

VICTA: HOW IT ALL BEGAN

Lynley Hood, July 2013

LYNLEY'S STORY

My introduction to visual impairment came on 20 December 2009. I was reading in bed when my left eye went blurry. "Time to put the light out," I thought. Next morning it was still blurry. I had lost the central vision in my left eye, suddenly and permanently. Then the vision in my right eye began to deteriorate. Fear of blindness kicked in. Throughout history people have been more afraid of blindness than of any other disability.

My greatest concern was that if I lost the central vision in my right eye as suddenly as I had lost it in my left, I would be in big trouble. What would I do? How would I cope?

My first thought - gotta read all those books on my bedside table while I still can - was followed by a more practical consideration - If I lose the central vision in my right eye as suddenly as I lost it in my left, can I find the right button on the phone to dial 111?

Before long my every activity was dominated by the thought: "How would I manage this if I couldn't see?" I knew it was getting silly when I found myself wondering how I would feed the parking meter if I couldn't see. Oh... that's right, I wouldn't be driving. Clearly, I needed information.

There are checklists in the Yellow Pages for floods, earthquakes and volcanic eruptions - such things may never happen but it's good to be prepared. But I could find no information on preparing for possible vision loss. In view of the number of older people losing their sight gradually, this seemed like a grave oversight.

When I ask friends, "What would you do in my situation? Where would you go for advice?"

The reply is always, "Foundation of the Blind".

LOOKING FOR HELP

Most people assume, as I assumed, that as with the Arthritis Foundation or the Cancer Society if you phone a charity in search of advice or information, the person on the other end of the phone will do their best to help. So I called the 0800 number for the Royal New Zealand Foundation of the Blind (RNZFB).

"Are you a member of the Foundation?"

"No."

"I can send you a registration pack and application form. You need to get it signed by an ophthalmologist or an optometrist. You will be informed within six weeks whether you are eligible to join."

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She told me the criteria for RNZFB membership. I had no idea what she was talking about.

"I'm not legally blind," I said. "I'm just looking for information - like if I need a new microwave, or a new cell phone, what should I look for to ensure it'll be easy to use if my sight deteriorates further?"

"I can send you a registration pack...."

I called the local branch of the RNZFB. No, there was no misunderstanding. No, I had not struck the national receptionist on a bad day.

"To give you an indication," she said. "If you fail the eye chart test for being allowed to drive, you have to be twice as bad as that before you qualify for help from the Foundation."

If the RNZFB won't help, who will? I phoned everyone I could think of: Age Concern, hospital disability services, community disability services, occupational therapy services, my MP, the Consumers Institute, the Retirement Commissioner, the Health and Disability Commissioner....

The response was either "Have you tried the Foundation?" or "Yes, there is a gap in the services, we've had a lot of complaints."

A GAP IN SERVICES

The gap is huge. According to the 2001 post-census disability survey, almost 95,000 New Zealanders have a visual impairment that cannot be corrected by glasses or contact lenses. But only about 11,500 of them (that's only 12% of people with irreversible vision loss) are blind enough to be registered with the RNZFB.

The survey also found that most visually impaired adults, whether they're living at home or in residential facilities, need magnifiers, large print books, audiobooks and other special equipment, but only a small minority actually receive this help. Since vision loss escalates with age, with our ageing population the problem is bound to get worse.

How did this situation arise? Why are there services, support groups and advocacy groups for other disabilities, but next to nothing for those facing vision loss?

Part of the problem lies with the reality that getting through the day can be an all-consuming struggle for people with low vision. According to the post-census disability survey, of all types of disabilities - mobility, hearing, visual, psychological, intellectual and so on - visually impaired people are the second most likely to need help with everyday activities like personal grooming, meal preparation, travel, shopping, housework and personal finance. Only the intellectually handicapped are more in need of help. And we're not talking about blind people here. Statistics NZ defines visual impairment as having difficulty or being unable to read ordinary newsprint or recognise faces across the room. If the inability can be corrected by glasses or contact lenses, the person is not counted as having a visual impairment.

The flow-on consequences of vision loss can be devastating. If you have trouble reading ordinary newsprint, you have trouble reading your mail, you have trouble paying your bills, and your relationship with the daily paper, with the books on your bookshelves, and with the magazines and newsletters that keep you connected with the world is over. You have trouble cooking because you can't see the controls on your oven or the water level in your saucepan. You have trouble looking smart because you can't see the food stains on your clothes or the cat hairs on your coat.

You have trouble doing housework because you can't see the dust and spills. You have trouble shopping because you can't read the price tags. You have trouble getting around because you're not allowed to drive, or you're too scared to drive, or you're a menace on the road. In *Faces in the Water* Janet Frame wrote of how the ice flow she was on broke off from the ice flow the other people were on and started drifting away. She was talking about mental illness, but vision loss is like that too.

