AUSTRALIAN FINANCIAL, PLANNING & SUPPORT RESOURCES GUIDE FOR SMS FAMILIES

Smith-Magenis Syndrome Australia | 2026 update | Prepared 15 October 2026

This guide provides starting points for Australian individuals with Smith-Magenis Syndrome (SMS) and their families. Eligibility, discounts, fees and program arrangements can change. Check official sources before applying. SMS symptoms and support needs differ between individuals.

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1. Concessions, payments and support for carers

Centrelink payments for carers

Carers may be eligible for specific financial support payments from the Federal Government to assist with their living costs. Carer Payment and Carer Allowance have different care, residence and means-testing rules. Carer Supplement and other assistance may apply. Check eligibility directly with Services Australia. A diagnosis alone does not determine entitlement.

https://www.servicesaustralia.gov.au/caring-for-someone

National Companion Card

State and territory administered scheme for eligible people who need lifelong attendant care to participate at venues and activities. Participating affiliates issue a companion ticket without charge; this is not necessarily one adult for every event, and eligibility is assessed under each jurisdiction's rules. Cards are generally recognised by participating affiliates across Australia. Apply in your home state or territory.

https://www.health.gov.au/our-work/companion-card

State and territory application sites:

- **ACT:** https://www.act.gov.au
- **NSW:** https://www.nsw.gov.au/community-services/companion-card
- **NT:** https://ntcompanioncard.org.au

- **QLD:** https://www.qld.gov.au/disability/out-and-about/subsidies-concessions-passes/companion-card
- **SA:** https://www.sa.gov.au/topics/care-and-support/disability/companion-card
- **TAS:** https://www.companioncard.tas.gov.au
- **VIC:** https://www.companioncard.vic.gov.au
- **WA:** https://www.wacompanioncard.org.au

Queensland Carer Business Discount Card

Provides discounts at participating businesses for qualifying carers throughout Queensland. Carers must meet eligibility requirements. Check the current requirements on the Queensland Government page.

https://www.qld.gov.au/community/support-for-carers/carer-card

Victorian Carer Card (We Care)

Participating business and service discounts for eligible Victorian carers. Please verify your eligibility and the current offer list directly, as this may have changed since publication of this document.

https://www.carercard.vic.gov.au

Energy, water and utility concessions

Concessions vary by state, retailer and concession type. Check your state concession authority and seek hardship assistance early. The National Debt Helpline provides practical bill-management guidance.

https://ndh.org.au/debt-problems/electricity-gas-and-water-bills

Hoyts Carer Concession (Carer's Australia)

Hoyts Cinemas currently offers discounts to carers who attend movie sessions with the person they care for. Carers must produce their state or territory Carers Association card or any other card with government-recognised carer identification, such as a Healthcare Card or Centrelink Pension Card.

https://www.carersaustralia.com.au/hoyts-carer-concession

Qantas Carer Concession Card

Administered by People with Disability Australia. Eligible cardholders and a nominated carer can access discounted eligible fares, subject to current fare class, availability and booking rules. The published scheme includes discounted domestic economy fares; some international and other class concessions may apply. Book through Qantas assisted channels, not a standard online booking.

https://pwd.org.au/services/qantas-carer-concession-card

Air travel with rare disease disability — Rare Disability Toolkit (Rare Voices Australia – RVA)

The Rare Voices Australia (RVA) Rare Disability Toolkit includes an air-travel guide, checklists for travellers and carers, medical practitioner letter guidance, an airport screening notification card and a complaints checklist. Particularly helpful for SMS families planning sensory, behavioural, communication, medication and routine-related supports when flying.

https://rarevoices.org.au/rare-disease-disability-toolkit-community

Carer Gateway

Free carer-support entry point, offering counselling, coaching, peer support, planning and respite-related pathways depending on eligibility and local services.

https://www.carergateway.gov.au

Carers Australia SANE Forums

Free and anonymous forum for mental health carers, allowing users to share stories and information that help find positive pathways through their experiences caring for people with mental health issues. The Forums are moderated 24/7 by health professionals employed by SANE Australia and partner organisations.

https://carersaustralia.saneforums.org/boards/friends-families-carers-hubforum-board

2. Financial, health and disability support

National Disability Insurance Scheme (NDIS)

The NDIS funds eligible disability-related supports according to applicable legislation and rules. For children under 9, the early childhood approach and early connections may provide pathways even where a child is not yet an NDIS participant. Check the latest NDIA guidance, including changes to legislation and evidence requirements.

https://www.ndis.gov.au

https://www.ndis.gov.au/applying/children/guide-early-childhood-approach

NDIS access and eligibility toolkit — Rare Disability Toolkit (RVA)

A high-value resource for SMS applications and reviews. The NDIS and Rare Disease Disability guide explains terminology and evidence, and provides a clinician letter-of-support checklist and guidance for health professionals. This toolkit aims to assist families in documenting how the individual's diagnosis (e.g. SMS) impacts everyday functioning, supervision, communication, safety and support needs rather than relying on the diagnosis name alone.

https://rarevoices.org.au/rare-disease-disability-toolkit-national-disability-insurance-scheme-ndis

