

Submission on NDIS Access Changes

October 2026

Executive summary

Emerge Australia supports clearer and more consistent NDIS access decisions based on functional impact rather than diagnosis alone. The reform is an opportunity to reduce inequities in NDIS access for people with ME/CFS and long COVID. It must address barriers to obtaining clinical evidence, establishing permanence and participating safely in assessments. ME/CFS and long COVID can involve interacting physical, cognitive, neurological, autonomic, sensory and other impairments. Access decisions must assess their combined effect across all relevant domains of functional capacity rather than considering individual symptoms, diagnoses or activities in isolation.

ME/CFS and long COVID require a condition-informed approach because conventional assessment methods may not adequately capture their functional effects:

- For applicants with the level of functional impairment relevant to NDIS access, capacity remains profoundly limited, whether it fluctuates within that restricted range or shows little meaningful variation.
- Post-exertional malaise (PEM) is a core feature of ME/CFS and occurs in many people with long COVID. It can cause delayed and prolonged deterioration following even minor physical, cognitive, social or emotional exertion, orthostatic stress or sensory exposure (CDC, 2024; CDC, 2026; NICE, 2021).
- Multiple interacting body systems, symptoms and co-occurring conditions can affect several functional domains at once and cannot be accurately assessed in isolation.
- There is no established evidence-based treatment pathway that reliably substantially alleviates or remedies the core impairments of ME/CFS or long COVID. Treatment expectations must reflect current evidence and the applicant's individual clinical circumstances.
- No single medical specialty is responsible for the full range of impairments. Relevant evidence may be distributed across GPs, medical specialists and allied health practitioners, with each observing only part of the person's condition and functional impairment.

An access process that relies on a one-off observation, a standardised tool or a single specialist report without considering other relevant evidence risks inaccurate decisions and harm. Without appropriate safeguards, the process risks disadvantaging applicants with these conditions.

The access process must not require applicants to undertake inappropriate or harmful treatment, repeatedly prove an unchanged impairment, attend inaccessible assessments, or obtain additional specialist reports where existing evidence is sufficient. Eligibility must be

determined against the applicable access requirements. Access must not be refused or withdrawn merely because another service system is assumed to meet the person's disability support needs.

The access process must be safe, clinically informed, evidence-based and capable of recognising the full presentation of complex and poorly understood conditions.

Equitable access also requires a clinically appropriate and transparent approach to permanence. Treatment suitability should be determined by the treating doctor in consultation with the applicant. Relevant clinical evidence that all available and appropriate treatments have been undertaken, or that no available treatment is clinically appropriate and likely to substantially alleviate or remedy the impairment, should be sufficient to address the treatment aspect of permanence. Symptom management must not be mistaken for resolution of disabling impairment.

Recommendations

No	Recommendation
1	Require assessors and decision-makers to have appropriate knowledge of ME/CFS and long COVID, including their multisystem impairments, interacting co-occurring conditions, fluctuations, different presentations and PEM.
2	Do not turn permanence into a treatment-exhaustion test. Only treatment that is evidence-based, safe, clinically appropriate for the individual, practically accessible and likely to substantially alleviate or remedy the impairment should be relevant. Access should not be denied on treatment grounds where relevant clinical evidence establishes that all available and appropriate treatments have been undertaken, or that no available treatment meets these requirements.
3	Assess the combined functional effect of physical, cognitive, neurological, autonomic, sensory and other impairments across all relevant domains. Do not consider symptoms or co-occurring conditions in isolation.
4	Assess functional capacity by what a person can do safely, reliably, repeatedly, sustainably and within a reasonable time, accounting for delayed and cumulative deterioration and the assistance, adaptations, rest and recovery required. Do not infer broader capacity from a single appointment, isolated observation or one-off activity.

