

Unexplained Loss of Vision: The Importance of a Team Approach

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Thank you. I'd like to acknowledge the contribution of my colleague Paul Kallaras to this presentation. Unfortunately he was unable to be here to co-present this case study.

We found this client and the process to assist her, her school and her family really interesting, as in our 15 plus years of working in the low vision and paediatric areas, myself as an orthoptist and Paul as an educational and developmental psychologist, this was the first time we'd come across an individual who presented as severely vision impaired, but with no pathology to explain their vision loss. We just wanted to share some of what we learnt with you.

Background

- Past history of bilateral uveitis
- Inconsistencies in visual behaviour
- Mixed opinion among teachers



A Vision Support teacher from an independent Sydney highschool contacted me at RIDBC Assessment Service to assess the vision of a 14 year old young lady who they were struggling to cater for.

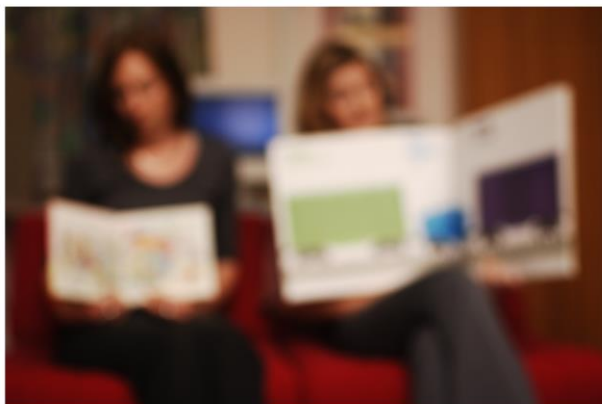
This young lady had been seen by us in the past and had a history of bilateral pan uveitis. Uveitis is inflammation of the iris, the ciliary body and the choroid. It can be quite a serious inflammation if left unmanaged.

The teacher mentioned that there were mixed opinions among the young lady's teachers about the severity and extent of her visual difficulties and that was causing some friction between the student and some of her teachers.

That comment and the young lady's previous vision assessment through our organisation made me think of malingering as a possibility. However, the records I had to hand indicated her visual diagnosis could be unstable, perhaps she'd had a flare up, I didn't know when she'd last seen her ophthalmologist... I didn't have answers to these questions so went in and tried to keep an open mind.

Assessment Results

Unable to read N48 print



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I went out and saw this young lady at her school. Her visual acuity was right eye hand movements and left eye 0.5/60. She was unable to read print size N48 and low vision aids didn't assist her. (On the slide is a simulation photo of approximately 1/60 distance vision and size 48 Arial print).

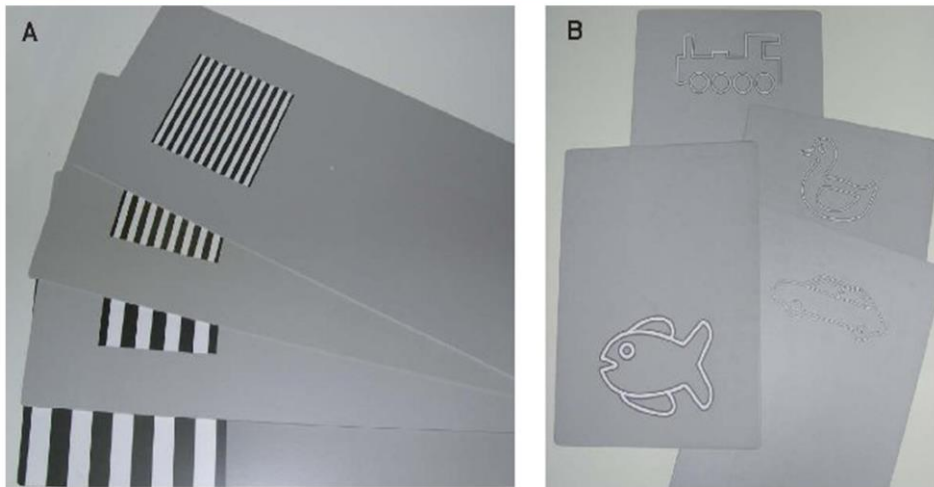
The first thought that popped into my head was: How on earth is this young woman coping at school? How is she able to access the curriculum?

In the normal course of events, a student with this level of vision would be a braille user.

When I asked her how she was managing in class she said that she got a lot of help from friends and a teachers aide who were able to read things out to her. In terms of submitting work, she was still writing some things out but also typing out assignments. Theoretically she may have been able to touch type but at the assessment I was not able to see her use a keyboard.

During conversation she displayed some behaviours that were not consistent with her presenting level of visual acuity. For example, her eye contact was great. It was steady, sustained, and central. She was polite but didn't say much. Her affectation was pretty typical of a 14 year old; you could tell she didn't really want to be there.

