

Submission on NDIS New Framework Planning Rules and NDIS Supports Transitional Rules

October 2026

Executive summary

Emerge Australia supports more consistent, equitable and transparent NDIS planning, greater participant choice and control, and reduced administrative burden. These reforms must result in a planning process which assesses the support needs of people with ME/CFS and long COVID accurately, including the effects of post-exertional malaise (PEM), and translates those findings into funding that enables participants to obtain and use appropriate disability-related supports.

We welcome the proposed assessment's use of several components and opportunities for participants to check information. However, the consultation materials do not yet explain how post-exertional malaise (PEM) will be considered when assessing support needs and deciding funding. This includes the functional impact of delayed worsening of symptoms after activity, the time needed to recover, and the cumulative impact of activities over a day or longer. Standardisation alone cannot ensure an accurate assessment. If the process overlooks or underestimates PEM, the resulting funding may underestimate the participant's support needs.

Our Community Advisory Panel (CAP) consultation identified difficulties participating safely in assessments, communicating support needs, correcting errors and using allocated funding. These accounts concern existing processes. They identify barriers the reform should address, rather than establish how the proposed framework will perform.

Drawing on the CAP findings, clinical guidance and our analysis of the consultation materials, Emerge Australia identifies four priorities, given effect through the six recommendations that follow:

- **Assessment that captures sustainable capacity.** Assessment must capture PEM, including delayed and cumulative effects and the time needed to recover, as well as consistently restricted capacity. Develop and test a dedicated PEM module, and ensure assessment findings inform support needs and funding decisions.
- **Safe participation and correction before approval.** Participants must be able to take part in assessments, check the record and seek corrections within their cognitive, sensory and energy limits. They should not need reassessment or appeal to correct errors that can be resolved before plan approval.
- **Budgets and changes that fund assessed need.** Budgets must fund assistance that reduces exertion and enables essential activities and participation from home, including recurring support needs during PEM or deterioration. Variations must be prompt when support needs change.
- **Supports that can be obtained and used.** The supports rules must preserve access to appropriate items for energy conservation and sensory access and explain funding flexibility clearly. Participants must have access to individually assessed assistance to organise and manage supports where cognitive impairment or limited energy prevents them from doing so independently.

Safeguards governing assessment, correction and funding should be specified in the rules where appropriate, and supported by accessible templates, practical guidance, assessor capability standards and testing with affected participants before rollout.

Recommendations

1	Assess sustainable capacity and the support needed. Assessments must capture PEM, including delayed and cumulative effects and the time needed to recover, alongside interacting impairments and consistently restricted capacity. These findings must inform assessment ratings, the type and amount of support funded, and budgets. Require assessors to understand ME/CFS, long COVID and PEM and consider all relevant evidence. Develop and test a dedicated PEM module with participants, carers, clinicians who understand these conditions and Emerge Australia. Publish worked examples linking assessment findings to funding.
2	Make participation safe and accessible. Give participants questions and explanations in advance. Allow them to provide written responses over time, as their health permits, and to have a support person assist with communication. Offer remote or home-based assessments, flexible scheduling and multiple shorter sessions, with enough time between sessions for rest and recovery. Participants must be able to stop and resume when their health allows, without penalty. Do not require demonstrations of activities likely to worsen their health. Provide assistance to prepare for the assessment where needed.
3	Allow correction before approval. Give participants enough time and any assistance they need to check the completed assessment report and relevant draft plan information, taking account of their cognitive, sensory and energy limits. Correct factual errors and reconsider disputed interpretations that could affect support or funding before the plan is finalised. Where disagreement remains, record it and explain the reasons for the decision. Correcting an error should not automatically require a new assessment. Explain when a new assessment is necessary and why. Provide interim support where delays would otherwise leave essential needs unmet.
4	Fund assessed needs and explain funding decisions. Publish the calculations, assumptions and evidence used to determine budgets, and check that allocations cover the realistic cost of the participant's individually assessed disability-related supports. Fund assistance and equipment that conserve energy and help prevent PEM or deterioration, including home-based delivery and one-to-one assistance where individually needed. Before reducing funding because of unpaid support, establish what assistance carers can realistically and sustainably provide, taking account of their willingness, health and other responsibilities, and what support is needed when they are unavailable. Allow individual adjustments where standard funding amounts are insufficient. Identify whether difficulties obtaining support arise from inadequate funding, a shortage of suitable providers, or both.