No	Recommendation
5	Do not require applicants to physically demonstrate an activity or undertake performance-based testing where this could trigger PEM, worsen symptoms or cause deterioration. Accept existing clinical evidence, the applicant's account, and evidence from carers, support people and treating practitioners.
6	Do not use I-CAN or another standardised tool as the sole or primary basis for access. Use any standardised tool alongside other relevant evidence and appropriately qualified human review, and validate it for complex multisystem disability, including cognitive, sensory and autonomic impairment and PEM.
7	Consider relevant evidence from applicants, carers, treating practitioners, existing records and previous assessments. Evidence requirements should reflect the eligibility criterion being assessed. No single assessment tool or practitioner report should be expected to capture the full functional impact of complex, multisystem disability.
8	Reuse existing evidence and publish clear, accessible guidance for applicants and clinicians on evidence requirements, clinical reports, permanence and treatment history. Include practical examples or report templates without imposing a rigid checklist. Allow people to correct inaccurate information or address possible misinterpretation before a decision, avoid repeated proof of an unchanged impairment and require the NDIA to pay the cost of additional evidence it requires.
9	Offer flexible assessment formats chosen by the person, including telehealth, home-based, written and asynchronous options, shorter or split appointments, questions in advance and nominee or advocate participation. Allow the person to pause and resume later where a rest break is insufficient.
10	Determine NDIS eligibility against the applicable access requirements. Do not refuse or withdraw access merely because another service system is assumed to meet the person's disability support needs. Any proposed alternative must be appropriate, available and accessible, with an accepted referral and a confirmed timeframe for commencing the required support.
11	Continue existing plans and supports while reassessment and internal or external review are underway and preserve accessible human review and appeal rights.
12	Develop and test condition-specific implementation guidance with people living with ME/CFS and long COVID, carers, clinicians and representative organisations before the access changes commence on 1 January 2028.



About Emerge Australia

Emerge Australia is the national organisation leading action on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), long COVID and overlapping conditions. We work to improve the lives of those impacted through clinical education, policy and advocacy, biomedical research and health and support services.

This submission is informed by consultation with our Community Advisory Panel (CAP), alongside knowledge gained through our ongoing interactions with people living with these conditions and their families about barriers to accessing the NDIS. We welcome the opportunity to respond to the consultation on the future NDIS access process.

ME/CFS and long COVID can cause profound and persistent functional impairment across several domains. Symptoms may include PEM, profound energy impairment, cognitive impairment, orthostatic intolerance (OI) and other autonomic dysfunction, unrefreshing sleep, pain, muscle weakness, headaches, breathlessness, temperature dysregulation and sensory hypersensitivity. People may also live with interacting co-occurring conditions such as mast cell activation syndrome (MCAS), fibromyalgia, hypermobile Ehlers-Danlos syndrome (hEDS) and irritable bowel syndrome (IBS). The combination and functional impact differ between individuals.

A person's ability to leave home occasionally does not establish their overall functional capacity. Assistance, assistive technology and substantial recovery may make an occasional outing possible. Assessment must consider whether the activity can be undertaken safely, reliably, repeatedly, sustainably and within a reasonable time. Eligibility must be determined from individual evidence rather than diagnosis, illness severity or housebound or bedbound status.

Community consultation

This submission draws on a September 2026 consultation with 10 members of Emerge Australia's Community Advisory Panel. Nine respondents were people living with ME/CFS, including two who also had long COVID and one who was also a carer. One respondent was a carer for a person living with both ME/CFS and long COVID. Respondents included three current NDIS participants, two people with experience of an unsuccessful access application, people who had not applied, and family or carer perspectives on NDIS participation and access. Given the small number of responses, this submission uses the consultation as qualitative lived-experience evidence rather than presenting it as representative community data.

CAP respondents raised concerns about whether standardised assessments would capture functional capacity and PEM accurately, and whether assessors would understand ME/CFS and long COVID.

“The government needs to get this right. The number of people in this country who are disabled by ME/CFS and/or long COVID is far more than many would realise. ... The NDIS systems need to be able to offer safe assessments to ensure people with ME/CFS and long COVID get just access to the support they desperately need.”

— Carly

Quotes are included with contributors’ consent, including permission to use their names as presented in this submission.

Response to the consultation questions

Question 1

Do the draft guiding principles provide the right foundation for a future NDIS access process?

They provide a reasonable starting point, but only if they are strengthened and translated into binding design requirements. The principles appropriately refer to human rights, lived experience, evidence, consistency, person-centred practice, safety, accessibility, transparency and continuous improvement. These commitments align with Emerge Australia’s established position.

