



## Module 1837

# Pharmacists' role in autism management

From this pharmacy CPD module on autism you will learn:

- The interventions that are used in the management of autism
- More about the role of parents and carers in managing patients with autism
- Pharmaceutical interventions that may be used
- How pharmacists can help and support patients with autism and their families

## NAIMAH CALLACHAND, PHARMACIST

Autism, generally referred to as autism spectrum disorder (ASD), has no cure, but requires lifetime management. This can be achieved through a range of specialist educational and behavioural programmes. There are many interventions available for the management of ASD, and many of these focus on important aspects of childhood development, including:

- communication skills
- social interaction skills
- imaginative play skills and academic skills.

As ASD varies from person to person, it can be difficult to choose the most appropriate intervention. A management strategy should therefore be decided on a case-by-case basis.

### How should autism be managed?

Coordination of care in children and young people with ASD should involve a multidisciplinary team. This team should ensure that each person diagnosed with ASD has a key worker to manage their condition, as well as assisting in their transition to adult care.

Before deciding on a management approach, both parents and carers should be well informed on the interventions that are available. In this context, an intervention refers to any kind of activity – such as a treatment, therapy or provision of a service – that is designed to improve the quality of life for people on the autism spectrum.

The charity Research Autism was set up to investigate autism interventions and provide an objective evaluation of the scientific evidence behind the most commonly used interventions (see [www.researchautism.net](http://www.researchautism.net) for more information).

Research Autism provides advice on how to decide on which approach to use, the key principles that each intervention should follow, and questions that should be asked about each approach.

It also refers to 'red flags' – which highlight where a so-called intervention may not be as good as it seems. This can include approaches that have celebrity endorsement, claims of high success rates, use outdated or incomplete research, or argue that other – proven –

interventions are unnecessary or harmful.

### SPELL interventions

The mnemonic SPELL (Structure, Positive, Empathy, Low arousal, Links) is one of the most commonly used interventions in ASD. It is the National Autistic Society's framework for understanding and responding to the needs of children and adults with the disorder.

SPELL recognises the individual and unique needs of each child and adult, and emphasises the planning and interventions that can be organised on this basis. It can be applied across the entire autism spectrum – including Asperger's syndrome – and can complement other approaches. SPELL focuses on five key principles:

- **Structure** – creating a structured environment using visual information (such as coloured pictures, symbols or written words) to encourage independence, build confidence and reduce anxiety
- **Positive** (approaches and expectations) – re-establishing self-esteem and reinforcing self-confidence
- **Empathy** – encouraging supporters of those with ASD to understand, respect and relate to

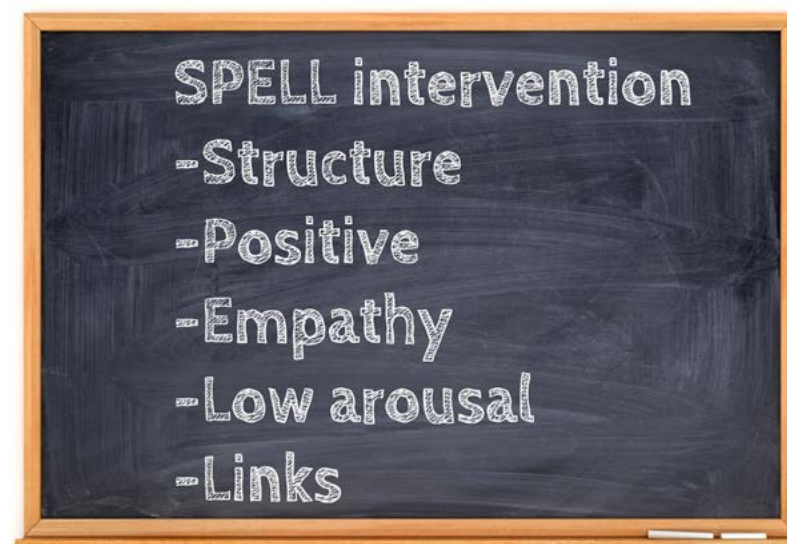
those with the condition

- **Low arousal** – reducing anxiety and helping with concentration by ensuring interactions and environments are calm and ordered, with few distractions and clear information given, so as not to bombard the individual
- **Links** – ensuring parents and supporters are recognised as partners working alongside those with ASD, and information gathered by the multidisciplinary team is shared with them. This helps reduce the risk of misunderstanding or a fragmented approach to care. Links should also be created and maintained with wider support networks in the community.