5	Make funding periods and variations responsive. Fund assessed recurring needs, including during PEM or deterioration, in initial budgets. Explain how to request changes to funding periods, including bringing allocated funds forward for urgent needs. Provide timely variations for increased needs or changed support arrangements, with funding adjusted where warranted. Do not require full reassessment solely because a temporary increase is substantial. Use existing evidence where sufficient, set urgent decision timeframes and maintain essential support during changes and reviews.
6	Preserve access to supports and help participants use their plans. For both old and new framework plans, ensure the supports rules allow assistance and equipment that meet the person's assessed disability-related needs, including help with daily activities, mobility and communication, as well as conserving energy and managing sensory limitations. Ensure that removing the replacement-support pathway does not leave participants without appropriate items or services needed to meet their assessed disability-related needs. Assess whether participants need help to organise and manage their supports, and fund that help where needed.

About Emerge Australia and the evidence used

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 people affected through clinical education, policy and advocacy, biomedical research, and health and support services.

This submission responds to the August 2026 consultations on New Framework Planning Rules and NDIS Supports Transitional Rules. It covers assessment, budget development, participant plans and changes under new framework planning, and the proposed categories, exclusions and replacement-support changes affecting old and new framework plans. It builds on our February 2026 planning submission and recent submissions on NDIS access, Support Coordination and Connection (SCC), and the Inclusive Communities Fund. [5, 6, 7, 10]

The submission draws on a September–October 2026 consultation with eight members of our CAP, comprising people living with ME/CFS or long COVID and carers, with experience of NDIS participation and planning. Respondents answered questions according to relevance and capacity. The consultation provides qualitative evidence of barriers and priorities; it was not designed to estimate their prevalence or represent the wider community. [4]

Clinical guidance provides a separate basis for the assessment concerns. NICE describes PEM in ME/CFS as symptom worsening that can be delayed and involve prolonged recovery, and recommends energy management that accounts for overall physical, cognitive, emotional and social activity. [11] CDC guidance also recognises PEM in long COVID. [12] The recommendations concerning PEM apply where it affects the individual participant; diagnosis should not determine a uniform assessment outcome or budget.

Why a functional lens matters: PEM and energy-limiting conditions

ME/CFS is a complex chronic illness, and some people with long COVID have a similar pattern. Its defining feature is post-exertional malaise (PEM): a worsening of symptoms after physical, cognitive, emotional or social exertion, often delayed by hours or days, with recovery that can take days or longer. [11, 12] A task completed once therefore says little about whether it can be repeated, and recovery time and cumulative load must be recorded.

Other features with functional consequences include debilitating fatigue, unrefreshing sleep, cognitive difficulties, orthostatic intolerance and sensitivity to light and sound. [11] Severity ranges from mild to very severe. People with severe or very severe illness may be housebound or bedbound and unable to tolerate sustained interaction. [11]

Management centres on energy management. NICE recommends against programmes based on fixed, incremental increases in activity, which can make symptoms worse. [11] Assistance and equipment that reduce exertion can therefore serve to preserve capacity.

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1. Assessment that captures sustainable capacity

The proposal and the unresolved gap

The planning paper proposes a modified I-CAN version 6 core assessment, the Personal and Environmental Circumstances Questionnaire (PECQ), targeted assessments and assessed support categories. [1] The concern is therefore the performance of the complete process, rather than I-CAN considered in isolation.

Assessment must record the person's individual functional limitations, including consistently limited capacity and changes within that range. Completing an activity once does not establish that it can be repeated safely or sustained alongside other essential activities.

The supplied materials do not demonstrate how these distinctions will be incorporated into both domain ratings and the assistance subsequently funded. Narrative references to PEM are insufficient if ratings or support quantities still reflect only observed task completion. The Department should publish worked examples showing how assistance, delayed consequences, recovery and interacting impairments change assessment and funding outcomes.

