

NDIS Functional Impact Guide

For rare, episodic, fluctuating and underrepresented disabilities

Including ME/CFS, Familial Mediterranean Fever (FMF), Ehlers-Danlos syndromes, POTS/dysautonomia and other poorly understood conditions.

A note before using this guide

This free resource is designed to help people understand and describe the functional impact of disability when navigating the NDIS.

It provides general information only and is not legal, medical or professional advice. Every NDIS application is assessed individually. Using this guide does not guarantee NDIS access, funding approval or a successful review.

I have done my best to provide accurate and useful information, but the NDIA makes the final decision. Where appropriate, use this guide alongside advice from treating professionals, disability advocates or legal services.

To the fullest extent permitted by law, I cannot accept responsibility for decisions, losses or outcomes arising from reliance on this guide.

Rare and fluctuating disabilities

Rare, fluctuating, episodic and underrepresented disabilities can be difficult to explain in an NDIS application, particularly when symptoms are invisible, vary significantly over time, or are unfamiliar to the person assessing the application.

Examples may include:

- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Familial Mediterranean Fever (FMF)
- Ehlers-Danlos syndromes (EDS)
- Postural Orthostatic Tachycardia Syndrome (POTS) and other forms of dysautonomia
- Myasthenia gravis
- Periodic paralysis disorders
- Complex Regional Pain Syndrome (CRPS)
- Narcolepsy and cataplexy
- Idiopathic hypersomnia
- Behçet's disease
- Adult-onset Still's disease and other rare autoinflammatory disorders
- Hereditary angioedema

- Mitochondrial diseases
- Muscular dystrophies and rare neuromuscular disorders
- Functional Neurological Disorder (FND)
- Rare genetic syndromes causing substantial physical, cognitive or adaptive impairment
- Severe vestibular disorders affecting balance and mobility
- Long COVID where there is evidence of permanent or likely permanent impairment and substantial functional impact
- Other chronic, rare or poorly understood conditions that cause significant and ongoing impairment

Having one of these diagnoses does not automatically make someone eligible for the NDIS. The way your evidence is presented to the NDIS is really important as planners are trained to make funding decisions based on Functional Impact, risks and value for money.

Planners are not evil flying monkeys who take pleasure in hurting and disadvantaging people with a disability. They are following orders. They have to justify every single dollar allocated to a participant to a group of executives who hold it over their head if they don't allocate funding in line with the legislation and don't tow the line of ensuring the agency spends as little money as possible.

For more on this, please refer to section 24 and 34 of the NDIS Act.

For example, here's some examples I have seen from FCAs as an ex planner and why they are effective/effective less effective at ensuring the person gets the funding they need

✗ Less effective

"The participant's wife is burnt out and needs funding for respite so she can have a break."

This focuses mainly on the needs of the informal carer. NDIS funding must address the participant's disability-related support needs, rather than primarily benefiting the spouse, parent or siblings etc...

✓ More effective

"Mr Smith relies heavily on his wife to meet his disability-related daily living needs. The intensity and frequency of this unpaid care is no longer sustainable and is placing strain on the marital relationship. Without additional funded supports, there is a risk that Mr Smith's informal support network may reduce or break down, resulting in unmet daily living needs, reduced independence and increased risk to his wellbeing. Additional disability support is recommended to reduce his reliance on informal care, maintain his safety and independence, and allow his wife to continue primarily in the role of spouse rather than carer."

A useful formula

Disability-related need → current informal support → why it is no longer reasonable or sustainable → risk to the participant → funded support required

Relevant risks may include:

- Falls or injury
- Difficulty accessing food, hygiene or essential daily activities
- Deterioration in health or functioning
- Social isolation or loss of community access
- Loss of independence
- Difficulty maintaining a safe and stable home
- Vulnerability to abuse, neglect, exploitation or financial harm
- Risks related to impaired decision-making or self-management
- Missed healthcare, appointments or essential responsibilities
- Unsustainable reliance on family or unpaid carers
- Informal caring responsibilities preventing family members or partners from maintaining a normal relationship with the participant
- Increased future support needs if appropriate supports are not provided early

For example, providing assistance at home may help a participant maintain their independence and reduce the likelihood that significantly more intensive supports are required later.

Another useful formula is:

Impairment → functional difficulty → risk → support needed

Example:

Severe disability-related fatigue → unable to stand long enough to cook → risk of inadequate nutrition → assistance with meal preparation

Describe what happens when your impairment is at its most severe, rather than presenting only your best days. The aim is not to exaggerate your situation. It is to clearly explain what can happen without appropriate disability support, how the requested support reduces that risk and ensures you have enough funding should you have increased flares, your informal supports become unavailable or an emergency.

