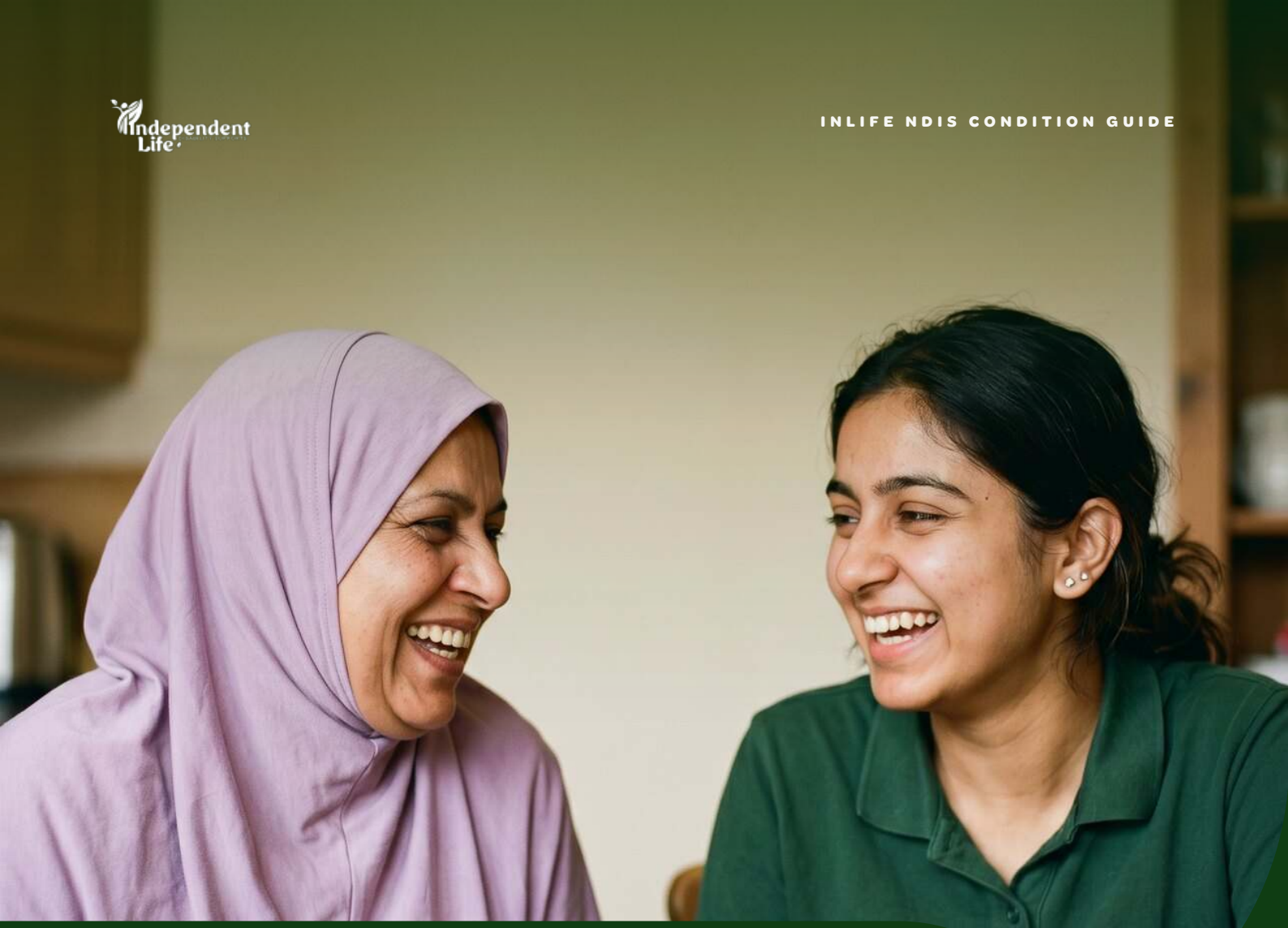

Rett syndrome and the NDIS

A guide for participants, families and carers working out what the NDIS funds for Rett syndrome, and how to ask for it.

