

Ophthalmic Services Guidance

Low Vision: the essential guide for ophthalmologists

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Review date in 3 yrs

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Introduction

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It is never easy to tell someone that we cannot offer a treatment for their sight loss, or to offer them registration. However, there are many simple strategies that can be incorporated into the way the ophthalmologist practices – even during the busiest clinic– that will ensure the people we encounter experience a smoother journey into accepting their low vision and living with it.

We were delighted that The Royal College of Ophthalmologists recognised the need for training in this area by including it as part of the syllabus for ophthalmologists in training. This publication is designed to support that curriculum.

Anne Sinclair and Barbara Ryan

Chapter 1: Definitions of low vision

Practical definition

Ophthalmologists often ask, "Which patients should be referred to low vision services?", or "Is there a level of visual acuity below which a patient should be referred?" As in referral for cataract surgery, it depends on the functional vision of the patient, and their visual requirements for daily living.

In the UK, low vision has not been defined in legislation. The definition for low vision adopted by the UK Low Vision Services Consensus Group (which had representation from all relevant professions and organisations) is:

A person with low vision is one who has an impairment of visual function for whom full remediation is not possible by conventional spectacles, contact lenses or medical intervention and which causes restriction in that person's everyday life 1.

This definition includes, but is not limited to, those who are registered as severely sight impaired (SSI) and sight impaired (SI). Details of the certification and registration processes in use in the UK are outlined in Chapter 4.

WHO definition

The International Classification of Diseases 11 (2018) classifies vision impairment into two groups, distance near and presenting vision impairment ².

Distance vision impairment:

- Mild presenting visual acuity worse than 0.3 LogMar (6/12)
- Moderate presenting visual acuity worse than 0.5 LogMar (6/18)
- Severe presenting visual acuity worse than 1.00 LogMar (6/60)
- Blindness presenting visual acuity worse than 1.30 LogMar (3/60)

Near vision impairment:

• Presenting near visual acuity worse than N6 with existing correction

A potential problem with this definition is that it may exclude many people with a visual impairment whose ability to perform everyday tasks is greatly reduced. For example, someone whose distance visual acuity is 6/12 part would not meet the DVLA's criteria for driving.

The number of people with low vision

Registration data are very useful in considering the extent of low vision in the UK. There are about 350,000 people registered as having a sight problem in Scotland³, Wales⁴, Northern Ireland⁵ and England⁶. The Royal National Institute of Blind People (RNIB) estimates that more than two million people are living with sight loss in the UK today⁷.

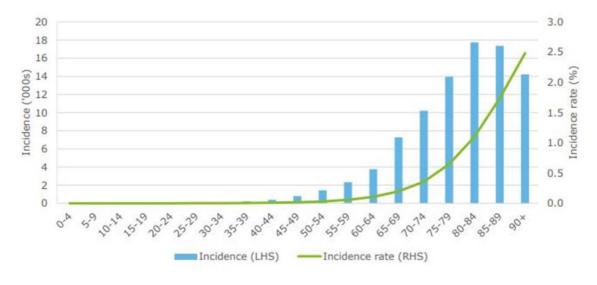
People who are aged 65 years or older accounted for 90% of new cases of permanent sight loss in the UK in 2016-178. The number of people in this age group is predicted to increase by almost 50% over the next 20 years9,10. Figure 1 shows the incidence and the incidence rate (number of new cases per unit of time) of permanent sight loss or blindness in the UK by age, 2016-17.

Although the prevalence of sight impairment in children is low, there has been a greater than twofold increase in the incidence of blind/severely sight impaired and partial sight/sight impaired in children in England between 1982 and 2019¹¹. For more details on low vision in children, see chapter 8.

There are ethnic variations in the preponderance of causes of sight loss. South Asians have a higher risk of cataracts and of diabetic eye disease than other population groups12,13 and the risk of glaucoma is much higher for the black population compared to the white population14.

The incidence of sight loss is greater in areas of social deprivation. This may partly be due to late presentation related to the costs of travel and treatment^{15,16}.

Of the 609,000 people in the UK with moderate visual impairment in the MRC trial17, 74 per cent were women. Globally, women bear excess blindness compared to men. In these surveys, overall, women account for 64.5% of all blind people. The excess of blindness in women was marked among the elderly and not due only to differential life expectancy18. Globally, 216.6 million people are affected by moderate to severe visual impairment, of which about 36 million are blind19.



Source: Deloitte Access Economics calculations.

Figure 1. Incidence (blue bars) and incidence rate (green line) of permanent sight loss or blindness in the UK by age, 2016-178.

Causes of low vision

Figure 2 shows the causes of sight loss that led to certifications for sight impairment in England and Wales for the year ending March 2013²⁰. The proportion of certificates with a main cause of degeneration of the macula and posterior pole - mostly age-related macular degeneration (AMD) - was 50% of SSI and 52.5% of SI. This was a decrease from 2008, for which the use of anti-VEGF drugs is the most likely reason.

Glaucoma remains the second most common cause (11% of SSI; 7.6% of SI). The introduction of national diabetic retinopathy screening services and improved management of both diabetic retinopathy and diabetes have led to the reduction in sight impairment caused by diabetes. Hereditary retinal disorders have overtaken diabetes as the third leading cause of SSI.

2021/PROF/441

In a comparison of new vision impairment certifications in England in 2017/18 and 2010/11, it was found that the total number of certifications fell from 43/100,000 to 41/100,000. Certifications for AMD in those aged 65 or over reduced from 132/100,000 in 2010/11 to 107/100,000 in 2017/18; glaucoma certifications in those aged 40 or over remained stable. For diabetic eye disease the reduction in those aged 12 or over was from 4/100,000 in 2010/11 to 2010/11 to 3/100,000 in 2017/18 ²¹.

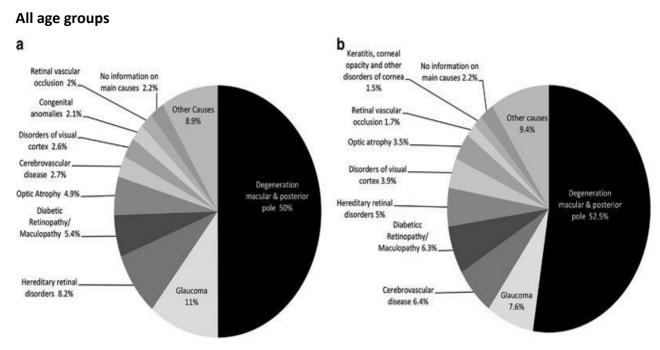


Figure 2. Main causes of (a) severe sight impairment and (b) sight impairment in England and Wales: certifications April 2012–March 2013²⁰.



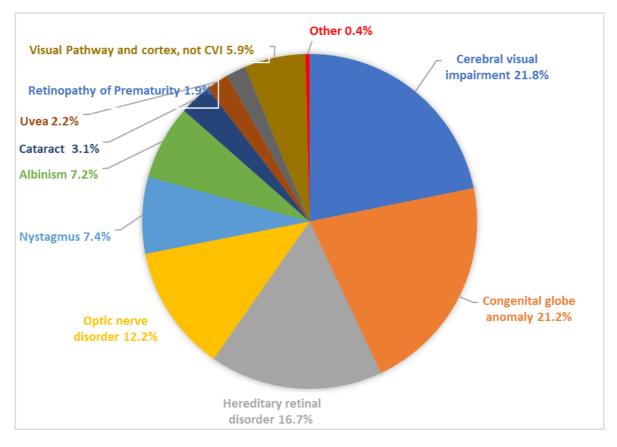
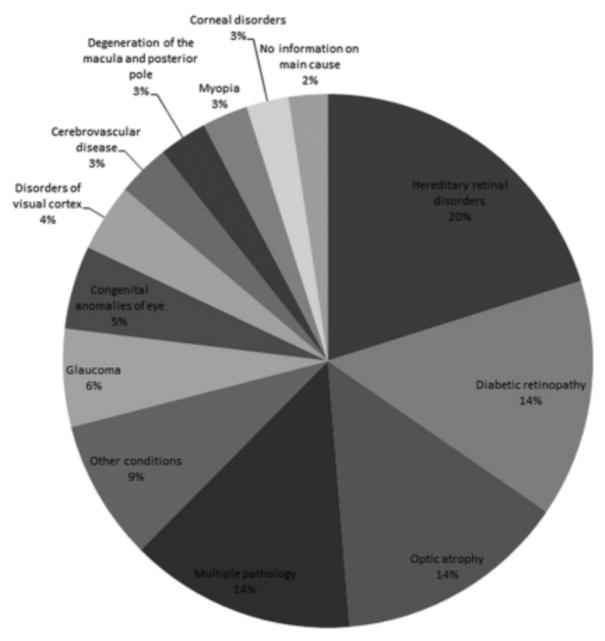


Figure 3. Causes of visual impairment (SI and SSI) paediatric certifications in the years 2009/10 in England and Wales²².

The major causes of visual impairment in the 0 to 16 age group are distinctly different from those in the adult population (Figure 3) ²². In England and Wales, cerebral visual impairment is now the commonest cause of paediatric SSI certification and hereditary retinal dystrophy and congenital globe anomalies are the commonest causes of SI certification. For more details on low vision in children, see chapter 8.

Age 16-64





For the first time in at least five decades, diabetic retinopathy/maculopathy is no longer the leading cause of certifiable SSI among working age adults in England and Wales, having been overtaken by inherited retinal disorders (Figure 4) ²³.

Global causes

The top three causes of global blindness in 2015 were, cataract, uncorrected refractive errors and glaucoma, and for visual impairment uncorrected refractive error, cataract and AMD. There were large differences in distribution of blindness by region¹⁹.

Chapter 2: General health and sight loss

The effects of deteriorating general health and sight loss are interwoven and complex, particularly in older people. For example, people with vision impairment are more likely to fall, which may lead to reduced mobility, isolation, and the development of depression.

Patients aged 65 years and older with visual impairment have a broad range of physical and mental health comorbidities compared to those of the same age without visual impairment and are more likely to have multiple comorbidities¹. For example, hearing loss or dementia can be compounding factors.

Stroke

"Approximately 30% of all stroke patients suffer from post-stroke visual impairment. Hemianopia is the most common symptom, but also neglect, diplopia, reduced visual acuity, ptosis, anisocoria, and nystagmus are frequent. Partial or complete recovery of visual disorders can occur, but many patients suffer permanent disability" 2. An estimated 60 percent of stroke survivors in the UK live with sight loss immediately after their stroke and the impact on reading, self-care and navigation³.

In addition to the vision loss associated with their stroke, many patients admitted for stroke rehabilitation have uncorrected refractive errors; one study found that 25 per cent did not have their glasses with them⁴.

