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Letter from the editor

Hello and welcome to issue 2 of ISLRR VIEW, the new look newsletter from the International Society for Low Vision Rehabilitation and Research. The theme of this issue could be "**Looking to the future**".

Portable electronic magnifiers have become cheaper and more effective and I can't be alone in wondering if they will replace optical magnifiers as the mainstay of providing magnification, at least in wealthy countries. A large study based in Manchester, UK has investigated the relative merits of optical and electronic magnifiers and I am delighted that Taylor, Dickinson and colleagues have shared some of their interesting data with us.

Maybe low vision rehabilitation in the future will involve high-tech neuroscience interventions. Bernhard Sabel describes some interesting results of alternating current stimulation for improving vision in people with severe vision loss.

We are also looking forward to **Vision 2017**, the 12th International Conference on low vision, in The Hague, Netherlands. Ger van Rens provides a tantalising taster of the conference in this issue. I always really enjoy this three-yearly event and have been to every one since my first international conference, Vision 2002 in Sweden.

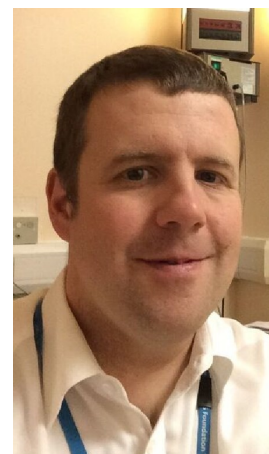
One thing I particularly enjoyed about the international meeting, Melbourne 2014, was the emphasis on the experience of people with low vision. I am delighted that GF Mueden, a nonagenarian with low vision, shares some of his experiences with us.

Add to that the continuation of our "Letter from..." series with a dispatch from Portugal, a film review, and the return of Ask Iris, and I hope you'll find this an enjoyable and informative read.

Please keep your suggestions and articles coming! The next issue will be out early in the new year.

Michael Crossland

E-mail: islrrview@gmail.com



The p-EVES Study: A Summary

**Dr. John Taylor, Prof. Chris Dickinson & The p-EVES Study Group.
Manchester, UK**

Background:

Optical magnifiers are used successfully by many individuals with visual impairment (VI) especially for near vision activities involving reading. For many years, electronic magnifiers have also been available to help people with such tasks but the recent introduction of portable (hand-held) electronic magnifiers (p-EVES) has made this option increasingly popular. However, more research was required to investigate their clinical benefit, the impact they have on people's quality of life, and the exact role that p-EVES devices can play within low vision service provision.

The Study:

The aim of The p-EVES Study was to find out how well individuals with VI performed their everyday near vision activities, and particularly how well they were able to read, using p-EVES devices compared to their existing optical magnifiers. Participants were recruited to the trial between April 2013 and November 2014, and the final study visits were carried out in April 2015. In total, 100 optical magnifier users from the Manchester Royal Eye Hospital clinics (UK) agreed to help with the research, with 82 people completing the study. Everyone chose a p-EVES device (from a selection of 4: Optelec Compact+, Optelec Compact 4HD, Schweizer eMag43, Eschenbach Mobilux Digital) and was given their preferred p-EVES device to try for a period of 2 months alongside their existing optical magnifiers to investigate which they preferred (and why), and which magnifiers gave better performance.

The cost effectiveness of p-EVES devices was also calculated, based on questionnaires to assess visual function, capability and well-being, and health- and vision-related quality of life (QoL).



The p-EVES Study: A Summary (cont.)

