



**Let's
talk about
vision loss
Real stories**



Acknowledgements

Vision Australia gratefully acknowledges Amy, Ben, Brenda, Brittnee, Cheryl, Deena, Paul and Tony who shared their very personal stories of blindness or low vision to help others facing similar experiences.

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Vision Australia

Blindness. Low Vision. Opportunity.

This book is dedicated to the people who are new to vision loss and to those who are supporting someone going through this life transition. When you're ready, we're here for you.

Vision loss can be life-changing - you might be wondering "What's next?"



You might be wondering how you'll keep doing the things you love.

You might be wondering how your family and friends will react to your news.



Listen to the stories of others living with vision conditions. When they were ready, they connected with various supports that helped them to continue doing the things they've always done, such as reading, travelling, working and much more.

If you or someone you love is experiencing vision loss, read and listen to the stories in this booklet and ask us about the services, government benefits and other support that you can access.

Meet Paul: still building hot rods and BBQing

"I was sitting in my office at work and my right retina detached. It was like someone just pulled a blind across my eye."

After living for 53 years with reasonable vision, Paul experienced severe vision loss over just a few hours, and 18 months later, blindness.

"All of a sudden the whole world, as I had known it, changed," he said.

"I didn't really know who I was, or what I could offer anyone. I even considered not being here."

What didn't change was Paul's grit that helped him to rebuild his life. He's relearnt how to build hot rods and still works as an engineer.

"There aren't many things I can't do these days. I can still use a BBQ after getting help from an occupational therapist.

"There's such a wealth of knowledge out there that can help you do anything you want," he said.





**Listen to Paul's
full story.**

Highlights include:

- **The impact on his marriage.**
- **How sharing his feelings
changed his outlook on life.**

Meet Brittnee: business owner and optimist



Listen to Brittnee's
full story.

Highlights include:

- How illicit drugs affected Brittnee's vision.
- What her new and fulfilling career looks like.



An up-and-coming hairdresser, Brittnee was looking forward to a long and successful career when she lost her vision.

"I kept thinking I hadn't opened my eyes, and I kept turning the light switch on and off, wondering what was going on," she said.

Diagnosed with diabetic retinopathy and macular degeneration, she felt the immediate consequences of this life-changing moment.

"My boss told me there's no point coming back," she said. "That was probably the time when I locked myself in the house for about a week.

"Also, I had lots of friends through playing netball, so because I couldn't play anymore, I started attending games. But they stopped inviting me out."

Eventually, Brittnee experienced a key turning point when she shared her feelings with others going through similar experiences. From that time, she not only felt better but it also gave her a new perspective about life after vision loss.

This has resulted in lots of good things happening to Brittnee since then. She's launched a consulting business, discovered new joys and relearnt how to do many things she used to do before losing her vision.

"With time, you can be content with losing your vision. I'm happy with how I perceive myself and how I have gotten on with life."

Meet Ben: science whizz and uni student

Diagnosed with retinitis pigmentosa at the age of eight, Ben is about to embark on a career as a genetic counsellor.

“When I started to lose my vision as a kid, it was just when I was really getting into reading books,” he said. “It was quite a devastating time to lose something that I was just getting into and loving.”

However, the challenges he’s faced have led to growth, and he says that speaking up about his needs has been fundamental to that growth throughout his life.

At university, his technology skills have helped him immensely because he’s been able to successfully do all of the required work, while continuing to enjoy reading.

And whenever he feels a little nervous about his budding career, he reminds himself that having low vision gives him an advantage over his peers.

You’ll have to listen to his story to find out why.





**Listen to Ben's
full story.**

Highlights include:

- **Why having low vision gives him an advantage over his peers.**
- **Managing tough days.**

Meet Deena: government advisor and mother



Listen to Deena's
full story.

Highlights include:

- Parenting without vision.
- How she makes the most of her iPhone.



“You don’t need to do everything at once. Small and steady wins the race,” is Deena’s advice to anyone facing blindness or low vision.

As an advisor for the state government, and mother to her five-year old, she’s used to offering advice. She is also blind.

Born with congenital glaucoma, she can tell when the sun is out and when she’s in shade, but very little else.

“During school, I was in big denial. I would push away and refuse things like having an integration aid,” she said.

“I was embarrassed and didn’t want to look different.”

Her attitude to living with an eye condition has significantly changed over the years.

“I’m part of the NDIS and it’s been an absolute game-changer – for both me and my husband.

“I don’t rely on my mum any more than sighted people do. She doesn’t do any more than a typical grandmother would do.”

Her final word of advice? “Just take one step at a time and be open to support.”

Meet Cheryl: artist and traveller

All her life, Cheryl had been conscious of her eye health. “My mum had an eye condition so it was very likely that I would get it.”

And when Cheryl was 60, the eye specialist confirmed what she had always suspected. “The doctor told me that I should prepare for what would be significant vision impairment by the time I was 70,” she said.

While the retired nurse was able to accept her vision loss, she refused to give up her independence.

“The saddest day was when I had to hand over my driver’s licence. I was about 40 when I got my licence, so I had really treasured it.”

But that hasn’t stopped her. While most retirees are slowing down, Cheryl is still travelling to all the places that matter to her, as well as pursuing her passion for art, and doing much more.

