

voice

Ageing Well

Growing up and
getting older

EXERCISE ALWAYS MAKE ME FEEL YOUNG
FIT AND STRONG WHICH IS R IMPORTANT
AS I GET OLDER.

DEAN

World Down
Syndrome
Congress 2024
booklet
inside



Down Syndrome
Australia

December 2023



Down Syndrome
Australia



Supporting positive change for our community

As non-profit organisations, Down Syndrome Australia and its members are dedicated to supporting, informing and advocating for the needs of people with Down syndrome and their families across Australia.

Our teams work diligently to support people with Down syndrome through developing resources, advocating for positive change, engaging with the community and implementing innovative programs focused on creating an inclusive future for all.

Your ongoing support enables us to continue with this important work and together, shape the future for people with Down syndrome throughout Australia and beyond.

Your donations help us make a real difference.



All donations, no matter the amount, help us to continue our important work.

To make a donation, scan the QR code or visit:

www.downsyndrome.org.au/get-involved/donate/



All donations over \$2 are tax deductible.

Editorial



Hello there,

I'm Nathan, and I've recently started as editor of *Voice*.

I'm a writer and editor based in Melbourne, and I originally come from a small town surrounded by bush and sea in the southwest of Australia. I've

worked on a range of magazines and books in the past, and one of my favourite things is working with people to tell their stories. I think stories help us to know ourselves and each other better.

I'm especially happy to be with Down Syndrome Australia putting together this journal for you. I hope to get to know lots of people in the community, and maybe even share your story in an upcoming issue of *Voice*. Please feel free to email me if you have an idea for an article or would like to tell your story. My address is voice@downsyndrome.org.au

In this issue, we look at ways people with Down syndrome can age well, and lead happy and healthy lives throughout adulthood. We share stories of individuals who are planning for their future when it comes to living arrangements, medical care, assets and retirement; and talk about what it means to live a fulfilling life.

It doesn't matter what age you are, the articles in this issue are full of useful information and real stories about growing up and getting older.

You'll also find a special lift-out all about World Down Syndrome Congress 2024, which DSA is excited to be hosting in Brisbane from 9–12 July next year. The booklet features everything you need to know about what happens at Congress, how to register, how to submit an abstract for presenting at Congress, and where it'll be.

It also includes top things to do in Brisbane from our friends at Down Syndrome Queensland, and stories from past Congress attendees about their experiences and why you should take part.

I'd like to give a big thanks to the team at Down Syndrome Australia for helping me put together this issue of *Voice*.

I hope you enjoy it,

Nathan Scolaro
Editor

In this issue...

Message from the CEO	4
DSAN Update	5
Looking after your health	6
Moving out of home	8
Sibling bonds	10
Families and future planning	12
Keeping fit	14
Deciding to retire	15
How I keep healthy and enjoy life	16
Getting outside my comfort zone	20
Creating a will	21
Talking about death and dying	22
Trusts and Estate Planning	24
Out and About	26
Our Voice	28

Message from the CEO



It's hard to believe that I've been with Down Syndrome Australia for nearly 12 months now. It has been a great year for DSA, and I feel incredibly proud of the work

we have done and the exciting times we have ahead.

We have recently seen the outcome of the Disability Royal Commission as well as the NDIS Review, probably two of the most important reviews to occur in the disability landscape in Australia. To some extent, whilst the outcomes of these reviews have been delivered, the work is just beginning now to ensure that governments (Local, State and Federal) implement the recommendations so that people with Down syndrome in Australia are valued and have full access to social and economic inclusion in order to achieve their full potential.

Rest assured that this is front of mind for DSA for 2024 in our role as the national voice of people with Down syndrome.

We are also excited to be hosting the World Down Syndrome Congress 2024 in Brisbane from 9-12 July. Congress is an opportunity for people with Down syndrome, families, advocates, professionals and researchers to meet and share knowledge, insight and experience with others from different countries and environments around the world. People come to share experiences with other parents and families, gain information and knowledge, and network with people from different cultures and countries. If you have not already thought about coming along, please make sure it is on your list for 2024 – you can find out more at www.wdsc2024.org.au.

This issue of *Voice* explores the topic of ageing well for people with Down syndrome. Ageing is an issue that affects everyone but for people with Down syndrome it is something that is a relatively new challenge as people with Down syndrome are living longer and healthier lives than they have in the past. The average life expectancy of a person with Down syndrome in Australia is 60 years of age. This is a dramatic increase from 25 years in 1983.

To plan and prepare for the future, family members and support networks need to understand and know how to support the ageing process for people with Down syndrome from both a health perspective but also from the perspective of other changes that may be needed in terms of support for that person. This includes living arrangements, the involvement of siblings, and keeping an active and meaningful involvement in communities.

In this issue, we offer guidance and advice on how to plan for these aspects of the future. We also highlight the experiences and perspectives of people with Down syndrome and their families who have faced these situations.

We hope that this issue will inform, inspire and empower you to pursue a healthy and fulfilling ageing process for yourself and the people with Down syndrome you support.

Finally, I would like to wish you all a joyful holiday season with your loved ones.

Darryl Steff
CEO DSA



DSAN update



The Down Syndrome Advisory Network have been working hard this year. In October, we found out that we had won a World Down Syndrome Award for our leadership.

We are so excited and honoured to win this award.

The award recognises DSAN for our work to ensure that the voice of people with Down syndrome is at the heart of DSA's work.

We work nationally but also join our local State and Territory Association to help with local initiatives.

We have also helped build other people's skills in leadership through the 'Becoming a Leader' training that we developed. Members of DSAN co-present the leadership training.

It has been so great to win this award, especially for everyone on DSAN to have our hard work recognised.

We are very happy we have won and want to also congratulate all the other people nominated and the other award winners.

We had our first face-to-face meeting in a long time at the end of November in Brisbane.

It was great to meet everyone in person from DSAN. We enjoyed talking about the World Down Syndrome

Congress and visiting the Brisbane Convention Centre. We also talked about DSAN's plans for 2024.

We want as many people with Down syndrome as possible to go to the Congress Brisbane in 2024. You can find out more at: www.wdsc2024.org.au

In October we welcomed two new members to DSAN. We have Bella from South Australia and Lisa from the Northern Territory. Michael Cox from Queensland has also recently joined.

It is great to have more members on DSAN from other parts of Australia to share their experience and ideas and thoughts.

On behalf of DSAN we also want to thank Claire Mitchell for her work on DSAN from the very start. Claire will be an Associate DSAN member in 2024.

Claire shared her experience and her thoughts as a DSAN member and we are very grateful to have had her leadership.

As members of DSAN from all over Australia, we want to share our voice and ideas to help other people with a disability.

DSAN members would like to wish everyone a Merry Christmas and a Happy New Year.

We look forward to 2024 and helping DSA with their work helping people with Down syndrome.