FOR PARTICIPANTS & FAMILIES PUBLISHED SEPTEMBER 2026 VERSION 2.0

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About this guide

This guide is for people living with Rett syndrome, and for the families and carers around them. It is written by Independent Life Disability Supports (InLife), a registered NDIS provider working with families across Victoria.

We wrote it because the NDIS is complicated, and the people who need it most usually have the least time to work it out. We have kept it plain. Where the NDIS uses jargon, we explain it. Where Rett syndrome has its own vocabulary, we explain that too.

WHO THIS IS FOR

Three groups of readers

People recently diagnosed with Rett syndrome, or told they may qualify for the NDIS. Families and carers supporting someone living with it. Health professionals helping a person prepare an application.

WHAT YOU WILL FIND

Six sections, and the last is yours

What Rett syndrome is, and how it affects daily life. How the NDIS works and how to apply. The supports it commonly funds. How InLife works as a provider. Who to call. Pages to fill in and bring to your planning meeting.

A NOTE ON LANGUAGE

This guide is written in English. InLife supports families in Farsi, Urdu, Hindi, Punjabi and English, and this guide is published in eleven languages. Ask, and we will work in the language that suits your household. Interpreters are free at every NDIS meeting, and you never have to ask a family member to interpret their own health conversation.

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THE WORKBOOK IS YOURS

The last four pages are a workbook: your details, a map of your week, and space for your goals. Fill them in and bring this guide to your planning meeting. A planner who can see your week does not have to imagine it.

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SECTION ONE

About Rett Syndrome

What Rett syndrome is, how it affects daily life, and where the NDIS fits in.

What is Rett?

Rett Syndrome is a rare genetic condition caused by a change to the MECP2 gene on the X chromosome. It affects almost exclusively females — around 1 in 10,000 — though a small number of males are also diagnosed. Development typically appears typical for the first six to eighteen months, followed by a regression where acquired skills (purposeful hand use, spoken words, social engagement) are partially or fully lost. After the regression, a long period of stabilisation follows, during which many participants live full lives with the right supports.

Rett is lifelong. Receptive understanding is consistently far stronger than what the body can express — this is the central truth of Rett care. Most people with Rett communicate through eye- gaze, and for many an eye-gaze AAC device opens a world that the body cannot. Mobility varies: some women and girls walk independently, some walk with support, some use wheelchairs. Seizures, scoliosis, breathing irregularities and gastrointestinal differences are common. The NDIS funds the supports that turn what is medically complex into a coherent, dignified life.

Common signs and symptoms

- Loss of purposeful hand use, often replaced by characteristic hand stereotypies (wringing, clapping, mouthing).
- Loss or significant reduction of spoken language, with receptive understanding usually preserved.
- Communication via eye-gaze — often unlocked by an eye-gaze AAC device.
- Mobility differences — some walk, some use wheelchairs, gait often unsteady (apraxia).
- Seizures — present for around 60–80 per cent of people with Rett.
- Scoliosis — common in adolescence and adulthood, often requiring orthopaedic management.
- Breathing irregularities — breath-holding, hyperventilation — usually not dangerous but characteristic.

The medical context

- Rett is confirmed by genetic testing of the MECP2 gene — over 95 per cent of classical cases carry an identified mutation.
- Around 1 in 10,000 female births, with a very small number of male cases (usually severe presentation).
- Trofinetide (Daybue) is approved for Rett in the US, Canada and Israel (originally developed by Australian company Neuren Pharmaceuticals) — as of May 2026 it is.
- Seizure management is led by a paediatric or adult neurologist — common medications include valproate, levetiracetam, lamotrigine.
- Scoliosis monitoring is part of routine care — bracing and sometimes surgery in adolescence.
- Multidisciplinary clinic care — neurology, genetics, gastroenterology, orthopaedics, allied health — is the gold standard.

RETT IS NOT

Rett is not an intellectual disability in the way many people assume. The hand stereotypies, lack of speech and unsteady gait can obscure the fact that the person inside understands what is happening around her — often in great detail. Assumptions about cognition based on what the body can do are wrong and harmful. Eye-gaze AAC has shown again and again that what is locked in is profound and articulate.

