The learning disabled patient in practice

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Patients with learning disabilities can provide some of the biggest challenges of a professional career but also some of the biggest rewards.

The Foundation for People with Learning Disabilities estimates that there are 1.5 million people in the UK who have a learning disability. There is no precise definition of what a learning disability is, and it is often not a specific condition. For instance, someone with cerebral palsy, whilst having a physical disability, may or may not have a learning disability.

Emerson and Heslop categorise a learning disability (LD) as “a significantly reduced ability to understand new or complex information (and) learn new skills’ combined with ‘a reduced ability to cope independently’, and starting before adulthood and having a lasting impact on development. The learning disability can be classified by cause, or by severity: profound, severe, moderate or mild. The most common cause of LDs is Down’s syndrome (26 per cent) but for many individuals the cause is non-specific or unknown.

One area that can cause confusion is that a LD is different from a specific learning difficulty (SLD), which is a term used to refer to conditions such as dyslexia, although the UK is the only country to make this distinction. However, the terms have been used synonymously in the past. This is not to belittle people who struggle with dyslexia but it is an important distinction. SLDs can, however, be so severe as to cause an individual LD.

The number of people with a LD in the UK is increasing. This is partly due to better healthcare and increasing life expectancy but also to better survival rates for disabled children. Successive governments have committed to improvements in healthcare provision for individuals and the latest report, Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance (2009) has recommended “providing personalised care and support for people with a learning disability”. It recommends that this is delivered in a person centred manner and facilitated by use of a Health Action Plan. The gold standard of the action plan is to have annual health reviews in a primary care setting. This means that we are all more likely to see increasing numbers of people with a LD in our practices.

PREPARING FOR PATIENTS WITH LDS

Some of the anxiety that is felt, the ‘Will I be able to help?’ and ‘What do I need to do?’, whilst coming from wanting to do the best for our patients, can be likened to a culture shock. We normally have a great deal in common with our patients, such as similar lifestyles and hobbies, and it is fair to say that in this day and age most people drive, read, watch TV and use a computer of one sort or another.

Yet patients with LDs are perceived as having very different lifestyles and pastimes and hence different visual needs, which can lead to us feeling out of our depth. In reality, each person that we see in the practice has a unique set of needs and abilities and a unique set of problems to be solved, which we must identify regardless of the presence of a LD.

The most common causes of anxiety about seeing patients with LD amongst healthcare professionals is the perceived problems of communication with the person and problems with challenging behaviour. Statistics that up to 16 per cent, or one in six people, have challenging behaviour only serve to compound this worry.

However, in 20 years of practice with patients with LDs I can only recall a couple of incidents where the behaviour has been so challenging as to risk injury – and even then I was culpable by getting too close to a patient who was distressed. Many ‘disruptive behaviours’ are simply a way of communicating that someone is unhappy with a situation. By responding to the implied message, the behaviour trait will often stop.
Small changes to normal routines can reap large rewards and the most common challenge that behaviour poses, in my experience, has been patients who refuse to get out of the car to attend the practice. However, this can be countered with the right response.

Patient preparation is useful. This may involve sending information before the appointment, which can be as simple as photos and the names of the people who will see the patient. Experience has shown how much carers and patients value knowing who they are going to see. Other patients may respond to a visual timetable. This will usually consist of pictures of where and what will happen. Typically, this may be the outside of the practice, then the waiting area, the consulting room and the dispensing area and the dispensing optician and then home.

Other patients may wish to visit the practice before the appointment. In primary care, it is not uncommon for young children to accompany an older sibling to an appointment so they can see what happens before they have their own eye examination – and this is simply an extension of that practice. It is ideal to pick a time when the practice is quiet so that the patient can familiarise themselves with the practice, and meet the people involved in calm surroundings.

