



TSA

Tuberous
Sclerosis
Australia

Living with Tuberous Sclerosis Complex (TSC)

A Guide for NDIS Planners

Purpose of this guide

This guide helps NDIS planners understand how Tuberous Sclerosis Complex (TSC) presents as a significant and permanent condition that impacts a person's functional capacity across many life areas. It outlines key support needs and helps link these to NDIS funding categories.

Having TSC is like walking through a minefield. You get over one thing and you walk right into another. That's what sets this disorder apart from epilepsy. It's not just the seizures. It's not just the brain involvement. It's everything.

- Dr Elizabeth Thiele, Director, Paediatric Epilepsy Program and Carol and James Herscot Center for Tuberous Sclerosis Complex at Massachusetts General Hospital and Professor of Neurology, Harvard Medical School.

Phone: 1300 733 435 (Australia only)

Email: info@tsa.org.au

Address: 18 Central Road, Beverly Hills NSW 2209

www.tsa.org.au

©Copyright 2025 Tuberous Sclerosis Australia

What is TSC and how does it affect people?

TSC is a lifelong condition due to a rare genetic change that causes tumours to grow in various parts of the body, including the brain, kidneys, heart, skin and lungs. It affects every person differently and can result in a broad spectrum of physical, cognitive, behavioural, neurodevelopmental and emotional challenges and disability. Early intervention and coordinated supports are essential for quality of life.

People living with TSC often have highly individualised and complex needs due to the condition's impact across multiple domains — medical, developmental, cognitive and behavioural.

Supporting people with TSC requires a flexible, person-centred approach that respects the individual's values, strengths and goals. **Families often play a central role in care, advocacy and decision-making, especially when the person has intellectual disability or high support needs.**

TAND

TAND stands for **Tuberous Sclerosis-Associated Neuropsychiatric Disorders**. For almost all people with TSC, TAND presents significant challenges to daily life and has a substantial impact on daily functioning.

Almost **every person with TSC** will experience at least one TAND feature during their lifetime, and most people have many features, although the type and severity can vary greatly.

TAND is grouped into six different domains:

- **Psychiatric** conditions, such as autism spectrum disorder, ADHD, anxiety and depression
- **Behavioural** challenges, such as aggression, self-injury, hyperactivity and sleep disorder
- **Intellectual** disabilities ranging from borderline cognitive function to moderate/severe intellectual disability
- **Academic and learning difficulties**, including reading, writing or maths difficulties
- **Neuropsychological impairments, such as** attention and concentration, memory or executive function issues
- **Psychosocial impacts**, such as family stress, social isolation and low self-esteem.

The impact of TAND on daily functioning across all life domains, especially schooling, social participation and independent living, is substantial.

Neurological functioning

- **Epilepsy** is common in people living with TSC and often begins in infancy. In TSC, epilepsy is often severe and difficult to treat and can lead to developmental delays or intellectual disability.
- People with severe epilepsy, especially children, may require constant supervision for their safety, provided by people with training in emergency seizure management.

Physical health

- Growths in the **kidneys, heart** or **lungs** may affect organ function and require monitoring or treatment.
- **Skin lesions** are very common, have a negative impact on self-esteem and often require dermatological management.
- Some people with TSC have **mobility issues** due to seizures or physical complications.

What supports may be needed for people living with TSC?

1. Core supports

- **Assistance with daily living:** This may include personal care, meal preparation or assistance at home. For those with high support needs, respite for carers should be considered. For children, this may additionally include aides at kindergarten or school.
- **Support workers** to help build social skills, access the community or assist with behavioural needs.
- **Consumables**, such as continence aids or epilepsy-related medical supplies.

2. Capacity building supports

- To address developmental delays, communication challenges or emotional regulation, **evidence-based therapies**, such as occupational therapy, speech pathology, psychology, physiotherapy or behavioural support may be needed.
- **Children with substantial developmental delays may need access to intensive early intervention programs, such as the Early Start Denver Model (ESDM).**
- **Support coordination** to help manage complex needs and connect with appropriate services.
- **Skill development** to assist with daily living, relationships and building independence.

3. Capital supports

- **Assistive technology**, such as seizure monitors, communication devices, sensory tools, prompting systems for cognitive support or mobility aids.
- **Home modifications** if mobility or safety is an issue due to seizures, behaviours (such as impulsivity or risk of absconding) or physical impairments.