WHERE TO LEARN MORE

Rett Syndrome Association of Australia maintains a current clinician directory and family library. The International Rett Syndrome Foundation (rettsyndrome.org) is the global research hub.

How Rett Syndrome can affect daily life

Everyone's experience of Rett is different. The list below covers areas the NDIS commonly funds support around — it is not a prediction. The conversation with your treating team and the NDIA Planner is what shapes your supports.

COMMUNICATION

How she connects

Eye-gaze is the channel. Receptive language is strong. An eye-gaze AAC device — set up everywhere, used by everyone — is what turns presence into participation.

THE SPINE

How the body changes

Scoliosis is part of Rett for many people. Bracing, seating and sometimes surgery in adolescence keep the body upright, comfortable and able to use AAC.

DAILY LIVING

How life flows each day

Personal care, mealtimes, school or day program, getting out into the community. Support workers who know her and use her AAC make routine into rhythm.

MOVEMENT

How she moves

Some women and girls walk, some walk with support, some use wheelchairs. Apraxia makes movement effortful. Physio across the lifespan keeps the body comfortable and as mobile as possible.

SEIZURES

How seizures fit

60–80 per cent of people with Rett have seizures. Workers trained in seizure response and a clear plan turn an unpredictable event into a managed one.

ADULT LIFE

How life unfolds

Adulthood with Rett is still a full life — day programs, supported accommodation, family relationships, community connection, friendships built across years. The plan grows up with her.

An ordinary life

A diagnosis of Rett is not a closed door. The NDIS exists to fund what each person needs to live an ordinary life — to work or study, to spend time with family, to participate in

> **"A girl or woman with Rett Syndrome is not absent from her own life. She is here, listening, choosing — and when we hand her the right tools, she tells us so."**

INDEPENDENT LIFE · HOW WE BEGIN EVERY PLAN

What an ordinary life can look like

- their community, to enjoy the things they enjoy.
- What "ordinary life" looks like
- School with eye-gaze AAC, real curriculum, real friends
- Living at home with family or in supported accommodation
- Music therapy, hydrotherapy, riding for the disabled, sensory experiences
- Day programs and community participation as an adult
- Family travel, holidays, weddings, birthdays — fully present
- Time at the gurdwara, mosque, church or community centre
- Eye-gaze choices — what she wears, what she eats, where she goes
- Long, trusted relationships with workers and peers
- Adapted creative work — art, music, photography via eye-gaze
- A predictable rhythm of week with the same faces and routines

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SECTION TWO

The NDIS basics

What the scheme is, whether you can access it, and how to prepare for a planning meeting.

What is the NDIS?

The National Disability Insurance Scheme funds the supports a person needs because of disability. It is not income support and it is not health care.

THE WORD	WHAT IT ACTUALLY MEANS
National	It runs across the whole country, wherever you live.
Disability	It funds support for intellectual, physical, sensory, cognitive, neurological and psychosocial disability, where the functional impact is substantial and likely to be lifelong.
Insurance	It takes a lifetime view, investing earlier so that less support is needed later where that is possible.
Scheme	It funds what you need to build skills, stay independent and live an ordinary life.

Who runs it

The **NDIA** (National Disability Insurance Agency) makes funding decisions. The **NDIS Quality and Safeguards Commission** regulates providers, handles complaints and protects participant rights.

The NDIS in one sentence

It funds "reasonable and necessary" supports so you can live an ordinary life. What that means in practice is the conversation you will have at your planning meeting.

Can I access the NDIS?

The four basic rules

- You are under 65 when you apply.
- You are an Australian citizen, permanent resident, or hold a Protected Special Category Visa.
- You have a permanent disability that substantially affects how you do everyday activities.
- You need support in at least one of: communication, mobility, social interaction, learning, self-care, self-management.

How to apply

- Phone the NDIA on 1800 800 110 to request an Access Request Form.
- Your GP or treating team completes the evidence sections. They are usually the ones who can describe your functional impact.
- The NDIA aims to decide within 21 days of a complete form.