Our concern is that general principles can coexist with assessment practices that remain unsafe or inaccurate. The consultation paper promises a process that works for fluctuating, episodic and complex disability, but does not yet explain how functional capacity will be measured, how delayed deterioration will be identified, how treatment will be judged, what protections will apply during reassessment, or how assessment tools and processes will be validated for these forms of disability. These details will determine whether the reforms are equitable in practice.

Emerge Australia therefore supports the proposed principles subject to stronger requirements for condition-informed, multi-domain assessment of complex disability, together with safe processes, appropriate evidence standards and continuity of support.

Question 2

Should any principles be added, removed or changed?

Emerge Australia recommends retaining and strengthening the seven principles and adding a principle on continuity of support during reassessment and review.

1. Aligned to the NDIS Act and the human rights of people with disability. This principle should require the process to safeguard dignity, autonomy and privacy, avoid unsafe or degrading means of proving impairment, and give effect to Australia’s obligations under the UN Convention on the Rights of Persons with Disabilities in gathering evidence and making and communicating decisions.

2. Informed by lived experience, including people with disability, families and carers. This principle should require continuing co-design and testing with affected cohorts, using accessible methods that enable people with substantial physical and cognitive impairments to participate within their energy limits.

3. Evidence-based and consistent. Consistency requires a common decision standard, with evidence and adjustments suited to the disability being assessed. Standardisation must not mean identical assessment.

4. Person-centred and strengths-based. Assessors must understand the combined functional effects of the person's impairments, including whether activities can be undertaken safely, reliably, repeatedly, sustainably and within a reasonable time.

5. Equitable, inclusive and safe. Equitable access requires evidence and assessment processes that enable applicants to demonstrate whether they meet NDIS eligibility requirements, taking account of their disability and barriers to participation. This principle should expressly recognise complex multisystem disability, PEM and delayed deterioration, and require assessments and treatment expectations to avoid harm.

6. Transparent, proportionate and accessible. This principle should require clear published evidence standards, reasons for decisions, access to the information relied upon, an opportunity to correct inaccuracies and address possible misinterpretation, and accessible review rights.

7. Continuous quality improvement. This principle should require publication of access and review outcomes by disability cohort, while protecting privacy, so systemic exclusion can be identified.

- A continuity principle should be added for reassessment: existing supports should remain in place until reassessment and review are complete.

Question 3

What do we need to consider when designing an access decision-making process that is fair, consistent, transparent, disability-informed and evidence-based?

Assess the combined functional effects of impairments

For ME/CFS and long COVID, the central design requirement is to understand the full pattern of impairment and how its components interact. These conditions can affect mobility, self-care, communication, learning, social interaction and self-management through different combinations of physical, cognitive, neurological, autonomic, sensory and other impairments.

For example, orthostatic intolerance may limit standing and sitting upright; cognitive impairment may affect memory, planning, communication and sequencing; pain, sleep disturbance and sensory sensitivity may further restrict activity and the environments a person can tolerate; and co-occurring conditions such as MCAS or IBS may add care, dietary and environmental needs. PEM causes a disproportionate exacerbation of symptoms and reduces

function following even minor physical, cognitive, emotional or social exertion. The deterioration may be delayed, can persist for days, weeks or longer, and may further restrict function across multiple domains. PEM therefore affects not only whether an activity can be repeated, but whether it can be undertaken safely and sustainably at all. Assessing these effects separately can substantially underestimate the person's overall disability and support needs.

The access process should assess the combined effect of these impairments across all relevant functional domains. A person should not be required to establish that each symptom or comorbidity is independently disabling before its contribution to the overall functional presentation is considered. Nor should a support need be disregarded merely because it is difficult to attribute to one diagnosis within a complex clinical presentation. Complexity is a reason for a more informed assessment, not a basis for reduced access.

"I was told by my Local Area Coordinator the NDIS doesn't deal well with complex or multiple conditions, but this is the reality of living with ME/CFS. It's the reason why we need more support to access appropriate care, not less."

— Andrea

Assess safe and sustainable capacity

A person may complete an activity once but be unable to repeat it, require substantial recovery time, or deteriorate afterwards. Recording completion of the activity without considering its consequences can overstate independence and understate support needs.