Diplopia can affect rehabilitation and activities of daily living (ADL) such as reading, mobility and depth perception.

Reading is difficult with hemianopias; left-sided field loss makes it difficult to find the start of a line and with right-sided loss the person is reading into their "blind side". Homonymous hemianopia is a criterion for certification as sight impaired and the patient will no longer meet DVLA driving criteria.

Perceptual and processing problems can make the complex task of reading more difficult than tests of visual function would indicate. Facial and object recognition can also be affected. Visual hallucinations are a common finding in those with homonymous hemianopia and often a worrying symptom for the patient.

Multiple Sclerosis

Multiple Sclerosis (MS) is a leading cause of disability in young adults. The commonest ocular disorder, occurring in approximately 50% of patients is optic neuritis (ON), and this is the initial presentation of MS in 15-20%⁵.

Self-reported visual functioning can remain significantly affected after ON, and measurable visual dysfunction can occur in MS in the absence of any acute episodes of ON6. It is possible to detect clinically subtle visual dysfunction, even among patients with 0.00LogMAR (6/6) or better high-contrast visual acuity and no history of acute ON.

OCT studies have demonstrated thinning of the retinal nerve fibre layer in eyes of MS patients, even without a history of acute ON5, 7. Therefore, it is important to take a careful history of visual symptoms from the patient and to ensure that low contrast visual acuity and/or contrast sensitivity are assessed.

Less commonly, visual fields can be affected by chiasmal and post-chiasmal lesions. A wide variety of defects can occur including diffuse loss, central scotomas, and altitudinal defects.

Efferent syndromes associated with MS can result in visual dysfunction and oscillopsia, with consequent difficulty reading and focussing on near tasks⁶.

Low vision and rehabilitation support should address the multiple symptoms that usually coexist, producing a complex pattern of disability. For example, tremor and motor weakness may determine the appropriateness of various optical or electronic aids.

Diabetes

Difficulty with simple tasks such as reading pharmacy or food labels, seeing a blood glucose monitor, or setting an insulin delivery device at the correct number of units may interfere with diabetic control. Hence, support with alternative "easy to see" or talking devices can help patients manage their blood sugar control independently⁷. Where sight loss and lower limb neuropathy co-exist, there will be an increased risk of falls⁹, 10, and exercise levels will be adversely affected.

Falls

Older people with sight loss are at a higher risk of falls than their sighted peers11,12. Almost half of all falls in the population with sight loss are directly attributable to sight loss13, although recurrent falls are seldom due to a single cause. The NICE clinical guideline on falls recommends that multifactorial assessments undertaken by falls services should include investigation of sight loss14. The risk of falls may be reduced through various interventions, including home safety changes and housing adaptation15. Poor contrast sensitivity increases the likelihood of falling and good lighting is essential in falls prevention for the elderly16.

Dual sensory loss

A high proportion of older patients with sight loss also have a hearing impairment. Of the estimated 390,000 deafblind people in the UK, at least 222,000 are aged over 7017. Many deafblind people communicate using clear speech but some use interpreters (for example British Sign Language or deafblind manual) or communicator guides. The combination of vision and hearing impairment makes lip-reading difficult, and audio information is difficult to use.

Dementia

Many people live with both dementia and sight loss; the RNIB estimate the number in the UK with this co-morbidity to be around 250,00018. The prevalence of visual impairment is disproportionately higher in people with dementia living in care homes19.

Sight loss may be under-diagnosed in people with dementia and vice versa because the effects of each condition may conceal the presence of the other. Dementias also have direct patho-physiological effects on the brain and visual system and can have a visual-spatial impact. Impairment of near vision is associated with cognitive decline, probably by reducing participation in stimulating activities²⁰. Memory is assisted by visual clues and without good vision dementia may be "unmasked".

Subtle cognitive impairment, often previously undetected, can have an adverse effect on low vision rehabilitation as poor concentration makes the use of even simple magnifiers and technology problematic. Joint working is vital in supporting people with dementia and sight loss to maintain a balance between risk and independence²¹. The co-morbidity of dementia and sight loss increases the risk of disability and depression²².People with dementia are less likely to have eye examinations, and late presentation may mean they are less likely to benefit from treatments, such as for AMD²³.

The Royal College of Ophthalmologists and the VISION 2020 UK Dementia and Sight Loss Committee have developed a quality standard to help eye clinics and ophthalmology departments provide high quality care for patients with dementia²⁴.

Depression

A recent study of the prevalence of depression in adults with sight loss attending a low vision service in the UK was 43%25. As depression influences the ability to benefit from rehabilitation strategies, treatment is important for enabling coping skills. There is evidence that rehabilitation services (low vision clinical services, mobility and other skills training, counselling, optical device use, and adaptive device use) significantly contributed to a reduction in depression among a sample of older adults with age-related sight loss26. The effectiveness of the treatment of depression in people with vision impairment is unknown, but several studies are ongoing.

Visual hallucinations

Patients with sight loss who experience visual hallucinations may fear that they are developing a mental illness or dementia, and it important for them to understand that there are other causes. Hallucinations because of sight loss are known as Charles Bonnet Syndrome (CBS), named after an eighteenth-century Swiss scientist and philosopher who first described the condition in his own grandfather.

Prevalence of CBS in people with AMD related sight loss has been reported as 27 per cent²⁷. While this may settle with time, up to 40 per cent of people with sight loss have long-term visual hallucination²⁸. Although CBS is widely considered a transient condition without adverse consequence, one third of people affected have negative experiences and outcomes such as frequent, fear-inducing, longer-lasting hallucination episodes, or attribution of hallucinations to serious mental illness²⁹.

It is important to note that in CBS there are no associated auditory or tactile perceptions. Reduced acuity, poor contrast sensitivity, older age and female gender are risk factors for visual hallucinations. Despite a long recognition of the syndrome, there is no evidence-based medical treatment. Current best practice is to identify the condition, provide an explanation of the symptoms and reassure the patient to reduce unnecessary anxiety. Some practical measures that may help include the patient getting up and making tea (i.e. activity) or turning on a bright light if the room is dark.

Smoking and Lifestyle

Four modifiable behaviours- smoking^{30.31}, physical inactivity^{30,31}, poor diet³¹ and drinking alcohol³⁰ have been shown to be associated with reduced vision. Smokers are also three times more likely to develop nuclear cataracts. Ex-smokers reduce their risk³³. Smoking, by accelerating atherosclerosis, is related to retinal artery occlusions, Referral to smoking cessation programmes is therefore strongly recommended, particularly for patients with AMD who have already lost sight in one eye.

Toxic-nutritional optic neuropathy can occur when essential nutrients, particularly folic acid and vitamin B complex, are lacking from the diet. It is most associated with malnutrition or poor dietary habits, often linked with chronic alcohol abuse. With early treatment the visual prognosis can be very good³⁵. Drugs of abuse can cause severe vision loss from a range of visual disorders such as retinal emboli, maculopathy, endophthalmitis or occipital lesions³⁶.

There is strong evidence that smoking is causally linked with age-related macular degeneration (AMD), and that the risk increases with the intensity of smoking. The risk for

current smokers is two or three times that of never-smokers. Ex-smokers have a reduced risk³². Smoking is also a risk factor for amaurosis fugax³⁴.

Sleep disorders

Obstructive sleep apnoea (OSA) has been linked to several eye conditions, particularly primary open-angle and normal tension glaucoma, non-arteritic anterior ischaemic optic neuropathy and floppy eyelid syndrome^{37.} Patients with OSA should have routine sight tests, especially to screen for glaucoma, because up to 27 per cent of people with OSA have been reported to have glaucoma³⁸. Blindness carries a significant risk of sleep disruption due to disorders of circadian rhythm. Melatonin may be helpful for some patients^{39,40}.

Chapter 3: Low vision in daily ophthalmological practice

Although few ophthalmologists participate directly in low vision clinics, they will routinely see patients with low vision. Whether for their initial diagnosis or for follow up management, people with significant sight problems will attend eye departments, especially certain specialties such as macular or diabetic eye clinics.

The patient's experience

People who have poor sight are likely to have difficulties accessing healthcare services and visits to eye clinics can be very unpleasant experiences. Hospital Eye Services need to be mindful of this from the readability of clinic appointment letters, to signage and lighting. Overcrowded waiting rooms, and poor illumination and contrast add to the stress of the clinic visit, and staff with little awareness of the problems associated with visual impairment may compound the difficulties¹.

The support and understanding of ophthalmic nurses and Eye Clinic Liaison Officers (ECLOs) are extremely important, but even in a busy clinic, patients appreciate an ophthalmologist who understands the impact of sight loss and does not only focus on their eye condition.

Meeting a patient with a visual impairment

Calling the patient's name from a distance and walking away, ensures that the consultation gets off to an unnecessarily bad start. How could it be done better?

- 1. Check the case notes for an indication of visual impairment before calling the patient.
- 2. In the waiting room, actively find the patient and approach them directly.
- 3. Introduce yourself and explain where you are going. For example: "I'll take you into the clinic room now."
- 4. If you think they need help, offer to guide them (see below).
- On the way, give instructions about where you are going. For example, "my room is the next door on your left" or "the examination chair is a few paces straight ahead of you".

Guiding a patient with a visual impairment Guiding a person who has a visual impairment (Figure 1) is not difficult but most people are understandably nervous about offering to guide if they have not had previous experience or training.

Introduce yourself, communicate clearly when offering help and listen to their response (they will confirm if they want assistance).

- Ask where and how they would like to be guided. Allow the patient to take your arm, rather than holding or grabbing their arm.
- 2. Point out steps as you approach them and say whether they go up or down. Mention any potential hazards that lie ahead and say where they are.

Figure 1: Guiding a patient to your room can be helpful



- 3. If you are guiding someone into a seat, place their hand on the back of the seat before they sit down, so they can orientate themselves.
- 4. Say when you have finished providing assistance make sure they know where they are and which way they are facing.

For more detailed instructions on guiding, see the RNIB website2.

History taking

Ophthalmologists do not usually have time to ask patients in detail about the impact their sight loss has on their daily lives, but should at least have sufficient knowledge and understanding of local social and rehabilitation services to be able to offer referral to other professionals according to the needs and wishes of the patient. A supply of information in accessible formats, particularly large print, is essential, as verbal information is often misinterpreted or forgotten. Where ECLOs are employed, this task is much easier. In a busy clinic, a few open questions such as "how is your sight problem affecting your daily life?" and, if necessary, a few direct questions on the following subjects will give the doctor a quick assessment of the overall situation.