Preferential Looking Tests



On the slide are pictures of two tests often used to assess very young children or clients who are unable to name or match symbols. On the left are the Teller Acuity Cards and on the right is the Cardiff Acuity Test. They are called preferential looking tests and rely on very early visual responses where we 'prefer' to look at a visual stimulus or complex scene (such as the stripes or pictures) over a blank surface of uniform brightness. So the black and white stripes or pictures start off very thick and bold and become finer and thinner until they are indistinguishable from the grey background. It's a very reflexive response which is difficult to suppress.

Usually I wouldn't be using this kind of test with a 14 year old, single disability student, but they are often used by orthoptists in cases where subjective responses on a vision chart are questionable. Unfortunately I didn't have a set of either of these tests with me and from this case I've learnt to take a set with me even if there's just a hint of something not quite adding up. I might leave them permanently in the boot of my car!

Help! Nil objective reason to explain poor vision



At that assessment, the teacher also gave me a copy of some more up-to-date ophthalmic reports which stated the young lady's uveitis was controlled, and that there was **nil objective reason to explain poor vision**. That was her ophthalmic diagnosis. It would have been great to have this information before hand but sometimes that's just how things are. It was reassuring at least to know that her inconsistent responses had been observed and documented by others.

Regardless, this young woman required assistance. This had been going on for quite some time. She needed better access to the curriculum and her family and school needed some answers and suggestions so that they could move forward with her. This was out of my area of expertise so when I got back to work I made contact with Paul, who agreed that more needed to be done.

Functional inconsistencies

- Able to navigate successfully around busy room.
- Able to reach out to accurately grasp hand to shake in greeting.
- Locates table and chair without difficulty.
- Maintains good eye contact.



With parental consent, Paul visited the young lady at her school. They were very accommodating and gave Paul access to observe the young lady during lessons and in the playground. Paul met with the young lady in the morning to introduce himself and to discuss difficulties she had been experiencing at school. He informed her that he was there to see if he could provide her and her school with any assistance. All the while, Paul observed and documented her general functioning and observed a number of inconsistencies, such as the young lady's ability to navigate her way successfully about a busy room, reaching out to accurately locate his hand to shake in greeting, and maintaining good eye contact, including catching her gaze from across the room.

Of particular concern to Paul was that the young lady was now in a life skills program for all of her core subjects, and her vision problems appeared to be directly related. He was concerned because he wanted to be sure that this was the right fit for her and wanted to be sure she was reaching her academic potential.

Paul felt that organising a team assessment at RIDBC would be helpful in observing the young lady engage in a variety of tasks that the team regularly use to assess other children and adolescents with vision impairment. It was hoped that the collective thought of the team, given their experience in sensory impairment, might be able to dispel some of the confusion being experienced by school and home.

Time for a team approach



- Educational & Developmental Psychologist
- Orthoptist
- Speech Pathologist
- Occupational Therapist
- Paediatrician



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The young lady attended the RIDBC Assessment Service for a full trans-disciplinary team assessment, involving ourselves, a speech pathologist, OT and paediatrician. Her vision was assessed, as well as her cognition, language, and everyday functional skills to gain an understanding about her academic potential, and to observe her reported vision difficulties. Questionnaire's were also completed through interview with the young lady's father to screen for behavioural, emotional, and executive functioning concerns.

Results

- Vision - 6/6 on Teller and 6/7.5 on Cardiff
- Cognition (verbal reasoning, working memory) – *low average to average*
- Language – *low average to average*
- Behaviour/Emotional Wellbeing – evidence of somatic and depressive symptoms



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Her vision on formal testing (i.e. letter chart) remained poor but was normal on preferential looking tests which I had with me this time. She was 6/6 on Teller and 6/7.5 on Cardiff. The results on verbal aspects of the assessments ranged between *low average* and *average* for her age. So her verbal reasoning, auditory working memory, and language skills were at a level which suggested she is capable of functioning at a higher level at school than she currently is, even *with* vision difficulties.

The young lady did not attempt any items requiring her to use her vision. She reported that she could not see the visual stimuli, even when the test materials were significantly enlarged. Her inability to perform the tasks was inconsistent with observations of how she used her vision functionally during the day which were similar to what Paul had observed at her school. It was also inconsistent given the visual materials presented to the young lady were the same materials used with many other children with significant vision impairment, who were able to *at least* attempt some of the items. The young lady appeared to become distressed when encouraged to give the enlarged materials a try and wasn't pressured to do the tasks at that point.

Permission to video the sessions was given by the young lady's father. The footage was closely reviewed afterwards to analyse the young lady's behaviour.

Paul used standardised questionnaires to interview her father which indicated the young lady had clinically elevated results for somatic symptoms such as frequent headaches and nausea, as well as depressive symptoms such as sleep problems, lack of enjoyment, not getting socially involved, and keeping things to herself.

[illegible]

Following discussion and deliberation amongst the team, it was decided that the young lady's vision problems were psychological in nature and a formal diagnosis of Conversion Disorder was proposed. It was strongly recommended that the diagnosis and comorbid depressive symptoms were reviewed and confirmed by a psychiatrist and/or clinical psychologist who was experienced in these symptoms and disorders.

