

Low vision rehabilitation needs of visually impaired people

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GOC competencies: Optometrists

- 1.2 The ability to impart information in a manner which is appropriate to the recipient
- 2.2.6 Makes an appropriate judgement regarding referral and understands referral pathways.
- 4.2 The ability to advise on and to dispense low vision aids

GOC competencies: Dispensing Opticians

- 1.2 The ability to impart information in a manner which is appropriate to the recipient
- 6.3 The ability to advise on the use of and dispense appropriate low vision aids
- 6.4 The ability to advise, refer and provide aftercare to low vision patients

Summary

It is difficult for visually impaired people to know what rehabilitation services are available that may be of benefit to them. Appropriate services are covered by health, social care and voluntary sectors, with significant differences in the services available in different areas of the UK. The eye care practitioner has an important role, not only in providing optical advice and low vision aids, but also in signposting patients to those services that go beyond the practitioner's own remit. Referral pathways to health care, local authority sensory service teams, and local voluntary societies for the visually impaired are discussed.

Author biographies

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Abstract

It is difficult for visually impaired people (VIPs) to know what rehabilitation services are available that may be of benefit to them. Appropriate services are covered by health, social care and voluntary sectors, with significant differences in the services available in different areas of the UK. The eye care practitioner has an important role, not only in providing optical advice and low vision aids, but also in signposting patients to those services that go beyond the practitioner's own remit. At a minimum, practitioners should know how to refer their patients to hospital eye service low vision services, to local authority sensory service teams, and to local voluntary societies for the visually impaired. Additional providers of relevant services for practitioners to be aware of are discussed, and links to further resources provided. There is a lack of good quality evidence of the

need for low vision services and of service effectiveness. Such evidence is needed for guiding commissioning decisions regarding provision of future low vision services.

There is a danger that 'low vision' can sometimes be thought of as a specialist area for eye care practitioners with limited relevance to primary care practice. However, there were thought to be approximately 1.8 million visually impaired people (VIPs) in the UK in 2008, defined as a visual acuity of less than 6/12, and numbers are projected to rise to nearly 4 million by 2050 as the population ages (Access Economics, 2009). Thus the need for low vision services is great and increasing, and the role of the primary eye care practitioner is becoming more, rather than less, important in low vision services.

One aim of the UK Vision Strategy (2013) is to 'provide excellent services for those with sight loss'. Rehabilitation services for VIPs cover a wide range of needs cutting across both health and social care, and are therefore associated with a wide range of service delivery and funding models. In a climate of reduced funding for services and increasing demand, in order to provide 'excellent services' it is important to know what the service needs of VIPs are, and what services and service delivery methods are most beneficial and cost effective.

For the optometrist or dispensing optician in primary care practice, understanding what services their patients might benefit from and how their patients can be signposted to access relevant services is of key importance. Barriers to VIPs using rehabilitation services are complex and multifactorial (Lam & Leat, 2013). However, significant issues include that people often do not know what sort of help they could benefit from, or what services are available (Lam & Leat, 2013, Overbury & Wittich, 2011, Rabiee et al., 2015). Even if service needs are understood, a VIP will find seeking out information about services a challenge, so eye care practitioners are ideally placed to refer or signpost patients to relevant services. The aim of this article is to provide an overview of rehabilitation services appropriate to VIPs, comment on what is known about the importance and efficacy of these services from the research literature, and outline how practitioners can find local services to refer their patients to, in line with College of Optometrists' guidance (College of Optometrists, 2016). The emphasis is on adults with acquired visual loss.

Information

VIPs often need additional information on their eye condition and prognosis. Whilst they may well have been given excellent information at the time of diagnosis, people are likely to be so shocked at a diagnosis of visual loss that they will not take in much of what they are told. Asking patients if they understand the problems with their eyes, and offering to explain a diagnosis can be very helpful, as patients may not want to ask of their own accord. Supplementing verbal information with written details, in a print size that can be accessed, is also useful. Several of the charities supporting people with specific forms of visual loss (see Table 2) have excellent leaflets which practitioners can order

free of charge. In addition, a recent publication from the RNIB called 'Sight loss: What we needed to know' (RNIB, 2016), sets out the kind of information that practitioners may want or need to pass on to their patients.

