



Adult Sibling Toolkit™



**NATIONAL
DOWN SYNDROME
CONGRESS**

Empowering Individuals with Down Syndrome and Their Families Since 1972

The National Down Syndrome Congress was founded in 1972, by a group of parents and professionals, who pushed back against a system which routinely recommended that babies with Down syndrome be institutionalized. Rather, these parents decided to keep their children at home with them and raise them alongside their other children. Their vision? A world with equal rights and opportunities for people with Down syndrome.

Over forty years later, people with Down syndrome are living into their 40's, 50's, and even 60's, and for the most part, they continue to live in the family home with their parents. We recognize that for many families, not just those affected by Down syndrome, conversations between parents and adult children on the topics of death, medical incapacitation, healthcare directives and wills, are difficult. They are often put off, and in worst cases, these conversations NEVER HAPPEN.

At the NDSC, we are committed to providing information, advocacy and support concerning all aspects of life for individuals with Down syndrome. We want to help families work through these issues, and facilitate conversations that will lead to actions which will secure the future of their adult children with and without Down syndrome, bring peace of mind to all those involved, and result in the best possible continuum of care for the family member with Down syndrome.

Adult siblings, who want to be involved in their brother or sister's life, but are not familiar with the details involved, can use this toolkit to have discussions with their parents, and learn how to be an effective advocate, friend and perhaps, caregiver for their sibling after their parents are no longer able.



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