

How can you encourage medicines optimisation for people with a learning disability?

In this article, **Anne Cole** complements the information in the medicines optimisation briefing on learning disability.

These briefings have been developed for pharmacists and pharmacy teams working in England and Wales.

Medicines optimisation is all about supporting patients so that they get the best possible outcomes from their medicines. It means using effective consultation skills (see: www.consultationskillsforpharmacy.com) in talking and engaging with individuals to understand their beliefs and concerns about their medicines and what they would like their medicines to achieve. It also involves ensuring that the medicine chosen for the patient is clinically appropriate, safe, effective and will help them to achieve their goals. It is about supporting the patient to continue to use their medicines in a way that fits with their lifestyle.

The medicines optimisation briefings we have produced are for pharmacy professionals working in all sectors of healthcare. We believe that, as experts in medicines and their use, pharmacy professionals are well placed to support patients to get the best outcomes from their medicines.

Medicines-taking or administration to people with a learning disability

The briefing distributed with this issue of *The Pharmaceutical Journal* focuses on medicines use by people with a learning disability. This is one of a series of briefings that complement and build on each other. The content is not intended to be exhaustive; the aim is to improve your approach to, and understanding of, people who have a learning disability.

Background

People with a learning disability are a diverse group of people in terms of age, degree of disability and associated health problems. They may have multiple long-term and complex needs which require access to a combination of health and social care as well as educational services. The majority of their care is provided in the community¹ or in care environments specifically registered for people with a learning disability.

What is a learning disability

The Department of Health² states that a learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently which starts before adulthood with lasting effects on development (impaired social functioning).

Prevalence of learning disability

The prevalence of learning disability in the population is approximately 18 per 1000 people.³

In England in 2013, there were 1,068,000 people with a learning disability, 84 percent of whom were adults aged 18 years or over.⁴

In Wales in 2015, there were 15,010 people on registers of people with a learning disability, 81 percent of whom were aged 16 years or over.⁵

Causes of a learning disability⁶

A learning disability occurs when the brain is still developing – before, during or soon after birth – and can range from mild to profound. Examples of causes include:

- certain genetic conditions (see below)
- maternal accident during pregnancy
- prematurity
- lack of oxygen during childbirth
- early childhood illnesses.

Learning disability in association with other conditions

- Autism spectrum disorder (ASD) – around 20-30 percent of people with a learning disability may have behavioural characteristics of ASD which can lead to difficulties in management, ranging from those requiring minimal support to lead an active life, to those requiring lifelong specialist support.⁷
- Cerebral palsy – people with a diagnosis of cerebral palsy may also have a learning disability.
- Down's syndrome – a person with Down's syndrome (also known as Down syndrome) will have some degree of learning disability.
- Epilepsy – children with early onset epilepsy are highly likely to experience neurodevelopmental compromise that may result in a learning disability.³
- Foetal alcohol syndrome – this is caused when a mother drinks alcohol during pregnancy; this can affect the development of the child's brain and other organs. Each individual with the condition will be affected differently and some will have a learning disability. The effects range from mild to severe.
- Fragile X syndrome – a genetic condition characterised by an X chromosome that is abnormally susceptible to damage, especially by folic acid deficiency. Most people will need support with their speech and language, and with social and emotional interaction with others.
- Other rare genetic conditions – there are a number of other genetic conditions that can result in an individual having a learning disability. For further details visit the [Other conditions](#) page of the Mencap website.

What is the difference between a learning disability and a learning difficulty?

Distinguishing between a learning disability and a learning difficulty is a complex issue and having a learning difficulty does not necessarily mean that a person has a learning disability.

Learning difficulty

A learning difficulty is defined as a difficulty in acquiring knowledge and skills to the normal level expected of those of the same age but does not affect general intelligence.⁷

Examples of specific learning difficulties⁷

- Developmental co-ordination disorder (DCD), also known as dyspraxia
- Dyslexia
- Attention deficit hyperactivity disorder (ADHD)

Learning disability, long-term conditions and medicines

People with a learning disability have more health and social problems than the general population, are less likely to access help and have a shorter life expectancy. Examples include:

- Epilepsy – it is estimated that the prevalence of epilepsy is 15 percent in people with a mild learning disability and 30 percent in those with a severe learning disability.³
- Mental health problems – just like everyone else, people with a learning disability may or may not experience a mental health problem at any point during their life.⁷ Behaviour described as “challenging” is often observed in people with a learning disability.
- Diabetes – people with a learning disability may have a lifestyle that increases their risk of developing diabetes, eg, poor diet and lack of physical activity. They may also be prescribed medicines that increase the risk of diabetes, eg, antipsychotics.

As a consequence the treatment regimens of people with a learning disability can be complex, involving several different prescribers with medicines frequently used outside their product licence.

