the medication, particularly out of hours, is a priority for many parents and carers. Where parents and carers

had a clear point of contact following prescription, they reported more positive experiences for themselves and their young person.

Communication during prescribing – case study

"My daughter's community paediatrician is really helpful. We have yearly meetings with her. My daughter has been on the waiting list with CAMHS for two years for art therapy for her anxieties. Her anxiety really affects her sleep. The paediatrician had a lengthy discussion with me about melatonin. I said I wasn't keen - we'd always been against medication. It's the service that she needs. I felt the art therapy would have helped the anxiety which would have helped the sleep.

So they gave me the prescription [for melatonin] and said you don't have to use it if you don't want to, but it's here just in case, contact me with any questions. But my daughter had a really tough time at school - she didn't sleep at all for about 3 days. So we got the melatonin and started it and she did sleep. I just needed her to sleep because she was getting so poorly.

We still give it to her on school nights. These were the conversations I had with the community paediatrician, that she didn't have to take it every night and could have breaks in the school holiday. But I do feel that if we'd had the services beforehand, then she wouldn't have had to take the medication. She has now started art therapy, and her anxiety and her coping strategies are just so much better.

I can call [the paediatrician] anytime via the secretary. She always says she will answer any questions or call back, and a few times I have had to contact her, and she always responds. I wanted her input for the EHCP needs assessment and she was really helpful."

How to take the medication

The name, dosage and timings for taking medication will usually be set out clearly. Autistic children and children with a learning disability might have health or sensory needs that make consideration of the form of the medication important. For example, they might not be able to take a tablet, so talking about options like liquids and other forms of medication might be key.

"My daughter wasn't tolerating the liquid form. The slow-release tablet worked much better."

"Different brands and levels of medication can make a big difference. Sometimes a lower level of melatonin works better."

Pharmacy colleagues highlight the importance of having child-friendly dosage equipment, such as 1ml measures, alongside the standard 5ml ones. Some areas have specific prescribing guidelines or pathways for certain conditions which might be helpful to share. For example, this sleep disorder pathway and melatonin dosage guideline, kindly shared by NHS South East London.

"If you have any questions, you can go and speak to the pharmacist. They tend to have more time and are well-trained. They might have to go and look it up and come back to you, but they can be a lot more accessible than paediatricians and others. Their drug knowledge is second to none. Don't forget that they're there."

Some medication might have options for additional doses or for taking breaks from the medication safely. For other types of medication this can be dangerous, so it's important to be clear what the guidelines for your specific medication are. Parents and carers say that the brand, format, and dosage of a medication can have a large effect on how it works for their child.

"Once when our medication wasn't available and we were given a slightly different one. It didn't work...So I swiftly went back and I said no that's not the one that works for my child."

Some children may be taking multiple medications. An understanding of which different medications a child is taking, and any interactions or heightened risks caused by the combination, is key to taking them safely.

Reviewing and managing the medication

NICE guidelines set out that medication for autistic children and young people or those with a learning disability should be reviewed within 12 weeks of being started. Where possible, being able to agree the date for review at the point of prescription gives parents and carers peace of mind that this will happen.

"There was absolutely no follow up whatsoever. We couldn't even book a review as they only take appointments a week in advance."

Some medication might have significant monitoring requirements, such as blood tests. Understanding these at the outset will help with the decision of which – if any – medication is in the young person's best interests overall.

NICE Guidance is clear that parents and carers should be given a written plan from the start that includes how the medication will be reduced or stopped, or if it is a medication the young person is likely to need to take into adulthood.

"My concern was will they be reliant on it? Will they need this for the rest of their life now? But education can really help: the melatonin is making up for a chemical 'deficiency' – it's correcting a biological issue. So if they do need it for life that is not necessarily a problem."

We look in more detail at medication reviews in section 5
Here are additional resources for those that want more information

Links

The Spectrom project supports the STOMP Campaign. It is funded by the National Institute for Health Research, and the National Institute of Health Research and based at Imperial College, London. It has produced easy read leaflets about different types of medication-

<https://spectrom.wixsite.com/project/easy-read-medication-leaflets>

Easyhealth has produced accessible information about medication-

<https://www.easyhealth.org.uk/resources/category/114-medication>

The charity Mind has produced provides detailed information on all antipsychotic drugs currently available in the UK.A-Z-

<https://www.mind.org.uk/information-support/drugs-and-treatments/antipsychotics-a-z/overview/>

There are useful, short, free e-learning sessions on psychotropic medications on the [MindEd Hub](#). These include some of the names of the different types of medication which you might recognise, and what they are used for.

Resources to record information about prescribed medication:

[The Mencap Pharmacy Project](#) has produced a resource booklet for pharmacists, people with learning disabilities, family members and carers

[The SPECTROM project Yellow Medication Passport](#)

[Cheshire and Wirral NHS Information About My medication](#)

[MENCAP and Northamptonshire – How to Take My Medicine](#)

[MENCAP and Northamptonshire – How to Take My Medicine \(multiple medicines\)](#)

[Dignity and Risk Medication sheet](#)

[Dignity and Risk Prescribed Regular Medication Record](#)

[VODG- Preparing to Visit a Doctor Guidance](#)