Reading

Most people with low vision will report difficulties with reading. Problems can be experienced with instructions on packets including medicine packets, newspaper print, television listings and computer text. Some people may be happy for others to read their letters and bills for them, but many will wish to do this for themselves. Referral to a low vision clinic for a magnifier may be life changing and can help people maintain their independence (Figure 2).



Figure 2: A low vision service may provide a magnifier for shopping.

Social situation

It is important to know the person's home situation – for example, whether they live alone, have family support or are in sheltered accommodation. An elderly blind patient living alone might require a referral to social services. For those who are particularly vulnerable (for instance at risk of falling, misuse of medication or suffering burns) a phone call to social services may be needed.

Cooking

Those who cook for themselves may not be able to see dials on the cooker or microwave, read recipes, buy food, read instructions on packets, or chop food and pour liquids safely. These issues may be resolved by equipment and training (Figure 3). Failure to address these issues can result in poor diet, burns and scalding, and have resultant health implications.



Figure 3: A rehabilitation worker can add tactile markers to appliances.

Mobility

People with a visual impairment are less likely to go out alone and more likely to have difficulties using public transport. It is easy to lose confidence in crossing roads, for example, and not being able to get out can lead to isolation and loneliness. Referral to sensory needs should be offered to provide orientation support and training which can often help maintain independence

A symbol cane may be all that is required for some people who just need others to be aware they may need assistance. These can be provided by social services.Communication

Communication with others helps to prevent isolation. Large button phones and free directory enquiry services are helpful. Writing a letter or a list, or just signing one's name, can be difficult for someone with sight loss. Equipment and training are usually available from rehabilitation services. (Figure 4). Learning the basics with

technology can provide significant benefit for patients who have a VI. Referral to tech training at RNIB or local societies is extremely helpful. In enabling patients to have all communication options available to them.



Figure 4: Social services provide equipment and training to aid communication

Medication

Most people with a visual impairment take some form of medication. Determining which tablet to take, measuring injections, instilling eye drops and reading the name and dose can be difficult.

A magnifier or alternative medication options such as dossette boxes can prevent errors. Where this is not possible highlighting these concerns to their GP is important so that support can be arranged in the community. (Figure 5).



Figure 5: A magnifier for reading medication instructions.

Glare

Various types of glare may be experienced by people with poor vision.

- 1. Disability glare impairs visual function by casting a veil over the retinal image. Vision is reduced in contrast without necessarily causing discomfort.
- 2. Discomfort glare does not necessarily impair visual function.
- 3. Photophobia causes intense discomfort and affects visual function.

Light and dark adaptation

People with low vision, especially those with age-related macular degeneration (AMD), may have a much slower adaptation to increases in ambient illumination. It can take several minutes for vision to be optimised. Patients with retinitis pigmentosa (RP), end-stage glaucoma or those who have had PRP laser may have slow light and dark adaptation. Assessment of home lighting is an invaluable part of the rehabilitation worker's role.

Assessment of visual function

People with poor vision can feel upset or even humiliated by the way in which visual acuity is tested at an eye clinic. (Figure 6). For an accurate assessment, it is important to adapt assessment techniques appropriately, giving the person enough time to respond.

Distance visual acuity

The distance visual acuity chart should be placed at a distance where the patient can read a line or two of letters.

At a functional level, there is a practical difference between a vision of 1.0 LogMAR (6/60) and 'hand movements'. Care should be taken to obtain an accurate assessment between these levels by using the chart at closer distances if necessary. The "Counting fingers" method is not an accurate and its use should be discouraged.

Traditional Snellen charts are not recommended for assessing low vision patients, because there are very few letters at poorer acuity levels and increments between lines are largest at poorer levels of acuity. Letters on lower lines are also more 'crowded' than those at the top, causing a variation in the task difficulty.

LogMAR Distance Visual Acuity Charts (Figure 6) are much more useful within the low vision context³. Each row has five letters, and if the chart is brought sufficiently close low vision patients will be able to read an entire line of letters rather than a single "top letter", which is psychologically better. There is no variation in 'crowding' and results are legitimate at any distance. There is also uniform progression of letter sizes, rather than the large steps at the top of a Snellen chart. Similar charts are available as electronic, on screen or projection charts.



Figure 6: LogMAR charts are preferable to Snellen charts for low vision patients.

Near visual acuity

Traditional near charts do not have sufficiently large text for many low vision patients. Near acuity threshold charts have been developed with the needs of the low vision patient in mind. For example, the Bailey-Lovie near chart⁴ (Figure 8) incorporates print from N80 to N2.5.



Figure 7: A Bailey-Lovie near test chart

Contrast sensitivity

Contrast sensitivity has found an increasingly important place in visual assessment of people with low vision. The Pelli-Robson letter chart (Figure 8) is easily understood and produces clinical results which are easy to interpret⁵. The chart has letters of a fixed size and is held at a viewing distance of one metre. The contrast of triplets of letters reduces so that a value for the threshold contrast is obtained⁶.

Loss of contrast sensitivity causes difficulties in many areas of daily life, from distinguishing money to seeing food on a plate. It affects visually-impaired readers more than normally sighted people⁷. The inability to see an approaching car, find a door in a room or locate the position of a chair affects outdoor and indoor mobility.



Figure 8: Pelli-Robson chart.

Reduced contrast sensitivity has been found to be one of the most significant visual factors in older people falling⁸. Informing rehabilitation professionals that a patient's contrast sensitivity is reduced is important for mobility assessment; in addition, improvements can then be made to contrast and lighting in the home to facilitate daily living tasks. (Table 1) (see Chapter 7).

It should be noted that visual acuity is a high contrast task and therefore it is possible to have excellent visual acuity but very poor contrast sensitivity. The risks and difficulties faced by that patient would be missed if visual acuity alone was measured.

 Table 1: Pelli-Robson chart contrast threshold values, adapted from Rumney9.

Level of function	Contrast threshold	Chart letters		Contrast threshold
Severe loss	99%	VRS	KDR	63%
consider non-sighted techniques	44%	NHC	SOK	31%
Significant loss	22%	SCN	OZV	15%
requires contrast enhancement	11%	CNH	ZOK	7.8%
Noticeable loss	5.6%	NOD	VHR	3.9%
may benefit from improved lighting	2.8%	CDN	ZSV	1.9%
Normal	1.4%	КСН	ODK	1.0%
	0.7%	RSV	HVR	0.5%

Visual fields

Visual field testing in a patient with low vision can provide an understanding of functional visual problems. For example, orientation and mobility is most affected by overall constrictions to the visual field or by inferior or central scotomas¹⁰; hemianopias and central scotomas interfere with reading tasks. In assessing visual fields where the visual acuity is poor, the fixation target should be adapted to improve its visibility, and fixation monitoring is usually best turned off.

Confrontation fields with both eyes open may give sufficient information in many cases. If the patient is being referred for a mobility assessment and training, a copy of the field plot should be made available to their rehabilitation worker. Kinetic visual field assessments will provide much more useful data than threshold automated static perimetry and will prove much less arduous for the vision impaired patient.

Amsler grid

Amsler grid testing can give useful information in a small number of patients who are able to describe the size and location of a central scotoma or distortion. An Amsler chart with intersecting lines that form a cross at the centre may help those with central scotomas to maintain fixation.

Breaking bad news

In ophthalmology clinics, there can be a tendency to concentrate on the medical aspects of sight loss whilst assuming that 'others' will attend to the rest. However, it is important that the way in which the news of sight loss is broken or confirmed has a huge impact on the person and remains an enduring memory for each individual. Changes in medical training have meant that it is now rare for people to recall with anger the way they were told about their eye condition. However, a rushed or matter-of- fact explanation of a diagnosis can mean that the person spends months or years without knowing the name of their eye condition, or the prognosis. Working closely with Eye Clinic Liaison Officers (ECLOs) (see

below) and/or other clinic support staff can be supportive and educational for ophthalmologists of all grades.

Breaking bad news 'well'

So, what is important when explaining, updating or confirming a diagnosis with a patient? The key points can be summarised as follows:

- 1. Invite the patient to bring a relative or friend into the room if they would like someone else to hear the information you are about to give concerning their eye condition.
- 2. Take the time to sit down with the patient and after inquiring about how much the patient already knows, explain the facts in a clear supportive way, avoiding medical terminology, and as if you are not in a hurry.
- 3. Give the name of the condition; explain what it is and how it will affect the patient's sight. Give them a leaflet about the eye condition. If this is not possible, at least write down the name of the condition for them.
- 4. Explain that help is available to enable them to make the most of their remaining sight and provide a signpost to someone who can give more information. This might be their local social services department, local society or a national organisation, such as RNIB, Guide Dogs or the Macular Society.
- 5. If appropriate, bring up the subject of certification and registration and what they mean.
- 6. Acknowledge that you have given them a lot of information to take in, confirm their understanding, and ask the person if they have any questions. Refer them to resources such as "Sight Loss What we needed to know" available at <u>https://www.rnib.org.uk/sites/default/files/Sight_Loss_WWNTK_2020.pdf</u>
- 7. If the patient is obviously upset and has no accompanying carer, ask a nurse or other colleague to sit with them and to make sure that they will not leave the building until they have had further support and information.
- 8. When patients have been given bad news, it is essential they are followed up promptly by social services.
- 9. When a patient is discharged from the eye clinic, they should be made aware of the circumstances under which it would be advisable for them to request a further referral. They must not be made to feel abandoned by the ophthalmologist; especially not with the words "nothing can be done" etched in their memory.
- 10. This approach carries a positive message, which can make it easier for the patient to seek support from other services. The Royal College of Ophthalmologists includes a section on the breaking of bad news in its learning outcomes for ophthalmology trainees¹² and recommends various resources including the use of "SPIKES", the six-step protocol developed within the oncology profession.

Eye Clinic Liaison Officers (ECLOs)

In recent years, Eye Clinic Liaison Officers have been employed in many eye clinics, providing immediate support and information to patients following their consultation. Having time and appropriate training, they greatly enhance the experience of patients at the difficult time of their diagnosis with sight loss13. In August 2017 the CVI was modified introducing a section specifying support from an ECLO.

Identifying Depression

Be alert to possible depression and consider asking patients who may have depression two questions, as outlined in the NICE guidelines¹⁴, specifically:

- 1. During the last month, have you often been bothered by feeling down, depressed or hopeless?
- 2. During the last month, have you often been bothered by having little interest or pleasure in doing things?

Patients who may be clinically depressed should be referred promptly to their general practitioner.

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Chapter 4: Certification, registration, and early referral

- Certification: The consultant ophthalmologist certifies the sight impairment by completing the CVI form with the patient.
- Registration: The social services/social work department, on receiving the CVI, registers the person (with the person's permission) and provides relevant support.
- Early referral: Referral from health to social services when CVI criteria not met.