Optical magnifiers and lighting

Many VIPs' needs for optical low vision aids (LVAs), particularly for close work, can be managed in practice using reading additions greater than +3D, recommendations for task lighting, and simple magnifiers. In a recent study (Tabrett & Latham, 2011), the primary LVA used for reading by a group of VIPs who had been assessed in a hospital low vision clinic was, in 56% of cases, either reading spectacles or a hand magnifier. Also including stand magnifiers and a flat-field magnifier accounted for 92% of patients. These types of LVA can be straightforwardly dispensed in practice, and practitioners are encouraged to stock a basic range of magnifiers that can be demonstrated by the optometrist and / or dispensing optician, and avoid having to refer the VIP on to secondary care unnecessarily. Most suppliers of optical LVAs have relatively low cost 'starter kits' of commonly used appliances.

A further area where practitioners can usefully contribute is in explaining the requirements of good lighting (Table 2), and specifically by recommending task lighting for detailed tasks such as reading. Lighting in the average home is frequently sub-optimal in terms of illuminance, or the amount of light falling on specific areas (O'Neill et al., 2003), and recommending how lighting can be improved can make a significant impact to the usefulness of a VIP's residual vision. A practical demonstration of the inverse square law can be extremely useful in persuading a patient of the benefits of good light. Start by showing the patient a reading chart illuminated by only a ceiling light. Adding a task light will improve vision, even when it is positioned a reasonable distance away from the chart. Moving the task light closer to the chart then demonstrates how illuminance can be greatly increased by reducing working distance: specifically, halving the working distance from a light source to a reading chart increases the light falling on that chart by four times.

Local voluntary societies for the visually impaired (Table 1) often have a resource room which would include a variety of optical LVAs and lamps for purchase. If a patient requires LVAs that the practitioner does not have access to, signposting them to such a resource with appropriate clinical information such as acuities, approximate magnification required, or suggested specific aids is helpful.

In the home nations other than Wales, more complex LVAs may require referral of the patient to another provider such as the Hospital Eye Service (HES) Low Vision clinic. This would be relevant

when a patient's needs go beyond the LVA stock or interests of the practitioner, or if simple aids are cost prohibitive to the patient and are required on permanent loan.

Electronic aids

In some ways, the need for optical LVAs may be reducing as VIPs increasingly utilise electronic visual enhancement systems (EVES). Consumer electronics such as smartphones and tablets have many features that are useful to VIPs (Crossland et al., 2014), including photographing and enlarging items of interest in lieu of a magnifier, flexibility of text presentation, text to speech facilities, and a wide variety of apps either useful to or designed for those with poor vision. While many VIPs will be confident in using technology, others may need help in making the most of these options, and some suggested resources are given in Table 2. In addition, EVES specifically designed for those with low vision (Wolffsohn & Peterson, 2003) can often be tried and compared through voluntary society resource rooms.

Statutory health and social care services

Referral to the HES is obviously indicated where diagnosis or treatment are required (Table 1). If a patient has not been registered as visually impaired but would potentially be eligible (see Table 2 for links to criteria), referral for a consultant ophthalmologist to consider a Certificate of Visual Impairment (CVI; BP1 in Scotland; CVI(NI) in Northern Ireland) is appropriate. Since registration is voluntary, being able to inform patients of the benefits of registration can be helpful (Table 2).

In addition, a number of HES departments now have an Eye Clinic Liaison Officer (ECLO), whose role is to provide information and emotional support to eye clinic patients and their families (Gillespie-Gallery et al., 2013). It is well worth determining whether your local hospital(s) has an ECLO, and how patients can be referred to them for advice and support. They will be a mine of information on local services and resources of relevance to your patients: if you do not know where a VIP can access a particular service, your ECLO probably does.