What your application should explain

Your evidence, often through an FCA, should clearly explain:

- Your diagnosed condition
- The impairment caused by the condition
- How the impairment affects everyday functioning
- What you cannot reliably do without assistance
- How often difficulties occur
- How severe they are
- How long episodes, flares or crashes last
- Why the impairment is permanent or likely to be ongoing
- What disability-related supports you require

How functional impact should be addressed in an FCA

Example: Ehlers-Danlos Syndrome (EDS)

✗ Less effective

“The participant has Ehlers-Danlos Syndrome. They experience joint pain, fatigue and frequent dislocations. Their symptoms vary from day to day. They sometimes struggle with daily activities. Their family helps when symptoms are bad. They need 24/7 2:1 funded support.”

Why this is weak

This describes the diagnosis and symptoms but does not clearly explain:

- The participant’s functional impairment
- How often difficulties occur
- How severe they are
- What assistance is required
- Why the support need is ongoing
- Why the specific level of support requested is necessary

✓ More effective

- **Diagnosis:** *“The participant has a confirmed diagnosis of Ehlers-Danlos Syndrome (EDS).”*
- **Impairment:** *“EDS causes joint instability, recurrent subluxations and dislocations, chronic pain, fatigue and reduced physical endurance.”*
- **Functional impact:** *“The participant has substantially reduced capacity to stand for prolonged periods, walk longer distances, prepare meals, complete household tasks and undertake personal care. This includes difficulty standing long enough to shower safely and brushing or detangling their hair sufficiently to prevent matting.”*

- **Reliability:** *“Although the participant can complete some activities on better days, they cannot do so safely, consistently or repeatedly without increased pain, fatigue or risk of joint injury. When the participant pushes through activities without assistance, their symptoms may significantly worsen and they may be unable to get out of bed the following day.”*
- **Frequency:** *“The participant experiences functional limitations every day, with periods of significant deterioration following joint injury, physical exertion or symptom flare.”*
- **Severity:** *“During periods of increased impairment, the participant requires assistance with showering, dressing, grooming, meal preparation, cleaning, shopping and mobility within the home and community.”*
- **Duration:** *“Periods of increased pain and reduced mobility may last from several hours to several days. Recovery time varies depending on the severity of the flare or injury and whether assistance is available to reduce physical exertion.”*
- **Ongoing nature:** *“The participant’s treating team considers the condition lifelong. Treatment and therapy may assist with symptom management and reducing complications but do not remove the underlying impairment.”*
- **Support required:** *“The participant requires disability-related assistance with daily living, household activities, community access and appropriate assistive technology to maintain safety, independence and participation.”*

A strong FCA should clearly demonstrate:

Diagnosis → impairment → functional impact → frequency and severity → ongoing need → support required

The six functional areas

The NDIS considers substantially reduced functional capacity across six main areas.

Alongside your FCA, it will help to keep a record of how your disability affects you in each area. Tick anything that applies and write down real examples by way of a log in your phone or a physical diary to fill in when you experience an example.

1. Mobility

This means your ability to move around safely and independently.

- ☐ Difficulty walking
- ☐ Difficulty standing
- ☐ Difficulty getting in or out of bed
- ☐ Difficulty getting out of a chair
- ☐ Difficulty using stairs

- ☐ Periods where you need to remain in bed
- ☐ Pain, weakness, dizziness or fatigue affecting movement
- ☐ Need for mobility aids or equipment
- ☐ Need for another person to physically assist you
- ☐ Difficulty leaving home independently

Examples:

2. Self-care

This means looking after your basic personal needs.

- ☐ Showering
- ☐ Bathing
- ☐ Dressing
- ☐ Toileting
- ☐ Eating
- ☐ Preparing basic food
- ☐ Grooming
- ☐ Personal hygiene
- ☐ Getting safely in and out of the shower
- ☐ Completing personal care without excessive exhaustion or worsening symptoms

Examples:

3. Self-management

This relates to managing everyday life.

- ☐ Organising appointments
- ☐ Attending appointments
- ☐ Managing medication
- ☐ Planning activities
- ☐ Managing household responsibilities
- ☐ Managing finances
- ☐ Remembering important tasks
- ☐ Maintaining routines
- ☐ Making decisions
- ☐ Organising supports
- ☐ Managing several tasks at once
- ☐ Adjusting plans when symptoms change
- ☐ Recognising when assistance is needed

Examples:

4. Communication

Communication involves more than being physically able to speak. Consider whether your impairment affects your ability to:

- ☐ Understand information
- ☐ Process verbal information
- ☐ Explain your needs
- ☐ Follow conversations
- ☐ Find words when severely fatigued or unwell
- ☐ Communicate during flares or crashes
- ☐ Understand complex written information
- ☐ Advocate for yourself when unwell