**Dr. John Taylor, Prof. Chris Dickinson & The p-EVES Study Group.
Manchester, UK**

Key findings:

In general, addition of a p-EVES device allowed users to:

- read much smaller print comfortably
- perform more tasks independently (tasks that they had previously needed help with, or couldn't do at all)
- read for longer durations, because they could see more letters of text on the screen, and
- sit in a more comfortable position to read
- experience much less difficulty in performing a range of everyday tasks at near

In comparison, optical magnifiers were:

- used more frequently
- used for a wider variety of tasks
- preferred for very short reading tasks (such as checking a price label) because they were quicker and easier to set up

In addition:

- Reading speed was approximately the same with both optical magnifiers and p-EVES.
- p-EVES devices were found to be a cost-effective way to improve near visual function, but there was no effect on well-being or capability.
- The cost per quality adjusted life-year (QALY) was high, but a sensitivity analysis suggested that a realistic reduction in the commercial price of the p-EVES device could reduce incremental cost-effectiveness ratios by up to 75%, bringing the cost per QALY below £30,000.

Conclusions:

The p-EVES Study provides evidence that p-EVES devices can play a useful role in supplementing the range of low vision aids used to reduce activity limitation for near vision tasks, but are unlikely to replace conventional optical devices. With a targeted prescribing strategy for p-EVES and a reduction in the cost of the devices it may become cost-effective for p-EVES devices to play a role in national low vision service programs.

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E-mail: chris.dickinson@manchester.ac.uk



Current Stimulation of the Brain Restores Vision in Patients with Glaucoma and Optic Nerve Damage

Bernhard Sabel, Magdeburg, Germany

Background:

Vision loss due to glaucoma or optic nerve damage is generally considered irreversible. Now a new prospective, randomized, multi-centre clinical trial demonstrates significant vision improvement in partially blind patients after 10 days of non-invasive, transorbital Alternating Current Stimulation treatment (ACS). In addition to activation of their residual vision, patients also experienced improvement in vision-related quality of life such as acuity, reading, mobility or orientation. The results are reported in PLOS ONE.

ACS treatment is a safe and effective means to partially restore vision after optic nerve damage by probably modulating brain plasticity and re-synchronizing brain networks, which were desynchronized by vision loss. This class 1 evidence is the first ever large-scale multi-centre clinical trial in the field of non-invasive brain modulation using electric currents and suggests that visual fields can be improved in a clinically meaningful way.

The Study:

In a study conducted at three German clinical centres (University of Göttingen, Charité Berlin, and University of Magdeburg), 82 patients were enrolled in a double-blind, randomized, sham-controlled clinical study: 33 patients were diagnosed with visual deficits caused by glaucoma and 32 with were diagnosed with anterior ischemic optic neuropathy caused by inflammation, optic nerve compression (due to tumours or intracranial haemorrhage), congenital anomalies, or Leber's hereditary optic neuropathy. Eight patients had more than one cause of optic nerve atrophy.





Current Stimulation of the Brain Restores Vision in Patients with Glaucoma and Optic Nerve Damage (cont.)

Bernhard Sabel, Madgeberg, Germany

The groups were randomized so that 45 patients underwent 10 daily applications of ACS for up to 50 minutes per day over a two-week period and 37 patients received sham stimulation. The only difference between groups before treatment was that the stimulation group included more men than the sham group; no other differences were found, including age of the lesion or visual field characteristics. ACS was applied with electrodes on the skin near the eyes. Vision was tested before and 48 hours after completion of the treatment, and then again two months later to check if any changes were long-lasting.

Key findings:

Patients who received ACS showed significantly greater improvements in perceiving objects in the whole visual field than individuals in the sham-treated group. Specifically, when measuring the visual field, a 24% improvement was noted after treatment in the ACS group compared to a 2.5% improvement in the sham group. This was due to significant improvements in the defective visual field sector of 59% in the ACS group and 34% in the sham group which received a minimal stimulation protocol. Further analysis showed improvements in the ACS group at the edges of the visual field. The benefits of stimulation were found to be stable two months later, as the ACS group showed a 25% improvement in the visual field compared to negligible changes (0.28%) in the sham group.

