

Example Personal Information Form for a Child with tuberous sclerosis complex (TSC)

Tuberous Sclerosis Complex (TSC) is a rare, non-contagious, genetic condition that can cause growths (non-malignant tumours) to develop in many organs of the body, including the brain, skin, heart, lungs and kidneys. Any or all of these organs may be affected. TSC causes different signs and symptoms in each person who is affected and can range from treatable skin abnormalities, to severe epilepsy, developmental delay and autism.

PRIVATE & CONFIDENTIAL

To be completed by the family of the child with TSC.

Child's name

Oliver

Child's date of birth

4/4/08

Child's

Medicare No.

Parent's names

James and Julia

Parent's contact details

Other emergency contacts

Mary (grandmother)

How does TSC affect your child?

Seizures (well controlled on medication)

Autism

Anxiety

Inattention

Slow processing speed

Poor working memory

What does this look like?

Oli is compliant and likes to follow rules.

It may appear he has understood instructions but multi-step instructions are difficult for him.

Work takes longer to complete, especially in a noisy or busy environment.

How has this changed over time?

He has difficulty maintaining peer relationships.

Oli's anxiety has improved however his autism has become more obvious; increasingly prefers special topic, Minecraft. Cognitively he's (so far) tracked his peers.

What things do you notice upset or frustrate your child, or cause anxiety or pain?

Competition and time pressure are often resisted.

Anxiety triggers include insects (flies) and storms (wind).

What activities or rituals soothe or calm your child?

What would your child like to share with his/her teaching team?

break tasks into steps.

Repeat instructions and don't assume I've understood.

Have high expectations but expect me to take longer to complete my work.

What concerns do you particularly want to highlight to your child's teaching team?

Oli will need help to embed friendships, he may need help to find them at break times.

He would enjoy clubs and groups but needs assistance to join in.

Potential target of bullying.

What would you like the teaching team to do if they notice changes in your child's behaviour?

Firstly, ask him if he could be having a seizure (look for any signs). Be aware of potential triggers of behaviour - such as competitive, time-constrained, noisy activity. Give Oli time to calm down before moving on.

Date Name of Medication Dosage and how/when it is administered

Known side effects

Levetiracetam
(Keppra)

900mg @ 0700
@ 1900

None identified in Oli.

Everolimus
(Afinitor)

5mg @ 0700

Immunosuppressant
-mouth ulcers

YOUR CHILD'S KNOWN ALLERGIES

Who else is part of your child's health care and support team?

Date	Name of Doctor/Health Care Professional	Specialty/Area of Practice	Telephone Number
	Dr Rosa [REDACTED]	G.P.	[REDACTED]
	Dr John [REDACTED]	Neurologist	[REDACTED]
	Dr Joanne [REDACTED]	Paediatrician	[REDACTED]
	Tanya [REDACTED]	Psychologist	[REDACTED]
1	Aaron [REDACTED]	O.T.	[REDACTED]
	Antoinette [REDACTED]	Speech Therapist	[REDACTED]