"I am able to leave the house once a fortnight on average, with all of my NDIS-funded supports and AT [assistive technology], but I then need to spend the rest of the week largely bedbound."

— Tracey

For some people with ME/CFS, necessary rest may involve lying down or remaining in bed with minimal physical, cognitive, social and sensory stimulation for hours, days or longer. It should not be interpreted as a brief seated break after which the person can resume activity.

The assessment must consider the assistance, adaptations and rest required to complete an activity; whether it can be performed safely, reliably, repeatedly, sustainably and within a reasonable time when needed; and whether attempting it causes PEM or other delayed or cumulative deterioration. Performing an activity once, particularly in the controlled circumstances of an assessment, does not establish functional capacity. The access process must assess each person's actual functional capacity and support needs. It must not infer broader capacity from an isolated activity.

Use multiple sources and evidence over time

A standardised assessment should be considered just one source of evidence, not a substitute for clinical and lived-experience evidence. No single practitioner will necessarily observe every aspect of a complex multisystem condition. The decision-maker should consider existing records, evidence from relevant treating practitioners, the person's account, carer evidence, symptom and activity records, and previous assessments. Together, these sources can provide longitudinal evidence of the person's functional capacity, including delayed or cumulative deterioration that may not be apparent during a single assessment. Apparent inconsistencies between sources may reflect different observation periods, environments, levels of assistance, or delayed or cumulative deterioration following exertion. They should be investigated rather than treated as evidence that a source is unreliable or automatically resolved in favour of the standardised tool.

Require condition-informed human decision-making

Generic disability training will not be sufficient. Assessors and reviewers must understand the multisystem impairments associated with ME/CFS and long COVID, their combined functional effects, and PEM. They must recognise that capacity may fluctuate within a substantially restricted range or remain consistently limited. Training must cover profound energy impairment, cognitive impairment, orthostatic intolerance and other autonomic dysfunction, unrefreshing sleep, pain and sensory hypersensitivity. Automated assessment or decision-making must not replace appropriately qualified human review.

Ensure permanence decisions are consistent and transparent

As discussed further in response to Question 6, a fair and consistent access process also requires transparent decision-making about permanence. The NDIA should publish evidence-based guidance explaining how assessors will determine whether impairments associated with ME/CFS and long COVID are permanent or likely permanent, including how prognosis, treatment history and evidence from treating practitioners will be considered. This guidance should be publicly available and regularly updated to reflect current clinical evidence, so applicants and health professionals can understand how permanence will be assessed and what evidence is required.

Question 4

How could the access decision-making process, including referral pathways, be designed to reduce administrative burden and make it easier and more equitable for people with disability, their families and carers to understand what information is needed and how decisions are made? How could this support a proportionate approach to minimise the assessment burden on persons who are clearly eligible with very significant functional impairment?

Administrative accessibility is a safety issue for people with energy-limiting conditions. Long appointments, repeated form-filling, travel, phone calls and sustained self-advocacy can trigger PEM and prevent participation. The process should use existing reports and offer telehealth,

shorter or split appointments, written or online responses, and protection from having to demonstrate potentially harmful activities.

“The process of applying to the NDIS and trying to coordinate evidence causes so much burnout and often physical harm to both participants and their carers.”

— Lisa

A proportionate process should:

- avoid a further full assessment where existing evidence is sufficient to establish the relevant NDIS eligibility requirements. Where additional assessment is necessary, its scope and format must be proportionate to the evidence needed and take account of the applicant’s functional limitations and risk of harm;
- provide one clear list of required evidence and seek additional material only where it is necessary to decide a specific criterion;
- not require repeated proof of an impairment that has not improved;
- accept evidence from GPs and existing treating practitioners without routinely requiring specialist evidence, particularly where further specialist review is unavailable, unaffordable or not considered clinically necessary by the person’s treating practitioners. Evidence requirements must account for barriers to accessing clinicians with appropriate knowledge of ME/CFS and long COVID;
- have the NDIA pay the cost of additional assessments it requires;
- provide one contact person who can explain requirements and resolve problems;
- allow information to be provided gradually and through a carer, nominee, advocate or support person; and
- give the person an opportunity to see and correct the factual information used, and to address any possible misinterpretation of their evidence, before a decision is made. The NDIA should also provide clear written feedback identifying any gaps in the evidence, why the existing evidence is considered insufficient and what additional information is required.

