

It really does all work out!

Written by Rebecca Francis, 2019.



Welcome to the albinism community!

Our son Harvey is 3 with Ocular Albinism but it feels like yesterday that we were in your shoes. The shock and emotion of it all for me was all consuming for some time, but as others said it really does all work out. With the right support your child will be up and running like any other kid before you know it.

The first thing we did was get a visual teacher at the Royal Institute for Deaf and Blind Children and joined their playgroup to get assistance with being aware of what Harvey would need. He could only see roughly 10cms back then but can see at least a metre quite clearly now. Vision Australia is also great if you don't have an RIDBC near you. They will help you with amended ways to help your son crawl/walk/run/ride a bike. Also with speech if that is a little delayed.

Once you have your diagnosis, contact NDIS to get your funding up and running, apply for that carers pension and a little down the track when you want to go to shows there is a companion card as well.

Sunlight was Harvey's biggest issue, through NDIS we had our house audited by Vision Australia and then we put a plan together for tinting of our car windows, his window in his room, lighting modifications and shades for outside. If our curtains weren't good enough we probably could have added those as well.

The sunglasses that Harvey liked the most as a baby were Retro Banz Wrap Around by BabyBanz.
<https://australia.babybanz.com/collections/eyewear>

Harvey does swimming, little kickers, gym, music and goes to a mainstream pre-school.

He didn't have glasses until this year, but they want him to get used to them before he starts school.

The best advice we were ever given was to just treat Harvey exactly the same as if he didn't have the impairment. If there are any modifications that we need to make, then we make them, but otherwise we just work with his support team to make sure he is hitting the appropriate milestones and he figures out the rest.



Just keep pushing through these early days, you and your family will adjust as your little one grows and shows you how capable they are of doing things independently.

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**Albinism Fellowship of
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