**HOW TO BE DISABILITY-FRIENDLY**

Talking about alterations to the practice and normal routines can sound daunting but they are really just good practice for any patient. All practices should be disability friendly; there is an obligation to provide access for all so there should already be room for wheelchairs but making sure that there is room for wheelchairs to manoeuvre within the practice is often overlooked when displaying products.

Allow carers to sit with wheelchair users or have the facility to move a waiting room chair to allow it. It is also best practice for wheelchairs to enter and leave rooms facing forwards. If this is not possible, as is often the case in a consulting room, the person should be brought in forwards to see the room before being taken back out and brought in backwards.

It is essential to establish how a person communicates right at the start of the appointment. Some people may have recognisable speech or their own way of verbalising yes, no and simple requests; others may sign and others may respond in different ways through body language.

When talking to patients, address the patient rather than the carer. It may be the carer who responds but still address the patient. If you do need to talk to the carer, ask the patient if that is OK. Carers will often respond by asking the patient if it is OK for them to answer. This stops the patient from becoming disenfranchised, it keeps them at the centre of the process and is more likely to encourage compliant behaviour and be less likely to result in disruptive behaviour.

It is important to allow the patient plenty of time to respond. Many patients with LD take time to process spoken language and then take time to form their response. First, allow time for this process before repeating the question and if you don’t understand the answer, apologise and ask for clarification.

During the questioning stage, it is important to establish how patients fill their time. A typical weekly daily routine may include, exercise; swimming is very common, it is low impact and a safe environment. It may sound counterintuitive to say that swimming is a safe environment but when you have one-on-one or one-on-two support, it is quite difficult to get into trouble. Other exercise can include cycling, usually side by side bikes or trikes, and rebound or trampoline.

**UNDERSTANDING LD PATIENTS’ NEEDS**

It may sound surprising but many LD patients work; this is often voluntary but can be paid and is a great source of pride to many of the patients. Typical examples are café work or volunteering in a charity shop. There are often day centre sessions, which can include various therapies such as sensory rooms and music sessions as well as craft work (Figure 1), and tea and biscuits is very popular.

School age children will often be learning life skills. These can be structured within the national curriculum requirements. An awareness of money is important and preparing a shopping list, going shopping, paying and checking change and then baking a cake will fulfil numeracy and literacy requirements.

Obviously all these activities are important and all have large visual requirements, and a range of tool such as the Seeability pre-test questionnaire and functional vision assessment have been developed. These tools can give some insight into an individual’s behaviours and what their needs are. The tools are based on observations of the patient and give us an insight into their lifestyle as well as any problems they may be experiencing.

This highlights the fact that observation is a very important skill, which we all use. However, being conscious of observing the patient with LD can pay dividends. How do they react while sitting and waiting? Are they visually exploring the room? Do they interact with those next to them? Are they using an iPad? Watching them as they move, are they confident walkers or do they have a head down, shuffling walk? Are they hesitant with a change of surface such as laminate to carpet? What about steps, and a change of ambient lighting for instance from a bright waiting area to a more relaxed dispensing area?

All of these observations give clues to the way that someone uses their vision and also to how we can best help. For example, when dispensing, there are considerations of the patient’s dexterity. For the average dispensing, it may be obvious that a patient would benefit from a PPL but if someone has a head tilt and tremor and is in a wheelchair with a head support, a frame may constantly move or sit at an angle rendering a PPL inappropriate. The obvious next choice on paper might then be two separate pairs but if a patient is unable to handle their own frames and change the glasses, is this appropriate?

There are anecdotal tales of patients being prescribed two pairs and returning two years later having broken both pairs. The carers very proudly tell you that he wore the glasses all the time. The first pair were stronger, as he wore those all the time for the first 18 months and he’s only been using the spares for the last six months before the recall arrived. Or other carers who remembered that he needed to change the glasses for close work and religiously
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put the brown (reading) ones on for TV and then changed to the black (distance) ones whenever he was doing close work.