Patient safety measures were maintained at a high level, in line with previous studies. Current flow was assessed using sophisticated computer simulation models. No participants reported discomfort during stimulation, although temporary dizziness and mild headaches were reported in rare cases. The study results are in line with previous small sample studies in which efficacy and safety were observed. Those studies revealed that well-synchronized dynamic brain functional networks are critical for vision restoration. Although vision loss leads to de-synchronization, these neural networks can be resynchronized by ACS via rhythmic firing of the ganglion cells of the retina, activating or “amplifying” residual vision.

While additional studies are needed to further explore the mechanisms of action, our results warrant the use of ACS treatment in a clinical setting to activate residual vision by brain network re-synchronization. This can partially restore vision in patients with stable vision loss caused by optic nerve damage.

In summary, vision loss, long considered to be irreversible, can be partially reversed. There is now more light at the end of the tunnel for patients with low vision or blindness following glaucoma and optic nerve damage.

E-mail: Bernhard.Sabel@med.ovgu.de



VISION 2017, We are on the road!

Prof. Ger van Rens, VU University Medical Centre Amsterdam

Dear friends and colleagues,

For the last 4 years we have been working hard to organise the next Vision congress. It has been an interesting journey. Today I am proud to let you know that despite 3 bankruptcies of agencies and professional congress organisers and some other experiences, we are able to open the call for abstracts and the subscription of the congress as planned on October 1st 2016. Also, we are able to organise the congress according to the dues we agreed with ISLRR in our 2013 bid-book. Many of you have already volunteered to organise either a symposium or a workshop within the Vision 2016 congress.



Both ISLRR, ESLRR (the European Society) as well as the Dutch society (VRS) will have a prominent role within the congress. In addition, Vision 2020: The Netherlands and the Daisy Consortium will organise sessions devoted to their special interests. Please be aware that the congress is meant for both practicing workers in the field of Low Vision Rehabilitation and for scientists. We strongly invite those who want to share their knowledge (be it practice based or scientific outcomes) during this unique three-annual meeting where practice meets science.

Also, Vision 2017 is a unique opportunity for those who want to expose their firm or their products to a broad public involved in low vision rehabilitation, we still have some openings for stands during the congress.

Besides the congress, there will be several occasions to meet in an informal setting. There will be a welcome reception in "little Netherlands" and an evening barbeque on the North Sea beach. So don't hesitate and visit www.vision2017.org.

Hope to see you all in 8 months!

On behalf of the organisation committee,
Ger van Rens, E-mail: rens@vumc.nl





“Once Upon a Time in Low Vision...”

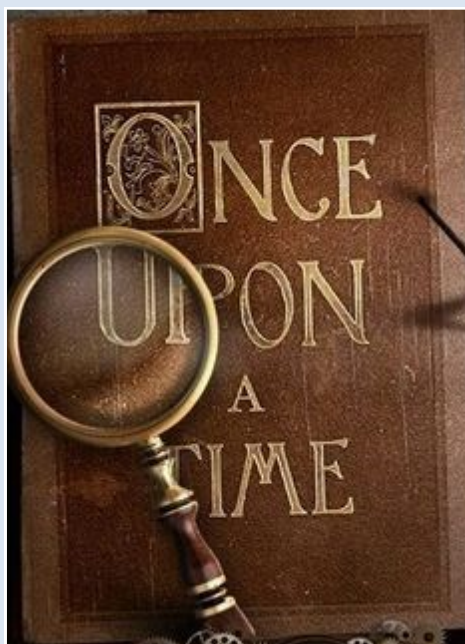
In the next issue of ISLRR VIEW, we will start a new regular feature called
“Once Upon a Time in Low Vision”.

In each edition, a long-standing low vision researcher will provide an anecdote or
insight into low vision research and rehabilitation in the past.

We have a fantastic first submission lined up, but require many more.

Please put your reminiscing hats on and send any submissions to

islrview@gmail.com



Hadley Institute for the Blind and Visually Impaired Offers Free Training Materials for Older Adults with Low Vision.