One specific benefit of CVI completion is that a patient's details are passed on to the local authority, who hold the register of visually impaired people. Registration should then automatically result in the local authority's social services contacting the person to determine their needs. The personnel that deal with adults with visual impairment vary, but in many areas are termed the 'sensory impairment team' or 'sensory services' (Rabiee et al., 2015), and will be termed as such in the remainder of the article (Table 1). The remit of sensory services is to help service users maintain their independence, and some of the potential services available through sensory services are highlighted in the sections below. However, CVI registration is not necessary to access support from

sensory services. Patients can self-refer for support, and it is worthwhile practitioners knowing the appropriate contact details to be able to give to patients, with initial contact often through a telephone call centre. Practitioners can also stock a 'low vision leaflet' (see Table 1) to enable patients' self-referral. Discussing the role of sensory services with VIPs can be a sensitive issue, as some patients may have concerns about the implications of 'being referred to social services'. Reinforcing that the role of sensory services is to help people maintain their independence can be crucial.

Non-optical aids

A wide range of non-optical and non-electronic gadgets exist to make tasks easier for someone with visual impairment. These often fall into the categories of 'easier to see' (e.g. large print stationery, typoscopes), auditory substitution (e.g. liquid level indicators, talking clocks) or tactile substitution (e.g. 'bump on' markings, or braille). Most voluntary societies have a resource room that stocks such gadgets (Table 2). Home adaptations (including lighting) are also often provided by sensory services, as a result of a home visit following CVI registration.

Training

'Training' is used here as a broad term to cover a range of skills that VIPs may need to learn, or relearn in a different way, in order to help them remain independent and come to terms with life with visual impairment. Common providers of such training include rehabilitation workers working with sensory services or for local voluntary societies.

Orientation and mobility training aims to give users more confident access to their environment. Training may include practicing specific routes, using public transport, and/or using mobility aids. Symbol canes, or short white folding canes, can be provided as an indicator of visual impairment. Guide canes and long canes can be used to avoid obstacles and travel independently, and require more training in their use from a qualified Rehabilitation Officer. Guide dogs can also aid in independent travel, and interested patients can be put in touch with the Guide Dogs charity (Table 2). Electronic devices and apps that use echolocation and GPS to aid in orientation and mobility are also becoming more widely available. There is surprisingly little evidence in the literature on the effectiveness of mobility aids (Virgili & Rubin, 2010), although guide dogs have been shown to allow greater speed and ease of movement (Zabihaylo et al., 2005) and the use of mobility aids significantly reduces difficulty in avoiding inferior obstacles (Latham et al., in press).

Daily living skills training might include skills such as cooking and looking after the home, and is often provided by sensory services or local voluntary societies (Rabiee et al., 2015). One particular

charitable organisation offering daily living skills training is Blind Veterans, which provides support for anyone who has served in the UK armed forces. As many older people are likely to have undertaken National Service, it is well worth routinely asking new patients with vision loss if they have previously served and providing contact details where appropriate.

The Macular Society offers training in eccentric viewing and steady eye strategy, called 'Skills for Seeing' (Table 2). This training is designed to help people with central vision loss identify a 'preferred retinal locus' (PRL) of working peripheral vision outside the central scotoma and to use this fixation point more effectively for tasks such as reading or identifying faces. Whilst this training does not benefit everyone who undertakes it, and it is difficult to predict in advance who will benefit, some people do show marked improvements in reading speed (Dickinson et al., 2016).

Braille training may also be relevant for some patients and might be offered by local voluntary societies. Braille is not restricted just to those visually impaired from a young age, and can be learnt later in life. Even if someone is not intending to read long documents such as books in this format, it can be a useful skill for accessing short pieces of communication such as medication labels or bills.