This illustrates that it is not just the numbers in the prescription that influences our prescribing, we need to think about how the glasses will be used. It is often more useful to prescribe low adds for constant wear. If someone is a non-driver, do they need 6/12 to 6/9? How far away do we regularly look and how blurred is the distance anyway?

USEFUL TESTS AND TOOLS

Obviously there will be modifications to the eye examination. A traditional letter chart may be of little use with someone who is non-literate. Many of us will be familiar with picture tests such as Kay Pictures (Figure 2). It was developed by Hazel Kay, an orthoptist, and is generally used at three metres8,9. It consists of a set of picture symbols of decreasing sizes arranged in blocks of four symbols per acuity surrounded by a crowding box. The measurable acuity is in the range of 3/30 to 3/2.4. It also has a matching card and a near acuity test card. The great advantage for use in a LD clinic is that it can be named signed or matched as the symbols all have simple Makaton signs.

Makaton is a modification of British Sign Language that was developed by a group of speech and language therapists. It is a language system that is designed to integrate speech, symbols and signs (Figure 3), although many individuals will only sign to communicate, many of us will inadvertently be familiar with some of the signs as it is used by Mr Tumble on CBeebies10.

One advantage of the Kay test is that it has a good correlation with Snellen. This means that we can explain to carers the implications of reduced acuity or uncorrected prescription by simulating it on a letter chart.

Some individuals may be unable or unwilling to participate with naming, signing or matching and for them, a preferential looking test can be used such as the Cardiff Cards. This relies on the principle of vanishing optotypes, where the detail of an object is made smaller and smaller until it is indistinguishable from the background and the fact that people will look at a more interesting scene rather than a plain one9.

Patients are shown a card with a picture either at the top or the bottom without the examiner knowing where the target is. If they can see the target, they will look towards it. The test relies on the skill of the examiner to judge the eye movement and also to engage the patient to continue the test, as after the first couple of presentations it can become quite dull.

Often only a binocular acuity is measured as we are interested primarily on how the patient is going to manage ‘out in the real world’ and that is their habitual state. Ideally, monocular and binocular corrected and uncorrected acuities would be measured but with some patients that is just not possible.

Some patients are just not able to participate in a formal acuity test but are still obviously very visual, investigating the room when they walk in, making and maintaining eye contact, seeing and taking the toys in the toy box. We would record these patients as being Visually Curious (VC) as recording no vision measurable implies very reduced acuity or even lack of light perception.

Anecdotal reports tell of carers who have been told patients are blind so fail to provide any visual stimulation, even to the
extent of not turning the lights on in a room as it is not necessary. This serves to highlight another very important function of the eyecare team: to educate the carers about the implications of the individual’s vision.

**MAKING A DIFFERENCE**

Other aspects of vision can be affected with LD. This might be visual field, contrast sensitivity or processing such as face recognition. Various studies have shown that the incidence of prescription and the degree of the correction required is higher in LD than the general population and that the use of correction is below average.

An understanding of what a patient fills their time with informs any prescribing decision. Glasses are supplied to fulfil a need. While this need may be obvious in the average patient, such as needing to meet the driving standard with a patient who has LD, it may be less obvious.

One of the issues surrounding prescribing spectacles for someone with a LD is that they are a vulnerable adult or child and we are seen by some as being ‘glasses shops’. The need for glasses can often be demonstrated by showing carers the difference that prescription makes by getting them to look through trial lenses – or better still having a range of glazed frames that someone can try and watching for changes. It is rewarding to see the changes in someone when they first wear a glazed prescription.

There are obvious challenges when helping patients who have learning disabilities but the rewards are also huge. The look of delight on a child’s face when they first realise what they can see with their new specs, or meeting someone who now has a voice through using a communication device and knowing that you played a part in them being able to do that are priceless.

Not everyone will have a practice that sees large numbers of patients with LDs but as we become a more integrated society, we will all see more of these patients and a few simple changes and a willingness to help and to learn are all that are needed to provide life-changing opportunities.

**REFERENCES**


**FURTHER READING**


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