“At the time [of NDIS assessment] I was bedbound for 23 hours a day, with no light, sound, reading or speaking tolerance. The assessor had misunderstood the many references to ‘rest’ in my documentation. They had assumed this meant a five-minute sit down and then continue on with daily tasks.”

— Tracey

Eligibility must be determined against the applicable access requirements. If the NDIA proposes to refuse or withdraw access because another service system is considered responsible, it must not rely on a general assertion that other supports exist or provide only a list of possible services. It should identify a specific, accessible and appropriate service that can provide the type, amount and duration of disability support required. The receiving service should have

accepted the referral and confirmed that support can commence within a reasonable time. For current participants, existing NDIS support should continue until alternative support has commenced, including while any review is underway. Applicants should not be required to contact multiple services or obtain repeated refusals to prove that an appropriate alternative is unavailable.

Question 5

What should be considered to ensure the access decision-making process, as well as referral pathways, works well for all disability cohorts including people with communication, cultural, cognitive, degenerative, fluctuating, episodic or complex support needs?

Assessment processes must accommodate the applicant's energy, cognitive and sensory limits without worsening their health. Adjustments should be offered as standard options, allowing the person to select the combination that meets their needs. These should include telephone or video appointments, home visits, written or online responses, asynchronous completion, shorter or split appointments, rest breaks, questions in advance, reduced light and noise, flexible scheduling and easy rescheduling.

A short rest break during an appointment may not be sufficient. By the time a person needs to stop, they may have exhausted their available energy and require several days, a week or longer to recover. Some people cannot rest effectively while an interaction continues, and applicants may only recognise that they are approaching or have exceeded their energy limits once an assessment is underway. They must be able to pause or stop the assessment at any point and resume when their health allows, without penalty. This flexibility should include completing assessments across separate sessions or providing written responses progressively over a longer period.

Adjustments must not depend on the person having an informal carer. Some people live alone, wish to preserve independence, or cannot safely rely on family support. Others may be unable to communicate during periods of significant deterioration and need a pre-authorised nominee or deterioration communication plan.

Applicants should not be required to physically demonstrate an activity or undertake performance-based testing where this could trigger PEM, worsen symptoms or cause deterioration. Functional limitations must be capable of being established through existing clinical evidence, the applicant's account, and evidence from carers, support people and treating practitioners. The effects of the assessment itself should be recorded and considered, including cognitive, autonomic, sensory or other deterioration that becomes apparent during or after the appointment.

The CAP consultation included an account of an existing NDIS participant's trial of I-CAN, a support needs assessment tool. The respondent reported that their disabilities were not adequately captured across the available modules, requested communication adjustments were not met, and two long telephone sessions caused a significant crash (PEM). This account

concerns a support needs assessment trial, rather than an assessment under the proposed access process. It illustrates risks that access assessment design must address. I-CAN, or any standardised instrument, should not be used as the sole or primary basis for an access decision. Any tool must be used alongside relevant clinical and lived-experience evidence and appropriately qualified human review, and validated for complex multisystem disability, including cognitive, sensory and autonomic impairment and PEM.

Referral pathways must connect people to appropriate and accessible services whose availability is confirmed. See Question 4 for the proposed referral and continuity safeguards.

Emerge Australia supports better coordination between the NDIS, health, community services and Foundational Supports. However, a referral is not an outcome. Mainstream health services generally provide diagnosis and treatment, not the ongoing personal care, domestic assistance, assistive technology and disability support required by people with substantial and enduring functional impairment. Informal care should not be treated as an alternative service.

Question 6

What factors and evidence should be considered when determining whether an impairment is permanent or likely permanent, including whether appropriate treatment is likely to improve the functional impact of an impairment?

There is currently no established evidence-based treatment pathway that reliably substantially alleviates or remedies the core impairments of ME/CFS or long COVID. Treatment may help manage symptoms or co-occurring conditions without resolving the impairment that causes disability. Whether further treatment is likely to substantially alleviate or remedy an applicant's impairment must be assessed using current evidence and their individual clinical circumstances (CDC, 2024; CDC, 2026). Consistent with proposed principle 3, access decisions must be grounded in current evidence rather than assumptions that further treatment will restore functional capacity.

