

# What we can do for you – Family support from your local organisation

by Parent Support Australia

**All across Australia, your local Down syndrome organisations have fully trained Family Support staff who are there for our members and the community. The state & territory organisations offer support to families covering all stages of life but here we take a look at the resources available to new parents and families with a child under 18.**

## Queensland

Down Syndrome Queensland has a dedicated Member Support Officer, Kellie, who supports new and expectant parents at the beginning of their journey—usually at the time of diagnosis. We offer support to parents of a child with Down syndrome as a whole of life service, so we give advice around behaviour, ageing, resources, education and beyond.

We like to respond to our families in a personal and individualised way. We offer new parents a visit from our staff and the family can decide the venue that works best for them. We are often asked for recommendations for therapists and health professionals that specialise in Down syndrome (which we know are few and far between).

Kelly, Member Support  
Queensland



We get many requests from schools to support children with Down syndrome in mainstream classrooms and our Education Consultant can do school visits if required. Often parents call to chat about issues they may be having and just the chat to our staff can be enough for them to help find their own answers and troubleshoot the issue.

Each year we run workshops around Better Start (now NDIS First Steps) which focusses on early intervention, funding and also support for parents. It is a wonderful way to connect with families and also for parents to network amongst themselves. We are currently looking to run workshops in the future for health professionals around delivering a diagnosis of Down syndrome and the best ways to support new parents.

**Down Syndrome Queensland PH: (07) 3356 6655**

## Australian Capital Territory

Although we are small we still service our members with excellent information and support. We do this over the phone and with monthly digital newsletters. Once a month we have morning teas for parents with children under the age of five where we discuss issues related to health, education, and—of course—NDIS. There is also our annual community event, StepUp!, where we celebrate the achievements of people with Down syndrome.

We are always happy to visit families in hospital and, in association with the hospital social worker, we ensure that families receive the information packs.

Currently because our resources are limited we have not yet been able to supply school support but we do see a need for visiting school.

We try to help over the phone and field questions like:

- What things other than speech therapy can I do for my child who isn't speaking?
- What types of NDIS services do other families use?
- Questions about self-managing the NDIS.

- What do I look for in choosing a school?
- How do I talk to my child about who is a friend and who is not a friend (e.g. strangers and people on TV)
- Puberty questions
- Behaviour concerns with teenagers when verbal communication is limited
- Which high school do we choose (disability based, mainstream, integrated or inclusive)?

In the future we aim to recommence workshops for the under five's as well as provide workshops on puberty and teenagers.

**Down Syndrome Australian Capital Territory**  
PH: (02) 6290 0656

### Western Australia

Hello from Nikki in WA. DSWA offers a New Parent Morning Tea once a term held at the office in South Perth, which is central for most suburbs of Perth. I run these events and quite often we will have a physiotherapist or a Local Area Coordinator (NDIS) out to talk to the parents and make sure they are accessing the correct services. We also have our developmental playgroup for the 0-5 year age group that runs fortnightly in the school term on Fridays. Our playgroup leader, Tara, is an OT and has a son with Down syndrome who is a teenager now. I am the assistant and I also have a son with Down syndrome who is in primary school. DSWA has a closed Facebook group that families of all ages can use to ask questions and support each other.



Nikki  
Western Australia

When a new baby with Down syndrome is born, I can visit the family either in hospital or at home depending on what the parents would like. I have visited a family on the day their child was born in hospital, as they really wanted to talk and have the New Parent Pack that day. Some families wait till they are settled at home and the initial medical appointments have slowed down—then I visit them at home. We also speak to new parents prenatally and can put them in touch with other families that have had a prenatal diagnosis.

New parents often want to meet other parents of a child with Down syndrome. Common questions are about developmental milestones; schooling in the future; how the diagnosis of their child may affect the family unit and sibling relationships.

When asked, we can visit children at school plus we also run workshops. In the past we have run the Early Days Workshops for new families—these will continue into the future but will focus on the NDIS as people transition into the scheme.

**Down Syndrome Western Australia**  
PH: (08) 9368 4002



Robyn MacDonald  
New South Wales

### New South Wales

Hello, I'm Robyn from Down Syndrome NSW. We provide peer-to-peer support, information, resources—or just a friendly ear to families who have a member with Down syndrome. Our team is available to talk about a range of situations they may be facing at any stage from new babies, going to school, health issues or employment.

You can access us via email, phone or by coming into the office for a chat. We love to meet new families and share our experience with you; to explore your concerns; connect you to services and supports and/or link you with other families in your area. We can meet with you where you feel most comfortable—at the hospital, at home or in our office.

Our Training Team provides workshops and seminars for families on different topics across all life stages and can provide schools with in-house training on request.

Everyday at DSNSW we have a number of requests for information with most common ones being:

- Transitioning to child care, school or employment,
- Activities in their local area,
- Resources from our extensive library,
- How to support their family member with Down syndrome to achieve a milestone at any stage of life.

**Down Syndrome New South Wales**  
PH: (02) 9841 4444

Henri Wollensack with Veronika Davie

## Tasmania

Down Syndrome Tasmania has collated a great range of valuable resources that make up our New Parent Packs. There are packs available for viewing at all hospital birthing units throughout the state. Similar packs are available to all new families and are provided upon personal or hospital contact after a baby is born. The packs include a DVD (Down syndrome: The First 18 Months); the booklet—'An overview of development of infants with Down syndrome (0-5)' by Sue Buckley and Ben Sacks; along with current information from Down Syndrome Australia and resource materials.