FOR RETT SYNDROME SPECIFICALLY

Rett Syndrome is on the NDIS List A (conditions that automatically meet the disability requirements). Access is straightforward where genetic confirmation is documented. The strongest applications include the MECP2 test report, a paediatric neurologist or geneticist letter, and a recent Functional Capacity Assessment from an OT. For adult participants diagnosed in childhood, an updated FCA showing current functional capacity carries the most weight.

IF YOUR APPLICATION IS DECLINED

You can ask the NDIA for an **internal review** (a section 100 review) within three months of the decision. If you are still dissatisfied, you can apply to the **Administrative Review Tribunal** on 1800 228 333 or at art.gov.au. The ART took over this work from the AAT in October 2024, so older letters and websites may still use the old name. Many decisions are changed at the internal review stage once stronger evidence is supplied, so it is worth gathering evidence before you escalate.

Before the planning meeting

The planning meeting is where your first plan gets built with the NDIA. It runs about ninety minutes. Going in prepared changes what comes out.

ONE

Write your goals

Big and small. Where do you want to be in twelve months? In five years? Goals are written in everyday language, not medical terms.

TWO

Map your day

Use the workbook at the back of this guide. Note where help would change things, and be specific about the hard parts of the day.

THREE

Gather evidence

Functional Capacity Assessment, GP letters, hospital discharge summaries, allied health reports, current medication list.

FOUR

Bring someone

Family, an advocate or a support coordinator. You can ask for a free interpreter, and you should if English is not your first language.

EXAMPLE GOALS

Goals are written in everyday language, not medical terms. The NDIA accepts goals like "I want to be able to make my own breakfast" or "I want to volunteer at the local library."

At the planning meeting

The meeting is run by an NDIA planner or a Local Area Coordinator. Both can build your plan with you.

What they will ask

- Your personal details and how you would like to be contacted.
- Which community or mainstream supports you already use: GP, hospital, family, church, mosque, gurdwara, temple.
- Your safety at home and in the community.
- Your goals, for the next twelve months and beyond.
- The kind of support that would help you reach them.

What you can do

- Take your time. Pause, think, ask for the question again.
- Use pictures, photos or other communication aids.
- Have family or a support person speak on your behalf.
- Ask for an interpreter, at no cost to you.
- Decline to answer anything that feels invasive.

> **BRING THIS GUIDE**
>
> The workbook pages at the back are designed for this meeting. Filled in, they give the planner a coherent picture of who you are and what you need, without you having to hold it all in your head on the day.

“Reasonable and necessary” supports

Your plan is built from supports the NDIA considers reasonable and necessary. Reasonable means fair, taking into account what is already available to you. Necessary means you need it to live an ordinary life or work toward your goals.

A support must meet all six tests

- Related to your disability, not general living costs.
- Value for money, judged against the alternatives.
- Likely to be effective and beneficial, with evidence behind it.
- Takes into account informal supports: family, carers, community.
- Most appropriately funded by the NDIS, not by health, education or housing.
- Not a day-to-day living cost everyone has, such as rent, food or ordinary internet.

WHAT THIS LOOKS LIKE FOR RETT SYNDROME

For Rett Syndrome, supports that pass the test almost always include allied health (Speech for eye-gaze AAC — central, OT for daily living and equipment, Physio for mobility and scoliosis, Music Therapy where appropriate, Dietetics for swallowing and nutrition), an eye-gaze AAC device with comprehensive training for everyone around the participant, support workers trained in seizure response and AAC, postural seating and mobility equipment, scoliosis management equipment, and home modifications. Capacity-building therapies are funded to maintain function and build communication across the lifespan.

Three ways to manage your funds

At the planning meeting you choose how your funding is paid out. You can change this at any time during the plan, and you can use a different method for different parts of your budget.

OPTION ONE

NDIA managed

The NDIA pays your providers directly. No paperwork for you, and no invoices to check. You can only use registered providers.