So you either struggle on, or you curl up in the foetal position, pull the duvet over your head, and give up. There are numerous studies showing that the emotional impact - the fear, the depression, the anxiety and the risk of suicide - of gradual sight loss is far greater than that of sudden blindness.

DUNEDIN VISUALLY IMPAIRED PEOPLE (VIPS) GET ORGANISED

My first year with low vision was a lonely, isolating experience. Then, in December 2010, an article in the *Otago Daily Times* highlighted the need for comprehensive, accessible low vision rehabilitation services in New Zealand. That article led to the formation of Dunedin VIPs, an informal support group for visually impaired people of all ages, their family members and friends.

Dunedin VIPs meet monthly to listen to an invited speaker and to share information, support and practical knowhow about managing everyday tasks with low vision. Past and future meeting topics include:

- * Eyes and eye disorders.
- * Adjusting to vision loss.
- * Lighting and magnification.
- * Getting out and about.
- * Independent living.
- * Safety in the community.
- * Safety in the home.
- * Useful gadgets.
- * Preparing meals.
- * Shopping.
- * Hobbies and skills.
- * Standing up for your rights.
- * Supporting someone with sight loss.

The group loans MP3 players loaded with useful podcasts and Kindles loaded with e-books. Dunedin VIPs also work with Occupational Therapy students from Otago Polytech and design students from the University of Otago on projects to make life easier for people with low vision, and with Dunedin Public Library staff on projects to ensure that people new to vision loss can continue to read.

The Dunedin VIP group has no formal structure, no treasurer, no paid workers. The group is run by visually impaired volunteers. The group's costs are covered by koha.

Over time the numbers attending meetings grew, unmet needs were identified, projects were devised, a formal structure was required. In March 2013 VICTA - the Visual Impairment Charitable Trust Aotearoa NZ - was established.

WHY VICTA IS SPECIAL

VICTA is the only New Zealand charity providing an independent consumer voice for the 88 percent of New Zealanders with irreversible vision loss who are not blind enough to qualify for membership of RNZFB.

VICTA has important work to do. In the US, UK and Europe, low vision rehabilitation services transform people with high support needs into active, independent citizens; in New Zealand the need for comprehensive accessible low vision rehabilitation is not only largely unmet, it is largely unrecognised. Most New Zealanders know that hearing loss occurs on a continuum, but vision loss tends to be regarded as an either/or phenomenon: blind or not blind. We describe people who can't hear very well as "hard of hearing" but we have no equivalent expression for people who can't see very well. VICTA has a key role to play in ensuring that the sight loss continuum is better understood, and that the unmet needs of all those who fall along that continuum are recognised and addressed.

VICTA's charitable status ensures that the important work being pioneered by Dunedin's VIP group can be properly funded, developed and extended. Our formal structure also enables VICTA to become a Ministry of Transport Total Mobility Agency for all Otago people disabled by visual impairment.

As well as facilitating Dunedin VIP meetings and projects, working with the Dunedin Public Library on projects to ensure that people new to vision loss can continue reading, and working with Dunedin road safety organisations on a pilot project to ensure that pedestrians with low vision are more visible, VICTA, the RNZFB and other sight-related charities plan to work together on future projects.

At a local and national level, VICTA is working for the restoration of Low Vision Clinics in public hospitals (there used to be ten, now there are only two). Our 0800 number enables callers from throughout New Zealand to obtain advice, support and information about coping with sight loss. Our trustees raise community awareness about low vision by speaking to local and national groups.

Creating a charitable trust requires teamwork. VICTA would never have happened without the whole-hearted support, expertise and commitment of Associate Professor Gordon Sanderson of the Eye Department at the Dunedin Public Hospital and the Dunedin School of Medicine. Gordon and I set the process in motion. As founding trustees we were joined by former Reserve Bank Governor Dr Don Brash and events and conference manager Kerry Buchan. For our trust deed our warmest thanks go to Dunedin lawyer Garth Lucas for his generosity and expertise. Our beautiful logo is a gift from Dunedin graphic designer Stewart Robertson of AdArt. We are honoured to have Dame Catherine Tizard as our Patron.

Because the need for comprehensive, accessible low vision rehabilitation services is a national problem, VICTA is a national charity. However VICTA is Dunedin-based. Our projects and publications are being developed, tested and refined in Dunedin with enthusiastic input from Dunedin VIPs (the best focus group ever!) prior to being distributed more widely. VICTA's Dunedin-based pilot projects are helping pave the way for the establishment of a network of comprehensive, accessible low vision rehabilitation services nationwide.