Her advice to anyone going through vision loss is what got her through the tough times: “Whatever you do, just don’t give up, and don’t stop doing the things that you like.”





Listen to Cheryl's full story.

Highlights include:

- **Tips on staying independent.**
- **Her favourite equipment around the home.**

Meet Tony: celebrity chef and teacher



Listen to Tony's
full story.

Highlights include:

- Tips in the kitchen.
- Accessing the right services.



Imagine the Foxtel Network calling you and asking you to star in a cooking series. And imagine that you're so good, you star in 4,000 live shows across 100 television networks.

Welcome to Tony's career as a celebrity chef.

"I was cooking up a storm on stage. I was tossing pots and pans around and cooking things in 30 seconds," he said.

But while he was taking a break from his hectic career, Tony noticed his vision wasn't quite right. As his sight deteriorated, it looked like cooking was virtually impossible.

"I lost my confidence in the kitchen. I was burning things," he said.

It took some time for Tony to regain his confidence in the kitchen – and that's understandable, considering kitchens can be dangerous for anyone, let alone someone who is blind.

Yet Tony has come so far.

Thanks to the right services and training, he's still cooking perfect meals from his collection of 500 recipes, and now he's helping others with vision conditions cook up their own wonderful creations in the kitchen.

"I discovered a new way of cooking," said Tony. "There's nothing we can't do."

Meet Brenda: pianist and volunteer

Brenda is something else. At 91 years of age, she's a disability advocate, volunteer, and founder of a much-loved lawn bowls group.

What's more, all of these achievements came after she lost her vision, which at the time seemed to be devastating.

"The ophthalmologist looked at my eyes and shook his head and said, 'You're in very grave trouble'. It all happened so fast. It almost seemed surreal," she said.

"One of the worst things was that I couldn't read music anymore. I'd always played the piano – it was a huge part of my life." With the right support, Brenda has overcome even that difficulty and continues to play the piano.

With time, the sadness of losing her vision became determination to make the most out of life.

This change set off a chain reaction that has seen Brenda say "Yes" to many opportunities.

"You only have one life to live. You must stay in touch with the world, the community. I learnt I had to do things differently."





Listen to Brenda's full story.

Highlights include:

- **How she still plays the piano.**
- **Her favourite services and supports.**

Meet Amy: mother and advocate



Listen to Amy's
full story.

Highlights include:

- How Amy responds to negative feedback.
- The government benefits available for carers.



The maternal health nurse looked straight at Amy and said, "Are you ready for this?"

When Amy's son Parker was just four months old, he was diagnosed with x-linked juvenile retinoschisis and nystagmus.

It can take time to adjust to life-changing news, and it was no different for Amy and her husband, Glen.

"When we found out, I thought I didn't want a blind child," she said.

Yet Amy is the first to admit that accepting the situation and getting the right supports for Parker and her family changed everything.

"The Vision Australia team saved our marriage. They are the most invaluable people to have in your life."

Today, Parker is thriving and doing what every independent child does best: playing, making friends and ignoring mum when it's time to brush his teeth.

Parker's being set up to be independent. And for him, that means using a white cane to get around and learning braille.

As Parker grows up, the services he receives will adjust to suit his goals and interests.

"He's a brilliant young man," said Amy, "and more than anything, I'm proud of the fact that he's blind."

What's next?

When you're ready, you can find out about the government benefits and many services that you can access.

As a leading national provider of blindness and low vision services, Vision Australia supports people of all ages who are blind or have low vision to help them live the life they choose.

We can help you find answers to questions you may have.

Contact us on 1300 84 74 66 or email info@visionaustralia.org.

Find out about government benefits you might be eligible for.

You might be entitled to government funding that will help cover the costs of some services. For example:

- **Disability Support Pension (Blind)**
- **Blind Age Pension for people over 65 years**
- **National Disability Insurance Scheme (NDIS) for people under 65 years**
- **My Aged Care for people over 65 years**
- **National Companion Card**

There are also some state-based government subsidies to help cover the cost of public transport.



There are many different types of support on offer.

Talk with others going through similar experiences

Emotional support groups are an ideal way to share what's on your mind and hear other people's stories. They offer social, emotional and practical support and operate in a confidential, safe and casual setting.

Life changing and easy-to-use technology

Using technology might feel daunting. We promise it's easier than you could imagine to continue to use the Internet, read emails, use your mobile phone and much more. And you can keep reading the daily newspaper and your favourite books via audio through the Vision Australia Library.

A safe home the way you want it

Qualified occupational therapists can suggest changes in your home that will allow you to continue using every space safely. They can show you tips such as using tactile features on kitchen equipment, ways to reach your front door, adding colour contrast to find cups easily and organising wardrobes and cupboards. They can also help you to maximise the use of your remaining vision.

Safe and independent travel

With the right support, you can learn to get out and about safely, whether by using public transport or equipment like a white cane. Mobility specialists can help you continue to go to all the places that matter.



Get in touch

If you have any questions, please contact Vision Australia.

Phone: 1300 84 74 66

(Monday to Friday, 8:30am – 5:00pm EST)

Fax: 1300 847 329

Email: info@visionaustralia.org

Website: visionaustralia.org

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Vision Australia acknowledges Aboriginal and Torres Strait Islander people as the First Australians and Traditional Owners of the Land across our working area. We pay our respects to Elders both past and present.

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