Lauren Murray
ACT DSAN member

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voice@downsyndrome.org.au

You can also let us know if you'd prefer to receive a digital copy of the magazine, rather than the printed version.





Looking after your health

Rohan Fullwood speaks with Nathan about health check-ups and how he takes care of his body and mind.

An important part of looking after yourself as you age is having a regular health check with your doctor – even if you aren't feeling sick.

45-year-old Rohan Fullwood recently went to his GP for a routine check-up.

The GP had results from various assessments, including:

- a blood screening,
- an ear, nose and throat exam,
- an ophthalmologist report, and
- a neurologist report.

In particular, Rohan and his GP talked about his recent neuro-psychology assessment.

"I did some memory tests and repeated words," Rohan says.

"My health is pretty good."

"There are times when I have my dizzy spells. Apart from that, I am doing okay."

Earlier this year, Rohan had a dizzy spell in the middle of the night at his apartment in Sydney. He knew what to do.

"It was about 4:30 in the morning and I had to go to the bathroom. I was feeling a bit light-headed and fell and scratched my arm."

"Then I called the ambulance – the first time I've ever done that."

"I put water on my face and lied down with my feet up until they came."

Rohan lives with a flatmate and has learned to take care of his health.

"I would say for people with a disability to make sure they have their pills with them and to keep a daily record and keep note of anything they are concerned about."

"It's also important to do exercise."

"I go down to Bicentennial Park, and walk around the park. There's also a pool and a gym in my apartment complex, so I go for a swim sometimes."

Rohan has had gout in the past and makes sure he drinks lots of water.

He fills up four Soda Stream bottles every morning – two with sparkling water and two with still water – and makes sure he drinks all of them by the end of the day.

“I also do my daily stretches morning and afternoon,” he says.

Rohan sees his physiotherapist every six weeks and gets new stretches depending on how his body is feeling.

“My physio gives me a massage in places where I’m sore.”

Other regular health appointments in Rohan’s diary include the podiatrist, to take care of his feet, and the dentist.

Sometimes, when he is on medication, he has blood tests to make sure there are no side effects.

In the past six months, Rohan has also been going to his local Men’s Shed, where he learns new skills and meeting locals with similar interests.

“Every second Thursday I go to Men’s Shed, and at the moment I’m building a shelf for my medals,” he says.

Getting involved in groups and activities, and staying connected with family and friends is good for mental health.

Rohan likes to Facetime his sister Laura, brother-in-law Tom and niece and nephew, Matilda and Jasper, who live in San Diego.



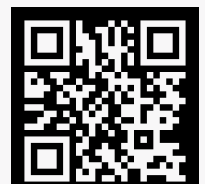
He is also getting ready to go on a trip with his mum to Toowoomba for six days, where they’ll be meeting up with old friends.

“We’ll be staying with friends of ours that I’ve known since I was little,” Rohan says. “I’ll be staying with my friend Dan.”



Key messages

- Have an annual health check-up with your doctor. You and your GP can use the Comprehensive Health Assessment Program (CHAP) tool to carry out your check-up. It is a questionnaire that gives the doctor lots of information about your health.
- Book a regular check-up with your dentist.
- Take extra care of your body by seeing allied health professionals such as physiotherapists, podiatrists and occupational therapists.
- Look after your mental health by getting involved in groups and activities, and staying connected with family and friends.
- Keep a record of healthcare appointments, hospital visits, test results and any medication you’re taking. You might also like to include how you are feeling. You can do this in the **Down Syndrome Health Record app**.
- To make sure you know about your own health and healthy choices download the **Down Syndrome Australia Good Health App** to help you www.downsyndrome.org.au/resources/apps/



Moving out of home

Lincoln Holt and his mother Janice Chan tell Nathan about the journey he's been on to live independently.

"I'm excited to be living out of home," Lincoln tells me. "I wanted to be independent."

Last year, at age 28, Lincoln moved out of his family home and into an apartment in the same suburb.

It was a journey that began with Lincoln and his family imagining the kind of living arrangement he would like for his future.

"When he was in his mid-twenties, I started asking Lincoln if he would like to one day move out," Lincoln's mother Janice explains.

"He said, 'No, I'm happy living here.'"

"Then we had a visioning session where the facilitator asked Lincoln what kind of house he would like to live in, how many bedrooms it would have, what kind of furniture, how many people would he live with, and suddenly he got excited."

"All of these details made sense to him."

Once he had a vision for living independently, Lincoln took off with it and began searching for places online.



He held sessions with his Circle of Support and learned about the practical things to think about when moving out of home.

Fast forward a year and Lincoln is now living in a ground floor apartment with his brother Curtis, and loving it.

"I do meal prep with my support person Avi," Lincoln explains.

"Last night I made fish fingers."

But not just any fish fingers, Janice tells me – hand-crumbed barramundi, one of Lincoln's favourites meals.

"It's my favourite living here," Lincoln says. "Curtis is a good flatmate, but sometimes his computer makes loud noises and I can't watch my show."

Lincoln enjoys going for walks around the park, and buying dinner down at the local Grill'd on Friday nights.

"Sometimes we bump into each other down on the main street, don't we?" laughs Janice.

One of the criteria for Lincoln living independently was that he remains close to his parent's house.

"I come to Mum and Dad's and have roast chicken on Sunday," Lincoln says.

“I’m excited to be living out of home, I wanted to be independent.”



Lincoln has a personal assistant who helps him plan and organise his week, and other things like booking movie tickets and restaurants, and texting friends.

Janice says the support has allowed Lincoln to be less dependent on her.

“Now I can observe it all happening smoothly and safely as I get older and just be a parent,” Janice says.

“I found I had to write role descriptions for his various support workers, because a lot of it was in my head, so I put it all down.”

Lincoln enjoys working at the local fruit and vegetable shop, doing drama at FOG Theatre and watching footy.

Janice says as a parent, she’s very glad he’s happy and settled. “There’s still some things to work out, but the big part of the move is sorted.”