ENVISAGE Families — free early-family support program

A national, free, evidence-informed program for parents/caregivers of children aged 0–8 years with disability or developmental concerns. Five interactive workshops, online options, led by a health professional and parent peer, build confidence, advocacy, family wellbeing and connection. No confirmed diagnosis or NDIS plan is required. Particularly valuable for recently diagnosed SMS families who are navigating services and adapting family routines.

https://envisage.community/envisage-families-program

NDIS Cuts Calculator — Free (The Growing Space) (October 2026)

This free interactive calculator helps participants and families estimate how the announced reductions to Social, Economic and Community Participation (SECP) funding may affect a current NDIS plan, support hours and weekly activities. Enter the current plan budget and dates; optional information about spending, protected supports and daily living funding produces a more tailored estimate. Families can explore weekly support arrangements and save or share their results to prepare for discussions with their plan manager, support coordinator or NDIA contact. This may be especially valuable for people with SMS who rely on structured community participation and consistent routines.

The Growing Space explains that the 50% SECP reduction applies when relevant plans are created, reassessed or renewed from 1 October 2026, with plan renewals affected from 1 February 2027; there are exceptions for certain protected supports and new-framework plans. A separate 10% reduction to Improved Daily Living is described but NOT calculated by this tool. The calculator is indicative only and is not an NDIA decision or advice about an individual plan; check current rules before making changes to supports.

Free access (no library subscription required):
https://www.thegrowingspace.com.au/apps/cutcalculator

Tips for sending documents to the NDIS (The Growing Space) subscribed members only

A practical member-library article (August 2026) about submitting reports and other evidence to the NDIS. Its publicly visible advice includes keeping copies of everything sent and clearly identifying the participant on documents; the remaining detailed tips require a member login. This is useful when supplying SMS diagnostic, functional, allied-health or behaviour-support evidence for access, reassessment, or funding requests. Maintain a clear submission record and use the NDIA's current official submission process.

Growing Space library login / annual membership required for full article:
https://www.thegrowingspace.com.au/tips-for-sending-documents-to-the-ndis

Health Care Card

Discounted Pharmaceutical Benefits Scheme (PBS) medicines and other possible concessions for eligible recipients. Some cards are issued automatically with qualifying payments; other categories have specific application rules.

https://www.servicesaustralia.gov.au/health-care-card

Ex-Carer Allowance (Child) Health Care Card

This card may be available to eligible full-time students aged 16–25 who previously held the relevant Carer Allowance Health Care Card at the age-16 transition. Review exact eligibility and claim steps.

https://www.servicesaustralia.gov.au/ex-carer-allowance-child-health-care-card

Disability Support Pension

For eligible people aged 16 or over who satisfy residency, income/assets and detailed medical and work-capacity requirements. Seek current evidence and pre-claim guidance.

https://www.servicesaustralia.gov.au/before-claiming-disability-support-pension

Pharmaceutical Benefits Scheme (PBS) Safety Net

For 2026, the published calendar-year thresholds are $277.20 for concession card holders and $1,748.20 for general patients; family PBS spending may be combined when eligible. A Safety Net card enables reduced costs for the rest of the calendar year. Thresholds change periodically.

https://www.servicesaustralia.gov.au/pbs-safety-net-thresholds

Continence Support

Aids Payment Scheme: Annual payment for eligible people aged five or older with permanent and severe incontinence due to a neurological or other eligible condition. Please review detailed clinical and residency criteria.

https://www.servicesaustralia.gov.au/continence-aids-payment-scheme

Continence Foundation of Australia: Advice and resources on continence management and the National Continence Helpline.

https://www.continence.org.au

Child Dental Benefits Schedule

Eligible children can access benefits for certain dental services; check the current benefit cap, reference period, qualifying payments and participating services.

https://www.servicesaustralia.gov.au/child-dental-benefits-schedule

Victoria: Multi-Purpose Taxi Program (MPTP)

Eligible Victorian members receive 50% of the trip fare subsidised, up to $60 per trip, subject to an annual subsidy cap (currently stated as $2,180 per financial year), provider rules and restrictions. Consult the webpage for eligibility criteria.

https://safetransport.vic.gov.au/on-the-road/multi-purpose-taxi-program/mptp-members/

Rare Disease Disability Management Plan — Rare Disability Toolkit (RVA)

This health toolkit includes a guide and fillable management plan to keep medical, disability, daily living, communication and support details in one portable document. This may be useful for new clinicians, hospitals, respite providers, schools and support workers. We recommend keeping it current and sharing selectively.

https://rarevoices.org.au/rare-disease-disability-toolkit-health

3. Preparing for adulthood

Future financial and legal planning

The Department of Social Services (DSS) provides guidance and resources for individuals with disabilities, their families, and caregivers to plan for future needs and secure long-term support (e.g. financial, legal). Use this information to commence early conversations about housing, decision-making support, wills, trusts, income, superannuation and enduring arrangements. It is always important to obtain current and independent legal/financial advice.

https://www.dss.gov.au

Transition plans for adulthood (Raising Children Network)

Practical planning for education, employment, housing, relationships, independence and disability services, ideally started well before school finishes.

https://raisingchildren.net.au

Moving Out: Preparing to Move Out of Your Family Home (The Growing Space) subscribed members only

This member-library course offers three learning modules and a workbook to help people with disability start planning a move from the family home. It covers budgeting, looking for a rental, managing mental health and hearing from people with lived experience of moving out. For adults and young people with SMS and their families, it can prompt early conversations about personal goals, daily living skills, preferred living arrangements, communication, safety and the supports required for greater independence. Use alongside individual housing planning, NDIS home-and-living advice and supported decision-making.