Examples:

5. Social interaction

Consider whether your impairment affects your ability to:

- ☐ Leave your home
- ☐ Maintain friendships
- ☐ Attend family events
- ☐ Attend social activities
- ☐ Participate in the community
- ☐ Make and keep plans reliably
- ☐ Sustain interaction without significant symptom worsening
- ☐ Cope with physically or cognitively demanding social environments
- ☐ Maintain relationships when illness causes frequent cancellations or periods of withdrawal

Examples:

6. Learning

Learning includes much more than formal education. Consider your ability to:

- ☐ Concentrate
- ☐ Process new information
- ☐ Remember information
- ☐ Follow instructions
- ☐ Learn new skills
- ☐ Apply something you have learned

- ☐ Sustain cognitive activity
- ☐ Complete tasks involving several steps
- ☐ Undertake education or training

Also consider:

- ☐ What happens after completing an activity
- ☐ Whether activity worsens your symptoms
- ☐ How long you need to recover
- ☐ Whether you can repeat the activity later that day
- ☐ Whether you can repeat it the following day
- ☐ Whether your capacity can be predicted in advance
- ☐ Whether you cancel appointments, work, study or activities because of your impairment

Examples:

Document what other people cannot see

Invisible disabilities can be particularly difficult to demonstrate.

Someone assessing you may see you:

- Sitting through a medical appointment
- Walking through a supermarket
- Attending a family event
- Working for several hours
- Speaking clearly during an assessment

They may not see:

- The preparation required beforehand
- Activities you sacrificed so you could attend
- Medication you needed
- Assistance provided by another person
- Symptoms experienced during the activity
- What happened when you returned home
- How long you needed to recover
- Activities you could no longer complete afterwards
- Whether you could repeat the activity the following day

Document the **full functional cost** of an activity, not simply whether you managed to do it once.

Medical and functional evidence checklist

Useful evidence may come from:

- ☐ GP
- ☐ Rheumatologist
- ☐ Immunologist
- ☐ Neurologist
- ☐ Occupational therapist
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Other relevant treating health professionals
- ☐ Hospital records
- ☐ Specialist records
- ☐ Functional Capacity Assessment
- ☐ Statements from carers
- ☐ Statements from family members or friends who regularly assist you

What should a professional report explain?

Treating professionals are not always familiar with NDIS access and funding requirements. Providing clear guidance can help them prepare evidence that accurately explains your disability and support needs.

Ask your treating professional to address:

- ☐ Your diagnosis
- ☐ The functional impairment caused by your condition
- ☐ Whether the impairment is permanent or likely to be lifelong
- ☐ Treatments already attempted
- ☐ Whether further appropriate treatment is likely to substantially improve the impairment
- ☐ Whether treatment manages symptoms rather than removing the impairment
- ☐ Your symptoms
- ☐ Severity
- ☐ Frequency
- ☐ Duration of episodes
- ☐ Whether your impairment fluctuates
- ☐ Whether the impairment is likely to worsen over time
- ☐ How each relevant functional area is affected
- ☐ Activities you cannot perform independently
- ☐ Activities requiring prompting, supervision or physical assistance
- ☐ What happens when you attempt activities without support

- ☐ Whether this affects your ability to work or study
- ☐ Whether activities cause deterioration afterwards
- ☐ Assistive technology or equipment that may increase independence and reduce reliance on support workers
- ☐ Impact on employment or education
- ☐ Impact on community participation
- ☐ Assistance currently provided by family or friends
- ☐ Why disability-related support is likely to remain necessary

Keep a functional impact diary

A diary can show patterns that may not be visible during a single medical appointment or NDIS assessment.

Record information somewhere easy to access, such as your phone's Notes app or a physical diary.

Date:

Symptoms:

Severity:

What could I do independently?

What couldn't I do?

What help did I need?

Who helped me?

How long did the episode last?

What triggered or worsened my symptoms?

What happened afterwards?

How long did recovery take?

What appointments, work, study or activities did I cancel?

Example

Tuesday: Severe abdominal pain, fever and joint pain. Unable to prepare food or shower independently. A family member prepared meals and completed household tasks. Spent most of the day resting. Cancelled a medical appointment because I could not safely leave home.

Connecting support requests to disability

The NDIS funds eligible disability-related supports. It generally does not fund services that another system, such as the health or housing system, is responsible for providing.

Depending on your circumstances, disability-related supports may include:

- Assistance with daily activities
- Assistance around the home
- Assistive technology
- Disability-related equipment
- Home modifications
- Assistance to participate in the community
- Other eligible disability-related supports

The key question is:

“What functional need does this support address, and why do I require it because of my impairment?”

The biggest mistake to avoid

Do not make your application only about **how sick you are**.