Travel services

Services to help VIPs with travel will vary from area to area, and might include 'dial a ride' type services, volunteer community transport schemes, 'blue badge' parking passes for carers, bus passes or taxi cards. Sensory services should be able to advise on services that people who are registered as visually impaired can access, and local voluntary societies are well placed to advise on local services.

Sport and physical activity

Taking part in sport or exercise can be challenging for people with visual impairment (Capella-McDonnall, 2007, Latham et al., 2015). VIPs can be signposted to British Blind Sport (Table 2), either to help maintain participation in current sports, or to find a new sport to take up. Local voluntary societies often also run sports teams or events.

Financial

Potential financial assistance because of visual impairment is a constantly changing area that practitioners would be unwise to offer specific information on. Benefits review can be offered by sensory services, or by the RNIB (Table 2). For people of working age, remaining in or gaining employment offers significant challenges (Clements et al., 2011, Latham et al., 2015). Patients can be

referred to the 'Access to Work' scheme (Table 2) for support with work-related costs such as equipment or transport.

Emotional support

The impact of acquired sight loss on emotional health is significant, and people must go through a period of adjustment to their visual loss, coming to terms with themselves in a new 'role' as a visually impaired person (Senra et al., 2014). Although a period of depression is to be expected as part of the normal process of bereavement and acceptance on losing sight, it has been shown recently that 43% of adults attending low vision clinics in the UK had significant depressive symptoms (Nollett et al., 2016), and that of these 75% were receiving no treatment. Eye care practitioners can play a significant role in recognising patients for whom visual impairment is causing distress, and referring on for support. It can often be obvious from a patient's presentation or case history that they are struggling with the emotional consequences of visual loss, but practitioners can also ask two questions suggested for identification of depression in patients with chronic physical health problems (NICE, 2009), which are:

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

If the patient answers 'yes' to either question, they should be referred to a practitioner competent to perform a mental health assessment. In the first instance, this will usually be the General Practitioner (GP), who can implement 'stepped care' management involving talking therapies and / or medication (NICE, 2009). Other resources may be available by referring the patient to local voluntary societies (Pybis et al., 2016), who may offer some form of counselling, often through a self-management programme or peer group support. Befriending or 'buddying' services are also offered either in person or by phone by various organisations, offering either general support or support for specific issues (e.g. Macular Society buddying schemes for people undergoing Lucentis treatment, or with negative experiences of Charles Bonnet syndrome). Local voluntary societies or local chapters of national charitable organisations also offer informal support through social events and outings.

Even if a patient does not screen positively for depression, 'having someone to talk to' is a key need for many people with vision loss (Pybis et al., 2016, RNIB, 2016). Referral of patients for emotional

support from an HES ECLO, local voluntary society, or relevant charitable organisation can be the most useful action that an eye care practitioner can take for someone with visual loss.

It should also be remembered that sight loss has a significant impact on a person's family and caregivers. Up to a third of carers of VIPs may have significant depressive symptoms (Bambara et al., 2009). Practitioners can consider asking caregivers who attend appointments with VIPs, such as partners, children or friends, whether they are receiving support in their role. Possible resources to signpost carers to are provided in Table 2. The support that carers provide can be vital for VIPs, but there is a danger that carers might overestimate the difficulty that their VIP has with some tasks (Latham et al., 2015) potentially leading to unnecessary loss of independence (Jang et al., 2003). Equally, difficulties in other areas such as communication or emotional health (Latham et al., 2015) may be underestimated by carers.

Service effectiveness

Despite the apparently obvious need for provision of a range of rehabilitation services for VIPs, there is a lack of good quality evidence of the effectiveness that such services have in improving outcomes (Binns et al., 2012, Rabiee et al., 2015). Very few randomised controlled trials have been conducted (Binns et al., 2012), partly because of the ethical difficulties involved in withholding services from some participants. This lack of evidence makes it difficult to prove to commissioners the value of low vision services, or to demonstrate the best ways of offering specific services. While it is clear that optical magnifiers allow VIPs to read smaller print (Binns et al., 2012), there is less evidence that particular types of magnifiers perform better than others in terms of reading speed outcomes (Virgili et al., 2013). There is little evidence of a greater benefit of multidisciplinary services compared to standard hospital based low vision services in the UK (Binns et al., 2012, Reeves et al., 2004), but the primary care based Welsh low vision service (Ryan et al., 2010) has demonstrated improved access to services, and reductions in self-reported visual disability. Rehabilitation services have been shown to have generally beneficial effects on functional ability, but less impact on quality of life (Binns et al., 2012, Rabiee et al., 2015).