Growing Space library login / annual membership required:
https://www.thegrowingspace.com.au/course_lms/moving-out-preparing-to-move-out-of-your-family-home

Your teenager and Medicare and Centrelink (ACD)

A guide to changes from adolescence including Medicare access, Centrelink payments, authorised nominees and the transition to adult service arrangements.

https://acd.org.au/your-teenager-and-medicare-and-centrelink

Turning 18 Checklist (ACD)

Practical actions regarding post-school plans, identification, NDIS, Centrelink/Medicare, healthcare, voting and decision-making.

https://acd.org.au/turning-18-checklist

Supporting your child with decision-making (ACD)

Supported decision-making should maximise the voice and preferences of the young person with SMS, including through communication aids and observation. Substitute decision-making arrangements depend on local law and should not be assumed automatically at 18.

https://acd.org.au/supporting-your-child-with-decision-making

4. Disability Navigation and Advocacy Resources

SMS Australia Families Portal

SMS Australia's own resources, family community and specialist connections may be particularly helpful. The existing guide referred to an internal joining PDF but did not provide a public link. Confirm current portal access instructions with SMS Australia before distribution.

https://smsaustralia.org/

The Growing Space

Australian disability information, NDIS navigation and practical learning resources. The new *NDIS Cuts Calculator* is FREE to use without subscribing (see Section 2). Annual library members can access additional articles and courses, including *Tips for Sending Documents to the NDIS* (Section 2) and *Moving Out: Preparing to Move Out of Your Family Home* (Section 3). Some other Growing Space materials may have different access conditions. Some individuals may be approved to claim the annual library fee (e.g. under Improved Daily Living Skills - Training For Carers/Parents – 15_038_0117_1_3 Capacity Building), however, you should not assume that this annual membership cost is NDIS claimable. Check current NDIA funding rules and obtain specific advice before using plan funds.

https://www.thegrowingspace.com.au

Navigating Education in Australia (SMS Australia)

School adjustments, classroom strategies, disability-related learning needs and collaboration with education staff.

https://www.smsaustralia.org/education-in-australia

Hidden Disabilities Sunflower

The Hidden Disabilities Sunflower is an optional identifier for you to voluntarily share that you have a disability or condition that may not be immediately apparent – and that you may need a helping hand, understanding, or more time in shops, at work, on transport, or in public spaces. This tool can signal a non-visible disability or additional support need in participating locations. Free Hidden Disabilities Sunflower lanyards, badges, and wristbands are available from participating public transport stations, airports, local councils, libraries, and shopping centres. Check with the relevant transport hub, council or shopping centre for information on where lanyards can be collected.

https://hdsunflower.com/au

Rare Disability Toolkit — master directory (RVA)

RVA is the national peak body for Australians living with a rare disease. Their nationally co-designed toolkit brings together community, health and NDIS materials for people with rare disease disability. It supports self-advocacy, smoother transitions between services and practical planning. SMS Australia is a registered RVA Partner Organisation and although resources are not syndrome-specific, SMS is recognised as a rare disease condition by RVA.

In 2026, SMS Australia was awarded a Rare Disease Disability Project grant by RVA to develop a self-advocacy tool for parents and carers of children with delayed development. We spoke to 20 parents whose children with a rare or undiagnosed disease also experience developmental delays. A project steering group made up of 9 parents of children with rare or undiagnosed disease developmental delay, were consulted at various stages of the project. The resulting "*Navigating care for rare disease developmental delay*" guide will be released in November 2026 and published in both the RVA Rare Disability Toolkit, as well as on the SMS Australia website.

https://rarevoices.org.au/rare-disease-disability-project/rare-disease-disability-toolkit

Disability Gateway

National information and referral directory to navigate disability supports, entitlements and services.

https://www.disabilitygateway.gov.au

NDIS Quality and Safeguards Commission

Understanding NDIS provider standards, incidents, complaints and participant rights.

https://www.ndiscommission.gov.au

People with Disability Australia (PWDA)

Independent disability advocacy and rights resources.

https://pwd.org.au

Disability Advocacy Network Australia (DANA)

Starting point to locate independent disability advocacy organisations.

https://www.dana.org.au

Association for Children with a Disability (ACD)

Family-friendly guides about schooling, advocacy, transitions and services, especially relevant to Victorian families though many resources are broadly useful.

https://acd.org.au

Raising Children Network

Australian guidance on child development, disability, behaviour, sleep and transition to adulthood.

https://raisingchildren.net.au

Healthdirect Australia

Provides general Australian health system navigation and reliable health information.

https://www.healthdirect.gov.au