Access to Services

The certification and registration process is an important gateway to services and benefits for people with low vision. When signed by a consultant ophthalmologist, the Certificate of Vision Impairment is the formal notification required by social services departments to register someone as sight impaired (SI) or as severely sight impaired (SSI).

Early referral of people with sight loss usually gives them access to some social care services. However, the CVI triggers the local authority to contact the patient to offer registration, which is then followed by a full assessment of their needs. Depending on the person's circumstances, registration may also entitle them to financial or other benefits.

While registration is a voluntary process and people can decline to be registered, it is in their best interest to accept registration, to facilitate access to the services available. However, if consent has not been given, the person should still be offered a needs assessment.

People registered as either SI or SSI may be entitled to:

- Free NHS sight tests
- Railcards and other rail or travel concessions
- Local travel schemes
- Free directory enquiry services from BT
- Protection under the Equality Act
- Free postage on items marked 'articles for the blind
- Free assessment by social service (However, if consent has not been given, the person should still be offered a needs assessment)

In addition if someone is registered as SSI they may be entitled to:

- Free loan of radios, cassette players and TV sound receivers
- Help with telephone installation charges and line rental
- Personal Independence Payment (PIP)
- Attendance Allowance
- Carer's Allowance
- Employment and Support Allowance
- Tax credits
- Housing Benefit
- Council Tax disability reduction
- Universal Credit *
- Pension Credit
- Free ticket for a guide at theatres, galleries and tourist attractions.

As this changes periodically, for an updated full list, see relevant websites, e.g. Macular Society¹ or RNIB benefits and concessions of registration <u>https://shop.rnib.org.uk/starting-out-benefits-concessions.html</u> free copies can be ordered in bulk for hospitals.

The RNIB also has a benefit checker through its helpline 0303 123 9999. Universal Credit began to be rolled out in 2019 and aims to incorporate several of the other benefits.

Collection of epidemiological data

The authorities that fund services for people with sight impairment use the epidemiological information gathered during the registration process to help determine the need for services. The World Health Organisation Global Action Plan stresses the importance of collecting this data in each country for use in priority setting and resource allocation². Therefore, certification and registration of those who are eligible is important to ensure adequate provision of relevant health and social services.

Role of the ophthalmologist

Despite the importance of the process to individuals and to service provision, significant numbers of patients are not certified as having visual impairment, despite consultation with an ophthalmologist. In fact, it is often the patients attending clinics with a chronic eye condition who are certified late or not at all.

This may be related to the difficulty in assessing fluctuations in visual function during successive treatments, or the perception by the ophthalmologist that certification/registration is an end-point which should not be considered while treatment is ongoing³ (Figure 1). The Royal College of Ophthalmologists' (RCOphth) curriculum seeks to ensure appropriate knowledge and practical skills of trainees in this regard⁴.

Consultant ophthalmologists are the only professionals who may complete a certification form on behalf of a patient with visual impairment. Ophthalmologists in training have a responsibility to alert their consultant to a patient's need for registration. In a busy clinic, it can be all too easy to decide that "it can wait until the next review". With ever-improving treatments for chronic eye conditions, fewer patients may be reaching the criteria for SSI5, but still have significant sight problems requiring support. There is a danger of patients having investigations and beneficial therapies while their low vision needs are still overlooked.



Figure 1: Patients undergoing long-term treatment may have their low vision needs overlooked.

The criteria for registration include both visual acuity and visual field measures. Patients with visual impairment due to visual acuity loss are more likely to be registered than patients with either visual field loss or mixed visual acuity/visual field loss⁶. The ophthalmologist should therefore consider registration in patients with gross peripheral field loss, for example in glaucoma or hemianopia, and not rely simply on the visual acuity criteria.

It is vital that discussions are handled in a sensitive manner; encouraging the person by outlining the advantages but allowing them to make the decision for themselves, as it is a voluntary process.

Information in an appropriate format, e.g. large print, should be given so that the patient can, if necessary, reconsider their decision after further discussion with family or friends. The introduction of Eye Clinic Liaison Officers (ECLOs) in many ophthalmology departments has taken the pressure off eye clinic staff and ECLOs' assistance with the completion of CVI forms is of great benefit to all concerned. However, doctors must still be alert to their patients' certification/registration status.

The process

Each of the four UK nations has its own CVI form with sections to complete concerning the person's demographic details, level of vision, diagnosis (using ICD codes), general health, social circumstances and the person's consent for certification as SI or SSI.

Ophthalmologists should make sure they are familiar with the form and process in the nation where they are currently employed, as there are variations. For example, the new CVI Scotland form is only for people aged 16 and over. Young people and children under the age of 16 are supported through the VINCYP Pathway (Visual Impairment Network for Children and Young People). There are also variations in the administrative process of the four CVIs, some having copies sent to the GP and/or patient. The means of data collection also varies throughout the four nations. The RCOphth website has links to each of the forms and the relevant explanatory notes7.

Driving

Information targeted specifically at those who may have a driving licence is highlighted on the CVI forms, warning drivers of the consequences of driving when vision fails to meet the standard requirements.

Early referral without CVI

The CVI may only be completed when visual impairment is relatively advanced, but there are many patients whose sight loss is not of such severity are still likely to need support and/or equipment to aid independence and improve quality of life. Patients falling into this group tend to be those whose vision is below the driving criteria but not at the point where registration criteria have been met (Low vision services should be offered to these individuals as early intervention can help with independence and particularly important if the condition is progressive. Local arrangements will dictate how such referrals are made to sight support services, either through social services, social work departments or local or national voluntary organisations.

Referral of Visual Impairment (RVI)

In some areas, hospital eye clinic staff, with the consent of the patient, can fill in a Referral of Visual Impairment (RVI). The form notifies social services about the person's situation, requests an assessment of need and states how urgently they think the person requires help.

Categories of certification

Summaries of the criteria are given below, but the explanatory notes for each nation's CVI form give more details of factors, which might merit consideration.

Severely Sight Impaired (SSI) – formerly "Blind"

- Visual acuity < 3/60
- Visual acuity > 3/60 but < 6/60 with a very contracted field of vision (unless this has been longstanding)
- Visual acuity of better than 6/60 with a very constricted visual field, especially in the lower part of the field (excluding people who suffer from homonymous hemianopia or bi-temporal hemianopia with VA better than 6/18)

Sight impaired (SI) – formerly

"Partially-sighted"

• Visual acuity of 3/60 to 6/60 with a full visual field

- Visual acuity of up to 6/24 with moderate restriction of visual field, media opacities or aphakia
- 6/18 or better with gross field defect (e.g. hemianopia) or a marked constriction of the field (e.g. retinitis pigmentosa)

Chapter 5: Multi-disciplinary working

The concept of low vision care has moved from provision of magnifiers to a holistic rehabilitation process involving a range of professionals¹. In the care of stroke patients, the physician works with a team of professionals, including physiotherapists, occupational therapists, speech therapists, nurses and social workers. Likewise, it should be standard practice for ophthalmologists to work in a multi-disciplinary team when caring for people who have impaired vision.

In recent years, this has been recognised as best ophthalmic practice. As with other rehabilitative programmes, the aim is to assist the person with low vision to stay as autonomous and independent as possible. Familiarity and good communication with local services, and knowing how to refer patients appropriately, can make the ophthalmologist's life easier and importantly, prevent excessive delays in obtaining support.

People with low vision may require input provided by a wide range of services and professionals which will vary according to the needs of individual patients. A 'one size fits all' approach will fail to address the issues facing each person trying to cope with sight loss. No two people have the same experience of sight loss even if their clinical situation is the same.

Health care services

In the UK, low vision services are not currently standardised in the level of provision on offer, and the support provided can vary greatly. Low vision services have traditionally been provided in hospitals by optometrists or dispensing opticians but also by orthoptists and, occasionally, ophthalmologists. Increasingly, these services are also provided in multi-disciplinary centres or in community optometry practice².

Low vision service provision offers a range of interventions which aim to minimise disability by making specific tasks easier to perform. This is achieved by helping people to make full use of the sight they have by ensuring their spectacles are serviceable and up to date, and providing equipment, training and advice.

Social services

When an ophthalmologist certifies a person as having visual impairment (SSI or SI), this should trigger a social services' assessment of the needs of a person with sight loss, via a sensory support team. Some of the services may be provided by external agencies or the voluntary sector on a contracted basis. There may be many different professionals within a social services department who are called upon to form this package of services, but usually they will be rehabilitation workers and social workers.

Rehabilitation workers

Rehabilitation workers are trained to work with the person in their own environment and provide practical aids and training to overcome the daily living difficulties resulting from

visual impairment. Their training includes knowledge of common eye diseases and an understanding of the consequent functional problems.

Rehabilitation workers are employed by social services departments and in some cases by local charities where services have been contracted out. They may work in sensory disability teams alongside social workers and others to provide services to people with hearing and/or visual impairments. They are sometimes known as Vision Rehabilitation Workers or Rehabilitation Officers Visual Impairment (or ROVI). But they have all followed the same training and qualification route. More information can be found on this practitioner on the Rehabilitation Workers Professional Network website. <u>https://www.rwpn.org.uk/</u>

Social workers

Some areas have social workers who specialise in working with people with a visual impairment, and who work within multi-disciplinary teams alongside rehabilitation workers. They may also provide emotional support where appropriate.

Types of social services (or voluntary sector) assistance provided:

Adaptations to the home: use the basic low vision concepts of good lighting, contrast enhancement and enlargement. New lighting may be installed, or non- optical low vision aids such as coloured chopping boards or large number watches may be recommended. Adaptations for the use of a magnifier may be advised, such as reading stands or task lighting.

Daily living skills: help people with low vision manage the tasks they need to do around the home by maintaining confidence and independence. A rehabilitation worker identifies problem areas and develops a training programme. This may include kitchen skills, personal care and general household tasks, including the use of low vision aids as appropriate.

Orientation and mobility: training may be provided to anyone who has a visual impairment and has difficulty getting about. The assessment and training will consider the routes the person wants to travel, their level of vision, mobility aids, low vision aids, physical fitness, preparation for a guide dog and use of a sighted guide.

Many other services may be incorporated into a care plan for someone with a visual impairment. A care plan is an agreement between the person and the support organisation about the impact their condition is having on their life and how they can be supported to best meet their health and well-being needs. These might include benefits rights, occupational therapy, counselling, day care and Meals on Wheels.

The ophthalmologist's role in relation to social services

Junior ophthalmologists should visit a local social services team and find out how they operate. A home visit with a social worker or rehabilitation worker is an invaluable part of ophthalmology training and is recommended in the Royal College of Ophthalmologists curriculum ³

Once appointed to a consultant post, he/she should again contact the relevant local social services professionals and ensure that good lines of communication are established and maintained.