Off-licence use of medicines

The presence of a feeding tube, swallowing difficulties or covert administration often result in questions about method and route of administration of medicines. This is not unique to people with a learning disability. Wherever possible medicines should be administered overtly, if this is not possible then the Mental Capacity Act 2005 must be considered. In the case of swallowing difficulties or feeding tubes, decisions around crushing tablets or opening capsules should be bounded by the knowledge, evidence and experience of administering medicines outside their product licence. Wherever possible a licensed formulation should be used, eg, an oral liquid should be prescribed rather than crushing a tablet (off-label use). See *Signposting pharmacy professionals (below)* for further information and where to find advice.

Multicompartment medicines compliance aids

Although this is not specific to people with a learning disability, it is important to consider how changes to medicines impact on any compliance aids that are in use. Information about the stability of medicines in compliance aids can be found at the [UK Medicines Information \(UKMI\) Medicines Compliance Aid \(MCA\) database](#).

How can pharmacy support people with a learning disability?

Here are some ideas for how pharmacy teams can help people with a learning disability to support medicines optimisation, in addition to those included in the briefing. As you will see, even if you do not specialise in this topic, there are still plenty of opportunities to make a difference.

- Practice person-centred care and shared decision-making by finding out from the person and their carer what works for them.
- Ask what support people want and need, rather than assuming you know the answer already.
- Accept that you may be an expert in medicines, but you are not the expert in each individual – the person, their parents (if they are children) and their carers are, so use them as a valuable resource.
- Ask yourself if you speak differently to people when there are physical signs of a possible learning disability compared to when there are no physical signs and consider whether this is appropriate or not.
- You may meet people with a learning disability regularly, so use the opportunity to build relationships and increase your understanding of the person and their carer.

- Ask the person and their carer if they have an up-to-date record of all medicines prescribed or purchased over the counter, including formulation and brand information and a record of changes and reasons. Help them to find a solution that works for them, such as My Medication Passport.
- Find out who has overall responsibility for the care of the person. This will help you to determine who to contact with any questions or issues with prescriptions and medicines. Ask the person or their carer first; they may already know the answer and this will also provide the opportunity to ask them for permission.
- Provide more clarity about decisions and communicate it to the person and their carer.
- Be there for the person and their carer, demonstrate empathy and consider how exhausted they may be, eg, if there is a supply problem with one of the medicines communicate with the prescriber and keep everyone informed.
- Obtain the contact details of your local learning disability pharmacist or nursing specialists and ask them for advice.
- If you say you are going to do something, let the person and their carer know when and how you will get back to them.
- Beware of diagnostic overshadowing (assuming other problems are due to the person's learning disability), eg, behaviour that challenges may be caused by an infection or pain that the person is unable to express. Look out for medicines that may be contributing, such as medicines with antimuscarinic side-effects that may cause confusion or constipation (discomfort and pain), leading to apparent behaviour that challenges.
- Behaviour that challenges may be associated with other physical or environmental causes so make sure these have been fully explored and rectified before any medicines are started inappropriately.⁸ Further information about behaviour that challenges and its management can be found at the Challenging Behaviour Foundation (CBF) website.
- Seek specialist advice from your local learning disability pharmacist about starting, stopping and switching medicines so this is done as safely as possible. This is especially important when reducing or stopping psychotropic medicines that have been taken for a long time. Appropriate risk assessments need to be completed, communication with all parties involved and non-pharmacological interventions put in place to support changes or stopping of medicines.
- Signpost to relevant support groups (see *Signposting people with a learning disability and their carer(s) below*).
- Be aware of the difference between a carer and a care worker; it is important to use the correct terminology for carers and care workers as you are likely to have contact with both.
 - A carer is someone of any age who provides unpaid support to family or friends who could not manage without their help. Carers may be juggling paid work with their unpaid caring responsibilities at home.
 - A care worker, or care assistant, receives payment for looking after someone.⁹

Monitoring

As part of medicines optimisation it is important to ensure that correct monitoring is being carried out.

- Does the person with a learning disability and their carer understand the reasons for monitoring and what this means?
- Are local shared care arrangements for prescribing medicines, including antipsychotics and antidepressants, with appropriate monitoring and review dates in place?
- Where medicines are prescribed for behaviour that challenges, are local guidelines, individualised care plans, clear responsibilities and regular reviews in place? While some people may need to remain on such medicines for an extended period there is a need to avoid unnecessary prescribing of psychotropic medicines to people with a learning disability. There should be clarity about how long they are to be prescribed with an expectation that measures should be put in place to manage the behaviours without psychotropic medicines. These should be reviewed regularly and monitored.
- Consider the level of training required for unqualified staff involved in the care of people with a learning disability, non-pharmacological methods of managing behaviours that challenge and standards required.