Timing and prioritising needs

Even when VIPs are made aware of low vision rehabilitation services, they may choose not to access these services for a number of reasons (Fraser et al., 2015, Overbury & Wittich, 2011), including not considering their vision 'bad enough' to require assistance, or not having reached a stage of acceptance of their visual loss allowing them to be ready to accept further intervention. However,

the role of the eye care practitioner in raising early awareness of the services that are available for when a patient is ready to access them is key.

Given the range of potential services that a VIP might benefit from, what are the needs that are most important to address, and how do these needs change over time? In the Netherlands, a questionnaire called the Dutch Activity Inventory has been used to identify the daily activity goals that people report as being most important and difficult for them, which are termed 'priority goals'. For adults with varying causes of visual loss (but almost half with age-related macular degeneration) entering visual rehabilitation, the goals that are of high priority for the most people are reading, acceptance of visual loss, writing, watching TV, feeling fit, managing personal correspondence and dealing with the emotional aspects of vision loss (Bruijning et al., 2013). These findings demonstrate that while optical interventions (e.g. LVAs for reading) are key, it is important to consider needs beyond those addressed by magnifiers, and being able to refer patients on for emotional support and help with accepting visual loss are particularly important. Changes in the importance and difficulty of these important domains over 12 months have been evaluated (Bruijning et al., 2014a, Bruijning et al., 2014b), and have been found to remain stable, despite VIPs having received rehabilitation interventions. Whilst early intervention with rehabilitation services is important, the need for help does not seem to diminish with time, so exploring the needs for referral for rehabilitation at any point after diagnosis is important. We are currently assessing what the principal needs of UK VIPs are, and whether they are similar to those in the Netherlands both at entry into rehabilitation and over time.

Conclusions

VIPs have many and varied rehabilitation needs, but the principal ones are likely to include the need for information (RNIB, 2016), LVAs (from the optometrist / dispensing optician, local HES or other clinics), rehabilitation (from local authority sensory services (Rabiee et al., 2015)), and emotional support (potentially from the GP, HES ECLLO, relevant charity, or local voluntary society). Services that are available to patients vary across the UK, and practitioners need to know what is available in their local area. At a recent VISION 2020 UK seminar (2016), it was agreed that a priority for low vision services is to develop national guidance or standards as to what should be available to patients, and use these to address inequalities of access to services. Meanwhile, as eye care practitioners our role is to provide the optical assistance that we can, and then to signpost our patients to these additional services.

Table 1. Basic rehabilitation resources all practitioners should be able to signpost their patients to. Consider contacting and / or shadowing relevant staff to gain a greater understanding of the role and impact of these professionals.

Service	May provide	Contact
Hospital Eye Service	Medical treatment, certification of visual impairment, optical low vision aids, ECLO.	Contact local hospitals to determine the extent of their low vision service, and whether they have an ECLO or someone in a similar role.
Local authority: 'Sensory services'	Services to help clients maintain their independence including home assessment (and lighting), rehabilitation training, benefits advice.	Sensory services should make contact with people registered as visually impaired. Registration is not necessary to access support however. Find your local authority services through a search engine, and determine appropriate referral routes that practitioners can use or patients can be signposted to. Low vision leaflet available from: https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2013_PROF_261_Visual_Impairment_Leaflet.pdf
Voluntary society	Services vary widely between societies but may include a resource room (optical, non-optical and / or electronic aids), emotional support (befriending, individual or group counselling), training, information and advice.	Visionary (www.visionary.org), the umbrella organisation for local VI societies, has a postcode search engine on its website to identify your local charity.