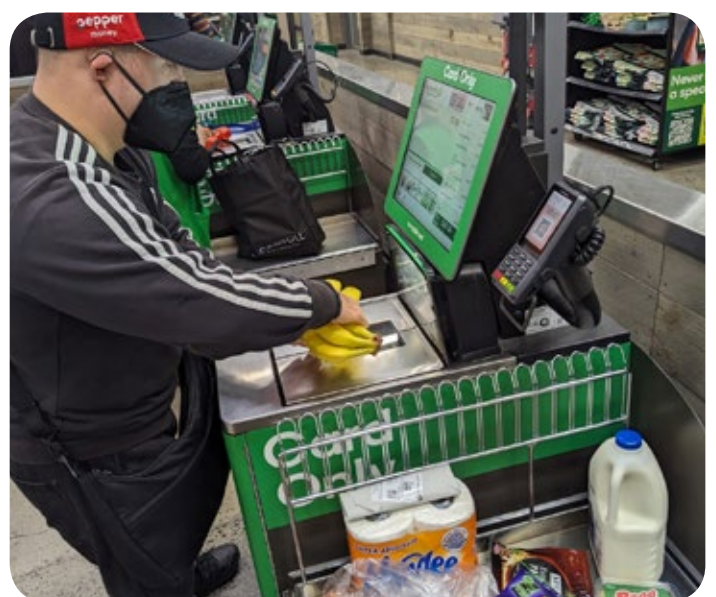
She says some of the key things to think about when supporting someone to move out of home include:

- Having a vision of the kind of living arrangement that best serves the needs of the individual and their loved ones.
- Creating a Circle of Support to help guide the process.
- Ensuring you have time and energy, and allowing 2-3 years for the transition to take place.
- Implementing safeguards including an up-to-date will, involving people that you trust, becoming known in your neighbourhood and using a locator app.
- Thinking about your fears and barriers, and addressing these in your list of safeguards.
- Creating role descriptions for each of the support workers.

“It is a complex and time-consuming process, so don’t put it off and give yourself time to work through all the details,” Janice says.

Janice works for Down Syndrome Victoria and, as part of the Pathways to Independence project, is running an 8-part series about Housing and Independence.

Starting with Vision and Planning, each monthly session will have a different focus with some guest speakers. Participants can gradually learn and build their plan over the course of the series. For more information email janicec@dsav.asn.au





Lucy Bain reflects on growing older with her sister Emily, who has Down syndrome.

In my experience, what it means to be the sibling of someone with Down syndrome has shifted and morphed over time.

In reviewing material for this article, I noted (not for the first time) that Siblings Australia talk about the sibling relationship being potentially the longest of any we have. Every time I come across this statement, I feel a little nostalgic: as I get older, so too does my younger sister, and my parents.

With the imminent celebration of my sister Emily's 40th birthday, I now have four decades of living and experiencing Down syndrome through a sibling lens.

I have no memories of 'before', which I find is often what sets adult siblings apart from parents on the same trajectory.

Like any sibling relationship, it can be a funny, changeable thing. Once, having a sister with a disability was nothing more than an interesting quirk, or something to get uppity in the school yard about (one of my most embodied memories of anger is shoving a boy in the chest when I saw him try to trade my sister a singular M&M for her lunch money).



But as the years have passed, our sisterhood has turned into something weightier. There's history, there's work to be done, there's responsibility.



But as the years have passed, our sisterhood has turned into something weightier. There's history, there's work to be done, there's responsibility.

Just as the fine lines slowly multiply in the corners of our eyes, so too do the layers of nuance, the balance of give and take.

Research shows that many adult siblings are active in disability sector professional roles. I've found this to be true. I met my husband, also a sibling, when we were (much) younger, working on a disability respite program.

I met another dear sibling friend while crossing over roles at a disability organisation I previously worked with. We have each shared instances where our siblings have been ill or the dynamics between ourselves and our parents have been rattled, and the realities of our futures are glimpsed.

A recent White Paper by Siblings Australia states that "many siblings worry from an early age about not having sufficient knowledge about financial matters related to future planning, including power of attorney, wills, trusts, benefits and funding."

While this is still ahead of me and I am in a position in our wider family where much of this information is shared, I still can't quite fathom the moment where my responsibilities increase further – where mine becomes more than a supporting role. The thought of it is unnerving.

I feel I've had an easy go of this sibling thing, so far. I haven't experienced many of the disadvantages I know some siblings feel acutely: low self-esteem, unresolved feelings of resentment from childhood, pressure to overachieve, grief.

At times, I have wondered what my sister would be like if she didn't have Down syndrome, but I always end in the same place: she would be a stranger. It's like asking what I would be like if I had Down syndrome – I'd be someone else entirely.

In middle-age and on the cusp of the sandwich generation, I realise that there is an increasing number of things that could turn pear-shaped in the coming years.

There is substantial research suggesting that for the relationships between siblings to prosper, and the vast amount of informal support provided by siblings in the family unit to be maintained, better acknowledgment and support of siblings is required.

I think this would make a difference within many family contexts, and to many siblings – including myself – who may at times have felt like they were looking in from the sidelines.

I Facetimed Emily last night. We talked about what we were watching on TV and what we cooked for dinner. I talked her through taking some medication she has been prescribed; she read the label out to me carefully with her phone balanced on the kitchen bench. We said goodnight.

For the most part, for now, it's as simple as that. The next decade will tell the story of where we're going next.

Families and future planning

By Siblings Australia

Future planning can be such ominous words. Siblings Australia explain what it all means for families of people with disability.

As is often the case with the parent/child relationship, a parent's role changes with the growing needs or independence of their child. Ultimately, their goal is to provide them with the love, care and support they need to lead a happy and healthy life and to grow and develop successfully into adulthood.

For the parent of a child with disability, this role often extends well into the child's adult life, and into a time when they themselves are facing challenges that ageing can bring about.

Suddenly, the sibling finds themselves piecing together the thousands of puzzle pieces that make up their brother or sister's carefully curated life, while attempting to keep the status quo with as little impact as possible.



This can be an important time for siblings to consider future planning with their parents and brother or sister. We often hear of siblings who have reached a point of crisis when a parent unexpectedly passes away or suffers from life impacting health challenges.



Whether you are slowly dipping your toes into the future planning pool or find yourself at a point of contention/crisis, Siblings Australia are launching a unique SibPlan website, which is designed to provide adult siblings with guidance on services and supports they can access at transitional junctures in their or their siblings lives, as the supports for their siblings change or grow.

While Siblings Australia is focused on maintaining the natural relationship between siblings, they know that changes in circumstances can lead to new challenges and they want to help support this transition as best they can.

Built from the sibling perspective, SibPlan has been created for all stages of the sibling journey and includes resources on important factors to consider such as:

- Circles of Support
- Supported Decision Making
- Funding Options (NDIS versus My Aged Care)
- Housing/Supported Independent Living (SIL)
- Estate Planning

The necessity for such planning and supports is detailed in the following personal account by Siblings Australia Board Chair, Peter Gill, whose brother Chris lives with Down syndrome.

HealthDirect, the Australian Government's virtual public health information service, states that, in the 1940s, a child with Down syndrome had a life expectancy of 12 years. Fast forward 30 years to the 1970s and people with Down syndrome were described as living into their 30s.

With increased knowledge, advanced medication and new caring services, that life expectancy has now doubled – with my brother Chris having celebrated his 60th birthday in 2023.





As people with Down syndrome live longer, there are a number of questions and challenges that require decisions by their siblings. Living arrangements are one example. If your sibling is living in supported independent living and sharing with several housemates, as Chris has done for nearly 20 years, there are a number of implications as each of the residents age.

