Rob McKrill

'My road less travelled: Living with albinism and low vision.'

Sometimes I imagine my dark-haired parents surprise when my bright white head appeared in the maternity hospital on that stormy day in May of 1960.

I was born in Perth, Western Australia where I still live with my wife and kids. I came into the world with oculocutaneous albinism (OCA) which leaves me with a partial lack of pigment in my hair, skin and eyes. I have white hair, pink skin and light blue eyes which dance from side-to-side due to nystagmus. When I was younger, I had a tinge of red in my beard. I am the only person with albinism in my family of origin, but my dad's cousin Alice has a son with albinism which highlights the presence of albinism in our family's gene pool.

My vision is impaired and quite low, like most people with albinism and my skin and eyes are sensitive to the sun. Australia is one of the hottest and brightest places on the planet. This has been a challenge but is manageable. The major barriers that I experience are created by my low vision.

I grew up as a child and teenager in the 1960's and 1970's. During this time disability was almost totally understood and viewed as a medical problem only. Like a lot of people with an impairment and disability at the time I went to a segregated 'special' school. Our broader society at the time didn't make changes or adjustments for people with a disability. The changes and the fixes were focused on the individual. Imagine this. A time when you couldn't get on to a bus if you were a wheelchair user. I was on a country bus service the other day and noted that there were two spaces between the rows of seats where two wheelchairs could be placed and secured. The bus had a clever electric hoist which folded into the side of the bus. In an attempt to put myself in the shoes of wheel chair users, I imagined myself getting onto a bus that only has wheelchair spaces and no seats. I imagined how uncomfortable and unwelcome and invisible and left out I would have felt. Imagine travelling two hundred kilometres and not having a comfortable or safe seat to sit in. We now live in a society that takes responsibility to make access, orientation and communication accessible to people with a disability.

My special primary school was okay, it did over protect me somewhat, and left me largely unprepared for high school. I did well academically in primary school, but when I landed into my local and regular high school with no help or concessions whatsoever, my grades plummeted. I was bullied, teased and eaten alive by the other kids because of my unusual appearance, thick glasses and low vision. This was traumatic and impacted my sense of self-esteem and self-worth. There was no such thing as disability awareness and the notion of inclusion, and the basic human rights of dignity and respect for people with a disability were still a couple of decades away. My family never used the 'A-word' and I felt very lost and alone.

I left school when I was age fifteen and entered the world of work. My mum arranged a job for me at a local bakery. I worked there for three months and quickly decided that a life of factory shift work wasn't for me. I worked in our family hotel for a while doing a range of things including maintenance and bar management. After about three years I left this job. I was in my early twenties then and at the time I was at a cross road faced with the question of how I wanted to spend the rest of my working life. I recall feeling quite anxious about finding something that fitted with the barriers that my low vision created. I felt vulnerable and recalled the frustration that I felt when sizing up potential barriers and hurdles that limited my options.

As chance would have it, I met and spent some time with a couple of social workers. I got a sense of what they did and the qualities, skills and knowledge that came with being a social worker. I remember when the penny dropped, and I decided that this is what I wanted to be. I started making plans.

I returned to a senior college for a year in 1984. I did the study that gained me university entry and the following year I commenced a four-year Bachelor of Social Work Degree course at Curtin University, here in Perth. I was highly motivated, more mature and I fell in love with the body of knowledge and philosophy underpinning the social work profession. As serendipity would have it, the personal learning journey that the social work course provided me, enabled a deeper understanding of the disability world, the social and human rights models of disability and helped me to understand and shape my own disability experience.

I started my first social work job in 1989 and I have worked continuously until now. During this half to 2025 I will be leaving my current job as a senior social worker at the Perth Children's Hospital to transition into retirement. I have worked as a professional social worker for thirty-five years.

In the early nineties I met Lisa my wife at work. We were married in 1995, and this year sees our thirtieth wedding anniversary. Lisa is also a social worker. Together we have four amazing kids, Grace, Sam, Nic and Ella.

As a person with albinism the main barrier for me is spontaneous and independent transport. I do use public transport and taxis and Ubers, but this is at times not as responsive or as flexible as I would like it. The second major barrier for me is accessing print. I have found work arounds, but I still find reading and viewing content on a computer slower and physically tiring than most other people. Having low vision as a constant barrier makes life more effortful. It's hard work having an impairment and disability. And this extra effort and the uncertainty of having to work harder to see the basics can be stressful.

I love photography! When I was age ten, my parents bought me my first camera. I was captivated and from about age fourteen I was hooked. I learned to use a darkroom at high school and photography has been my hobby and passion ever since. After high school I was able to study photography. I was thinking that I might be able to get a job in a photography lab or something similar. But as you can see, my job interest took a different direction. The knowledge that my young brain soaked up at the time has given me a solid foundation and launchpad for my ongoing love of photography. Digital photography and other technological advances like auto focus and large computer screens have continued to make photography more accessible for me. Things just keep getting better and easier.