Required findings and their use

The rules and assessor instructions should require consideration of:

- Combined physical, cognitive, communication, autonomic, sensory and other impairments across relevant domains, and how they interact.
- Assistance, prompting, supervision, monitoring, standby support, adaptations and equipment needed to undertake activities safely and sustainably.
- Delayed and cumulative consequences of activity, recovery requirements, and reduced capacity for other essential tasks.
- Support needed during periods of the person's typical level of functioning, as well as periods of deterioration and different times of day, without averaging away higher need. Consistently high support needs must also be recognised.
- What happens when support is unavailable, including unmet need and activities avoided because they are unsafe.
- Relevant participant, carer, provider and clinical evidence, with explanations where evidence is not accepted or is interpreted differently.

Where needs vary, the record should describe the frequency, duration and severity of higher-need periods and the support required across that pattern. This information should inform the support and funding allocated, without assuming that all days are alike or that the highest level of assistance is needed continuously.

A CAP respondent reported that vehicle modifications were refused because they could transfer into a car seat, despite the exertion involved and the PEM associated with transfers. Being able to complete a transfer does not establish that it can be done without worsening health. PEM following a transfer can reduce a person's functioning and ability to undertake other activities during recovery. A suitable vehicle modification could reduce that exertion and help preserve their capacity for other essential activities. Assessment should therefore consider the assistance needed, whether transfers can safely be repeated, and their delayed effects, rather than task completion alone. [4]

Testing and a tailored pathway where needed

The consultation paper lists 23 targeted modules but does not include a dedicated module for post-exertional malaise (PEM). [1, p. 18] The Department should develop a PEM module with people with ME/CFS and long COVID, carers, clinicians who understand these conditions, and Emerge Australia. It should guide assessors to identify delayed deterioration after activity, the time needed to recover, and the cumulative effects of exertion. It must also explain how these findings inform assessment ratings, the supports required and funding. Without explicit guidance, assessors may overlook PEM or mistake the ability to complete an activity once for capacity to sustain it, resulting in inequitable outcomes for this cohort. Test the module to establish whether it accurately captures these effects and leads to appropriate support. Support needs and budgets must remain individually assessed.

Testing should include participants with consistently high and changing needs, different combinations of impairments, varying informal assistance, and limited capacity for appointments, including people who cannot safely leave home or engage in prolonged conversations. It should compare identified support requirements with the supports the resulting budget can purchase, using realistic rates and delivery arrangements. Publish the findings, deficiencies and resulting changes before rollout.

Testing should also include people who cannot complete the assessment or use their funding. Distinguish inadequate allocation from provider shortages, inaccessible delivery and implementation barriers: each requires a different remedy. Assessment completion and expenditure alone cannot establish success. [10]

Assessors and delegates need demonstrated competence in applying these principles, including recognising stigma or assumptions that could distort interpretation. This should be assessed through accreditation and maintained through supervision. Access to specialist advice should not place avoidable burdens on participants.

2. Safe participation and correction before approval

Accessible evidence gathering

CAP participants described PEM or deterioration following assessment and planning, and difficulties communicating the extent of their needs. [4] These experiences support implementing practical safeguards alongside testing of the proposed process.

“For me personally, I would need to do the assessment in writing, eg via email or through an online form, and would need to do it over time, not in one sitting.”

— Karyn, CAP respondent

Give participants the questions in advance, explain why they are being asked and identify what evidence is needed. Allow written responses to be provided in stages, as the participant's health permits, and allow a support person to assist with communication. Offer a choice of remote or home-based assessment, flexible scheduling and multiple shorter sessions with enough time for recovery between them. Telephone, video and home-based assessments can still exceed a person's cognitive, sensory or energy limits, so the format

and duration must suit the individual. Do not require demonstrations of activities likely to worsen their health.

Participants must be able to stop and resume when health permits, without an adverse inference from being unable to continue. Brief breaks may be insufficient: a participant may need days before they can safely resume the assessment and may not recognise that they have exceeded their limits until the interaction is underway or deterioration follows. Assistance to prepare for the assessment should be available where needed, so that participants without family or carer help are not disadvantaged.

A CAP respondent who took part in an assessment trial described distress when answering questions about family contact, travel and community activities they could no longer undertake. Assessment design and assessor training should address the emotional impact of discussing lost function and participation, alongside physical, cognitive and sensory accessibility.

These arrangements should reduce repeated work. Collect relevant information once, reuse existing evidence where sufficient, and allow participants to nominate assistance rather than repeating their account across multiple stages.

