Muscular dystrophy and the NDIS

A guide for participants, families and carers working out what the NDIS funds for muscular dystrophy, 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 muscular dystrophy, 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 muscular dystrophy has its own vocabulary, we explain that too.

WHO THIS IS FOR

Three groups of readers

People recently diagnosed with muscular dystrophy, 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 muscular dystrophy 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.

CONTENTS

What is in here

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 Muscular Dystrophy

What muscular dystrophy is, how it affects daily life, and where the NDIS fits in.

What is MD?

Muscular dystrophy (MD) is a group of genetic conditions that cause progressive muscle weakness. There are more than thirty types — Duchenne, Becker, limb-girdle, facioscapulohumeral (FSHD), myotonic dystrophy, oculopharyngeal — each with a different onset age, pattern of muscle involvement, and rate of progression. What unites them is genetics: most are inherited, though new mutations also occur.

MD is a progressive condition, which means muscle strength changes over time. The pace and pattern vary enormously. For some types and some people, the changes are slow and predictable. For others, the changes are faster. The NDIS funds the supports that help a person live the fullest possible life across that journey — from independent mobility, through power wheelchair use, to advanced respiratory and personal care needs.

Common signs and symptoms

- Progressive muscle weakness, often beginning in specific muscle groups.
- Difficulty with mobility — walking distance, stairs, transfers.
- Fatigue earlier in the day than peers.
- Sometimes cardiac involvement (cardiomyopathy).
- Sometimes respiratory involvement requiring assisted ventilation.
- Difficulty with fine motor tasks as upper limb strength changes.
- Dysphagia (swallowing difficulty) in some types.

The medical context

- MD is diagnosed via genetic testing, muscle biopsy, and EMG (electromyography).
- Different types follow different inheritance patterns — X-linked, autosomal dominant, autosomal recessive.
- Cardiac monitoring is essential for many types, including annual echocardiograms.
- Respiratory monitoring becomes important when respiratory muscles are affected — often requires non-invasive ventilation (BiPAP) overnight.
- Some types (e.g. Duchenne) have approved disease-modifying treatments; others do not.
- Multidisciplinary clinic care (neurology, cardiology, respiratory, rehabilitation) is the gold standard.

MDISNOT

MD does not affect cognition in most types. A person whose voice or movement is affected by MD is often the same intellectually and emotionally as anyone else. Each type of MD is also distinct — Duchenne, for example, has a different trajectory than FSHD or myotonic dystrophy. Generalisations are usually wrong.

WHERE TO LEARN MORE

Muscular Dystrophy Australia and MDA Foundation Australia have type-specific information. Save MD (savemd.org.au) is a research-focused resource. The Australasian Neuromuscular Network publishes clinical guidelines for adults and children.

How Muscular Dystrophy can affect daily life

Everyone's experience of MD 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.

MOBILITY

How you move

Walking distance, stairs, transfers, fatigue. Mobility changes gradually with most MD types — the key is supports that keep pace, not catch up.

CARDIAC

How your heart manages

Some MD types involve the heart muscle. Regular cardiology monitoring is part of life. Most cardiac care is Medicare-funded, with NDIS supporting access (transport, medication management).

WORK AND STUDY

How you earn and learn

Many people with MD work full-time, especially in cognitive-demand roles. Workplace modifications, assistive tech and flexible scheduling make this fully possible.

RESPIRATORY

How you breathe

Some MD types affect respiratory muscles, especially overnight. Non-invasive ventilation early protects long-term health and dramatically improves sleep.

DAILY LIVING

How you live each day

Personal care, household tasks, getting to appointments. Support workers and equipment evolve as needs evolve — the right team grows with you.

FAMILY AND INTIMATE LIFE

How you connect

Relationships, parenting, intimate life — all possible. Family supports are part of the plan, and your privacy is paramount.

