

# Media Release

5<sup>th</sup> April 2024

## FOR IMMEDIATE RELEASE

### **Down Syndrome NSW x NSW Trustee and Guardian Partnership: Supporting Future Planning to Ease Midnight Anxiety**

Today, Down Syndrome NSW and the NSW Trustee and Guardian launched their partnership supporting future planning, wills and estates for the families of loved ones with Down syndrome, as well as people with Down syndrome seeking to put in place their own future planning instruments.

The life expectancy of people with Down syndrome is now 60 years old, in the 1980's it was just 25 years of age, and in the 1940's it was 10 years of age. Key to moving this needle is the advent of at home care, the reduction of institutionalisation, advances in medical care and greater services and supports.

This is a milestone to be celebrated but presents a number of challenges, not the least of which is future planning. So too, cooccurring diagnoses such as earlier onset dementia are coming to the fore as we experience this demographic shift in our community.

"As CEO of Down Syndrome NSW, the ageing dilemma is one of the biggest issues our members are currently facing. Ageing of our loved ones with Down syndrome and its associated biophysical, systemic and personal challenges is a key priority for Down Syndrome NSW, informed by our members with a need for more to be done in this important space." Emily Caska shared.

"As a sibling, I am acutely aware of the 'midnight anxiety' felt by parents and siblings when it comes to who will provide the very best care and act in the best interests of our loved ones with disability."

"I know for our family personally that wills, estates and future planning is something we have visited, stopped, revisited, avoided and struggled with due to the highly emotive nature of thinking about life after mum, with whom my sister Lucy is deeply close." Ms Caska continued.

The partnership announced today is one small step in supporting future planning and easing the midnight anxiety felt by so many.



**Brian Woods, Acting CEO, NSW Trustee and Guardian**

*"We are excited to be partnering with Down Syndrome NSW to provide their members and families with assistance, education and guidance on the importance of wills and estate planning for all parents, but particularly for those who have children with disability."*

*"Wills and estate planning is a vital service we provide for the community of NSW. I look forward to watching this collaboration with Down Syndrome NSW progress over time and hearing the many success stories that are sure to occur."*

The provision of information and resources will continue to evolve, informed by the needs of people with Down syndrome and their families. This milestone partnership marks a proactive step in drawing in expertise to better support families and their futures.

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