An effective checking process

The proposed process includes checks during discussion, delegate review and provision of the report. The draft report explicitly invites corrections before the plan is prepared and offers an optional conversation with the approver. [1, pp. 7–8; 8, pp. 1–2] We welcome this. Checking during an appointment is not the same as reviewing the completed interpretation, and the remaining gap is how a correction is received, assessed and resolved before it affects funding.

Cognitive impairment can make it difficult to compare a lengthy report with the information provided, identify omissions or explain a disagreement. Reading and responding may also consume energy needed for essential daily activities or trigger PEM. We recommend:

- A defined response period, extended according to disability-related need, with assistance to check the record and a named responsibility for responding to corrections.
- Inability to reply because of disability is not treated as agreement.
- Minor corrections are resolved without unnecessarily holding up the plan.
- The report distinguishes participant evidence, other evidence, assessor interpretation and conclusions, and is provided in the participant's preferred format.

A consequential error is one capable of changing assessed need, funding, a restriction or safe participation. Correct factual errors and reconsider disputed interpretations with this potential effect before the funding decision. Record unresolved disagreement and explain the decision. Extend supported checking to relevant draft plan information so participants can identify errors in how findings have been translated into allocations and restrictions.

Replacement assessment should be reserved for deficiencies that cannot be resolved through correction or existing evidence. Triggers should include omitted information affecting the outcome, failure to capture relevant PEM or persistent limitation, missing adjustments, relevant evidence overlooked, a participant unable to participate properly, or an unsafe process that made the findings unreliable. Replacement should be prompt, undertaken by an

appropriately knowledgeable assessor independent of the disputed assessment, and use existing evidence where sufficient. A significant change before approval should be addressed without requiring replacement where a narrower update is adequate. CAP participants and carers supported replacement where important information was wrong or missing, or the process was unsafe or unreliable.

Where unresolved deficiencies create an evidenced risk of interruption to essential personal assistance or other necessary support, provide time-limited interim arrangements with clear responsibilities and review dates. A participant whose cognitive or energy limits prevent them from completing a correction process promptly should not lose essential assistance because of that barrier. An assessment identified as materially unreliable should not determine a reduced budget while the problem is unresolved.

Changes to the assessment report template

The template already records multiple assessment dates, support frequency and level, narrative descriptions and targeted evidence. [8] The table below connects CAP findings with improvements needed.

CAP finding	Template issue	Requested change
Activity can involve PEM and substantial recovery.	Frequency and support-level ratings lack context on whether an activity can be sustained or repeated over time.	Record sustainability and repeatability of activity, delayed consequences and preventive support alongside each rating.
Communication difficulties can prevent accurate reporting.	Assessment circumstances may affect reliability.	Record adjustments, participation difficulties and other evidence used.
Errors can lead to burdensome reviews.	Inviting corrections needs an operational process.	Provide supported checking and resolve consequential errors before funding decisions.
Carer health can limit assistance.	Recording who provides unpaid assistance and how often they help does not show whether they can continue providing that support.	Record what assistance carers can realistically provide, taking account of their willingness, health and other responsibilities, and what support is needed when they are unavailable.

In addition:

- Provide an overall explanation of interacting impairments and their effect across domains, with cross-references so relevant effects are not lost between sections. Make differences between typical periods of function and deterioration explicit, while also recording consistently profound limitation. Broad labels such as “daily” and “independent” should not conceal how much assistance is needed or whether an activity can safely be repeated.
- Expand informal-support fields to record actual availability, willingness, sustainability, carer health, competing responsibilities and contingency needs, and explain the effect on any offset.

- Distinguish “no support need identified” from “not assessed” and “insufficient evidence”. Where evidence is insufficient, identify the specific gap, how it can be addressed, what assistance and cost coverage are available, and what happens to essential support meanwhile. Assessor comments on unmet requirements should give individual reasons rather than generic statements.
- Define numerical codes in plain language, record evidence sources, corrections and unresolved disagreement, and make clear which conclusions are the assessor’s interpretation.
- Map assessed support names to the categories used in plans. The example report uses terms such as “Daily Supports” and “Travel and transport arrangements” that need a clear mapping to the categories in the consultation materials. [8, p. 31]
- The degenerative-condition field should not substitute for recording deterioration risk. A person may need urgent changes because of PEM, relapse or reduced baseline capacity without being classified as degenerative.
- Provide a short participant summary and accessible navigation alongside the full report. The 32-page preview illustrates the burden of checking a lengthy report, although an individual report may be shorter. These are template and guidance changes; they should not require participants to complete additional lengthy forms.