### Other interventions

'Social stories' and 'comic strip conversations' are other approaches created to help people with ASD develop a greater social understanding, as well as stay safe (more information available at [tinyurl.com/autismSS](http://tinyurl.com/autismSS)).

They are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why. They present information in a literal, 'concrete' way, which may improve a person's



understanding of a previously difficult or ambiguous situation or activity.

Many people with ASD find counselling a useful approach, as it can put coping strategies in place for dealing with difficult situations, as well as relationship issues.

Approaches used in counselling can include cognitive behavioural therapy (CBT), which evidence has shown can reduce levels of anxiety in people with ASD. In addition, solution-focused therapy and psychoanalytic approaches can be used in counselling.

### The role of parents and carers

Parents and carers of children with ASD play a crucial role in supporting and helping children improve their skills. You can direct them to the National Autistic Society website ([tinyurl.com/asdfamily](http://tinyurl.com/asdfamily)), which provides valuable information on education and training for coping with ASD.

The charity also provides parental support programmes, such as the EarlyBird programme – a three-month course for parents whose child has been diagnosed with ASD, but has not started school – and the EarlyBird Plus programme, for parents whose child has received a later diagnosis of ASD and are aged between four and eight years old.

### Pharmacological interventions

In some cases, medication may be prescribed to treat some of the symptoms or conditions associated with ASD.

Sleep disturbances are common, and potential causes should be identified. If no cause is identified, non-pharmacological interventions – such as good sleep hygiene practice and restriction of daytime sleep – should be tried before medicine intervention.

Research has shown that melatonin may be beneficial in cases where sleep onset

is an issue, but it does not provide any significant improvement on the total amount of sleep or number of night-time awakenings. Hypnotics – such as sedating antihistamines and benzodiazepines – lack evidence for their effectiveness in children with ASD.

Behavioural symptoms often accompany ASD, including attention deficit hyperactivity disorder (ADHD), aggressiveness, self-harming behaviour and temper tantrums. Any identifiable causes should be determined prior to pharmacological interventions.

If no causes are identified, psychoactive medications such as risperidone might be considered. Consideration should be given to adverse effects associated with psychoactive drugs, such as drowsiness, sedation, increased appetite and nausea.

Selective serotonin reuptake inhibitors (SSRIs) have been studied for their use in ASD for the treatment of repetitive behaviours, obsessive-compulsive symptoms, aggression, anxiety, and depressive disorder. Consideration should be given to the common side effects associated with SSRI use, including dry mouth, insomnia, and nausea. SSRIs require caution and careful monitoring, as they carry a warning for increased risk of suicidal thinking and behaviour in young people.

Alternative treatments that have received publicity, but are not recommended, include:

- special diets, such as gluten-free or casein-free diets
- chelation therapy – a process to remove heavy metals from the blood
- auditory integration training – a music-based education system
- hyperbaric oxygen therapy – the process of breathing pure oxygen at high pressures.

### The pharmacist's role

You have an integral role in the multidisciplinary autism care team and can provide support and assistance to patients and carers when they are making decisions. Building a relationship with

### “Behavioural symptoms often accompany ASD, including attention deficit hyperactivity disorder (ADHD), aggressiveness, self-harming behaviour and temper tantrums”

these people can help you better understand the patient with ASD, allowing you to make your own informed decisions and provide the patient with optimal care.

You can counsel parents and carers on medication that may relieve the associated symptoms of ASD, and refer them to the GP when they think that pharmacological interventions are appropriate in condition management. You can also offer advice to parents and carers on the use of each medication, and make them aware of any potential side-effects or monitoring that might be required.

Going to the pharmacy can be stressful and a source of anxiety for both patients and caregivers of those with ASD. A busy pharmacy with bright lights may be a difficult environment and could cause sensory overload for the patient. A noisy pharmacy may also pose an issue as it may prevent them from recognising sounds, such as their name being called.

You can reduce this anxiety by encouraging approaches that will reduce stress when the individual has to see a healthcare provider. For example, you can encourage the patient or caregiver to call ahead when going to the pharmacy, so their prescription can be ready or the consultation room made free.

The lighting in the consultation room could be adjusted so as not to cause sensory overload. Alternatively, prescriptions could be delivered to the patient or brought out to their car to avoid them having to wait in the pharmacy – which could be distressing for someone who requires their own personal space.