Hadley Institute for the Blind and Visually Impaired is a nonprofit organization that has been supporting people with vision loss for nearly a century. Low Vision Focus @ Hadley is our newest initiative. The centerpiece of this innovative distance education program is a series of 10 free audio recordings available for streaming or download from our website, www.lowvisionfocus.org. The recordings cover a variety of suggestions and modifications that can be made to daily routine to ensure older adults with low vision maintain safety and independence at home.

Low Vision Focus @ Hadley's free instructional recordings include such important topics as:

- **Making the Kitchen User Friendly**
Making the kitchen safer and more functional, clearing clutter and using contrasting color and shape recognition
- **Low Vision Cooking**
Safe cooking techniques to make cooking an enjoyable experience
- **Basic Tactile Marking**
Using various materials to create tactile markers, marking different household items to distinguish them
- **Simple Home Modifications**
Tools and strategies to make the household more low vision-friendly
- **Keeping Prescriptions in Order**
Taking medications, getting prescriptions and managing prescription routines
- **Going Out for a Meal**
Tips and tricks for going out and enjoying a meal in public

In addition, Low Vision Focus @ Hadley offers 15 accompanying instructional videos on its website, with more in production. The website also features monthly webinars on subjects related to low vision, links to resources and helpful information about Hadley's free distance education courses.

All educational and training materials offered through the Low Vision Focus @ Hadley are provided at no cost to our participants.

LowVisionFocus.org
LowVisionFocus@Hadley.edu
700 Elm Street, Winnetka, IL 60093 U.S.A



Life with Low Vision: A 99-year old's Perspectives

GF Mueden , Rhode Island, USA

The writer has his computer display set to 150-200% and high contrast and uses a CCTV to read hard copy. That should tell you about how well he sees. Most of his reading is done online.

Low vision is not a single disability with a single fix (the fixes found in our computers) or adjustment (what the sender does to help). Most descriptions of "low vision" are seriously inadequate and do a disservice to the low vision community which is not served well by W3C (Worldwide Web consortium) or the WAI (Web Accessibility Initiative) guidelines.

The NEI's (National Eye Institute, USA) definition of low vision includes a spectrum that extends all the way from needing more help than glasses to having only tiny residual sight. It fails to point out that it includes two major, quite different groups, which I call **eye readers**: those who still read with their eyes but not well; and **ear readers**: those who read with their ears via text to speech technology. What helps eye readers is frequently of no use to ear readers and vice versa. Consequently, things described to help the low visioned may be of help to only one of the two groups. It is to be noted that some people move back and forth between the two groups according to their eyes, the task they need to perform, and the tools available to them at the time.

For this article I will stick to eye readers. Somebody else is needed to step in and tell how it is for an ear reader.

For eye readers, there are three principal elements of eye strength for reading:

- 1) Most everybody knows about visual acuity, sharpness of focus, and that magnification is the usual fix, but many are not aware that word wrap may be needed to keep the copy on the screen, as per the sender's accommodation. This is not always available. For hard copy to be read with a CCTV, a narrow column helps keep the copy on the screen.
- 2) Outside of low vision clinics, fewer people know about contrast sensitivity, the ability to distinguish between shades of grey or colours, the foreground from the background, and that the fix is using bold fonts. Magnification helps to see the print, but a larger thin font is still thin and hard to read. In serious cases, a white screen will blind the person as opposed to the black print, and a switch to using a high contrast display is indicated. These options are available in browser software, but sometimes finding these options is not as obvious, such as finding the Verizon Print button! Honestly, I had to be told where it is, and knowing where, I can now find it by mousing and a tag appears and the pointer changes when I hover. However, it is always a hit and miss when browsing websites. For example, the black stock rating stars in Morningstar.com have no tags and are invisible. Another problem for this group is the glare produced by graphics, which makes it hard to read a nearby copy. I often wish there were an easy way to delete these graphics. Tables and charts become illegible and do not lend themselves to the LeftShift+Alt+PrScr toggle to get high contrast quickly. They can be suppressed, but this tends to upset the formatting of the entire text.



ISLRR View: Letter from...