Education services, see Chapter 8.

Employment services: People who have a visual impairment can get help to find or stay in employment through the Access to Work scheme, which operates by giving one-off or ongoing grants, which may include:

- Adaptations to equipment or to work premises, e.g. provision of CCTVs, software for computers, Braille keyboards and task lights
- Support workers
- Travel to and from work

People of employment age who have a visual impairment and are not aware of the Access to Work scheme should contact their Local Jobcentre Plus. In Northern Ireland the support system is slightly different⁴. People who are sight impaired have much greater difficulty finding work and therefore they should be encouraged to seek the support they need to stay in work rather than leave their current work because of the difficulties they are facing. It should be noted that their employer is not responsible for putting them in touch with Access to work and without the right advice early enough they may miss out on this vital service.

Voluntary organisations

These can be divided into four main groups.

- 1. Disease specific groups exist for many eye conditions, including macular degeneration, glaucoma, nystagmus, retinitis pigmentosa and diabetic eye disease. All UK groups can be contacted by calling the RNIB Helpline or web pages.
- 2. Hobby-specific groups link people with a visual impairment who have similar interests. They include music groups and sports groups.
- 3. Voluntary organisations exist in most areas to provide advice and support at a local level. Most run social events and provide or sell adaptive equipment. Some offer extensive services and hold the Local Authority contract to provide rehabilitation services to people with a visual impairment in the area. You can find information about sight loss organisations operating in the patient's area by consulting the Sightline Directory on line. https://www.sightlinedirectory.org.uk/
- 4. National organisations such as The Guide Dogs for the Blind Association (Guide Dogs), and The Royal National Institute of Blind People, provide information and advice and campaign on behalf of people with visual impairment.

Chapter 6: Magnification and magnifiers

Many people with low vision find magnifiers useful to help them do short everyday tasks such as reading their post or instructions on a packet. Magnification increases the retinal image size. For people with a scotoma this may make an object easier to see, because although the retinal image size increases the area of visual loss remains the same size (Figure 1).



Figure 1: A schematic and simplified representation of how magnification can help a person to read short text.

Relative size magnification

This is a linear relationship: doubling the size of the object makes the image on the retina twice as large, creating x2 magnification. This form of magnification is usually limited to about 2.5x because of the physical limitations of enlarging an object. Examples of this type of magnification are large print books, watches or timers (Figure 2).



Figure 2: Making things bigger creates relative size magnification.

Relative distance magnification

This is also a linear relationship: halve the distance from the eye to the object and the retinal image becomes twice as large, creating x2 magnification. For example, viewing the television from 2m rather than 4m gives x2 magnification (Figure 3).



Figure 3: Moving things closer creates relative distance magnification.

This type of magnification can also be used for near tasks, e.g. bringing print closer to the eye from 40cm to 10cm gives x4 magnification. Children and young adults can use accommodation to provide this form of magnification, although excessive accommodative demand may cause eyestrain and limit duration of use. Myopes who take off their glasses can achieve some magnification without the need for accommodation.

Plus lens magnification

A plus lens creates magnification by allowing the person to adopt a closer viewing distance while focussing the object on the retina and accommodation can be relaxed. Most hand and stand magnifiers work on this very simple principle. The plus lens can be close to the eye, in a spectacle lens, or remote from it, in a hand or stand magnifier.

Limitations of plus lens magnifiers

- Field of view: Patients often ask for larger magnifiers, hoping that this will increase their field of view. However, as the power of a magnifier increases, the diameter of the lens decreases, due to the weight of the lens and physical constraints in manufacturing. Instead, they should be encouraged to hold the magnifier as close as possible to the eye, thereby increasing the field of view.
- Short working distance: Although the distance from the eye to the magnifier can be varied, the distance from the magnifier to the object is often very short, especially with stronger magnification. This makes it difficult to place implements such as a pen or screwdriver under stronger magnifiers and directing adequate light on to the object can be problematic.

Hand magnifiers

Hand magnifiers are useful for short 'survival' tasks such as looking at packets or the dials on a cooker. Most people find them socially acceptable and they are easy to carry in a pocket or handbag. There are countless designs available at low cost in a wide range of powers, and many are internally illuminated (Figure 4). People with hand tremors or grip problems may find them difficult to see.



Figure 4: A wide range of hand magnifiers is available, including folding and illuminated versions.

Stand magnifiers

Stand magnifiers allow the maintenance of a precise magnifier-to- object distance, which means they can be particularly useful for sustained tasks or where there are physical difficulties, such as tremor. The most commonly prescribed stand magnifiers are internally illuminated because the stand can obstruct light from getting to the object (Figure 5). As light rays from most stand mags are divergent when placed flat on the page, reading correction should be worn. Some lower-powered stand magnifiers allow tools, such as a pen, to be used (Figure 6). Their main disadvantage is that they can be very bulky.



Figure 5: Illuminated stand magnifiers are the most commonly prescribed stand magnifiers.

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The difficulties of plus lens magnifiers can be overcome by mounting them in spectacles as this gives the best magnification and greatest field of view. However, most patients do not like any magnifier that focuses less than 25cm from the spectacle plane.



Figure 6: A pen may be used under some low powered stand magnifiers.

Spectacle-mounted plus lens magnifiers

For people who can accept shorter working distances, spectacle-mounted plus lenses are sometimes tolerated because they give the best magnification and field of view and allow their hands to be free (Figure 7). As binocularity can prove difficult, an additional base in prism will be required with near adds of between 4 and 12 DS.



Figure 7: Spectacle-mounted low vision aids allow the person to do tasks that need both hands free, but only at a short working distance.

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Real image magnification

Optical magnifying systems are limited to a magnification of about x20. Real image magnification produced electronically is available in much higher magnifications of x50 and over.

Closed circuit televisions

Closed circuit televisions (CCTVs) produce real image magnification electronically using a camera to create a magnified image on a monitor screen (Figure 8 and 9). In theory, CCTVs should be the solution to all the frustrations of low vision aid users as they can produce high magnification, contrast and binocularity of the image with none of the postural difficulties of many other magnifiers. In practice, however, they are expensive, quite difficult for some patients to use and often bulky (and so not portable). Hence, only a small proportion of the low vision population use CCTVs. Increasingly many people now use their smartphones and tablets instead.

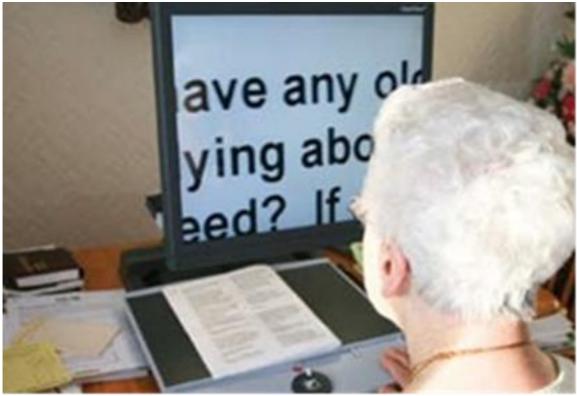


Figure 8: Various models of CCTV are available. The material to be viewed is placed on an X-Y table.



Figure 9: A TV reader.



Figure 10: A smart phone magnification App



Smartphone and tablet magnifier applications

These are often freely available, but the auto-focus and ease of use is variable (Figure 10). Examples are 'Magnifying Glass' for android and 'Magnifying Glass With Light' for the iPhone. In addition, people often simply take photographs of text using a phone or tablet and enlarge it.

Angular (or telescopic) magnification Telescopes and binoculars are very effective in producing magnification for distance, while allowing the person to stay at their chosen distance from a task, such as viewing a street sign. They can also be used for near tasks. Their main disadvantage is restricted field of view. Also, distortion of space and movement perception prohibits walking around while using the telescope. Their use requires considerable manual dexterity, skill and practice, particularly to follow moving objects. Only a very small proportion of people with low vision use them (Figure 11).

Figure 11: Devices that produce angular magnification: a

distance Galilean telescope used for TV viewing, terrestrial telescope and a pair of binoculars.

Further reading

- Dickinson C. Low Vision Principles and Practice. Oxford: Butterworth-Heinemann, 1998
- Macnaughton J. The Practical Management of Visual Impairment, 2018

• Jackson AJ, Wolffsohn JS. Low Vision Manual. Philadelphia: Butterworth-Heinemann-Elsevier, 2007

Chapter 7: Adaptations to daily life

When ophthalmologists think of low vision aids, an image of a magnifier usually comes to mind. However, many devices and strategies can enable a person with sight loss to use their residual vision and other senses to best advantage.

Postural aids

A common reason for not wishing to use a magnifier is that it requires an unnatural and uncomfortable posture. Clipboards and reading stands keep flimsy material flat, encouraging better posture (Figures 1 and 2).



Figure 1: A clipboard allows a person to rest their magnifier on a flimsy page



Figure 2: A reading stand allows a more normal posture.

Mobility aids

A mobility aid assists a person with navigating safely and comfortably from place to place. Increasingly people are using technological solutions to aid mobility including Apps.

Guide dogs

Only approximately 5000 people in the UK with a visual impairment use a guide dog (Figure 3). People with severe sight loss can self-refer for assessment with The Guide Dogs for the Blind Association², or may be referred by a social worker, rehabilitation worker, general practitioner or ophthalmologist. There is no longer a minimum age to becoming a guide dog owner but an applicant needs to be fit and active enough to walk for at least 40 minutes (around 1 mile) a day and be able to care for a dog. Applicants receive extensive training with the dog. The owner must be able to direct the dog as to a given route. Some working guide dogs have been trained to support clients with additional needs and so are "dual qualified". These include dogs working with people with combined hearing and vision impairment and those supporting people with physical disability, including wheelchair users with sight loss.



Figure 3: A guide dog assists with crossing roads and avoiding obstructions.

White sticks and canes

There are four types of white stick or cane (Figure 4):

- 1. A symbol cane is made from sections of folding lightweight tube. It is designed to indicate that the user has a visual impairment, e.g. in a busy shopping street. The user should have some training in its use. Symbol canes are available from social services and voluntary agencies.
- 2. The guide cane is longer and sturdier than the symbol cane and is used by people with some vision to identify kerbs, steps and stairs. It must be issued by a rehabilitation worker as instruction and training are required.
- 3. A long cane is a long, lightweight cane with a rubber grip and a roller ball tip. It is used by people who have very little vision to scan the ground ahead and identify obstacles or hazards. Again, a course of instruction is needed.
- 4. A white walking stick is used by people who need support for walking, and generally acts as a symbol rather than navigation aid. Occupational therapists or physiotherapists usually prescribe these.

People using red and white striped canes have both visual and hearing impairment.