The friendships forged lead to pretty harmonious households and relationships that keep such group houses on an even keel.

However, there does come a time when advancing age invariably requires change as one of the residents, for example, might require higher levels of care, disrupting long-standing relationships.

Such scenarios carry not only an emotional toll but also require decisions on practical issues such as: do you fill the vacancy left in the house? Those decisions often have to be made by the siblings.

As people with a disability live longer and their parents invariably pass away, their siblings have to understand and embrace an increasing level of

responsibility; making decisions that in earlier times had not been required of them. This scenario comes with many questions and mixed feelings as a beloved brother or sister may succumb, as many people with Down syndrome do, to dementia.

How do you respond, for example, to this new, unknown place? It's one in which verbal communication may no longer exist, where mobility may be compromised or non-existent, and where a good day with your brother or sister may be measured by whether you receive a smile on arrival.

Family is the foundation of society, and the sibling relationship is often the longest relationship in the life of a person with a disability. We need to make sure it is strong and supported.

As Siblings Australia enters its 25th year, it continues to provide services and supports such as SibPlan to help siblings navigate an ever-changing world.

For more information, visit siblingsaustralia.org.au

Keeping fit

Matt O’Neil talks to us about FitSkills, an evidence-based physical activity program for people with Down syndrome.

“I first did FitSkills in 2009 when I was 14 and skinny like a chicken,” Matt O’Neil says. “Now I have muscles. It feels good and makes me so much more confident when I go to the gym.”

FitSkills is a 10-week physical activity program designed for individuals with Down syndrome. Paired with dedicated volunteers, participants engage in weekly one-hour facilitated gym workouts, followed by a social meal with the FitSkills group to foster community.

The program, personalised by a physiotherapist, features user-friendly exercise programs and regular check-ins, with the aim of enhancing fitness and wellbeing in a supportive way.

Matt is a big advocate for the program, and has since become the FitSkills Ambassador, which involves co-designing workshops, making demonstration videos and welcoming new participants.

“FitSkills is the best program ever,” he says. “I get quite emotional about it because it means a lot to me. It’s important to keep fit and healthy because when you get older you get weaker. Active is better. It is positive for your mind as well. The mind is a muscle that you need to exercise to be stronger.”

Matt participated in the FitSkills pilot a decade ago at LaTrobe University. Since re-joining in July this year, he has observed significant improvements. It has helped



him make friends, given him energy and even broken some bad habits. “Like with the habit of having too many donuts at work,” he says. “Now I know I have to balance things.”

As part of the FitSkills program, Matt meets up with his volunteer partner for a workout, and then goes out for a meal with him.

“My partner’s name is David and he has a nickname called DVD,” Matt says. “He teaches me how to do stuff at the gym. I teach him some weight techniques as well. You put your thumbs out so you don’t hurt them and it gives you more power.”

“Then we go to dinner after and he helps bring out the best version of myself. We talk about what life looks like for us. I really love to have a chat wherever I go.”

Matt trains in Brunswick and Coburg, and says he likes to go to pubs and restaurants for a meal, and usually can’t go past a parma or steak.

Other things Matt does to stay fit and healthy include:

- eating a balanced diet
- going to bed early
- drinking filtered water and tea
- walking lots
- spending time in nature
- meditation

“Meditation helps you release stress from the body,” he says. “Cool, calm and collected. It’s important to me to have a positive mindset.”



If you live in Victoria, you can get involved with FitSkills by visiting www.downsyndrome.org.au/vic/fitskills-for-adults-with-down-syndrome/

Deciding to retire

We talked with Ben Wishart's mother, Jill about Ben's incredible working career and exciting retirement plans!

Ben Wishart was employed by the local council for 33 years. After a long and rewarding career as an administration assistant, Ben recently made the decision to retire.

Jill says, "Ben's employment with the council was simply a case of 'right place, right time!'"

Shortly after Ben finished high school, the local council received a grant to establish a cleaning team for people with disabilities. This is where Ben began his employment. Although he wasn't that keen on cleaning, he began to help with a variety of tasks in the office, and his true passion and talents were recognised.

Soon after, Ben was offered an opportunity to work in the administration team. He was enthusiastic and proficient. He loved the people and the challenge of work.

They offered Ben regular part-time work which eventually led to a permanent position with the local council for over 30 years. He was responsible for preparing 'new resident packages' including restocking pamphlets, photocopying, collating, postage and much more.

Over time, the team grew, and his work changed. Ben's job was dependent on other people being in the office, so when COVID-19 restrictions meant people worked from home, Ben had no work for a long time. Ben began to feel underutilised and became less enthusiastic about going to work every day. His family and support team also noticed a cognitive decline.

Jill, who has a degree in disability studies, recognised that Ben was needing additional support to manage better at work, gym and home. After a short time, Jill noticed his new challenges were only occurring at work.



Ben's workplace wanted to keep him, but it was time for Ben to retire, and they began to plan for his final day. Ben didn't know what retirement was. So, Jill talked about it a lot and placed signs around his home-office to explain what it meant.

Retirement is:

- Leaving work and never going back again.
- Missing friends that you work with.
- Less income and still having to pay a mortgage.
- Less spending money.
- A time to relax, enjoy hobbies and spend time with family and friends instead of going to work.

Although there was a plan in place, one day Ben took a tray of cupcakes to work (something he did regularly) and announced to everyone that he was leaving, and it was his last day. That weekend he wrote a retirement letter to his boss.

The local council organised a farewell party where people came from every department to say goodbye. They bought him a gift, contributed food and the boss gave a speech. Ben left a wonderful legacy.

Jill says, "He doesn't regard his 33 years of paid employment, recent retirement or his home ownership as anything special." But clearly all those around him did! Ben says he's not missing work but missing the people.

Thankfully, within weeks of retiring and the stress of work subsiding, Ben's language soared, and cognition returned. He plans to do lots more drawing, bike riding, gym and trips to the library now that he no longer goes to work.

As a classic car fanatic, particularly Ford Mustangs and Holden Toranas, Ben is looking for the ideal drawing class that shares his love of cars.



How I keep healthy and enjoy life

We gathered our DSA Health Ambassadors and asked them questions about ageing well and making the most out of life.

What is one good thing in your life right now?

Naomi Lake: "I enjoy being with my amazing family because they include me in everything."

Hugo Taheny: "The people around me in my community."

Kimberley Adams: "Having amazing parents in my life because they are proud of everything I have achieved."


Amelia Sloan: "I love singing. I'm singing at Hamer Hall in one month."

Rohan Fullwood: "My family and friends and social activities."

Gillian Gehrke: "Getting the support that I need. What I call the four Fs: "My faith, my family, my friends and the fun that I provide for myself."

Caitlin Woolley: "I am enjoying going out. Places like art, I have a great time going there."



One good thing in my life has to be spending time with the people I love and having a job and making lifelong friends. 

