

Smith-Magenis Syndrome Australia

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FACTSHEET

You are not alone. We are a dedicated team of volunteers, representing a local community of families, carers and professionals; supporting loved ones diagnosed with Smith-Magenis Syndrome.

QUICK FACTS ABOUT SMITH-MAGENIS SYNDROME

- A rare genetic disorder caused by deletion on the 17th chromosome (17p11.2) or a change to the RAI1 gene.
- Estimated prevalence is 1 in 15,000-25,000 people but SMS is highly underdiagnosed worldwide.
- Characterised by distinctive physical features, developmental delays, intellectual impairment and dysregulated behaviour.
- Rarely inherited and diagnosed through chromosomal analysis.
- Often co-diagnosed with other neurodivergent disorders, such as but not limited to Autism Spectrum, Attention Deficit Hyperactivity and Obsessive Compulsive disorders.
- Behaviours of concern include sensory processing, impulsivity, anxiety, outbursts, attention-seeking, and self-injury.
- Significant sleep disturbances result from an inverted melatonin circadian rhythm.
- Individuals with SMS benefit from early intervention, specialist education, allied health therapies, and sensory integration assistance.
- Despite challenges, people with SMS are engaging, affectionate, perceptive, eager to please, and have a great sense of humour.

ABOUT US

We are the national support network for Smith-Magenis Syndrome (SMS) and a registered Australian not-for-profit organisation. We were founded with a common desire to support children diagnosed with SMS and their families, drive a strong community connection and promote broader awareness of SMS. Our work includes raising awareness, interfacing with the specialist and educational community, disseminating the latest research and guidance, assisting families navigate government services, developing a strong network of families and professionals, and facilitating our biennial SMS Australia family camp.

OUR PRIORITIES

AWARENESS

We partner with disability, genetics, and SMS organisations locally and globally, to raise awareness of the common issues that people living with SMS and their families face. We leverage digital platforms and direct community engagement to drive knowledge and advocacy.

SUPPORT & EDUCATION

We serve as the first 'port of call' for families who are navigating a new diagnosis, providing them with critical information, resources, and connection to experienced professionals via our specialist registry. We facilitate a biennial Australian SMS camp which is tailored to the needs of people diagnosed with SMS while providing respite, education, and connection for families. The camp welcomes educators, medical professionals, allied health specialists, and support service providers, who benefit from guest Q&A panels, workshops and interaction with our community.

COMMUNITY

Through online forums and community activities, we enable a supportive family network which offers practical advice, resources, advocacy, empathy, and fosters a true sense of belonging with those who have shared lived experiences.

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