Life with Low Vision: A 99-year old's Perspectives (cont.)

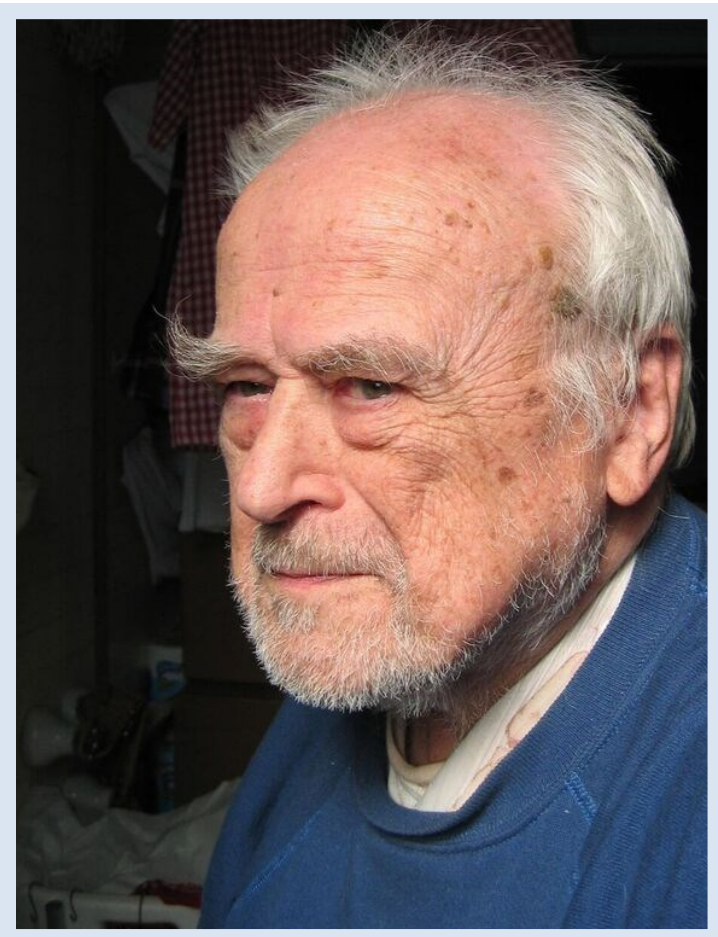
GF Mueden , Rhode Island, USA

- 3) For limited visual field, my fix is minimizing the screen width and pulling in the margins to give a narrow column of copy. This in turn calls for adjustment by senders of word wrap to keep the copy in the column. Browser adjustments of font choice and size, text size and zoom are not always available and how to override the sender's settings is often beyond me. To some eyes, the thin horizontals of sans serif fonts are invisible, leaving a forest of tree trunks with no branches. The adaptation should be not locking the design and letting the reader choose a font.

PDF files are a particular difficulty. Sometimes they are hard to switch to high contrast. Adobe's instructions and help are not written for the duffer and I dread going to its web site. Ditto Microsoft. The last time I went there I found myself charged by somebody else before I had received any help. Moral: Don't go there via Google lest you be hijacked. I would like to see an experienced ear reader tell about the problems of using screen readers, how they differ, and how writers and designers can help. This should be a cooperative thing, building a knowledge base that newcomers can consult.

Comments welcome.

GF Mueden
gfmueden@gmail.com



Barriers to Low Vision Services

António Filipe Macedo, Braga, Portugal

There is a major need for visual rehabilitation services in Portugal: in a total population of approximately 10.5 million in 2011; 892,000 people reported “problems to see with the best refractive correction” and 27,659 people reported “not being able to see”. These figures are not far from those estimated by a group of experts, working for the Minister for Health of Portugal, who that estimated that in 2007: 700,000 people had significant irreversible vision loss; 40,000 were blind; and 35,000 new cases of significant vision loss were occurring every year. An ongoing epidemiological study points to a figure of prevalence of visual impairment (acuity 0.3 decimal in the better eye) in Portugal of 1.3% (95%CI: 0.9 – 1.6). These numbers show that low vision in Portugal is frequent and better services are necessary.