Olivia Sidhu

How do you connect with friends, family and people in your community?

Emily Porter: "I keep in touch by texting, calling, Facebook, Facetime and seeing them face to face."

Naomi Lake: "I travel often to visit my sisters. I have a phone and iPad to stay in touch with my friends."

Caitlin Woolley: "We go to visit our extended family and sometimes we go on a holiday, like this year. I also go to DS Queensland activities, and seeing friends, like my 21st birthday party. Or going to the pool and church, and also being with support workers."

Olivia Sidhu: "I connect with my friends by spending time and talking with them, and going on holidays with my family."

Hugo Taheny: "I'm on my phone always. Call my siblings. Facebook and social media."

Amelia Sloan: "I connect with my friends on WhatsApp. I catch up with my friends. I go for holidays with my family. Disco."



Going to community groups, churches or societies. They're really important to stay connected with people that have the same values as you.

Gillian Gehrke



My mum is the Down Syndrome WA rep for the regional outreach program. We have regular picnics and catchups which helps me stay connected to my community.

Naomi Lake

What do you do to look after yourself and your health?

Naomi Lake: "I've got chickens. Chickens are always my friends. I eat a balanced diet to stay healthy and make sure I'm active and exercise, walk every day, swim and gym and gardening, and I belong to the local theatre which is good for mental health."

Hugo Taheny: "I go to the gym, I lift weights. I eat healthy, I be active. I got a puppy called Missy. Sometimes I take her for a walk on the beach, or farm. I got my own personal gym at home. I eat salad, carrots I like."

Gillian Gehrke: "I've got this little wellness wheel that I use, and it's a visual image of what we need to do to be healthy. I do something every day, well I try to. I've got to be physical to support my mental health. I talk to my psychologist a lot. As a mum with an intellectual disability, it's tough sometimes. So I'm always connecting with people and ticking off my wellness wheel. For me, it's all tied in, my mental and physical health conditions. I also do a lot of art, as much as I possibly can."

“For my physical health, I have some health checks with a doctor and specialist. For my mental health, I go on walks with my dog, and go swimming. I also go to the gym on Saturday. I also eat healthy food. I relax on the couch, watch movies and play board games.”

Caitlin Woolley



“I do walking, it keeps me calm and I don’t have to do real hard work. Also, dancing.”

Kimberley Adams

“I do walks around the block. I also go to the gym.”

Alishia Lindsay



“I see the psychologist. I go to the gym. I’m getting strong and healthy. Eat my veggies and drink lots of fluids.”

Amelia Sloan

Emily Porter: “Exercise, swim in the pool and ocean. Drink plenty of water. Eat, cook and choose healthy meals. If unwell, go to the doctors and get your shots, flu and Covid.”

Olivia Sidhu: “I go to the gym to stay active, and it gives me endorphins, and makes me feel good about myself. I drink strong flat whites when I go to work. Sometimes I go and clear my head and take my dog Charlie for walks at the park.”





Is there anything that worries or excites you about getting older?

Naomi Lake: I'm excited because my nieces and nephews are having families of their own. Especially my niece is expecting a baby in April and I'm becoming a great aunty! The bad news is I'm afraid of developing health issues that impact my life, and a fear of dying."

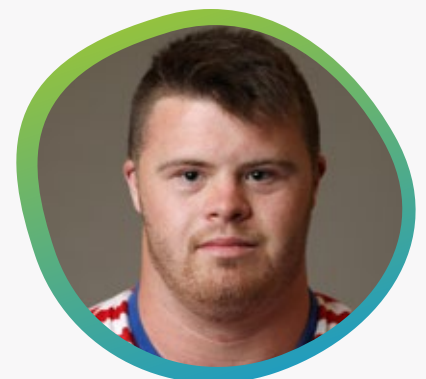
Emily Porter: "I'm afraid of getting sicker and getting grey hairs at the top of my head."

Olivia Sidhu: "It excites me to have a lease on life, and gives me a purpose about myself, and spend time with my loved ones."

Caitlin Woolley: "I would like to live in my own house, or living with some friends in a house. Go on some holidays and maybe travel to some places."

“ Making my own family with my own wife and kids. My own house, my own mansion, my own company, businessman. I want to teach my kids what my old man taught me when I was a kid. ”

Hugo Taheny



Getting outside my comfort zone

Gerard O'Dwyer is passionate about many things and shared with us some of the ways he enjoys life.

I keep myself healthy and fit by keeping very mobile, I always get out and about. In my normal routine I get up at 6:45 in the morning. I prepare my fluids the night before and put it in my bag to make sure I'm ready.

I then make my way to the gym. I stretch before I do anything – because I'm always tight and cramping. My favourite is running on the treadmill and increasing my speed. It keeps my weight down.

I enjoy going to the gym, but I mix it up. I also like watching the sunrise and going for a run in the morning when everyone is still sleeping.

I don't want to sit in my house all day. I like to get out in the fresh air, do something or go somewhere. I like to get out of my comfort zone.

Most days during the week I work in a theatre company, The Riverside Theatre in Paramatta. When I'm not working, I study acting at NIDA.

I am also part of Bus Stop Films, where I attend filmmaking classes on a Sunday. It teaches you about inclusive filmmaking and making films that matter. It is a place to make new friends and always have fun.

I've been with Bus Stop Films from the very beginning and made my first film, *Be My Brother* with Genevieve Clay Smith, who started Bus Stop Films. I am also an Ambassador for Bus Stop Films. I am really proud of that role because it allows me to promote and help raise money for our wonderful organisation.

As an actor, I make people laugh, I make people cry, I communicate with them, I interact with them. I love my acting, I'm passionate about it, it keeps me going.

I won Best Male Actor at the Tropfest Film Festival in 2009 for *Be My Brother*. I decided to memorise my lines from the script.



As an actor I spread my message about equality:

We are what we are in life, and we deserve to be treated like everyone else. We are not labelled by our disability. Everyone wants to be heard, given a voice through the arts. Never put anyone down but treat them equally.

I love watching *The Bold and The Beautiful* with my mother. I got to meet the whole cast at The Riverside Theatre. That was the best highlight ever. My two favourite actors from the show are Ronn Moss and Susan Flannery who I often impersonate.

I am a jetsetter too. I love travelling. I love being on the plane especially when it goes high. I love the service. I have been to many places with my mother and with Bus Stop Films.

When I went to Ireland just recently, it was my birthday. My cousins, nieces, nephews and mother were all there and yelled out "surprise!" My family means a lot to me.

Life is challenging but I face it head on. It doesn't stop me from participating in life, it doesn't stop me one bit, I keep going! I have learned so much, I have achieved a lot. I am surrounded by family and friends who love me for who I am.

Creating a will

Max Grinsell-Jones and his dad Alan talk to Nathan about creating a will and managing finances.