Whether a treatment is appropriate for an applicant should be a clinical decision made by their treating doctor in consultation with the applicant, taking account of their individual impairments, treatment history, contraindications and risk of harm. Applicants must not be required to undertake treatments that their treating doctor considers inappropriate or unsafe.

Treatment should only be relevant to permanence where it is:

- supported by credible evidence and relevant to the impairment;
- likely to substantially alleviate or remedy the impairment, rather than only manage symptoms;
- clinically appropriate and safe for the individual, taking account of PEM, previous adverse effects and other conditions;
- recommended by a treating clinician who knows the person and their condition;

- practically available within a reasonable time and accessible given cost, location and functional capacity; and
- consistent with informed consent and the person's circumstances and preferences.

Where no treatment meets these requirements, applicants should not be required to undertake further treatment before their impairment can be accepted as permanent. Evidence from an appropriately informed treating doctor that all available and appropriate treatments have been undertaken, or that no available treatment meets these requirements, should be sufficient to address the treatment aspect of permanence. Prognosis and other relevant clinical evidence should also be considered when determining whether the impairment is permanent or likely permanent. Specialist evidence should only be required where clinically indicated and directly relevant to the permanence decision; applicants should not be required to obtain separate specialist evidence for every symptom or co-occurring condition.

CAP feedback described difficulty proving treatments undertaken decades earlier, concern that outdated approaches such as graded exercise therapy may be required, and the physical and financial inaccessibility of specialist or off-label treatments. These concerns closely reflect those raised in Emerge Australia's May 2026 submission on the NDIS Amendment Bill.

NICE advises against offering graded exercise therapy for ME/CFS (NICE, 2021). Treatment expectations must reflect current clinical evidence and the individual's risk of harm.

A person should not have to risk deterioration to prove permanence. Limited research must not be treated as evidence that an effective treatment is available or that the applicant's impairment will resolve.

Protections for current participants

Although detailed transition arrangements will be considered later, reassessment is inseparable from the design of the access process. Current participants must be protected from loss of essential support because a reassessment relies on a narrow assessment tool, incomplete evidence, isolated functional observations, or an assessor who does not understand the person's complex and interacting impairments.

Emerge Australia recommends that:

- the existing plan continue until reassessment and any internal or external review are complete;
- existing evidence be used unless there is a clear reason to request more;
- reassessment not be based on a single appointment or isolated observation of activity;
- participants receive adequate notice, flexible timeframes and all necessary adjustments, together with clear written advice about any additional evidence required, why it is needed and who is appropriately qualified to provide it;
- the NDIA pay the cost of additional evidence it requires;

- participants receive clear written reasons and can correct inaccurate information or address possible misinterpretation of their evidence before a decision;
- review be undertaken by a human decision-maker with relevant disability knowledge; and
- accessible appeal rights and independent advocacy be maintained.

“We should not be requiring people to actively put themselves at risk to help them survive their daily lives.”

— Lisa

Conclusion

Emerge Australia supports reform that makes NDIS access clearer, more consistent and easier to navigate. For people with ME/CFS and long COVID, the process must recognise complex, fluctuating, multisystem disability and assess the combined functional effects of interacting impairments and co-occurring conditions across all relevant domains.

Permanence decisions must reflect current evidence and the applicant’s individual clinical circumstances. Applicants should not be denied access because research is misinterpreted, their impairments are poorly understood, or further treatment is assumed to substantially alleviate or remedy their impairment without supporting clinical evidence. The access process must also avoid causing harm.

The Government should use the period before commencement on 1 January 2028 to develop and test condition-specific guidance with people living with ME/CFS and long COVID, their carers, clinicians and representative organisations. The final process should reduce rather than reproduce the inequities that currently prevent people with substantial and enduring disability from accessing support.

“People living with ME/CFS must be seen as ‘the people the NDIS was designed for’ ... and therefore we must be specifically engaged in the design of all processes that will affect us.”

— Tracey

Emerge Australia would welcome the opportunity to contribute to the next stages of design and testing.

References

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