Make it about:

What your impairment means for your everyday life.

If your NDIS access application has been rejected

After you cry (because who wouldn't)

Recruit your inner lawyer pants and work through the following checklist. Ask a friend or family member to help you if you find it overwhelming.

1. Read the decision letter carefully

- ☐ I have a copy of the written decision.
- ☐ I know which access requirement the NDIA says I did not meet.
- ☐ I have identified whether the issue relates to permanency, functional capacity, participation, lifetime support needs or another requirement.
- ☐ I have asked for clarification if I do not understand the reasons given.

Respond directly to the reason for refusal rather than simply submitting the same evidence again.

2. Check your evidence against the Legislation (not the news or what your friend Judy told you)

Under section 24 of the NDIS Act, relevant considerations include whether:

- ☐ You have a disability attributable to an intellectual, cognitive, neurological, sensory or physical impairment, or an impairment to which a psychosocial disability is attributable.
- ☐ Your impairment is permanent or likely to be permanent.
- ☐ Your impairment results in substantially reduced functional capacity in one or more relevant areas.
- ☐ Your impairment affects your capacity for social or economic participation.

- ☐ You are likely to require NDIS supports for your lifetime.

Meeting one requirement does not automatically establish all of the others.

3. Check whether fluctuating impairment has been clearly explained

- ☐ Frequency of episodes documented
- ☐ Duration documented
- ☐ Severity documented
- ☐ Functional impact during episodes documented
- ☐ Recovery time documented
- ☐ Assistance required documented
- ☐ Better and worse days explained
- ☐ Unpredictability explained
- ☐ Ability to repeat activities explained
- ☐ Consequences of physical or cognitive exertion explained

NDIS legislation recognises that an impairment may still be permanent even when its intensity varies or the impairment is episodic or fluctuating. This may be particularly important for rare and episodic conditions.

4. Check your permanency evidence

- ☐ Has my treating professional specifically addressed whether my impairment is permanent or likely to be permanent?
- ☐ Have appropriate available treatments been identified?
- ☐ Does the evidence explain which treatments I have already tried?
- ☐ Does it explain the outcomes of those treatments?
- ☐ Does it distinguish between treatment that manages symptoms and treatment expected to remove the impairment?
- ☐ Does it explain why significant functional limitations are expected to remain?

5. Strengthen your functional evidence

Consider whether you have provided:

- ☐ GP evidence
- ☐ Specialist evidence
- ☐ Occupational therapy evidence
- ☐ Functional Capacity Assessment, if appropriate
- ☐ Physiotherapy evidence, if relevant

- ☐ Hospital or treatment records
- ☐ Functional impact diary
- ☐ Statements from carers, family or friends
- ☐ Your own functional impact statement
- ☐ Evidence of the assistance you already receive
- ☐ Examples covering several weeks or months
- ☐ Evidence describing what happens after activities
- ☐ Evidence explaining why activities cannot be completed reliably
- ☐ Evidence connecting each impairment to an actual support need

You may also consider assistance from:

- ☐ A disability advocate
- ☐ An NDIS appeals or advocacy service
- ☐ A community legal service
- ☐ Legal Aid, where eligible
- ☐ Another suitably qualified advocate or legal professional

Before submitting your application or review

Final checklist

- ☐ My evidence explains impairment, not only diagnosis.
- ☐ My functional limitations are clearly described.
- ☐ I have addressed all relevant functional areas.
- ☐ I explain what happens during flares, crashes or attacks.
- ☐ I have not based my application only on my best days.
- ☐ I explain frequency, duration and severity.
- ☐ I explain recovery after activities.
- ☐ I explain whether activities can be repeated reliably.
- ☐ I have described assistance currently provided by other people.
- ☐ My treating professionals have discussed permanency.
- ☐ Treatments attempted are documented.
- ☐ My evidence explains why impairment remains despite treatment or management.
- ☐ I have connected functional difficulties to disability-related support needs.
- ☐ I have included real-life examples.
- ☐ I have considered keeping a functional diary.
- ☐ Family, friends or carers have provided statements where appropriate.

- ☐ I have kept copies of everything submitted.
- ☐ If refused, I know the review deadline.
- ☐ If refused, I have addressed each reason for the decision individually.

Remember

A rare diagnosis does not need to be common or widely understood for its functional impact to be significant.

An invisible disability does not become less disabling because another person cannot immediately see it.

A fluctuating impairment does not necessarily stop being permanent because there are periods when symptoms improve.

Being able to complete an activity once does not necessarily mean you can complete it **safely, independently, effectively and reliably whenever everyday life requires it.**

Use these principles alongside a functional impact statement and other evidence that specifically addresses the relevant NDIS access and funding criteria.

GOOD LUCK! X GEM X