Something important for everyone to consider as they grow older is creating a will. A will is a legal document that lets people decide who gets the things they own when they die.

Recently, 22-year-old Max Grinsell-Jones went through the process of creating a will with his parents Alan and Catherine.

Alan is a lawyer, and when he retired, he decided it was time to organise wills for himself and his family members.

"Like a builder who never finishes his house, I was a lawyer who didn't have a will," Alan says. "When my wife Catherine and I decided to do ours, it seemed a natural thing to do one for Max."

Max has bank accounts in his name, a Disability Support Pension, and is a beneficiary of Alan and Catherine's wills. He also has jobs which give him an income.

"I do after school care Fridays," Max says. "I work at Go Boats. And I work at the FCAI (Federal Chamber of Automotive Industries) in the office on Thursdays."

It therefore made sense to do a will for Max.

Alan and Catherine used an online template for the will, and were able to create it themselves because of Alan's legal experience. They had a conversation with Max explaining the contents of the will, and then he signed it.

"There were no key considerations given Max has Down syndrome," Alan says. "We just treated it like any other will. We haven't done anything in terms of setting up a Special Disability Trust for Max, although I know a lot of people do that and it can be a good thing. Max has two older sisters, and they play a close part in his life, so we didn't see a need to set up that protection at this stage."

A Special Disability Trust is a way of leaving money to a person who will require help to manage that money.

Alan says it might be something to consider if Max decides to move out of home and live independently.

At the moment, Max is learning how to manage his money with an organisation called Grandma's Jars.

"Last Friday I went shopping with Phil (from Grandma's Jars)," says Max. "We were looking around at the different prices."

Max has also recently got his driver's licence and is learning to look at cars. Plus, he is a big footy fan and is learning how to purchase AFL tickets.

"I'm a Giants fan. I like to go to the games," Max says.



Talking about death and dying

It is important that everyone understands and talks about death and dying, so we can properly prepare for it. This Easy Read provides some key information.



Death and dying means that your body shuts down and stops working.

Death is a part of life.

Everyone will die. Everyone will know someone who dies.

People can die at any age.

Reasons why people die

There are lots of reasons that people die:

- An accident
- An illness that cannot be treated
- A condition where there is no more treatment that will help
- Old age



It is good to talk about dying because it helps your friends and family understand what you want when you get very sick or when you die.



Wills

You can write a will to decide who gets the things you own when you die.

You can write a will at any time. You don't have to be sick or dying to write a will.



Making decisions about medical treatment

If you are dying you can decide if you want to have medical treatment.

Some people decide they don't want medical treatment even if it will help them live longer. Some people who are dying want to have these treatments.



There is no right or wrong decision.

Your doctor is a good person to talk to. You can bring someone you trust to talk about these things with your doctor.

This information is part of a larger fact sheet created by and copyright of the NSW Ministry of Health. The information has been made Easy Read by the Council for Intellectual Disability.

You can access the full fact sheet at <https://www.health.nsw.gov.au/palliativecare/Documents/talking-about-death.PDF>

Trusts and Estate Planning

Planning for the future, especially when a family member has a disability, is a critical aspect of securing their wellbeing. Duncan Legal outlines 10 factors to consider for peace of mind regarding Trusts and Estate Planning.

1 Protective Trusts

Basically, a trust is a relationship between people who hold different interests in an asset.

A Protective Trust is a legal structure that enables the management and protection of assets for the benefit of a person with a disability.

The trustee takes on the legal ownership, decision making, responsibility for rates, taxes, maintenance and distributing income from the assets. The beneficiary receives income from, use and enjoyment of assets.

There are two main types of Trusts that aim to ensure the person with a disability gets what they need when you're not there:

- i) **All Needs Protective Trust.** Offers flexibility and requires a single trustee. It allows application of assets for various purposes such as holidays, maintenance and education.
- ii) **Special Disability Trust.** Specifically for individuals with a severe disability. It has fewer options but can hold valuable assets, offering unlimited spending on essential care and accommodation. However, discretionary expenses are limited. Eligibility requires a Centrelink assessment and involves two trustees or a trustee company.

2 Who to Appoint?

Think carefully about who you trust to manage things for your family member with a disability when you're gone. Selecting executors, trustees or attorneys requires trust and careful consideration. Close friends, family members, trustee companies or professional colleagues can be considered for these roles.

3 Trustee Decision Making and Beneficiary Input

People with disabilities have the right to be part of decisions that affect them. It's essential that they have a say in what happens with their money and their life.

The inclusion of a clause in your Will inviting beneficiary participation can facilitate their involvement in decisions aligning with their interests and capacity.

4 Pensions and Government Benefits

If someone with a disability receives a pension from the government, inheriting money might affect their eligibility to continue to receive that income stream. It may be important to plan very carefully if means-tested pension or government benefits need to be maintained after your death.

Often an accountant, actuary or financial planner can prepare financial projections to help you decide whether the inheritance you leave will be enough to self-fund your beneficiary with a disability or not.

5 Splits Between Beneficiaries

It can be hard to decide how to split your money among your family members, especially if one person needs more help because of their disability.

This decision requires careful consideration of financial needs and impacts on existing pension entitlements. It's a good idea to talk about this with your family so there are no surprises.



6 Personal Asset Accumulation and Bequests

Challenges can arise when a person with a cognitive disability accumulates wealth personally. Such persons may not be able to make a Will, and may also be vulnerable to being scammed by the unscrupulous.

Challenges also arise when a person with a disability receives a personal bequest that affect their pension entitlements. Advance arrangements can be made to anticipate and, if needs be, avoid these difficult situations arising.

7 Preservation of Main Residence?

What happens to the family home when you're not here anymore? There are things to consider, like taxes, accommodation funds and how long someone can stay in the house.

It's smart to get advice from a specialist when reviewing this step to ensure your family is cared for.

8 Asset Protection Strategies

There are ways to protect the assets you intend for a person with a disability from being eroded as a consequence of bankruptcy or family disagreements after you're gone. Strategies like moving assets to trust structures within your lifetime can keep those assets out of the Estate after your death.

Making superannuation nominations payable directly to a person can also put assets out of reach of any challenge to your estate.

9 Powers of Attorney

Making a Will is only half of your Estate Planning equation. The other, more important half is to appoint Enduring Powers of Attorney (POA).

POA are documents in which you appoint a substitute decision maker. These documents come into play if you lose capacity to make decisions for yourself.

If you have a dependent child with a disability, that substitute decision maker needs to be given authority to make decisions for your dependent with a disability in addition to yourself.



10 Superannuation

Superannuation doesn't automatically form part of your Estate. If you want to provide for a beneficiary with a disability through superannuation, you have to make a nomination that specifically directs it to be paid there.