Figure 4: There are four main types of stick that people with a visual impairment use:





Symbol cane.

Guide cane.





Long cane.

Walking stick.

Making things bigger

Large print can allow a more natural reading position, needs no training to use and has less stigma attached than magnifiers. Physical constraints such as size and weight limit the range of magnification. The size of commercially produced large print varies from 14 to 24 point (Figure 5). Ophthalmology services should provide appointment details and information to patients in their preferred format but all letters should be in at least 14 point print. Patients and their friends and families should also be encouraged to produce their own large print.

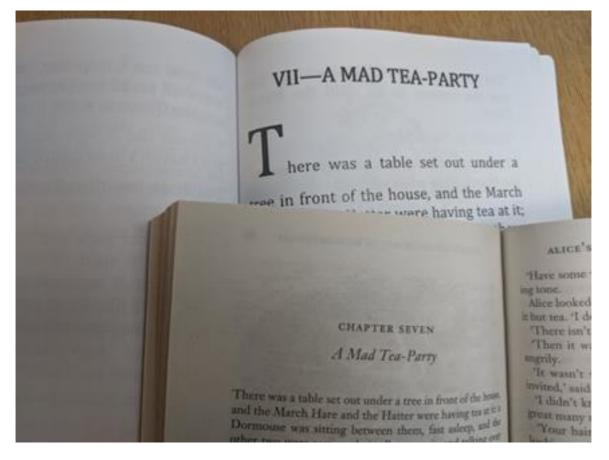


Figure 5: Various large print materials are available, including newspapers, recipe books, puzzle books, calendars, address books, magazines and dictionaries.

Copies of recipes, music and other shorter pieces of text can be made larger using the enlargement facility on photocopiers, although care should be taken because contrast may be reduced. Black felt-tip pens can be used to write large print phone numbers, lists, labels or letters. Computer settings can be adapted to make them easier to use, and good quality large print texts can then be printed. Many other 'bigger' items are available from social services and local and national voluntary organisations (Figure 6).



Figure 6: Many bigger objects are available, including watches, telephones and games.

Improving lighting

Appropriate lighting for people with sight loss is particularly important, because they may be functioning at their visual threshold. The use of magnifiers may not be necessary for certain tasks with adequate illumination. Elderly patients in particular are often unaware of the benefits of improved lighting in the home, and may be reluctant to change their living

environment. As many low vision patients suffer from discomfort glare, a change in their use of lighting may also improve comfort.

This is the lighting used in the home, or other indoor environments, that allows a person to get around and locate objects safely. In the main, people with a visual impairment need greatly increased ambient levels of illuminance.

People with poor vision often have longer light-dark adaptation, so it is important to keep light levels throughout the home even. Ceiling spotlights can cause marked differences in light levels and glare problems so are best avoided. Particular attention should be given to stairs and landings by ensuring they are well lit (Figure 7).



Figure 7: Dimly lit stairs can be Dangerous.



Figure 8: With improved task lighting, a magnifier may not be necessary.

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Task lighting

Localised task lighting is required for reading, using the telephone, over kitchen work surfaces and above eating areas. Table and standard lamps, which many people have in their homes as task lights, are not useful in a low vision context (Figure 8).

Adjustable angle-poise lamps are best for reading. The best position is below eye level, between the person and what they want to see, with the light directed towards the task. Many LED adjustable lights are now available. These are the bulbs of choice for prolonged reading tasks because they produce an even light and generate very little heat.

Reducing glare Visors and shields

Visors and shields protect from glare sources while not obstructing the rays of light from the object being viewed. Patients may wear sports peaks or a hat with a brim. Side shields are also useful if permanently attached to spectacles.

Tints

Prescribing tints for people with low vision is not easy. Many patients ask for a dark tint because they find bright lights outside distressing. However, the same people often need more light for near tasks and getting about safely. For a small number of patients who are photophobic (for instance, with albinism), the constant wear of tints may be necessary. However, for most low vision patients, flexibility is required. For most, the best solution is a cheap plano overshield that has side and top shields and can be removed or put on quickly (Figure 9).



Typoscopes

A typoscope is a rectangular black card with a central slit (Figure 10). In some cases, reflected light on a page acts as a glare source, and is scattered in the eye thus reducing the contrast of the retinal image. This is particularly apparent in patients with media opacities. A typoscope reduces the amount of light from the background, reduces scatter and thus increases the retinal image contrast.



Figure 10: A typoscope.

Improving contrast

Low vision patients have poor sensitivity to low contrast targets. There are many ways a person can improve contrast in their daily lives. Some examples are:

- Writing with a black felt-tip pen on white paper, which produces higher contrast letters.
- Putting white strips on the edge of darkly coloured stairs.
- Painting walls, floors, ceilings, doors and doorframes contrasting colours to make them easier to see.
- Chopping vegetables on contrasting chopping boards, e.g. an onion on a red board and a tomato on a white board.
- Marking switches and dials with contrasting coloured bump-ons.

Environmental adaptations

Since the introduction of disability legislation^{3,4}, there has been a dramatic improvement in adaptations to public places for people with a visual impairment, including talking, large print and Braille signs, tactile pavements and contrasting colour schemes. Providers of health services are now required to make reasonable adjustments to their practices to make them accessible to people with a disability, including people with a visual impairment.

Sight substitution

Over 80 per cent of information from the world around us comes from the sense of sight. Even when sight is impaired, it may still be the prominent sense. Other senses, mainly hearing and touch, may be used for some tasks but many people choose to use a mixture of sight substitution methods and sight enhancement. For example, a person may choose to read a newspaper or magazine using a magnifier but find talking books easier for longer novels.

It is untrue that people with a visual impairment have an enhanced sense of hearing and touch – they have simply had more practice using them. Many items are available which use sound and texture to assist people with a visual impairment with daily living tasks (Figure 11). These include:

- A liquid level indicator, which beeps when the liquid reaches it, so that cups or jugs are not over-filled.
- Audio-description, where the story is narrated over the original visual media.
- Talking microwaves, clocks, watches, thermometers and scales.
- Games with tactile counters, boards and cards.
- Bump-ons which can be used to mark dials on appliances so that positions can be seen and felt.

Braille and Moon

Braille is the best-known method of tactile reading and writing. Particular combinations of up to six raised dots, arranged like the numbers on a dice, produce each of the 63 symbols. Relatively few people read and write Braille; less than 10 per cent of blind people in the UK can write it. People may use it for labelling and for short texts rather than for reading books. Most Braille users are congenitally blind and will have learned it at school. However, most rehabilitation workers can teach it to adults. Moon is simpler to learn than Braille since its shape resembles letters, but very few people use it and there are not many books available in this format.

Talking books, newspapers and magazines

The RNIB's talking book service can be downloaded digitally or played on user-friendly machines. However, many people have their own e-readers and/or other digital services. The Talking News Federation (<u>https://www.tnf.org.uk/find-a-talking-newspaper</u>) is a national UK organisation which co-ordinates voluntary groups who produce versions of local newspapers on tape, CD and email.

Apps for people with sight loss

The number of android and iphones/ipads apps for people with sight loss is increasing rapidly. Apps are available to describe the world around us, to read text, to navigate, to

magnify and to identify objects. Most national and many local voluntary organisations have expertise in this area.



Figure 11: Many items are available which use sound and texture to assist people with a visual impairment, including Braille, bump-ons to mark dials, and a liquid level indicator.

Computers and visual impairment

As with all computer technology, adaptations for people with a visual impairment have progressed rapidly in recent years. Both sight enhancement and sensory substitution techniques can be employed so that anyone with a visual impairment, regardless of their level of vision can us them (Figure 12).

Navigation around a computer can be aided by magnifying or speech output software, and the contrast and colours can be changed easily. The information in a document can be enlarged, read to the user or processed onto a Braille pad. Input can be via a keypad with large characters or Braille characters, or speech. The equipment exists to allow the image from a CCTV to be displayed on a split screen with the computer document, and printing can be in large print or Braille.

Barriers to the use of computers are still evident for people who have not used computers previously but support to learn how to use these options are available from local societies and national organisations, age should not be a barrier to using new technology.



Figure 12: Computer adaptations for people with visual impairment have progressed rapidly

Chapter 8: Low Vision in Children

Visual impairment in childhood has long-term implications for both the child and the immediate family. It will have potential impact on a child's education, employment, emotional and social development. It is therefore critically important that appropriate support is given to minimise any consequent impact¹. This is particularly the case for children with complex or multiple disabilities as their visual needs are often overlooked 2,3.

Early intervention is essential to optimise the child's life opportunities. Low vision services play an important role in assessing a child's visual functions, managing refractive error, providing optical low vision aids, making appropriate recommendations in respect of the child's visual environment and in ensuring children and families are directed to other useful services⁴.

Epidemiology

Serious visual loss in childhood is uncommon, with 6 of every 10,000 children born in the UK each year becoming blind by their 16th birthday. An additional 12 children are likely to have become vision impaired within this timeframe (worse than 0.50 LogMAR or 6/18)⁵. Incidence rates are highest in the first year of life⁵ and in children with complex disability⁶. In England and Wales the incidence of certification of children has shown a steady increase between 1999/2000 and 2014/2015, from an estimated 8.2 (95% CI: 7.7–8.8) per 100,000 to 13.3 (12.6–14.0) per 100,000.⁷ Hereditary retinal dystrophies, cerebral visual impairment and nystagmus were the most common causes of certifiable sight impairment in children in 2014/2015.⁷

In developed countries, cerebral visual impairment and disorders of the optic nerve and visual pathways are together the most common cause of poor vision in children. At least 75 per cent of such children have disorders that are neither potentially treatable nor preventable with current knowledge and they are more likely to have additional disabilities⁵.

Causes of severe sight impairment in children

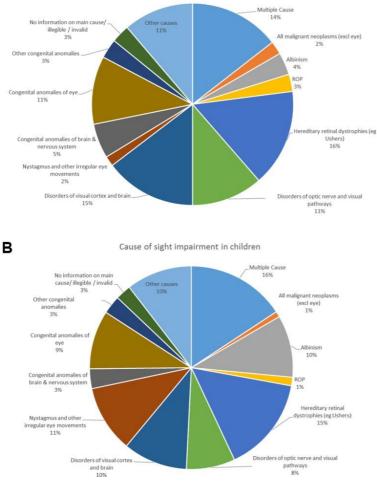


Table 1: (A) Causes of severe sight impairment in children in England & Wales, 2015/2015. (B) Causes of sight impairment in children in England & Wales, 2015/2015.⁷

Breaking news of visual impairment in a child

A study of parents of children newly diagnosed with visual impairment and/ or ophthalmic disorders concluded, although parents reported high overall satisfaction with services the need for better information was a priority⁸. The Royal College of Ophthalmologists' report on Ophthalmic Services for Children outlines all families should receive an explanation of their child's disability in language they can understand⁹. Children and their families are likely to have contact with many professionals, which can be very time-consuming, repetitive and confusing.