Physical health and lifestyle messages

People with a learning disability are entitled to receive the same level of support as people with any other long-term condition; however, for various reasons this does not always happen. Poor physical health can arise as a side-effect of treatment, eg, weight gain, cardiovascular disease and increased risk of developing diabetes and as a result of poor diet or lack of exercise. Healthcare professionals involved must ensure that people's physical health is regularly kept under review and opportunities to encourage improvements in lifestyle are maximised. (*Please refer to our previous medicines optimisation briefings and articles: [cardiovascular disease](#) and [type 2 diabetes](#).*)

- People with a learning disability should receive an annual health check from their general practitioner (GP). Pharmacy professionals should encourage people with a learning disability to have their annual health check.
- People with a learning disability may benefit from support and encouragement with lifestyle messages, so ask the person what, if anything, they would like to change, and help them with this. For example, you may find that they would welcome advice and support to reduce weight and you should offer this support as you would to any other person.
- Provide advice about healthy eating, alcohol intake, smoking cessation (or reduction), and exercise or gentle movement (especially if medicines known to cause weight gain are started).
- Recognise the need to individualise advice about drinking water due to behaviours associated with some learning disability syndromes that may lead to water intoxication.¹⁰
- Provide safe sex and contraception messages as you would to anyone else, taking into account the teratogenicity risk and/or reduced contraceptive cover of some medicines commonly used for conditions associated with a learning disability.

Signposting pharmacy professionals

- [British Institute of Learning Disabilities \(BILD\)](#) – supporting people with a learning disability to be valued equally, participate fully in their communities and be treated with dignity and respect
- NHS England. [Call to action - Urgent action pledged on over-medication of people with learning disabilities](#). 2015.
- Centre for Pharmacy Postgraduate Education (CPPE)
 - [Consultation skills for pharmacy](#)
 - [The Mental Capacity Act 2005 and covert administration of medicines](#) workshop
 - NHS Education for Scotland (NES) [Learning disabilities: pharmaceutical care of people living with learning disabilities](#)
- [Challenging Behaviour Foundation \(CBF\)](#) – charity for people with a severe learning disability who display behaviour described as challenging
- NHS. [Ensuring safer practice for adults with learning disabilities who have dysphagia](#). 2007.
- [Foundation for People with Learning Disabilities](#) – working with people with a learning disability, their families and the people who support them
- GOV.UK. [Off-label or unlicensed use of medicines: prescribers' responsibilities](#). 2009.
- Local learning disability pharmacist or nurse specialists
- Local NHS trust medicines information centre
- [UKMI MCA database](#)
- [NEWT guidelines to administration of medicines to patients with swallowing problems](#) (subscription required)
- National Institute for Health and Care Excellence (NICE) resources:
 - [NICE guidelines NG11. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#). 2015.
 - [NICE quality standard QS101. Learning disabilities: challenging behaviour](#). 2015.
 - [NICE pathway. Challenging behaviour and learning disabilities](#). 2016.
- [NHS England. Learning disabilities](#).
- Pharmaceutical manufacturer – telephone for information about off-licence drug administration
- [Royal College of Psychiatrists learning disabilities resources](#)
- [Social Care Institute for Excellence. Mental Capacity Act \(MCA\) Directory](#)
- [Bhaumik et al \(editors\). The Frith Prescribing Guidelines for People with Intellectual Disability. Third Edition](#). West Sussex: Wiley-Blackwell; 2015.
- The Handbook of Drug Administration via Enteral Feeding Tubes. Pharmaceutical Press and the British Pharmaceutical Nutrition Group. [www.pharmpress.com](#) or [www.medicinescomplete.com](#) (subscription required)
- [Jubraj B, Deakin A, Mills S and Grimes L. Pharmacy consultations with patients with learning disabilities](#). *The Pharmaceutical Journal* 2016; 296:7885.

Signposting people with a learning disability and their carer(s)

There are many websites containing useful information for people with a learning disability and their families and carers. Tailor the advice and signposting to the individual and their circumstances.

- [Royal College of Psychiatrists learning disabilities factsheet](#) – readable information for the public
- [Choice and Medication](#) – information for people who use services, carers and professionals, including easier read leaflets
- [Easy Health](#) – easy read healthcare leaflets and videos
- [Elfrida Society](#) – easy read leaflets about medicines
- [Mencap](#) – the voice of learning disability
- [Mencap local support groups](#) – find a local learning disability support group
- [NHS Choices learning disability](#)
- [Swallowing difficulties](#) – helping those who have problems with pills
- [Public Health England. To help you stop getting flu: Information for people with a learning disability](#) – easy read leaflet

Case study

Michael Bellis is a 68-year-old man with a learning disability who lives with his wife in a sheltered flat. Michael's wife also has a learning disability. Michael has visits from care workers but they do not help him with his medicines and he manages to take these himself via the use of a multicompartment medicines compliance aid. One of Michael's prescribed medicines is Epilim Chrono® for epilepsy which is not in the compliance aid. On one of their visits the care worker discovers 20 boxes of Epilim Chrono® in his flat, clearly indicating poor or non-adherence with the medicine and phones the community pharmacy that dispenses Michael's medicines for advice. The community pharmacist contacts the local learning disability pharmacist for advice and is signposted to the the [UKMI Medicines Compliance Aid database](#). By consulting the database the community pharmacist finds that the manufacturer advises that if the benefits outweigh the risks, Epilim Chrono® can be included in compliance aids if they are repackaged weekly and protected from moisture and humidity. Following discussion with Michael, his GP and care worker, arrangements are made for Michael's medicines to be dispensed weekly. This case highlights the issues around use of compliance aids, seeking expert advice, communication of decisions and responsibilities.

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March 2016

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