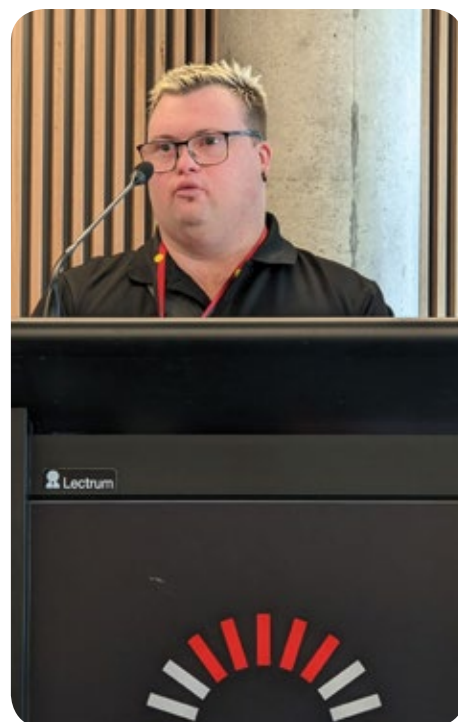
If you have made complex estate planning arrangements in your Will, consider making a superannuation nomination that is binding and non-lapsing, and that directs 100% of your death benefits into your estate. Your Will can then ensure that the money is applied tax effectively among your beneficiaries, and that any share for a disabled beneficiary lands in a trust for them.

For self-managed super funds, you can set up a cascading nomination that provides for a number of scenarios, and in some instances it may be possible to establish a tax-free income stream to your child with a disability.

Planning for the future when someone in your family has a disability can be complicated. It's a good idea to talk to an expert, like a lawyer or financial planner, who understands your family's situation. It is important to check these plans every 3-5 years because things might change.

Out and About

Presentations, outings, workshops and more – the events calendar for DSA and our state and territory counterparts is always full! Here is a snapshot of the fun that’s been had over the past six months.



Left: Stacey (EO of DS Tasmania), Matt (board member of DS Tas), Senator Anne Urquhart and DSA Health Ambassador Kim at the Speak Out conference. **Right:** Matt from Down Syndrome Tasmania speaking at Speak Out conference.



Left: Charlotte and Ehren from the ACT with *Alone Australia* winner Gina Chick. **Right:** Charlotte Bailey, being presented with her certificate as a nominee for ACT Young Australian of the Year, by Chief Minister Andrew Barr.

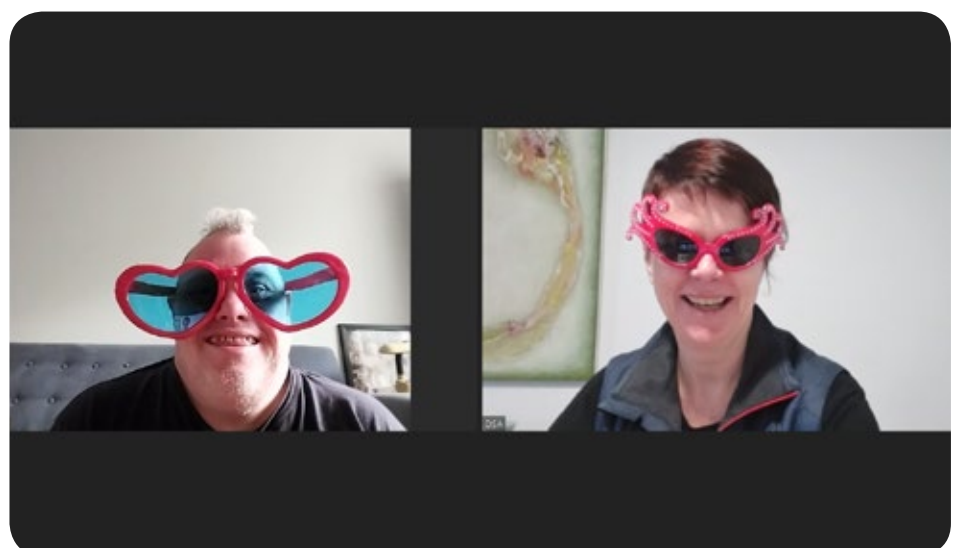




Left: Partners in crime (and husband and wife) Damien and Hayley taking a ride in the ACT police car. **Right:** Employment workshop participants in South Australia.



Left: It's game time. Ready to watch the Matildas take on England!. **Right:** DSA Health Ambassador Olivia, DSA CEO Darryl and DSA Senior Advocacy Manager Rachel at the closing ceremony for the Disability Royal Commission



Left: DSA Health Ambassadors Emily and Amelia presenting to medical students at Monash University. **Right:** "You've got have a bit of fun when you are doing this serious work" – Leigh Creighton. Leigh and Rachel having some fun while preparing for the NDIS Review consultation.

Our Voice



Australian Capital Territory

In August we hosted the 'Inclusion and Resilience in the Workplace' charity event. We heard stories from *Alone Australia* winner Gina Chick and disability advocate Elijah Arranz and ran multiple fundraising auctions. It was a fantastic night that saw us raise \$37,000.

The Science Alliance group has been busy learning about solar energy, and Math for Everyday Living has been studying percentages and discounts. The Confident Speakers group has been preparing a script based on their interpretation of the Barbie movie and we are just about to launch Dance Fitness on a Wednesday afternoon from 4-6.30pm.

Members Lauren and Angela have been doing an amazing job as advocates and educators, delivering 10 capacity building workshops with the support of Gemma. Kim, ACTDSA's Health Ambassador, has been working with the ACT Disability Health Strategy Steering Committee, assisting in the creation of the ACT Disability Health Strategy.

Down Syndrome Awareness Month was celebrated at our annual StepUP! family fun day. It was a lovely event with facepainting, a circus workshop, visits from the ACT Emergency Services and a fabulous performance Xtreme Stars.

We would like to congratulate our member Charlotte Bailey who was nominated for ACT Young Australian of the Year. We are so proud of everything she has achieved!

Shannon Kolak

CEO Down Syndrome ACT



Queensland

DSQ received a new grant for the Skilling Queenslanders for Work Initiative called 'Possibility Pathways' program, which aims to support young people with an intellectual disability to prepare for sustainable mainstream employment and beyond.

Our Support Services Team has been busy with many activities, including webinars (info sessions with Insight Disability Law & Planet Puberty), an all-abilities playgroup, outreach to various Queensland communities, a review of the 'Starting School Resources' pack, and making factsheets (on Future Planning and Puberty and Relationships).

We also held community engagement events across Down Syndrome Awareness Month, with a Family Picnic Day, the Rydges South Bank promotional week, StepUP! Townsville, Bunnings StepUP! held across three locations, Parents & Bubs expo and lunch at Parliament House. Exciting upcoming events include facilitation of a Parent Relationships Workshop, and a relationships course which culminates in a Speed Dating Event.

Our free ID:8 service, where the Education Team supports P-12 schools to include students with Down syndrome and/or other intellectual disabilities, was expanded from one visit per student per year to ongoing support throughout the school year. We are currently busy supporting schools with targeted consultations to assist with smooth transitions from the 2023 to 2024 school year.