OPTION TWO

Plan managed

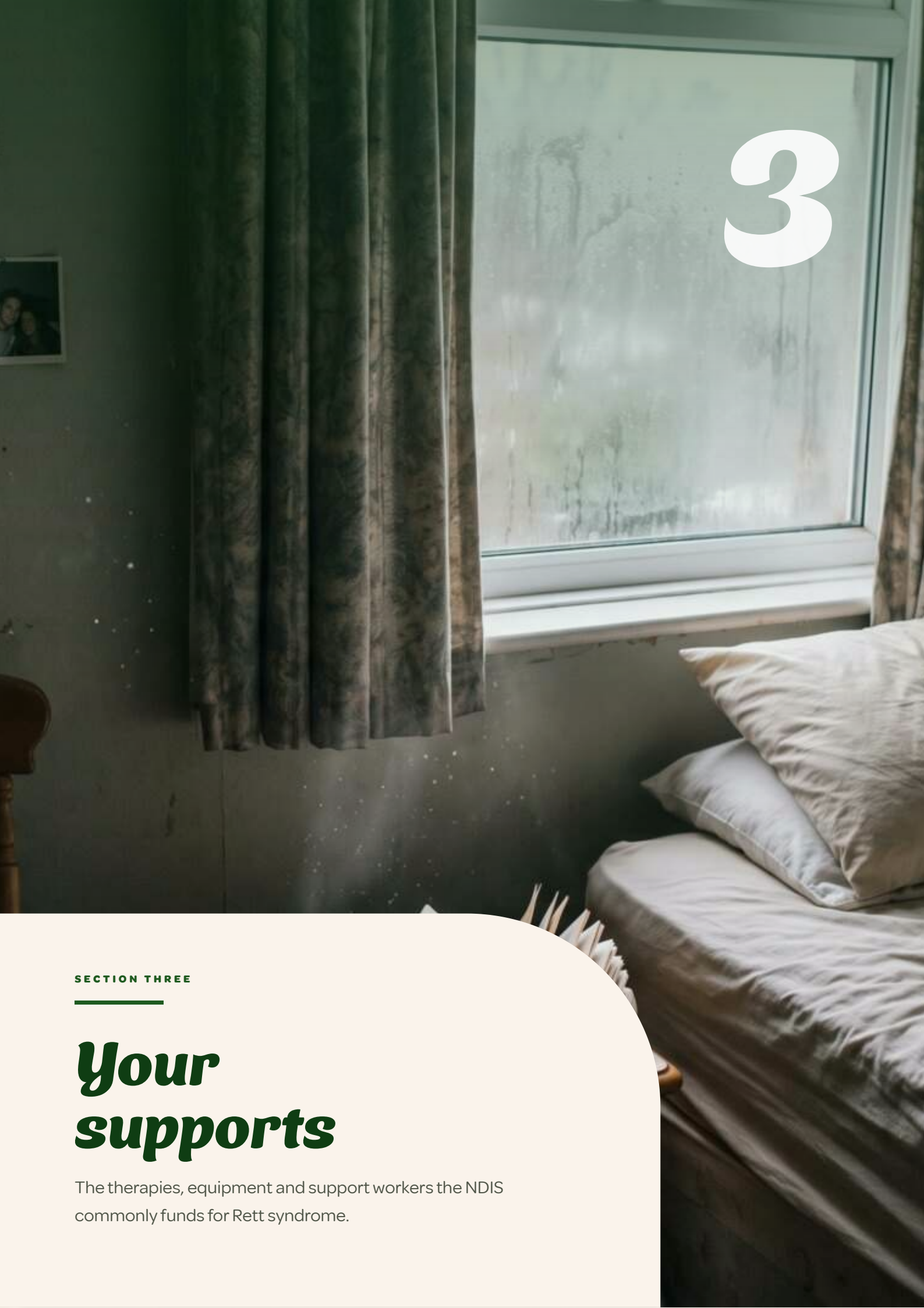
A plan manager processes invoices and tracks your budget. You can use both registered and unregistered providers. Plan management is funded by the NDIS on top of your other budgets, at no cost to you.

OPTION THREE

Self managed

You pay providers yourself and claim back from the NDIA. The most flexibility, including on price, and the most administration.