An ordinary life

A diagnosis of MD 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

> **"Muscular dystrophy changes the body, gradually. It does not change the person, and it does not have to change the life — when the supports keep pace with the change."**
>
> 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, TAFE, university — at every level
- Professional work — design, engineering, law, IT, creative industries
- Living independently with the right supports
- Driving a modified vehicle
- Travelling — domestically and internationally
- Sport — adapted boccia, wheelchair basketball, swimming
- Relationships, family life, parenting
- Music, art, theatre, advocacy
- Faith and community participation
- Starting a business

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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 MUSCULAR DYSTROPHY SPECIFICALLY

MD is on the NDIS List A (conditions that automatically meet the disability requirements). Access is straightforward where the diagnosis is documented. The strongest applications include genetic testing results, the neurologist or neuromuscular specialist letter, and a recent FCA showing current functional capacity. How to apply Phone the NDIA on 1800 800 110 to request an Access Request Form (ARF).

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 MUSCULAR DYSTROPHY

For MD, the NDIS funds equipment that keeps pace with progression (often updated every 3–5 years), allied health to maintain function and manage pain, support workers for personal care and community participation, home modifications, and modified vehicles. Respiratory and cardiac equipment is sometimes funded by Health (Medicare) and sometimes by NDIS — the funding boundaries matter and a Support Coordinator helps you map them.

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 muscular dystrophy.

Allied health for Muscular Dystrophy

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

PHYSIOTHERAPY

Physio — maintaining function

Stretching programmes, contracture prevention, pain management, transition planning as mobility changes. Critical across the lifespan.

SPEECH PATHOLOGY

Speech — voice and swallowing

Swallowing assessments where dysphagia is part of the picture, voice banking before significant voice changes, AAC trial.

DIETETICS

Dietitian — nutrition and weight

Nutrition for reduced activity, swallowing-friendly diet, weight management — particularly important where mobility is reduced.

OCCUPATIONAL THERAPY

OT — adapting the day

Equipment prescription (wheelchairs, hoists), workplace and home modifications, energy conservation, fine motor strategies.

RESPIRATORY PHYSIOTHERAPY

Resp Physio — breathing

Cough assist, airway clearance, work in collaboration with respiratory specialist. Especially important as respiratory muscles weaken.

PSYCHOLOGY

Psychologist — wellbeing

Mental health support, adjustment to progression, family counselling, transition planning.

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 muscular dystrophy.

EQUIPMENT	WHAT IT IS FOR
Manual wheelchair (early stage)	Distance mobility while walking is still possible for shorter distances.
Powered wheelchair	Independence in community and home once standing transfers become unsafe or fatiguing.
Power-assist add-on	Manual wheelchair with motorised assist — useful intermediate before full power chair.
Hoist (ceiling or mobile)	Safe transfers between bed, chair, bathroom. Reduces injury risk to participant and carers.
Adjustable bed	Pressure care, repositioning, head elevation for respiratory comfort.
BiPAP / non-invasive ventilator	Overnight breathing support. Often Medicare-funded but consumables and integration may be NDIS.
Cough assist machine	Clears airway secretions where cough is weak.
Modified vehicle / driving aids	Hand controls, ramped access, wheelchair-accessible vehicles.

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.