Chris McMillan

CEO Down Syndrome Queensland





South Australia

South Australia has hosted a range of catch ups in the last six months, including two great sessions for primary school kids at 'We Rock the Spectrum', where they had the opportunity to climb, swing and jump. For families and their supporters in the early years, we held a workshop with Key Word Sign South Australia. Health Ambassadors Hugo and Naomi visited a local primary school to share their achievements – the students were really excited to hear their stories and asked some great questions and the cheers at the end were very loud!

I had the opportunity to gather with a group of parents who have older adult children with Down syndrome to view the DSQ webinar on dementia and hear their experiences of ageing.

A big highlight of the year is always our StepUP! event. We had a great family day, with special guests Bumblebee and Alice in Wonderland, a sausage sizzle cooked by the Rotary Club of Unley and sports with the Auskick team. Some of our younger attendees enjoyed the giant Jenga and chess.

Kylie and Gemma from DSA came across to run two days of free workshops, looking at getting healthy, participating in the community, and getting ready for work. Parents and supporters focused on healthy living, community participation and housing.

Looking ahead, we have a two-day education event in March, which will include a professional development day for educators and a day for parents.

Samantha Roach

Information Officer for South Australia



Tasmania

It's been a bustling few months for us!

In August, we bid farewell to our longtime board president, Bec, and welcomed enthusiastic new board members during our AGM.

October was particularly busy as we shared our stories on multiple radio shows and in newspapers statewide.

Additionally, the lights on popular buildings and bridges across the state illuminated in blue and yellow. This provided a fantastic opportunity for our members to celebrate and raise awareness in the broader community.

Despite the cancellation of the North West StepUP! event due to inclement weather, the North and South events proceeded successfully, drawing both old and new members who enjoyed spending time together. Across the state, we organised carer catch-ups, with the North West and South regions embracing the well-received 'Paint and Sip' activity. The North event is on the horizon, promising another chance for carers to unwind, connect and explore new experiences.

Looking ahead, we're excited about the coming year as we gear up to celebrate our 40th anniversary. Mark your calendars for our fantastic family camp scheduled for February 23rd-25th – it's sure to be a memorable experience!

Stacey Jackson

EO Down Syndrome Tasmania



Victoria

It has been another exciting six months for DSV, seeing us recently host our 'come back' celebration of the year: the first StepUP! for Down syndrome event since 2019. We are thrilled to announce that we raised over \$60,000, an impressive achievement which reflects the support and dedication of our Victorian community, donors, partners, volunteers and friends who came together to make such an impact.

What was evident at StepUP! is the importance of connection and community. It was a complete delight to see the enthusiasm in the faces of our 650 attendees. The vibe was incredibly positive, not even a forecast of dubious Melbourne weather could put people off! Thank you to everyone involved in the day's proceedings.

In other news, we're pleased to present our freshly launched Annual Report, a comprehensive document that highlights our achievements and the impact of our initiatives over the 2022-23 period. Alongside the Annual Report, we have also published our new Strategic Plan 2024-26, outlining our vision for the future and setting the stage for the next chapter in DSV's journey. It provides a roadmap that aligns with our mission and values, guiding our efforts to achieve greater positive change for people with Down syndrome and families.

We look forward to a future filled with more accomplishments, growth and shared success. Your continued support is instrumental in our journey towards a brighter and more inclusive tomorrow.

Visit our website at downsyndrome.org.au/vic.

Dan Payne

CEO, Down Syndrome Victoria



Western Australia

Continuing our work on Down Syndrome Regression Disorder, we conducted a survey attracting 18 responses from across Australia providing valuable information that will enable us to develop further support for families affected by DSRD and engaging the medical and research communities. DSWA also has a new Dementia Support group and are embarking on a project to provide support and services for older people with Down syndrome and their families, starting with the 'Wills and Guardianship' workshop that was very popular.

100 members of the DSWA community attended morning Tea at Government House to celebrate Down Syndrome Awareness Month, a beautiful celebration where the Governor enjoyed a presentation from Sian King who has recently commenced work at Curtin University after completing 1:1 SLES training with DSWA.

The DSWA Employment Program continues to go from strength to strength with another three positions filled. DSWA now offers School Leaver training which is proving to be very popular.

StepUP! 2023 was a great success with over 280 people attending, and approximately \$15,000 raised. Regional Outreach, supported by Telethon, continues to be a high priority, with visits this quarter to the Midwest, Southwest and Great Southern.

There has been a high number of new babies born with Down syndrome in WA this year. Since June, we have welcomed 12 new babies and their families to our membership.

Cassandra Hughes

CEO, Down Syndrome WA



voice

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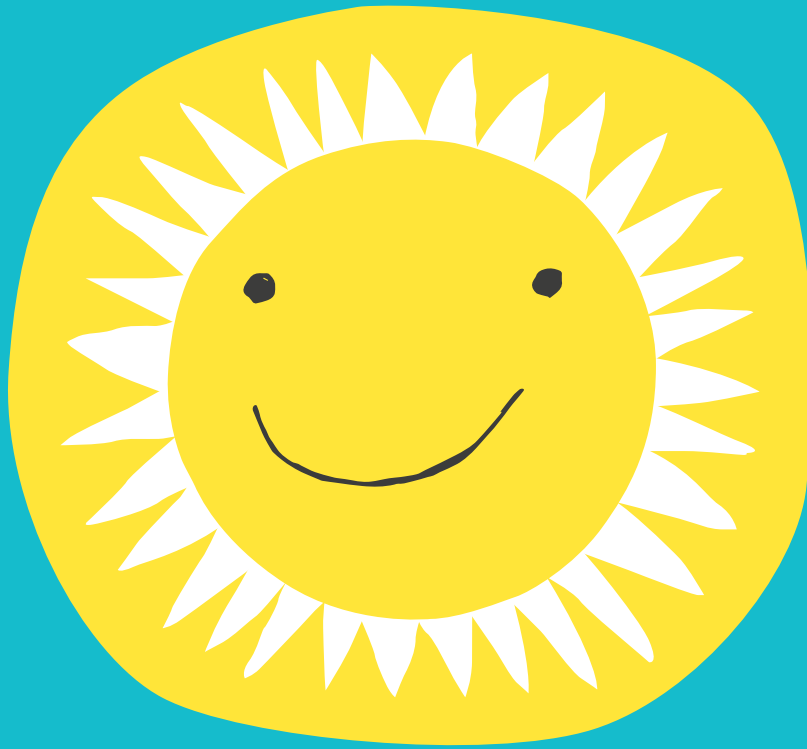
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9–12 July, 2024

To find out more and register, go to:

www.wdsc2024.org.au

We hope to see you there!



Down Syndrome
Australia

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