The employment of a key worker within a paediatric ophthalmology department has been shown to have benefits for patients, parents and other professionals within the team10. As it is difficult to predict the final visual outcome in young children, it is advisable to be cautious about giving a definite visual prognosis to parents of young children who appear to be blind. Some children with serious ocular disorders and apparently very poor vision can achieve better than expected overall visual ability11. This is particularly the case where there is evidence of neurological impairment as in many cases infants and children with profound and complex disability, who appear to be visually unresponsive, go on to acquire a form of usable vision as they develop.

Α

Certifying and registering children with a sight impairment Certification of a child as visually impaired can be a very emotive process and needs to be tackled sensitively. Registration may however be the key that opens the door to supplementary educational and social support, especially if the special education department works closely with sensory support services and the local visual impairment society. Registration of sight impairment has been discussed in Chapter 4.

The special guidance in relation to registering children on the English CVI states 'Children and young people who have congenital ocular abnormalities leading to visual defects should be certified as sight impaired unless they are obviously severely sight impaired. In infants and children, certification should not be postponed if the consultant considers that there is evidence of significantly impaired visual acuity and/or visual field".

In Scotland the CVI is from 16 years of age and before that time notification goes to Visual Impairment Network for Children & Young People (VINCYP)12. The consultant paediatric ophthalmologist will decide at what stage to raise the issue of registration, but this is unlikely to be at the first visit. The potential advantages of registration should be discussed with an unhurried approach and concerns about the possible stigma of registration should be allayed.

However, it is of the greatest importance that time is not lost in waiting for the registration to be carried out before the child and parents are referred for specialist support services. In many areas, referrals can be made to support services before registration. The assistance of an Eye Clinic Liaison Officer (ECLO) within a clinic to sensitively talk with all concerned can be hugely helpful13.

The system for providing support in education is slightly different in the four countries of the UK and may involve children being put on a special education needs register or having an education/care plan. Local authorities also keep a register of children with a disability to trigger social services provision for children.

Support services

The educational and support processes for children vary regionally and over time. Thus, it is important to have current and local knowledge when working in paediatric ophthalmology. Guide Dogs, RNIB¹⁴ and VINCYP¹² provide useful information for parents.

Habilitation

While sighted children learn about movement, mobility and managing the world around them by watching others, children with a vision impairment often need a little extra support. Habilitation is a structured programme of life skills training delivered by qualified Habilitation Specialists. It typically involves mobility, orientation and independent living skills. From supporting physical development in the early years, to navigating streets safely, preparing food, handling money, using technology and managing their appearance as they grow older. You can find out more about this key independence skills training at the Habilitation VI UK website. <u>https://habilitationviuk.org.uk/</u>



Education services

Children with a visual impairment have a right to educational assistance as laid down by legislation in each of the UK nations. Codes of practice set out the procedures that the education system follows in order to identify and assess children with special educational needs, including children with a visual impairment. If the child's progress is causing concern, the class teacher and parents work together to tackle the problem where possible.

Specialist Qualified Teachers for Visual Impairment (QTVIs) are central to this process¹⁴. An estimated 80 per cent of school tasks are based on vision¹⁵. It is therefore essential that each child is enabled to maximise the use of their residual vision.

Prior to the Warnock Report 197816, children with visual impairment were largely educated in specialist schools. Since that time, and with subsequent Education Acts, the emphasis has changed so that now children with visual impairment are included in mainstream schools. This has necessitated the adaptation of teaching materials and the use of specialised equipment, including more extensive use of low vision aids and adaptive optoelectronic devices.

Written information from an ophthalmologist about the functional implications of the eye condition and any low vision support provided can be hugely helpful to enabling informed decisions about the educational support needed. A report concerning the child's visual function should be written in plain language and distributed, with parental consent, to all health, educational and social care professionals involved in caring for the child. In this way, a child can benefit from all professionals being better informed.

Social Services

Social services deliver mobility and daily living skills training and will assess families for financial benefits.

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Visual assessment

Visual assessment follows the same principles as for adults (see Chapter 2). Different means of assessment are used depending on a child's developmental age, level of vision and ability to cooperate and communicate. A brief description of some relevant tests will be given, but a full discussion of ophthalmic examination of children is beyond the remit of this text.

Refraction

Children with a visual Impairment are much more likely to have a refractive error, of much greater magnitude, than their normally sighted peers. It is thus essential that all children are accurately refracted. Once a decision has been made concerning distance refractive error, attention needs to be paid to near vision requirements and potential. With the exception of post traumatic cases, children who develop vision impairment later in childhood are likely to have age appropriate accommodation, but this may not be the case in children with CVI or Downs syndrome17,18. Refractive error is likely to change over time as are visual requirements and as such, routine refractive review needs to be built into an ongoing clinical management plan.

Distance Acuity

For very young children, or older children with communication difficulties, the technique of preferential looking is used. The examiner observes the child's eye movements in response to a target placed on one half of an otherwise homogenous grey card. These tests can incorporate pictures for example, Cardiff Acuity Test, or gratings (Teller Cards) that an infant cannot ignore when presented with a forced choice alternative (Fig 1). Paediatric orthoptists and some optometrists who specialise in this area are an invaluable asset when quantifying vision in these children.

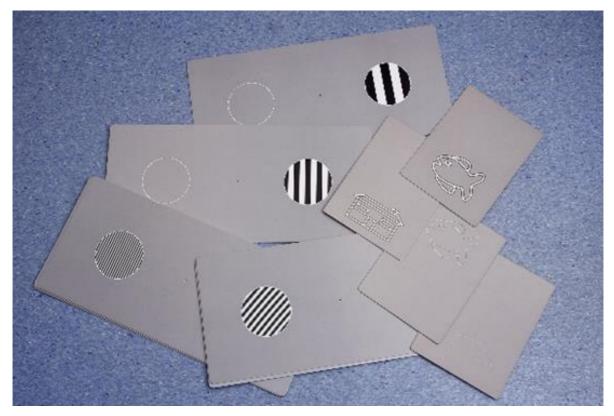


Figure 1: Keeler Preferential Looking and Cardiff Acuity Tests.

For older or more able children, distance visual acuity can be assessed using object (letter/number or symbol) recognition. In the first instance and where children find naming

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objects difficult one can use single or crowded matching target tests such as Sherridan Gardner Single Letters, Lea Single or

Crowded Symbols, Glasgow Crowded Letters or Landolts C's and Tumbling E'S. Many of these tests allow for logMAR acuity testing. (Fig 2)

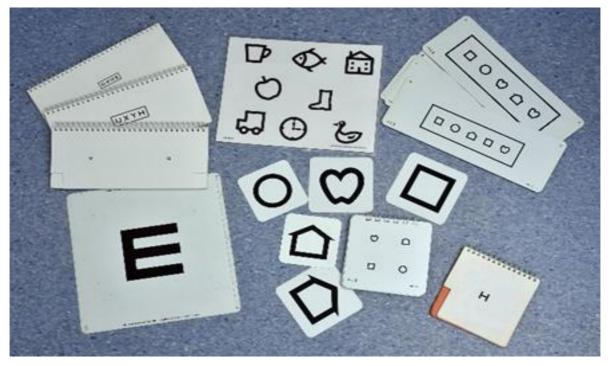


Figure 2: Distance Acuity Pictures and Letter Cards.

Near Acuity

In the UK Conventional near visual acuity is specified as print size (N8 = Newsprint, N14 School Textbooks). In the US print size is specified in M units (M1=N8, etc) Both of these measurements relate to the size of the target and are thus independent of working distance. Expressions of target characteristics as Snellen equivalent or LogMAR should always be accompanied by a test distance as these are angular measures. Good practice is always to provide a record of both the working distance at which the near acuity was recorded, and preferred working distance as observed in clinic. As with distance acuity, near acuity can be assessed using single letters, numbers or symbols (Fig 3).

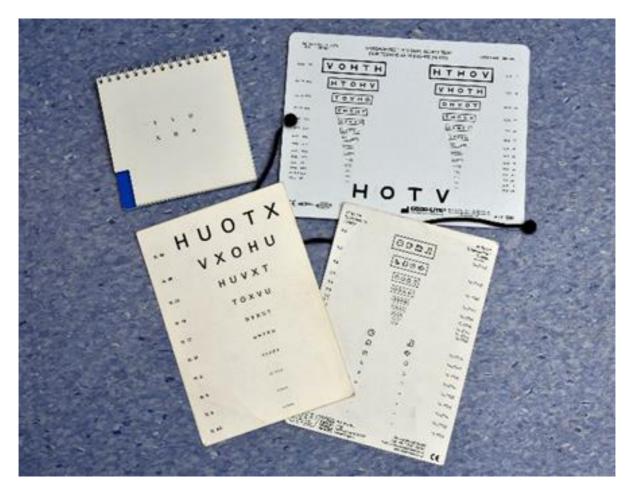


Figure 3: Near Letter Acuity & Symbol tests

Utilizing age appropriate unrelated words or text will however provide information, not only of near acuity, but of reading fluency, comprehension and strategy. (Fig 4).



Contrast Sensitivity

Contrast sensitivity provides an idea of the child's ability to detect subtle shades of grey, a measurement that equates with an ability to recognise facial expressions, see poor quality print against coloured or cluttered backgrounds, and see steps, kerbs and unexpected undulations on floors and pavements.

Contrast sensitivity can be tested by preferential looking with a modified series of Cardiff Low Contrast Acuity Cards, when Letter or number identification is too difficult. Younger children can be tested with Hiding Heidi cards. With this test one sequentially presents cards depicting increasingly paler faces and observes the child's response (Fig 5).

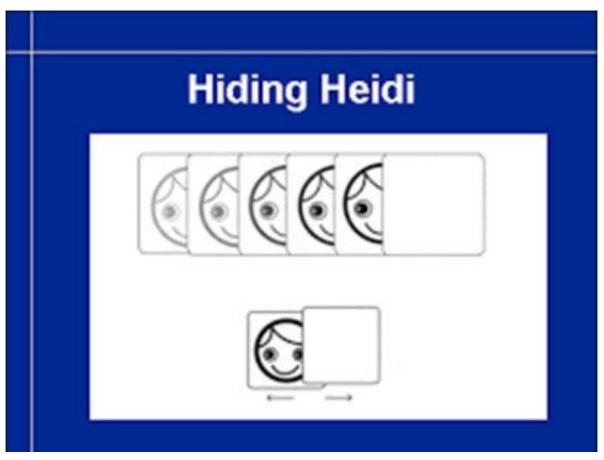


Figure 5: Hiding Heidi Cards

Alternative tests allowing comparison of high and low contrast letter, symbol or number performance, or the identification of high and low contrast discs on a card background, are available (Fig 6).