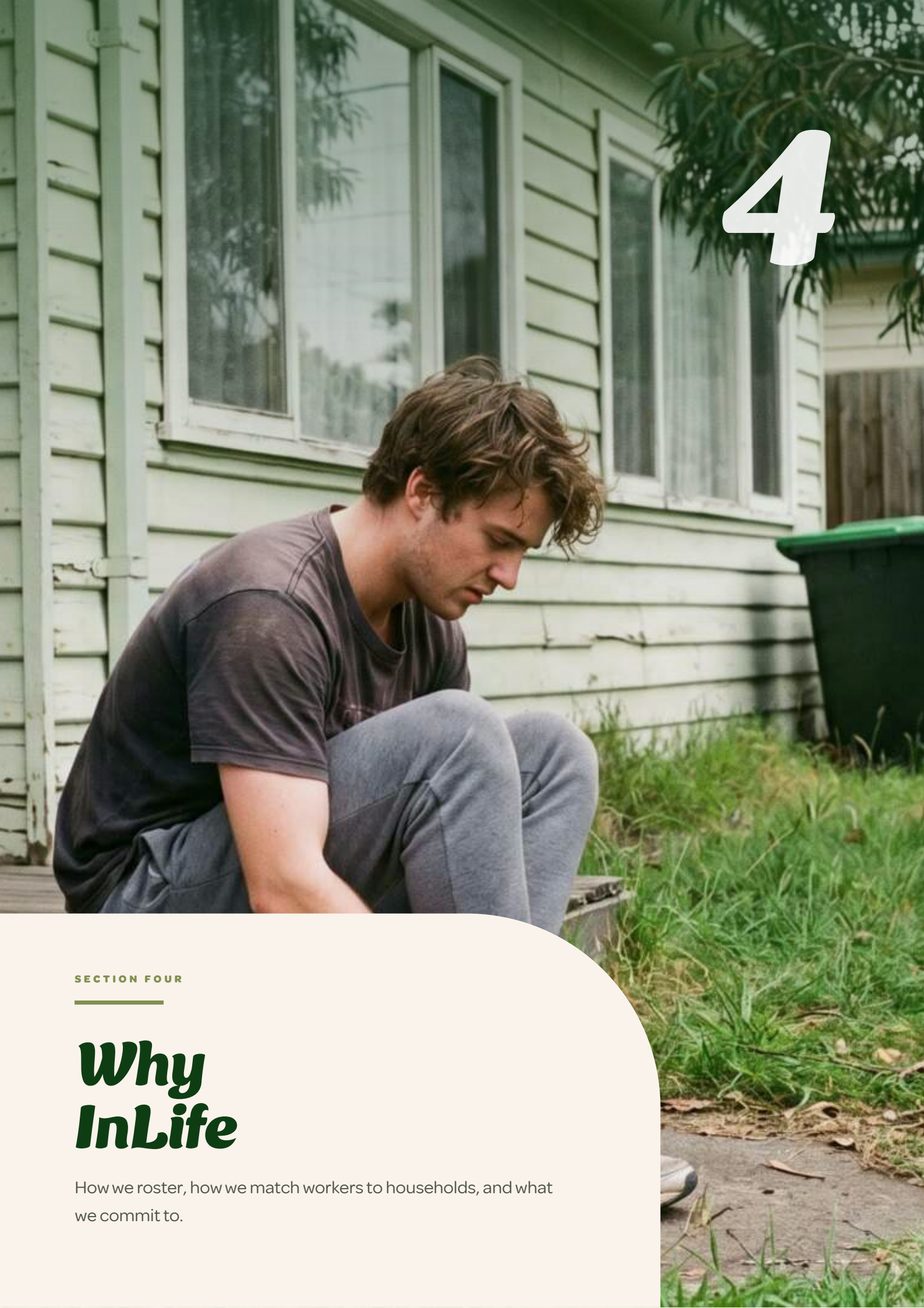
What good looks like

- 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 muscular dystrophy, 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 Muscular Dystrophy specifically

ORGANISATION	HOW TO REACH THEM	WHAT THEY DO
Muscular Dystrophy Australia	1800 656 632 · mda.org.au	National peak body. Information, support groups, equipment loan library, advocacy.
MDA Foundation Australia	mdafoundation.org.au	Research funding, family support, type-specific information.
Save Our Sons Duchenne Foundation	saveoursons.org.au	Duchenne-specific support, family connection, research.
FSHD Global Research Foundation	fshdglobal.org	FSHD-specific research and information.
Disability Sports Australia	1800 893 254 · sports.org.au	Adapted sport pathways — boccia, wheelchair basketball, swimming, table tennis.