3. Budgets that purchase assessed support

Publish the assessment-to-funding relationship

The proposed method uses quotations, set amounts and estimates of support hours. Detailed calculations remain subject to further testing and information release. [1, pp. 8–11] Publish the calculations, assumptions and supporting evidence with a further accessible opportunity for scrutiny. Standardisation may improve consistency, but it must preserve a route to individual adjustment when the standard method fails to fund evidenced disability support needs. Decisions on adjustments should explain the evidence considered, the outcome and the available review pathway.

Test budget adequacy by comparing the allocation with the cost of purchasing assessed quantities and arrangements at realistic prices. For this cohort, the arrangement itself can determine whether support is usable: travel, shared delivery, sensory exposure or prolonged interaction with workers may exceed a participant’s limits. The method should include individually justified home-based delivery, one-to-one assistance, sensory adjustments and delivery with minimal interaction. Record provider shortages separately from funding shortfalls so that each receives an appropriate response.

Assistance with personal care, meals, household tasks and other essential activities can reduce exertion that would otherwise trigger PEM or leave a participant unable to undertake other necessary tasks. Equipment and adaptations may serve the same purpose. Assessment should recognise evidenced preventive needs without requiring the participant to attempt an activity and deteriorate first.

“People with ME/CFS need support to prevent PEM.”

— Karyn, CAP respondent

During severe deterioration, for example, when experiencing an extended period of PEM (or a 'crash'), a person may need more assistance while tolerating less interaction; funding and delivery should accommodate that combination. Previous underspending should prompt examination of unmet need, inaccessible services and implementation barriers, rather than automatically establish that support is unnecessary. Explanations must be usable by people with cognitive impairment and available to a nominated representative where requested.

Informal support and participation

The proposed informal-support offset considers frequency and durability. [1, p. 23] CAP respondents raised concerns that funding could be reduced on the basis of unpaid support that was unavailable or unsustainable, and one account described a carer's progressive health conditions not being adequately considered in planning. Application of the offset should assess assistance genuinely available and sustainable, including willingness, carer health, competing responsibilities and contingency needs. Current unpaid assistance may reflect an unsustainable load. Participants and carers should be able to check the assumptions and understand their funding effect. This permits consideration of reasonable informal assistance while avoiding an inference of availability from family relationships alone.

Test the default community-support amount against individually assessed needs, with a route to adjustment where it falls short. [1, p. 23] Limited outings do not necessarily indicate limited need for assistance, and participation may occur from home, remotely or asynchronously. Assess essential assistance such as obtaining groceries or attending appointments under the appropriate support categories and funding responsibilities. Accessibility improvements in community organisations do not replace individual assistance required to reach or use their services. [6, 10]

A participant plan that explains the decision

The example plan distinguishes unrestricted flexible funding, category-restricted flexible funding and stated supports. Unrestricted funds can supplement restricted in-home and community funding but cannot supplement stated supports. [9] CAP respondents raised concerns about being unable to use available funding for the supports they needed and sought explanations of how allocations and restrictions were determined. We recommend that plans:

- Include a table linking assessed needs and evidence to each allocation, with support quantities, rates, assumptions, individual adjustments and reasons for unfunded requests. The example lists amounts without showing how they were produced, and refers to adjustments without explaining them.
- Explain each restriction, the evidence and safety rationale, when it can be changed, and the practical steps to access funding. Explain how to obtain timely additional stated funding where essential equipment or coordination needs exceed the allocation, since flexible funding cannot be used to top it up.
- Record goals in the participant's own terms, including maintaining function, preventing deterioration and safe participation from home where relevant. Reduced assistive-technology use or increased activity should not be implied as a universal goal.
- Provide decision-appropriate review information. The example directs the participant to external review by referring to an internal review outcome letter. Initial-plan and

internal-review versions should give the applicable pathway, timeframe and assistance. [9, p. 17]

- Provide a concise summary of funding, restrictions, conditions and next steps, with the full plan available. Check dates, totals, labels and cross-references before implementation.