4. Other considerations

- **Respite care** to provide family members or carers with a break and reduce carer stress and psychological harm.
- **Specialist disability accommodation or supported independent living (SIL)** if the person living with TSC has high support needs and requires ongoing assistance in a residential setting.

Supports specifically for school-aged children and young people diagnosed with TSC

It is important to note that children with TSC and TAND can need **significant educational supports**. These may include:

Learning supports

- **Educational aides** to assist with focus, transitions and task completion.
- **Specialist tutoring** (NDIS may fund therapy-based supports outside of the school curriculum).
- **Visual supports or assistive technology** for learning and communication.

Behavioural and emotional supports

- **Behaviour support plans** developed by a psychologist or behaviour therapist.
- **Social skills groups or 1:1 therapy** to help with peer interactions and confidence.
- **Psychological support** for anxiety, regulation, or trauma-related challenges.

Therapeutic supports in school settings

These are usually delivered outside school hours but coordinated with the school:

- **Occupational therapy:** Focus on sensory processing, fine motor skills or classroom access.
- **Speech therapy:** For expressive/receptive communication or augmentative communication systems.

Table 1: Supports that people living with TSC may require by funding category

Support Need	Description	NDIS Funding Category
Assistance with personal care	Support with dressing, hygiene or feeding due to physical, cognitive or behavioural impairments.	Core – Assistance with Daily Life.
Supervision for safety	Constant monitoring due to seizures or high-risk behaviours (such as self-injury or impulsivity).	Core – Assistance with Daily Life.
Support workers	To assist with social participation, behaviour management, outings or community access.	Core – Social and Community Participation.
Respite care	Planned or emergency respite to reduce family stress and maintain informal supports.	Core – Assistance with Daily Life.
Continence or epilepsy consumables	Nappies, incontinence products, seizure helmets, epilepsy-related safety equipment.	Core – Consumables.
Allied health therapy (Occupational Therapy, Speech, Psychology, Physiotherapy)	For regulation, communication, mobility, sensory integration and developmental skills.	Capacity – Improved Daily Living.
Behaviour support plan	Specialist behaviour intervention to address TAND behaviours (such as aggression, self-harm or sleep issues).	Capacity – Improved Relationships.
Psychology	To manage anxiety, trauma or emotional regulation linked to TAND.	Capacity – Improved Daily Living.
Speech therapy, including augmentative and alternative communication (AAC)	For expressive and receptive language delays or communication support.	Capacity – Improved Daily Living. Capital – Assistive Technology.
Occupational therapy	Sensory processing, fine motor development, daily routines or school readiness.	Capacity – Improved Daily Living.
Early intervention programs	Intensive early supports, such as early-start Denver model (ESDM) therapy for young children with developmental delay or autism spectrum disorder (ASD).	Capacity – Early Childhood Interventions.
Social skills training	Individual or group therapy to support peer interaction, confidence and communication.	Capacity – Improved Relationships.
Parent and carer training	Build capacity to manage behaviours at home and support daily functioning.	Capacity – Improved Daily Living.

Support Need	Description	NDIS Funding Category
Support coordination	Assist families in navigating complex medical and disability systems.	Capacity – Support Coordination.
Lifelong learning	Supports (training, advice and support) to assist the transition from school to further education, such as university or TAFE.	Capacity – Improved Daily Living.
Assistive technology	Seizure monitors, AAC devices, sensory tools or visual schedules.	Capital – Assistive Technology.
Home modifications	Changes to improve safety and accessibility, such as gates, ramps or secure spaces.	Capital – Home Modifications.
Specialist Disability Accommodation (SDA)	For people with high physical or behavioural needs requiring purpose-built housing.	Capital – SDA.
Supported Independent Living (SIL)	Daily support for people requiring 24/7 or overnight assistance.	Core – SIL.

Acknowledgements

This guide has been developed by TSA (Tuberous Sclerosis Australia). We are indebted to the valuable input provided by members of our TSC Community and TSC health care professionals. TSA exists to support people affected by TSC.

We value your feedback, and you can contact us by:

Email info@tsa.org.au
 Post TSA, 18 Central Road, Beverly Hills, NSW 2209
 Phone 1300 733 435 (Australia only)

You will find a wealth of information about TSC on our website tsa.org.au. TSA would also like to extend its thanks to Sanofi for providing financial support to make the development of this guide possible. TSA can assure readers that Sanofi has had no input into, or control over, the content of this resource, in accordance with this [Policy](#).