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

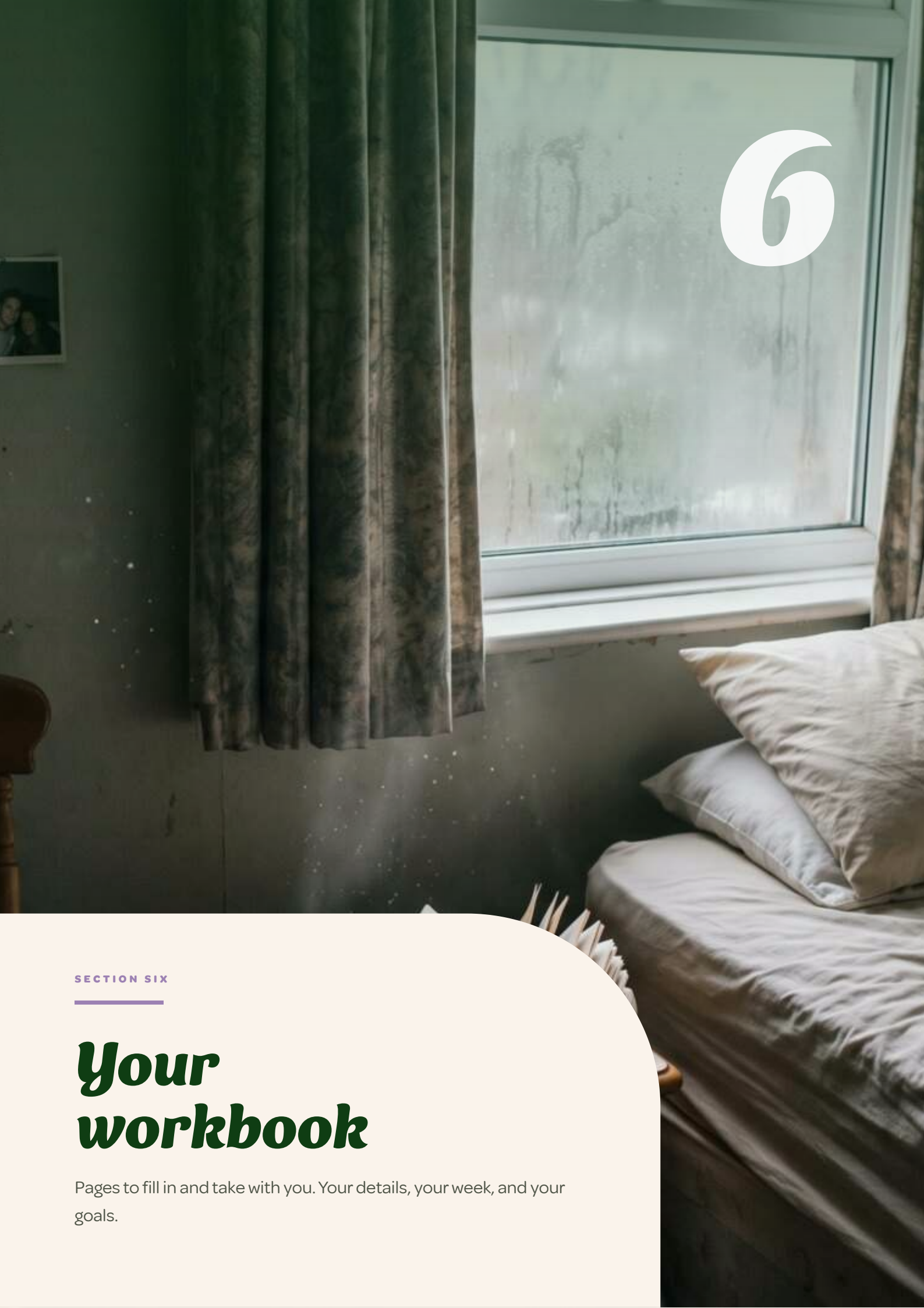
About a decision	NDIA · 1800 800 110
About a provider or worker	NDIS Commission · 1800 035 544
About InLife specifically	admin@independentlife.au, which reaches both managing directors
To appeal an NDIA decision	Internal review first, then the Administrative Review Tribunal · 1800 228 333
Independent 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.



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?

The right team builds a life around the person, not around the diagnosis.

Talk to us

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admin@independentlife.au

independentlife.au

Find us

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Melbourne VIC 3000

InLife serves

Victoria

Languages: Farsi · Urdu · Hindi · Punjabi · English