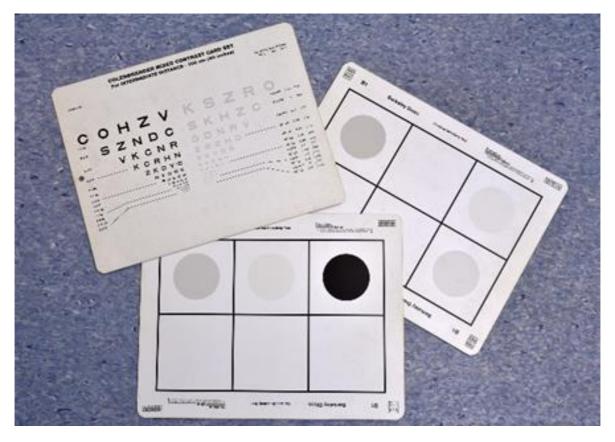


Figure 6: Contrast Sensitivity Tests

Colour Vision

Vision Impaired children are every bit as likely to have a congenital colour vision deficiency as their normally sighted peers. They may however also have a colour vision anomaly, that can develop as the vision impairment progresses. In the case of acquired disease, colour vision loss related to the defect will not obey the conventional colour vision classification system. Regarding testing, the PV16 jumbo colour button test is useful for assessing colour vision in children with a visual impairment (Fig 7).



Figure 7: PV16 test

Visual Fields

With the exception of potentially treatable conditions such as congenital glaucoma, there is little to be gained from putting children through full field threshold automated perimetry. Confrontation field testing with appropriate targets provides insight into the functionality of the visual fields and usually correlates well with mobility and night vision problems In most cases, as we are interested in overall functionality and mobility, it is the binocular as opposed to monocular field that provides the most useful information.

Glare & Photophobia

Other measures of visual function including the assessment of glare sensitivity and photophobia should be a assessed when symptoms indicate accordingly.

Optical Low Vision Aids

Prior to demonstrating LVAs it is essential to have obtained a measure of refractive status. Lennon et al found that 70 per cent of the previously non- spectacle wearers attending a paediatric low vision clinic were found to require a refractive correction⁴. Early intervention with low vision aids can improve long term visual functioning and there is evidence that their use should ideally begin before children enter primary education¹⁹.

The most useful LVAs for children with accommodative ability are the Dome and Wedge magnifiers which come in a variety of sizes and shapes^{20,21}. They provide magnification of between x2 and x3, act as light gatherers, allow for increased accommodation and are relatively unobtrusive (Fig 8). These LVAs are ideal for picture examination and in many ways behave like paperweights (Fig 8).



Figure 8: Range of flat field LVAs

Bar or ruler magnifiers provide less magnification and whereas they allow greater horizontal coverage on the page they tend to be less useful. Both types of magnifiers are available with line guides and partial shading, which in some ways enable them to mimic the effect gained when using a typoscope. (Fig 9).



Figure 9: Flat field magnifier

When high levels of magnification are required, folding hand magnifiers are appropriate (Fig 10).



Figure 10: Hand Magnifier

Children requiring magnification at distance can find binoculars or monoculars, available in a variety of designs and powers, useful (Fig 11). These devices are most useful for leisure activities, travel and watching sport (Fig 12). Many of the devices are exactly the same as those used by adults for hobbies (see Chapter 6).



Figure 11: Binoculars



Figure 12: Range of hand-held binoculars and monoculars.

Electronic Devices

One of the most fundamental changes to the low vision management of vision impaired children over the last 10 years comes from the proliferation of mobile phones and IPad type technology. These devices are now used by virtually every school age child. When used by VI children they allow users to photograph educational material at any distance and adjust screen size, contrast and colour to suit. See Chapter 7.

Non-Optical Aids

Children rarely use the plethora of daily living aids adopted by vision impaired adults. Within education they will however use large print, dark markers and should be allowed to exercise choice regarding "preferred size".

Utilizing tilting work stands and adjustable desks is likely to promote better posture and providing task specific supplementary lighting can be beneficial. To maximize benefit attention also needs to be paid to positioning within the classroom, natural and artificial lighting and how all of these impact on a child's self-confidence.

Chapter 9: Low Vision in Adults with Learning Disabilities

Low vision is much more common among people with learning disabilities (PLD) than in the general population. A report commissioned by RNIB estimated that PLD are 10 times more likely to have visual impairment than typical adults¹. Much of this is due to uncorrected refractive errors, a prevalence that will hopefully reduce as the eye care professions develop the awareness and skills to provide routine examinations for this vulnerable population.

The consideration of refractive error should be the first step when encountering a person with learning disabilities and symptoms of sight loss. Sight-threatening ocular conditions are also more common amongst PLD and any ophthalmology clinic should have appropriate protocols in place to provide examinations and treatment for such patients. There will remain a significant proportion of PLD who have uncorrectable or untreatable low vision and who will benefit from adapted low vision services.

Communicating with the patient

A person with learning disabilities may struggle to understand what is happening in an eye clinic and may have history of distressing medical interventions, and therefore may be very anxious. Add sight loss to this, and a visit to an eye clinic can become a terrifying experience. Staff should approach the patient with all of this in mind and take time to reassure the patient and to explain what is going to happen. It should be obvious that a longer consultation time will be needed.

Some simple sign language to accompany speech will help, and failing that, using gestures along with words will help the person to understand.

Hearing loss is common and difficulty with language can be a key feature of learning disability, so sentences should be short and words simple. Always face the patient and make facial expressions unambiguous. In general, be guided by the language that the carer or family member accompanying the patient uses, use the same words but always speak directly to the patient, even if the patient cannot respond. Many people will have a better understanding of what is being said than their ability to speak themselves might suggest. Some clinics find picture boards helpful in explaining what is going to happen, providing the pictures are simple and large enough for a person with sight loss to identify them.

Refraction (figure 1)

As discussed above, an accurate refraction and provision of spectacles is vital in improving vision. It is important to remember that PLD experience presbyopia just as adults in the general population do, and just because a person does not read, does not mean that he or she will not benefit from 'reading glasses'. It is best not to use the term 'reading glasses' to describe a near correction, to avoid carers misinterpreting the purpose. If an adult has not worn spectacles beforehand, it can be very difficult to get used to the magnification/ minification and aberrations inherent in any spectacle lens. Family members and carers will need to understand the function of the spectacles and when they should be worn. Having a leaflet to hand, in 'Easy Read' format so that the patient can look at it themselves, will be helpful.



Figure 1 Refraction

Measuring Vision

Just as with child patients, techniques for visual assessment should be adapted to suit the abilities of the adult with learning disability. The same tests may be suitable (Keeler LogMAR, Lea symbols, Kay Pictures, Cardiff Acuity Test etc) as long as the instructions to the patient are clear and the person is given time to respond.

Being careful of your language may be important to avoid patronising the patient. Many PLD will find crowded situations overwhelming, so finding a quiet and distraction free corner will be useful for acuity measurement. When a formal acuity measure is not possible, it can be very helpful to ask carers about the level of vision that they perceive the patient to have



Figure 2 Testing near vision

Certification

Most people with significant learning disability will be supported by Social Services but will still benefit from certification as sight impaired. Registration will ensure that the appropriate branches of social services are involved and will also inform family, carers and members of the Learning Disability Team of the visual problems. The ophthalmologist may need to use clinical judgement rather than formal measures in determining whether a patient meets the criteria for certification.

The Examination

Remember that a person with learning disability may not automatically know what is expected of them. Explain, in simple terms, what is happening and what the patient needs to do. Use gestures to emphasise your words.

Providing Information

When a typical patient has a diagnosis of an uncorrectable visual impairment, providing information to the patient is vital. When the patient has a learning disability, there are many more people that need the information, to allow them to appropriately support their family member or client. Referral to a social worker with experience of both learning disability and sight loss, through certification, is essential.

Family members accompanying the patient should be provided with as much information as possible, and the ECLO, if available, will be ideally placed to provide this. If the patient is in supported living, then it is important to remember that there will be several staff involved, and that staff turnover can be high. So written information is crucial Many adults with learning disability will have a 'Book About Me' (<u>https://www.mefirst.org.uk/resource/book-about-me-learning-disability/</u>) or equivalent that provides information about health, likes

and dislikes and so on. It will be important to find time to fill in the appropriate page of this book, so that diagnosis and advice are recorded.

SeeAbility is a charity that supports PLD and sight loss and has a wealth of information on its website. Signposting the patient as well as family members and carers will be useful. <u>https://www.seeability.org/</u>

Low Vision Aids

A learning disability should not be a barrier to the use of low vision aids, so a referral to a low vision clinic will be needed; the low vision practitioner should ideally be experienced with this section of the population. Changes to the environment may be the most important strategy, and it is essential that everyone supporting the patient is aware of their needs. Once again, a leaflet or an entry in the personal book, will be important.

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Authors

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Biographies

Anne Sinclair

Anne trained in ophthalmology in Scotland and spent a period in Africa. After returning to Scotland, she helped to establish the Fife Interdisciplinary Low Vision Service. Anne has published papers on low vision quality of life, diabetic and glaucoma blindness.

Barbara Ryan

Barbara is Professor of Optometry and Vision Sciences at Cardiff University.

Having worked in hospital low vision services and the multi-disciplinary low vision service in Birmingham Focus, she established the community-based Low Vision Service in Wales. She continues to practice one day a week in Monmouth.

Barbara has published extensively in the field of low vision and currently co-leads on three post-graduate modules on low vision at Cardiff University.

Jonathan Jackson

Jonathan is Head of Optometry, and co-chairs the Northern Ireland Clinical Research Network (Vision), at the Belfast Health and Social Care Trust in Northern Ireland He has specialised in Low Vision practice within the in- Hospital Service for over 30 years and has had clinical and academic placements in both the USA (University of California Berkeley) and Australia (Australian College of Optometry). He has published extensively in this area and regularly presents on Paediatric Low Vision Topics.

Maggie Woodhouse

Maggie is an Optometrist Senior Lecturer at Cardiff University who has specialised in eye care for people with learning disabilities for over 30 years. She has an extensive research portfolio, particularly in vision in children with Down's syndrome. Maggie leads a clinic for people with special needs, teaches undergraduates and leads four post-graduate modules, including one in Eye Care for people with Learning Disabilities.

In 2014 Maggie was awarded an OBE for her work in Optometry and with people with disabilities.