> **THIS IS YOUR CHOICE, NOT YOUR PROVIDER'S**
>
> Each option suits different households, and no provider should push you toward one. Ask your planner or Local Area Coordinator to talk you through the trade-offs, and change it later if it is not working. InLife works under all three.



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SECTION THREE

Your supports

The therapies, equipment and support workers the NDIS commonly funds for Rett syndrome.

Allied health for Rett Syndrome

Allied health is the clinical layer of your supports — therapies and assessments delivered by registered professionals. For Rett, the disciplines most commonly funded are: Allied health is funded under Capacity Building — Improved Daily Living.

SPEECH PATHOLOGY

Speech — eye-gaze and voice

Eye-gaze AAC assessment, device trial, vocabulary design, communication partner training. Speech is the lead clinician for Rett — eye-gaze unlocks the rest of life.

PHYSIOTHERAPY

Physio — movement and scoliosis

Gait training where walking is possible, transfer training, contracture prevention, scoliosis monitoring and bracing support, hydrotherapy. Critical across the lifespan.

DIETETICS

Dietitian — nutrition and swallowing

Reflux, constipation and swallowing changes are common. The dietitian coordinates with Speech on safe textures and with the gastroenterologist on nutrition.

OCCUPATIONAL THERAPY

OT — daily life and seating

Postural seating, equipment prescription, daily living routines, sensory regulation, home modifications. OT and seating specialists work closely with Physio on the body.

MUSIC THERAPY

Music Therapy — engagement

Music is consistently a strong channel for engagement, mood regulation, and communication building in Rett. Well-evidenced and often funded under capacity building.

PSYCHOLOGY / BEHAVIOUR SUPPORT

Behaviour Support — reading distress

Functional behaviour assessment, positive behaviour support plans, family coaching. Distress in Rett is often pain, discomfort or unmet communication — behaviour support reads it that way.

A NOTE ON FUNDING CATEGORIES

Allied health is funded under Capacity Building, Improved Daily Living, and is given to you in hours. You can use any registered allied health provider you choose. Hourly rates are capped by the NDIS price limits, so a provider cannot charge you above the cap. InLife coordinates allied health; we do not deliver it, and we are not registered for therapeutic supports.

Equipment commonly funded

The NDIS funds disability-related equipment under Capital, as assistive technology. These are the items most often funded for Rett syndrome.

EQUIPMENT	WHAT IT IS FOR
Eye-gaze AAC device	The communication system — voice output, vocabulary, mounted on chair or stand.
Custom postural seating	Seating designed for scoliosis, low tone and prolonged sitting — supports the body so eye-gaze AAC is usable.
Manual or powered wheelchair	Mobility appropriate to walking ability — many adult participants use wheelchairs for distance.
Standing frame	Supported standing for joint health, bone density, circulation and social participation.
Hoist and transfer aids	Safe transfers between bed, chair, bathroom — reduces injury risk to participant and carers.
Scoliosis bracing / orthotics	TLSO brace, AFOs, custom orthotics as recommended by orthopaedic team.
Seizure-alert mattress / wearable	Overnight monitoring for tonic-clonic seizures, peace of mind for family and supported accommodation.
Adjustable bed	Pressure care, repositioning, head elevation for reflux comfort.

How a request works

- An occupational therapist or other clinician assesses the need and writes a report.
- The report, with quotes where required, goes to the NDIA.
- Low-cost items can come straight out of an existing budget. Higher-cost items need the assessment and approval first.

Home modifications

Minor home modifications cost up to $20,000 and do not change the structure of the home. **Complex** modifications go beyond that, or affect the structure, and the NDIS funds a building construction practitioner to work alongside your home modification assessor. Neither is the same thing as Specialist Disability Accommodation, which is a separate funding stream for purpose-built housing.

Support workers, the everyday backbone

Support workers help with the daily tasks that disability makes harder: personal care, getting to appointments, cooking, medication prompting, community access, staying connected.

Most participants have a named team of three to five workers across the week. The right team feels like a small group of familiar people who know how you like things done, not a roster of strangers.

What good looks like

- The same workers week after week, not whoever is free that day.
- Workers who speak your home language at the door.
- Respect for your faith, dietary practice and household norms.
- Trained on your specific clinical needs before the first shift.