Despite this, low vision services are rarely accessed in Portugal. Our group has been working to determine why this problem exists:

First, it was decided by a group of experts that low vision services should be available only in ‘Plataforma A’ hospitals. These are large hospitals based in cities that might require traveling distances of more than two hundred kilometres. Even for treatments as urgent as anti-VEGF therapy, we have shown this system can delay access.

Second, in addition to the barrier of distance, organization within ophthalmology departments (even large departments) often leaves few resources for low vision services. Thus, many clinicians may not refer patients to those services because this is not well established in their everyday practice and so they don’t have direct experience of how useful low vision services can be. We agree with Binns et al. (2012) that more cost-benefit studies about rehabilitation interventions are necessary.

Barriers to Low Vision Services (cont.)

António Filipe Macedo, Braga, Portugal

In the past, most visually impaired persons were referred to Patient Associations to get rehabilitation and support services such as social and psychological assistance. However, these services are not optimized. For example, in the past patients who needed a CCTV would first go to the Association for the Blind and then get referred back to the hospital to get a “prescription” for the device (the term “prescription” is very simplistic in this case because there is a lot of paper work involved). Next, the patients (with the assistance of the organisation) would need to obtain 3 quotes from distributors and send papers to social security before they got (get?) the device. They would then need to go back to the association to seek assistance if they needed training on the CCTV. Often this would involve a delay due to limited response capacity from professionals. Fortunately, this process is less burdensome for children with visual impairment who are normally referred by the schools to the hospitals.

There are 2 hospitals located in Lisbon: 1 hospital located in Coimbra and 2 hospitals located in Porto with Low Vision departments. These departments normally serve to accelerate some of the processes. There have been some novel initiatives (public, private and charities) to increase the quantity and quality of the services provided. However, for different reasons, their impact has been limited.

What should we do to improve low vision care in Portugal? We have four suggestions: We need to re-think the organization of our institutions, from charities to hospital departments and make them more functional for people with visual impairment.

The information and procedures to obtain assistive devices need to be clear and standardized. Unfortunately, the hassle to get a device such as a magnifier is so big that people often give up on rehabilitation at once.

More and better human and material resources are necessary but their existence needs to be in congruence with improvements in organization.

Research and academia need to devote more attention to studies and education in the field of low vision.

I hope that with our current efforts to characterize the population in need of rehabilitation in public Portuguese hospitals, some or all of these initiatives can get started for the benefit of those with visual impairment.

António Filipe Macedo
Filipe3305@gmail.com



Notes on Blindness

Film review by Michael Crossland, London, UK

In the 1980's, academic John Hull started losing his sight. He carefully documented the process by recording his thoughts onto audio cassettes, which have been adapted into a newly released movie (initial release April 12th, 2014). In the film, actors play the role of John, his wife, and his children, but the voices heard are taken from the original tapes. The book which the film is based on, *Touching the Rock*, has long been a mainstay of blindness rehabilitation education, but how does it stand up as a film?