4. Funding periods and changes when needs change

Three different mechanisms must work together. Initial budgets should accommodate evidenced recurring patterns of support need, including deterioration and recovery. Funding periods should permit timely access to money already allocated. Variations should address additional needs or changed arrangements that the existing allocation cannot meet. Altering a release period does not increase the total budget.

The example releases funds quarterly and permits rollover. [9] It should explain how a participant can access allocated funds sooner when the current release is insufficient for evidenced need, and how to request additional funding where the total allocation is insufficient. Provide accessible request channels and proportionate evidence requirements.

The consultation paper anticipates that most updates will occur through variations rather than full reassessment. [1, pp. 11–12] We support this approach. CAP respondents supported variations for increased assistance during PEM or deterioration, temporary carer unavailability, urgent risks and equipment repair or replacement, using existing evidence where sufficient. A temporary increase should not be excluded solely because its cost is substantial. Participants should not have to submit a new request each time their needs increase during PEM or deterioration if their budget already includes funding for those periods.

A significant crash may involve a prolonged or permanent reduction in baseline capacity. Neither an assumption of rapid recovery nor a requirement to establish permanent worsening should delay necessary assistance. Where a participant's ongoing support needs have changed, the NDIA should first consider whether their plan can be varied to provide the support required. If a full reassessment is needed to understand those changes and determine appropriate support, participants should be able to request one. Asking for additional support should not, by itself, trigger a full reassessment.

CAP responses identified benefits from longer plans through fewer assessments, provided initial funding is adequate and changes can be made promptly. An unchanged, sufficient plan should not require repeated proof of the same needs merely because a set period has passed. Specify urgent decision timeframes, escalation and time-limited interim arrangements where delay creates an evidenced risk to essential support. Essential support should continue during plan changes and reviews, with arrangements that avoid a funding gap.

“Every day a request takes to be approved is a day of my life I have lost.”

— Tracey, CAP respondent

A CAP participant described repeated decision and review processes, deterioration from the effort required, and insufficient capacity to pursue all disputed supports. This illustrates why

formal review rights alone cannot ensure practical or equitable access to redress. Participants need clear reasons, assistance, disability-responsive timeframes and meaningful human reconsideration. A review should reconsider disputed evidence and assumptions, rather than simply repeat a calculation based on inaccurate inputs.

5. Support categories, exclusions and replacement supports

Explain flexibility across both frameworks

We support broader purpose-based categories and clarification that appropriate supports can be purchased from mainstream retailers. [2] Guidance should provide examples addressing energy conservation, sensory access, cognitive impairment and assistance with minimal interaction, alongside clear distinctions between assistive technology, consumables, ordinary living costs and health-system responsibilities. The broader categories and accompanying guidance must recognise supports that help people conserve energy, prevent PEM and manage sensory limitations. Participants should not lose access to appropriate supports because decision-makers do not understand their purpose. CAP respondents also raised concerns about useful low-cost items being excluded, reduced flexibility or delayed replacement from stated supports, and funding being unusable in the wrong category.

The planning paper describes pooled flexibility; the supports materials describe spending within a category; and the plan adds restricted and unrestricted flexible funding. [1, p. 9; 2, p. 8; 3, p. 5; 9] These descriptions may concern different aspects or frameworks, but their relationship is not clear. Explain which rules apply to old and new plans, what unrestricted funding covers, how restrictions are imposed or changed, and when approval is needed, with examples of changing therapy or equipment needs during longer plans.

Electronic noise-cancelling headphones

Reconsider the proposed exclusion of electronic noise-cancelling headphones. CAP feedback identified their importance for sensory access. [4] The Department should publish the rationale and explain how disability-related needs will be met if exclusion proceeds.

Provide an individual pathway that considers documented sensory limitations, the benefit of reducing sound exposure for safe activity or participation, whether suitable alternatives meet the need, and comparative cost. Ordinary retail availability should not prevent consideration of an item's specific disability-related function against applicable funding criteria.