And what you should expect

- Backup workers you have met and approved in advance.
- Shift notes shared within 24 hours, in plain language.
- One escalation point when something is wrong.
- The right to change your team without having to explain why.

> **THE INLIFE MEET-AND-APPROVE PROMISE**
>
> No worker meets a participant for the first time on a shift. You meet them, you decide, then we roster. That holds across every plan we deliver.

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SECTION FOUR

Why InLife

How we roster, how we match workers to households, and what we commit to.

How InLife is different

Plenty of providers fill shifts from a rotating casual pool drawn across several agencies. For someone living with Rett syndrome, that is the wrong shape. We roster deliberately instead: a named team around each household, and no worker on a shift the household has not already met and approved.

CONSISTENCY

The same workers

A named team who know your routine, your preferences and your clinical needs. No strangers on a Tuesday because somebody called in sick.

LANGUAGE

Your language at the door

Our team works in Farsi, Urdu, Hindi, Punjabi and English. Workers are matched to the language your household actually speaks, including the language you fall back on when you are tired or unwell.

ONE POINT OF CONTACT

No call trees

One phone number and one email, both reaching the managing directors. No agency switchboard, and no "someone will get back to you".

RECORDS

Written so you can read them

Every shift note and every report written in plain language, and a monthly summary of what has been used, copied to your support coordinator.

REGISTERED, AND VERIFIABLE

InLife is a registered NDIS provider, regulated by the NDIS Quality and Safeguards Commission, covering Core supports, Module 1 high-intensity daily personal activities and Module 2A behaviour support plan implementation. Every registration group is public on the Commission's provider register. We do not deliver therapeutic supports or Specialist Disability Accommodation, and we will tell you so rather than stretch to fit.

How we match workers to households

Matching is the part most providers skip. We treat it as the most important conversation we have with a new household.

ONE

Language

The languages spoken at home, including the one a person reaches for in moments of stress or confusion.

TWO

Gender

Cultural and personal preferences about who delivers personal care, taken as a requirement rather than a preference.

THREE

Cultural fit

Faith observance, dietary practice, household norms and family hierarchy.

FOUR

Clinical competency

The specific skills the person's support requires: medication, transfers, mealtime management, seizure response.

FIVE

Geography

Close enough that workers arrive on time and stay reliable over a long placement.

SIX

You decide

We shortlist, you meet them, you approve. Only then do we roster. If it is not working, say so and we change it.

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SECTION FIVE

Resources & next steps

Where to turn, how plan reviews work, your rights, and the words the NDIS uses.

Where to turn

About the NDIS

ORGANISATION	HOW TO REACH THEM	WHAT THEY DO
NDIA	1800 800 110 · ndis.gov.au	Access decisions, plan reviews, general NDIS enquiries.
NDIS Commission	1800 035 544 · ndiscommission.gov.au	Complaints about providers and workers, conduct, restrictive practices.
Administrative Review Tribunal	1800 228 333 · art.gov.au	External review of NDIA decisions after an internal review. Took over from the AAT in October 2024.
Disability Advocacy Network	1300 365 085 · da.org.au	Independent advocacy when you feel unheard.
TIS National	131 450	Free interpreting, in more than 150 languages.

For Rett Syndrome specifically

ORGANISATION	HOW TO REACH THEM	WHAT THEY DO
Rett Syndrome Association of Australia.	(03) 9615 7077 · rettaustralia.org.au	Australia's Rett peak body. Family connection, clinician directory, conferences, advocacy.
Rett Australia Research Coalition /.	via rettaustralia.org.au	Australian arm of the global research database — pathway into research participation and updates.
Rare Voices Australia	rarevoices.org.au · RARE Helpline 0499 549.	National peak body for rare diseases — advocacy, NDIS navigation, family support.
Communication Rights Australia	communicationrights.org.au	Advocacy and information for people who use AAC. Essential for Rett families.
Genetic Support Network of Victoria	03 8341 6315 · gsnv.org.au	Family information and peer connection for genetic conditions across Victoria.