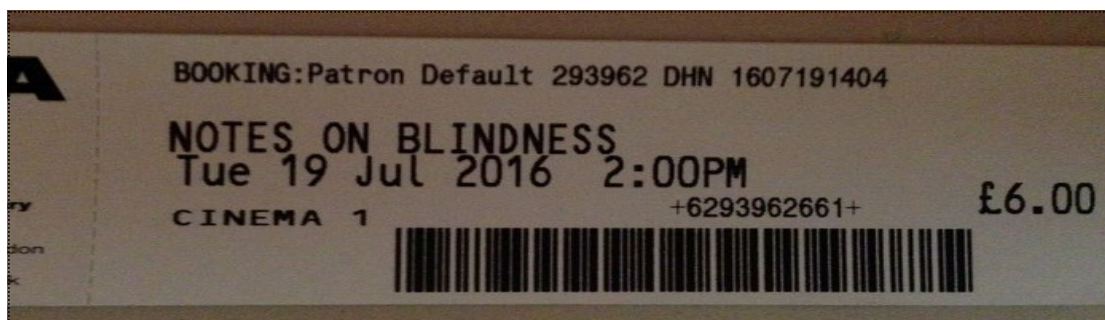
As a low vision professional, watching the journey from depression to some sort of acceptance of sight loss is very informative. I am sure most of us will identify phrases we have heard previously. One thing which particularly interested me was that it was at the very last stage of sight loss – from perception of light to no perception of light – when John Hull's mood started to change. The image of "the last thing I saw" – a church spire in Shrewsbury – is very powerful. This film is also very well made. The camerawork is artistic and simulates poor sight in several ways: with blur, with darkness and (impressively) with bright light. Despite the great visual scenes, I think the film would still be enjoyable for someone with no sight, as the eloquence of John Hull cuts through anything which is seen on screen.

Two particularly notable scenes for me were a dream/Charles Bonnet sequence in a supermarket which is reminiscent of Stanley Kubrick's "The Shining," and a beautiful scene where Hull uses raindrops as a form of echolocation – leading him to speculate on what life would be like if it rained continuously, even indoors. In some ways the film is dated. For example, in an early scene set in the 1980s, Hull (an academic) asks his social worker "how do blind people read big books," only to be told that "they don't". I hope technology, particularly screen reading and text to speech have improved this element of life. But the major theme of the film – what happens when a sense is lost – is universal.

Notes on Blindness is a moving, stylish, and informative piece of cinema and I recommend it to all audiences.

Notes on Blindness, directed by Pete Middleton and James Spinney, is 90 minutes long and out in theatres now. *Notes on Blindness* is currently playing in UK cinemas and on video-on-demand. More information about the film could be accessed through its official website: <http://www.notesonblindness.co.uk/>

E-mail: Michael.crossland@moorfields.nhs.uk





ISLRR View: Columns

Ask Iris: your low vision questions solved!

Dear Iris

I recently saw an older adult in our low vision clinic who had dual sensory loss. Previously, he relied on lip-reading for social conversation and when speaking to his partner. However, as his vision has got poorer, he found lip-reading increasingly difficult. In the clinic he struggled to lip-read me, which made the assessment challenging. Can you give some advice on how best to communicate with someone who lip-reads, especially when they have poor sight? I draw the line at wearing lipstick.

Yours,
Lippy

DUAL SENSORY LOSS



Do you have low vision questions for Iris,
ISLRR's very own agony aunt?

Email them to ISLRRview@gmail.com

Dear Lippy

Lip and speech-reading are indeed common and important skills for clients with combined sensory loss, and when the vision loss threatens this skill, suddenly the vision loss also becomes a communication disorder. Traditionally, we thought that once you are beyond an acuity of 20/200, speech-reading will not really be feasible anymore; however, recent research has indicated that there is still a lot of information that people can extract, even at much lower acuity levels. For example, body position (low spatial frequency information) or head position can communicate a lot of emotional information. These extra cues can assist the client to gain context about the conversation, and that often improves communication.

I would suggest that you try some simple techniques and strategies to allow your client to benefit as best possible from both your verbal and non-verbal cues, such as:

- Always face your client when you speak to him.
- If you are about to speak, give him a cue; like touching his arm or saying his name first.
- Speak clearly and adjust your speed as needed, but try to speak as normally as possible. Do not use baby-talk, since that would be insulting.
- Avoid glare by sitting in front of a lamp or light source (e.g. window), so your face is illuminated from the front.
- Ask if your client is wearing (or has turned on) his hearing aid.
- You can also invest in the purchase of a pocket-talker for your office, so you can offer amplification at on the occasions when someone forgets their hearing aid, the hearing aid may not be working, or the patient never decided to get one (even though they may need it!)

Yours,
Iris Clearview