All queries come through our main phone contact and parent support is offered through hospital or home visits by members of our organisation.

Many families continue contact with each other through Early Childhood Information Services and also through social events conducted by our organisation, including our newly formed Young BrightStars in the South of the State. We are hopeful for these classes to branch to the North and North West of the State in the near future.

We also run a closed Facebook group for Tasmanian families, which is a good source of support and information on local events and services. Facebook users can ask to be added to the group by contacting us through the public Down Syndrome Tasmania Facebook page or by other members of the group.

**Down Syndrome Tasmania PH: 1300 592050**

## Northern Territory

DSANT was founded by a group of proactive parents who, in the late 1970s, created our Association with the specific aim of parent support. Since that time we have ensured peer support programs remain the focal point of our service. Along the whole of life continuum, DSANT staff and peer mentors are on hand to share information, encourage families, and maintain a longevity of friendship contact.

This relationship often starts from the first hospital visit where we attend to meet the family and child, provide a supportive hospital pack of clear information and enrol the new family into our community membership. As families move interstate for medical issues or return home, a mentor is connected, often with a cultural or linguistic parity with the family, and will sustain home and community activity visits. Where families move back into their homes out on community, contact is established with medical and educational services in that community to introduce the family to further services. These environments include community medical clinics, family first services and child care centre based services.



In Darwin and Alice Springs DSANT provides a comprehensive support service, through a partnership with the NT Department of Education. We are responsible for two significant programs: Down Syndrome Schools Support Program which delivers individual, classroom and whole of school professional development regarding all aspects of the educational needs of a student with Down syndrome; and the Computer Aided Learning Program which provides individual 1:1 lessons in classrooms building on literacy, numeracy and communication skills with students.

The DSANT office is open six days a week and enjoys regular visits from families seeking some play time, information, a browse through the library or just a cup of coffee and some relief in the air conditioning!

**Down Syndrome Northern Territory  
PH: (08) 8985 6222**

## South Australia

It is DSSA's Vision to create:

*An inclusive South Australia where every individual with Down syndrome is given an equal chance to learn, grow and thrive.*

DSSA offers a range of services to support the growth and development of clients in the early years. The program reflects a family centred approach to Early Intervention providing home visiting, centre based services, child assessments and individual plans.

Pre and postnatal visiting in the hospital and home for babies and children to provide family support and information about the medical conditions and other developmental issues associated with Down syndrome and related developmental conditions.

Early Intervention groups, facilitated by Early Childhood educators with expertise in disability, are fortnightly and centre-based for babies, 2-3 and 4-5 year olds to provide an opportunity for play based early intervention, family support, networking and obtaining information on associated medical conditions, feeding, speech and language development including signing, motor skills, cognitive and social emotional development.

A Pre-Kindergarten program to enhance the development of routines and behaviours that are necessary for a successful transition to preschool. Children attend the preschool program supported by Special Educators from DSSA.

In addition a range of therapies are available to enhance child development. These include Occupational Therapy, Speech Pathology, Physiotherapy, Consultancy support from early childhood educators and allied health therapists.

**Down Syndrome South Australia**  
**PH: (08) 8245 4600**

## Victoria

My name is Dani, I am the Family Support Worker at Down Syndrome Victoria. I am also a parent of three boys. Our second boy was diagnosed with Down syndrome when I was pregnant. I have recently joined the wonderful team at DSV and am enjoying getting to know all our families, supporting new parents and connecting families with each other.

Dani and her son Bodhi  
Victoria



DSV offers support for families who have received a prenatal or postnatal diagnosis of Down syndrome. This support is offered face-to-face, over the phone and via email. We provide families with current, evidence-based information and help them to navigate the early days on a personal and practical level. New families receive a New Parent Pack and are advised about the resources available and our peer support options (MyTime, Family Network Groups, and our closed Facebook group).

I visit families at home and in hospitals. The first visit can make a real difference to families as they process the diagnosis. Most new parents have had little experience of, or interactions with, people with Down syndrome or their families; this means they have many questions and concerns. I show new parents a photo-book of my son and our family. This often sparks more conversation, questions and a spot of myth-busting.

We also hold Early Days workshops for new families, facilitated by Sue Blandford and myself. These workshops are conducted in small groups and we allow time for the families to connect with each other and share their stories.

Our Education Team support students and schools by delivering the Education Support Service into mainstream schools. In 2016, we supported 67 students with Down syndrome across Victoria and have introduced a Preschool-to-Primary program to assist parents with transitioning their child into school.

While most enquiries come from new families, we also hear from families at other key stages too: starting childcare or kindergarten; starting school; and starting puberty. Some of the other topics I provide information about are early development, working with health professionals and early intervention services, and positive behaviour support. Our Victorian families are a supportive community and are great for information sharing. Through our peer support networks like MyTime, Family Network Groups and our closed Facebook page, families are able to learn about strategies that other parents are using.

**Down Syndrome Victoria PH: 1300 658 873**

Did you know you can subscribe to VOICE on line?

You will find details at

[www.downsyndrome.org.au/subscribe.html](http://www.downsyndrome.org.au/subscribe.html)