Definition: Conversion Disorder

- Symptoms are not intentionally produced
- Individuals experience somatic symptoms
- Symptoms do not have an organic cause
- Response to stressors

(ICD-10 Version:2015 F44)

(DSM-5, Diagnostic and Statistical Manual of Mental Disorders fifth edition)



Conversion disorder is different to malingering in that the symptoms aren't intentionally produced. The individual is not consciously feigning vision loss; it may be sub-conscious. Conversion disorder results in individuals experiencing somatic symptoms like blindness or paralysis for example, but without a definable, identifiable organic cause. It is believed that the symptoms are a response to stressful situations or events that affect an individual's mental health.

Outcome



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While on face value the diagnosis may have seemed obvious from the beginning, a diagnosis such as conversion disorder is a complex neuropsychiatric condition which requires serious consideration. Giving feedback to the young lady, or to her family, that her vision impairment is in actual fact a psychological condition, could have serious implications. So there's a great need to be tactful and thoughtful when relaying information of that kind.

A meeting with the young lady's father was arranged with the team at a later date to discuss the findings. Importantly for me this was also a good opportunity to explain to her father the outcomes of previous vision assessments. I'm sure that on their visits to the ophthalmologist it was explained that the young lady's eyes were looking healthy but sometimes parents or carers may not always be ready to hear what you have to say; or they may need it said several times or in different ways. We were fortunate to have the luxury of time to be able to make sure her dad understood and had the opportunity to ask questions. For me it was great to see his light bulb kind of moment when I showed him the very fine grating his daughter was able to see on the Teller cards, in comparison to the Sheridan Gardiner chart, and explain the principle behind a preferential looking test as a reflexive response. I think it made more sense to him and he understood I think what people had been trying to explain.

Paul explained to the dad at that meeting that perhaps there were other factors at play and recommended referral to a specialist who could work through these issues with the young lady which her dad was very happy with. Paul also arranged a meeting with the school to discuss the outcome of the assessment and how the student could be assisted.

What next?

- Provide support for a severe vision impairment.
- May take some time to see changes in response to therapy.
- Follow the advice of the treating doctor.
- Gradually reduce supports as breakthroughs and improvements in other therapy is achieved.



Paul commented that following the meeting at the school, the overwhelming feeling expressed was relief. The staff supporting the young lady now had a plan and more of an understanding of her specific needs. They had something concrete to work with and less confusion about what was going on. The school was informed that, in the meantime, continuing to support the young lady for a severe vision impairment was very important, and that challenging her, knowing that she doesn't have an organic reason for her vision problems, may have significant implications on her mental health and have the potential to set her back in this instance rather than get better. It was also explained that an "overnight cure" was extremely unlikely, and it may take some time for the young lady to respond to therapy. Following the guidance of her treating doctor was recommended.

Recently, Paul received feedback from the young lady's father that the visit to the referred doctor hadn't gone to plan. The doctor didn't think that the young lady presented with signs of depression, and while he acknowledged the diagnosis of conversion disorder was likely to be accurate, he didn't persist in therapy with the young lady. Rather, he indicated that continuing to support her for a functional vision impairment was the best way forward.

However, in a turn of events, just before the Christmas holidays, we heard that the young lady's long term paediatrician, on receiving a copy of our report,

agreed that things couldn't be let go, and that there was a real problem that needed addressing. He referred the young lady to another doctor who sat down and had a conversation with her about getting help. She agreed that she needed help which was a major breakthrough. The young lady was then referred to another doctor who agreed to work with her. In the first week of therapy, the entire family attended a session and the next week, the young lady had an individual session. The feedback to the young lady's father was that it was a good session, as she had opened up a fair bit. The father couldn't give anymore feedback as he said that the sessions were confidential, but he appeared over the moon that something was finally being done. He was very grateful for our report and said it really helped set the wheels in motion.

Summary

- Holistic approach – how is this impacting in all areas?
- Trans-disciplinary reports helpful in highlighting issues.
- Be persistent if you feel something is not quite right.
- Know who you can call on or refer to in your area.



When a child or young person presents with vision loss that is unexplained, with no obvious organic cause, or things just don't add up, it's essential for us to consider the impact holistically and ask ourselves the question: how is this impacting on the child's learning at school? How are they managing daily tasks at home? I think the outcome in this case demonstrates that it requires a trans-disciplinary team assessment and report to really set the wheels in motion. A vision assessment report or a psych report on their own may not have necessarily raised enough of a red flag. I also think this case demonstrates that you need to be persistent. If you don't get a satisfactory outcome at first, keep plugging away.

I'm fortunate at RIDBC to have access to a multidisciplinary team of health professionals and specialist educators. In a busy school or health clinic it's not necessarily as easy but I think that knowing where some good educational and developmental psychologists are in your area, or knowing what the appropriate referral pathways are, is a great starting point just in case a young person like this student walks through your door.



As I alluded to earlier, this area can be tricky and there are cases where feigning vision loss is conscious but it can also be sub-conscious; and I think we owe it to our students to investigate these underlying reasons very thoroughly.

Thanks very much for your attention.