Table 2. A non-exhaustive list of additional resources that the authors have found particularly useful in managing the varying rehabilitation needs of VIPs.

Service need	Possible provider	Information	Contact
Electronic aids	IT Can Help	Offers IT support at home for disabled people.	www.abilitynet.org.uk/at-home
	RNIB Online Today	Helping people with sensory loss to get online	www.rnib.org.uk/online-today
	Macular Society leaflet 'Using technology'		Available at: www.macularsociety.org/resources . Free professional membership of the Macular Society is available.
Registration	Department of Health Guidelines	Guidelines for registration as 'Sight Impaired' or 'Severely Sight Impaired'	www.gov.uk/government/publications/guidance-published-on-registering-a-vision-impairment-as-a-disability
	NHS Choices information	'Blindness and vision loss' page includes information	www.nhs.uk/Conditions/Visual-impairment/Pages/Introduction.aspx

		on registration, and links to various resources	
Non optical aids	RNIB shop	Variety of aids and gadgets to buy online.	shop.rnib.org.uk/
Lighting	Thomas Pocklington Trust / RNIB	'Lighting Solutions guide' – a practical guide to improving home lighting	www.pocklington-trust.org.uk/project/lighting-homes-to-make-most-of-your-sight/
Training	Guide Dogs' 'My Guide' training	Sighted guiding training, which is relevant to all staff in optical practices who may deal with VIPs. VIPs can also access volunteer sighted guides through the service.	www.guidedogs.org.uk/services/my-guide
	Falls prevention services	Patients at risk of falling should be referred to local falls prevention services directly or through their GP.	www.college-optometrists.org/en/EyesAndTheNHS/policy-projects/focus-on-falls
	Blind Veterans	Provide a wide range of services including daily living skills training to anyone who has served in the UK armed forces (including National Service).	www.blindveterans.org.uk
	Eccentric viewing training	The Macular Society offers 'Skills for seeing' training to improve ability to read with peripheral vision.	www.macularsociety.org/skills-seeing
	Braille	The RNIB has resources for adults to assist in learning Braille.	www.rnib.org.uk/braille-and-moon-%E2%80%93-tactile-codes-learning-braille/braille-courses-adults
Travel	Disabled Person's Railcard	33% discount on train fares.	www.disabledpersons-railcard.co.uk/
Sport	British Blind Sport	Information on various different VI sports. Includes a national guide runner database.	www.britishblindsport.org.uk
	parkrun	Free, weekly timed 5k runs across the country. Currently undertaking a lottery funded programme to increase accessibility to VI runners.	www.parkrun.org.uk
Financial / work related support	RNIB	Advice on benefits	Helpline: 0303 123 9999 www.rnib.org.uk/benefits-and-support

	Access to Work	Equipment / funding to help VIPs gain or retain employment.	www.gov.uk/access-to-work/overview
	Action for Blind People	Advice and support for VIPs on gaining or retaining employment	www.actionforblindpeople.org.uk/support-and-information-page/information/everyday-life/employment/
Emotional support	Macular Society	Various support services, including specific 'CBS buddies' for those with negative experiences from Charles Bonnet Syndrome, and 'Lucentis buddies' supporting those receiving anti-vegF treatment. Free professional membership.	Helpline: 0300 3030 111 www.macularsociety.org/support-services
	International Glaucoma Association (IGA)	Local support groups. Free professional membership.	Helpline: 01233 64 81 70 www.glaucoma-association.com
	RP Fighting Blindness (RPFb)	Information and support for people affected by Retinitis Pigmentosa and associated conditions	Helpline: 0845 123 2354 www.rpfightingblindness.org.uk
	Carers UK	Information, advice and support for people supporting someone who is older, disabled or seriously ill.	Helpline: 0808 808 7777 www.carersuk.org

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