Reviewing your plan

About two months before your plan ends you will be contacted to begin a reassessment. This is your chance to reshape supports around the year you have actually had.

Questions worth bringing

- What worked? What did not?
- Which goals did you reach, and which need more time?
- Where did you underspend or overspend, and why?
- Are your funding categories the right shape?
- Has your clinical picture changed?

Reasons to ask early

- A hospital admission or a significant clinical change.
- You need more support hours than the plan funds.
- Equipment you did not know you needed at the start of the year.
- A change in informal supports, such as losing a primary carer or moving house.

> **BRING EVIDENCE, NOT ARGUMENT**
>
> Shift notes that show the gap, allied health reports, hospital letters. Your support coordinator can help you build the case. InLife will provide every shift note and report you need, and we do not charge you for asking.

Your rights, and raising a concern

As an NDIS participant you have the right to

- Decide what supports you receive, and from whom.
- Be treated with dignity and respect.
- Receive supports that are safe and culturally appropriate.
- Get information in your preferred language.
- Make a complaint without losing supports.
- Choose someone to act for you: a nominee, an advocate or a guardian.
- An interpreter, at no cost.

If something is wrong

About a decision	NDIA · 1800 800 110
About a provider or worker	NDIS Commission · 1800 035 544
About InLife specifically	admin@independentlife.au, which reaches both managing directors
To appeal an NDIA decision	Internal review first, then the Administrative Review Tribunal · 1800 228 333
Independent advocate	Disability Advocacy Network · 1300 365 085
Interpreter	TIS National · 131 450

COMPLAINING IS PROTECTED

Raising a complaint is a legally protected action. No provider may reduce your support, treat you differently, or end your service because you complained. That is enforced by the NDIS Commission, and it applies to us as much as to anyone else.

The words the NDIS uses

ARF	Access Request Form. What you submit to apply.
ART	Administrative Review Tribunal. Reviews NDIA decisions after an internal review. It took over from the AAT in October 2024, so older paperwork may use the old name.
Core	The flexible budget covering daily personal care, community access and consumables.
Capacity Building	Funding to build skills: allied health, support coordination, employment supports.
Capital	Funding for equipment and home modifications. It cannot be moved to other categories.
FCA	Functional Capacity Assessment. A clinician's report on what you can and cannot do day to day.
LAC	Local Area Coordinator. An NDIA partner who can build your plan with you.
NDIA	National Disability Insurance Agency. Makes the funding decisions.
NDIS Commission	NDIS Quality and Safeguards Commission. Regulates providers and handles complaints.
Plan manager	A third party who processes invoices and tracks your budget for you.
SC	Support Coordinator. A funded role that helps you put your plan into practice.
SDA	Specialist Disability Accommodation. A separate funding stream for purpose-built housing. It is not a home-modification threshold.

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SECTION SIX

Your workbook

Pages to fill in and take with you. Your details, your week, and your goals.

About me

Take this page to your planning meeting. The planner will want to know who you are before deciding what supports you need.

MY NAME

NDIS NUMBER

DATE OF BIRTH

PHONE

MY ADDRESS

PERSON HELPING ME

THEIR RELATIONSHIP TO ME

MY LANGUAGES

CULTURAL BACKGROUND

MY GP

MY SPECIALIST OR TREATING TEAM

EMERGENCY CONTACT

My week

Sketch a typical week as it is now, and mark the points where help would change things. The gaps are the argument.

Monday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Tuesday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Wednesday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Thursday

MORNING

YOUR WORKBOOK

AFTERNOON

My week, continued

EVENING

Friday

OVERNIGHT

MORNING

AFTERNOON

EVENING

OVERNIGHT

Saturday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Sunday

MORNING

AFTERNOON

EVENING

OVERNIGHT

My goals

Three things you want, and what would have to be true for you to do them. Written in your words, not clinical ones.

My top three goals for the next twelve months

1 _____

2 _____

3 _____

Three things I need to be able to do them

1 _____

2 _____

3 _____

QUESTIONS TO ASK ON THE DAY

What did you fund, and why that amount? Which budget does each support come from? What happens if my needs change mid-plan? Who do I contact if something is not working? When does this plan end?