Removal of replacement supports

The proposed removal affects both planning frameworks, with commonly requested smart devices and applications instead available as stated supports. [2, pp. 8–9] This does not yet demonstrate that every appropriate function served by approved replacements will remain accessible. Identify those functions, map them to the proposed pathways, and explain eligibility, approval burden and continuity for existing users.

Preserve a low-burden route for justified alternatives that meet applicable criteria, including consideration of effectiveness and comparative cost. Provide transition protection for people using approved replacements and a proportionate process for predictable replacement of appropriate low-cost equipment.

CAP respondents described refusals of meal delivery when a carer could not prepare meals, replacement light-sensitivity glasses, and vehicle modifications intended to avoid transfers that trigger PEM. These accounts raise concerns about whether decisions adequately consider the purpose of a requested support, the effects of PEM and sensory limitations, and the assistance carers can actually provide. They concern existing funding decisions and should be considered separately from the proposal to remove replacement supports. Guidance should explain how to distinguish ordinary living costs from disability-related assistance and when funding is an NDIS or health-system responsibility. Decision-makers should assess whether another funded support can meet the same need safely, rather than assume it is an adequate substitute.

6. Implementation and further consultation

People with ME/CFS or long COVID may need assistance to put their plan into use. Finding providers, explaining adjustments, scheduling workers, checking invoices and resolving service problems can require more cognitive effort and energy than a participant has available. CAP participants reported being unable to use existing funding because they could not manage these tasks. Assess whether participants need support coordination or other assistance to organise and manage their supports. An absence of change in a participant's health or support needs does not mean they can manage their plan independently. Cognitive impairment and limited energy may prevent them from organising services and managing providers, even when their support arrangements are established. [4, 7]

The process of putting a plan into use must also be accessible. Offer written follow-up, short interactions and one topic at a time, with assistance suited to the participant's needs. Allow participants to receive information and respond in writing over time, rather than requiring a meeting. Where participants prefer a meeting, offer a suitable format and duration. If remote participation requires equipment, internet access or communication assistance that the participant lacks, explain how these needs can be met and who is responsible for funding them. [10]

The next consultation stage should publish worked assessment-to-budget examples and enough detail to test these recommendations. Testing and guidance should be developed with participants, carers, condition-informed clinicians and Emerge Australia. Consultation itself must be accessible, with manageable information, adequate response time and low-energy ways to contribute. The Department and NDIA should publish how feedback changed the rules and materials, including findings from participants unable to complete the process or access supports, and explain deficiencies identified for this cohort and the changes made in response.

Use relevant existing evidence, including specialist reports, and avoid unnecessary assessments so participants do not have to repeatedly explain or prove the same support needs. Assessments should consider how support needs change over time, including during PEM or deterioration, what assistance carers can sustainably provide, and whether participants need help to use their funding. Better assessment and planning may reduce avoidable reassessments and reviews. Some safeguards will require additional resources.

Evaluate how long participants wait for support, how much effort the process requires from them, and whether assessment causes PEM or other deterioration. Check whether errors

are corrected before funding decisions, whether budgets cover the cost of the assistance assessed as necessary, and whether participants can find suitable providers and use their funding. Include feedback from people who could not complete the assessment or put their plan into use, so the evaluation captures those facing the greatest barriers.

Conclusion

Emerge Australia asks the Department and NDIA to ensure that assessments capture the effects of PEM and whether participants can sustain activities without worsening their health, and that these findings inform support and funding decisions. Participants must be able to take part in assessments and correct errors before decisions are finalised, with adjustments that meet their cognitive, sensory, energy and other needs.

Budgets must cover individually assessed disability-related support needs, with timely decisions on changes when existing funding or support arrangements no longer meet those needs. The supports rules must allow assistance and equipment that meet the person's assessed disability-related needs, including help with daily activities, mobility and communication, as well as conserving energy and managing sensory limitations. Participants who need help to organise and manage their supports must receive that assistance. We welcome further discussion and participation in testing to identify and address gaps before implementation.

Sources

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2. Department of Health, Disability and Ageing. NDIS Supports Transitional Rules: Consultation paper, August 2026, including the category mapping attachment.
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12. Centers for Disease Control and Prevention. Long COVID Clinical Guidance, managing post-exertional malaise. <https://www.cdc.gov/long-covid/hcp/clinical-guidance/index.html> (accessed 7 October 2026).