Patients who have difficulties communicating may find it hard to understand what a healthcare professional is asking them, or to explain how they are feeling. The use of visual supports should



Patients may need to try non-pharmacological interventions if no cause of sleep disturbance is found

be considered, as these can help explain the patient's condition. A 'show me where' tool can be used as a basic means of visual communication. These have pictures on a fan or chart that enable patients to point to where they feel pain or indicate if they want, for example, to use the bathroom or phone home. Social or emotion picture cards can also be useful aids for patients with ASD to express how they are feeling.

You can encourage patients, parents and carers to carry autism alert cards. These are available from the National Autistic Society ([tinyurl.com/asdalert](http://tinyurl.com/asdalert)) and give a brief explanation of what autism is for people who have difficulty understanding certain behaviours in ASD patients.

Another resource the charity offers is 'My Hospital Passport' (accessed at [tinyurl.com/asdpassport](http://tinyurl.com/asdpassport)), for people with autism who might require hospital treatment. This tool allows people with ASD to communicate their needs to doctors, nurses and other healthcare providers.

You may find this resource useful in the pharmacy, as it provides a description of how the patient prefers to communicate and interact with other people, as well as situations which cause them distress and how they can be avoided. These can be beneficial when a pharmacist is providing continuing care on discharge from hospital.

It also highlights the patient's medication history and current medications, allowing you to identify any potential drug interactions if a new treatment is initiated following discharge.

### Verbal and non-verbal communication

The language you use as a pharmacist when speaking to a patient with ASD is important. You should use the person's name, and make sure you are paying attention before asking them a question or giving an instruction. It is important to speak slowly and try not to bombard them with too much information.

Pausing between sentences can give someone

with ASD more time to process what has been said, and will also give them more chance to think of a response. A patient with ASD may take things literally, and idioms, irony and metaphors may be misinterpreted. You should therefore adjust your language to ensure you are speaking directly and clearly to the patient.

Patients may repeat what you have said, because they do not understand the question or how they should respond. Understanding can be checked with the use of visual supports, and patients should be encouraged to ask for help if they do not understand. A lack of eye contact from the patient does not necessarily mean they are not listening, and it should not be assumed that non-verbal patients cannot understand what has been said.

It is vital for pharmacists to understand how a person with ASD is communicating, because building a rapport with the patient can

help ensure they are receiving optimum care. ASD patients often find forms of non-verbal communication – such as gestures, eye contact and facial expressions – difficult to understand, and these should be avoided if possible. When speaking to a patient with ASD, you should be aware of the environment you are in, and consider that the patient may communicate better in a quiet area.

People with ASD may not understand personal space and they may come closer than expected. You should also be aware that the patient may want their own personal space, and if they feel this is being invaded it may be a source of anxiety.

### Knowing when to refer

If you suspect that a patient may have ASD, you should recommend to them – or, if appropriate, their parent or carer – that they make an appointment with their GP. This will allow them

to be referred on to the most appropriate healthcare professional.

If a parent or carer has concerns about the development or behaviour of their child, then autism should be considered. Pharmacists should be aware that older children or young people presenting with autism for the first time may have previously masked their symptoms with coping mechanisms and a supportive environment.

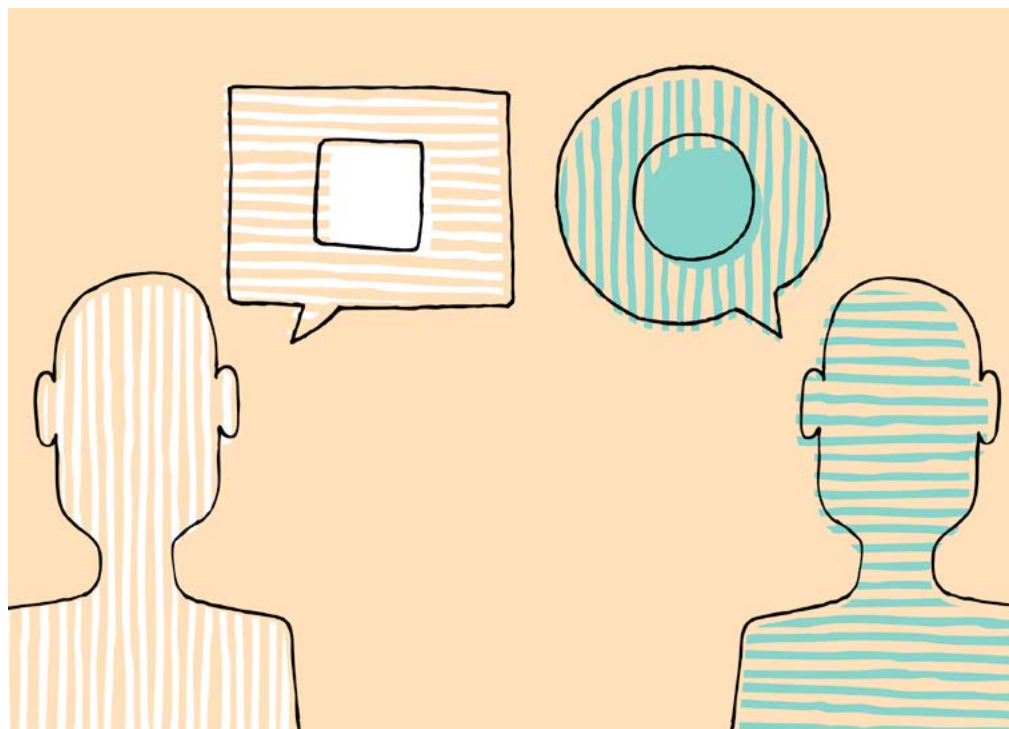
If a parent, carer or the patient themselves has not suspected the possibility of having a developmental or behavioural condition, raising this may cause significant distress. You should take care with how you suggest a referral to the GP, and understand that it may take some time for them to come to terms with the possibility.