On New Years Day of 2025 I uploaded a movie that I had been making over the previous couple of years. It's a documentary about my life as a person living with low vision and albinism. The YouTube link is included here for you to view. My movie is called 'The A-Word'. I've always wanted to make a movie, and I've also wanted to contribute to world-wide conversations about albinism. I'd love to hear your thoughts.

So, here I am. The eldest and only white-haired child of my dark-haired parents. I started my life feeling totally isolated in my albinism. This led me to drawing the conclusion early on that I was defective and worthless.

These days talking about my albinism no longer sticks in my throat, filling me with shame and embarrassment like it once did. The A-Word doesn't feel like a swear word like it did when I was a kid.

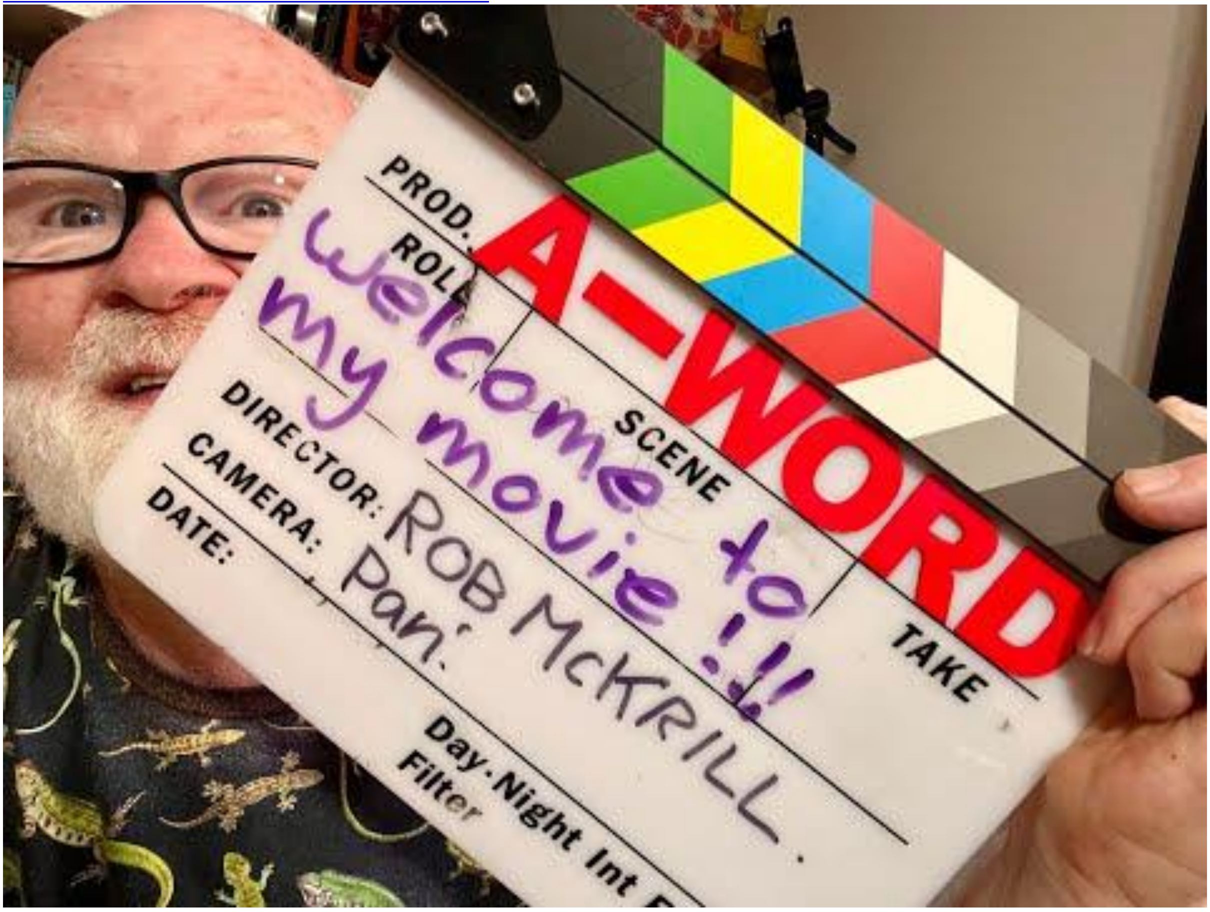
My albinism has at times been traumatic, causing me a lot of uncertainty, humiliation, exhaustion and frustration.

My low vision and albinism still create barriers and headaches for me, and I know that they always will. I still experience recurring and ongoing grief about not being able to drive a motor car.

I've developed some pretty effective resilience over time, and I've become very good at finding creative and innovative ways to adapt to the barriers that life throws my way. Think about this! I'm a legally blind man who takes photographs as a hobby, and I've just made my first movie!

I was talking with someone recently about the notion of radical acceptance. My favourite quote says it nicely. It's from Popeye the Sailor who said: 'I yam-what-I-yam'. The notion of radical acceptance really makes a lot of sense to me. I like who I am and I'm proud of my life and the unique course that it's taken. I am not defective or worthless. I now live with my albinism and low vision with greater understanding, confidence, self-acceptance, self-compassion and peace.

Preview YouTube video The A-Word



The A-Word