They may even reject the idea and be unwilling to make a GP appointment at all. Building up a rapport with the patient or carer will enable them to build trust in you and may help the discussion around their concerns of a potential ASD diagnosis.

You can then help to prepare the patient and their parent or carer for their appointment. You should recommend booking the first or last appointment of the day, as this will help to avoid busy waiting rooms.

You can also direct parents, caregivers and adults diagnosed with ASD to the appropriate resources and support groups:

- The Autism Services Directory ([www.autism.org.uk/directory](http://www.autism.org.uk/directory)) is a comprehensive directory of local services and support available for people with ASD and their families across the UK
- The National Autism Society website ([www.autism.org.uk](http://www.autism.org.uk)) can provide detailed information on coping mechanisms and strategies for support for both patients and carers
- Research Autism ([www.researchautism.net](http://www.researchautism.net)) is a charity set up to help parents or carers make an informed decision as to which intervention is most appropriate in ASD care.



# The pharmacist's role in autism management CPD

## Reflect

What is the SPELL intervention? What pharmacological interventions are used in the management of autism? How can pharmacists support patients with autism?

## Plan

This article contains information about the interventions used in the management of autism, the role of parents and carers in managing patients with autism, and some pharmaceutical options that may be considered. How pharmacists can help and support patients with autism and their families is also discussed.

## Act

- Read more about types of autism interventions, treatments and therapies on the Research Autism website at [tinyurl.com/asdisorder3](https://tinyurl.com/asdisorder3)
- Find out more about SPELL on the National Autistic Society website at [tinyurl.com/asdisorder7](https://tinyurl.com/asdisorder7)
- Read more about the EarlyBird programme on the National Autistic Society website at [tinyurl.com/asdisorder9](https://tinyurl.com/asdisorder9)
- Read more about My Hospital Passport on the National Autistic Society website at [tinyurl.com/asdisorder10](https://tinyurl.com/asdisorder10)

## Evaluate

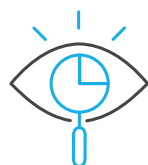
Are you now familiar with the interventions used in the management of autism? Could you give advice to patients and carers, and signpost them to reliable sources of information?

# Take the 5-minute test online

1. Autism is managed using a range of specialist educational and behavioural programmes.  
**True or false**
2. SPELL is the National Autistic Society's framework for understanding and responding to the needs of children and adults with ASD.  
**True or false**
3. The key principles of SPELL are structure, positive approach, exercises, low arousal and learning.  
**True or false**
4. 'Social stories' and 'comic strip conversations' are other approaches created to help people with ASD develop a greater social understanding, as well as stay safe.  
**True or false**
5. Counselling, CBT and psychoanalysis have been found to be of little use in patients with ASD.  
**True or false**
6. The Research Autism website provides the EarlyBird parental support programme for children diagnosed with ASD.  
**True or false**
7. Research has shown that melatonin is beneficial in ASD for improving the total amount of sleep and reducing the number of night-time awakenings.  
**True or false**
8. Sedating antihistamines and benzodiazepines lack evidence for effectiveness in children with ASD.  
**True or false**
9. Alternative treatments such as special diets, chelation therapy and hyperbaric oxygen therapy are not recommended for the management of ASD.  
**True or false**
10. The My Hospital Passport tool allows people with ASD to communicate their needs to doctors, nurses and other healthcare providers.  
**True or false**



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