

Foundational Supports

General Supports Consultation

‘A different lens’

An insight into energy limiting conditions:

ME/CFS and long COVID



Emerge Australia is the national patient organisation for people living with energy limiting conditions like myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID.

ME/CFS is a “serious, chronic, complex and multisystem disease that frequently and dramatically limits the activities of affected patients” (National Academy of Medicine, 2015). An estimated 45% of people diagnosed with long COVID meet the diagnostic criteria for ME/CFS.

Emerge Australia provides the following services and supports:

1. Evidence-based clinical education
2. Patient and carer support, telehealth and information
3. Collaborative research via AusME Biobank and Registry
4. Advocacy impacting health and disability support policy.

Executive Summary

While significant progress has been made in the support and inclusion of Australians living with disability, there is a long way to go to achieving whole of community inclusion and access for people living with invisible, energy limiting conditions like ME/CFS and long COVID.

Significant, systemic improvements in healthcare education and service provision are required to reduce the burden on patients and their families. Enhanced advocacy and awareness can help bridge gaps in understanding and support, which will lead to better health outcomes and quality of life for those affected by ME/CFS and long COVID. A significant increase in long term funding for organisations who specialise in energy limiting conditions, to assist in educating and awareness raising, is required to deliver effective, targeted and helpful General Supports.

ME/CFS is a disabling illness affecting more than 250,000 Australians. Many thousands more live with long COVID. Even those with 'mild' ME/CFS or long COVID experience a significant reduction in their capacity to complete day to day tasks. Those who are more severe, and are house or bed bound, lack the energy to undertake even the simplest daily tasks, like cooking or cleaning, and have no capacity for education, work or social activities.

*“I feel like lots of gov[ernment] disability is **based on intellectual disability** e.g. face to face, build skills slowly. And that may be ideal for that cohort. But I feel like we're all being **forced into that model** and that **does not represent my needs.**” (emphasis added)*

Despite this, only a small number of Australians living with ME/CFS or long COVID have been accepted onto the NDIS with these conditions as their primary disability. Therefore, there is a large and growing cohort of Australians living with energy limiting conditions who currently have no support at all, despite significant disability.

While the NDIS must better address the needs of Australians with energy limiting conditions where they are eligible for the scheme, Foundational Supports, both General and Targeted, will be crucial to ensure that all Australians have equitable access to services and supports tailored to their needs.

Emerge Australia conducted a survey asking Australians living with ME/CFS or long COVID, and their carers, about General Supports. Overwhelmingly, the call was for greater understanding, awareness and education about energy limiting conditions within health and disability support systems and government. Many respondents also disagreed with the government's focus on individual capacity building. Many were also disappointed that this reform was starting with General Supports instead of Targeted Supports and called for increased practical support to meet their greatest needs.

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Consultation

This report was prepared with combined input from both community consultation and Emerge Australia’s expertise.

1. Community consultation

We conducted a survey of Australians living with ME/CFS and long COVID and their carers on their views and concerns about General Supports. Our survey was designed around the government’s General Supports Consultation Paper and public consultation sessions, and was open for a two-week period in November 2024. We received 71 responses to our survey.

2. Emerge Australia’s expertise

In addition to the results of our survey, this report is informed by Emerge Australia’s extensive and direct experience with ME/CFS and long COVID. Our Support and Telehealth service has provided support to thousands of Australians living with ME/CFS and long COVID, almost half our staff have lived experience of ME/CFS or long COVID, and we deliver RACGP accredited training nationally to GPs and allied health professionals about the diagnosis and management of ME/CFS and long COVID. We have unparalleled insight into the challenges faced by and needs of Australians living with these conditions.

1. Information, advice and referrals

What information, advice and/or referrals have you accessed that have been helpful?
What was helpful about these supports?

Respondents emphasised the significance of online platforms, such as Facebook groups and Instagram accounts, as essential sources of information and support. These platforms were valued for providing a space to share their lived-experience and recommendations for medical specialists, fostering a sense of community and alleviating feelings of isolation. This peer-to-peer sharing of advice was particularly valued for its practical nature and was seen as instrumental for navigating complex healthcare systems and disability support systems, such as the Disability Support Pension (DSP) and National Disability Insurance Scheme (NDIS)

Emerge Australia's Telehealth and Information service was mentioned by numerous respondents as being a place to find helpful, relevant information and advice, delivered in a way that is tailored to their needs. This service is unique in Australia, providing case management and support for people living with ME/CFS or long COVID and their carers.

*“Emerge’s Telehealth Info[rmation Service] was **specific to my needs** without me wasting energy having to explain about my disability because **they are already knowledgeable and non-judgemental.**” (emphasis added)*

What challenges have you experienced when trying to access information, advice and/or referrals? How could these challenges be solved?

A significant theme in the survey responses was the widespread lack of knowledge and understanding about ME/CFS within the community, government systems and support services. This lack of knowledge and understanding often leads to inconsistent and inequitable access to necessary supports, with many reporting facing systemic barriers due to perceptions they are "not disabled enough" to qualify for certain supports or services despite living with significant impairment and disability.

While there is an abundance of information online, respondents reported difficulty knowing which sources are the most accurate for information about their disability and available services and supports. Cognitive impairments such as brain fog, an extremely common symptom, make it difficult for people living with ME/CFS and long COVID to navigate a complex system, and process and apply the information they find.

*“I would love a service that can **assess your situation** and **guide you correctly to what you are entitled to.**” (emphasis added)*

Respondents suggested several solutions to these challenges. Central to these solutions is the need for personalised, individualised services tailored to the unique needs of each person. This could involve trained case managers who are equipped to accurately assess and guide individuals through available supports, and delivering supports in accessible and suitable ways for people living with energy limiting conditions.

1. **Support services** to provide specialised assistance for navigating financial and disability support systems. This includes offering case management and advocacy to help individuals access appropriate resources.
2. **Government and community initiatives** to improve public and professional awareness of ME/CFS and long COVID, and ensure that government policies reflect the current understanding of the condition.
3. **Improved accessibility** to services for those who are housebound or bedbound through expanded telehealth services, home visits, and local support services.

*“I need access to a living human advocate who can **act as my arms, legs, brain and my mind.** A person who **understands my impairment...**” (emphasis added)*

2. Individual capacity building

People living with ME/CFS or long COVID live with a condition which limits cellular energy available for daily living. Like a battery that is almost flat and never fully charges, these individuals are at their capacity, all the time. The only way they will be able to gain capacity in their lives is with practical support provided by another person.

People with ME/CFS and long COVID who try to use more energy than available within the cell can cause themselves harm, as pushing beyond their available energy limits triggers post-exertional malaise (PEM), which is the exacerbation of all symptoms after exertion and reduction in function.

*“Any attempt to build my capacity tends to result in **backwards steps.** Participation in the community (as much as it seems a desirable thing) is **always detrimental to my functioning.**” (emphasis added)*

In our experience, and supported by findings below, people with ME/CFS and long COVID do not require a vast improvement in individual capacity building services, both because of the lack of scope to increase their capacity and because they generally aren't lacking in skills to manage their lives. Rather, they need practical support to build their capacity to remain independent and improve their quality of life.

What do you think about the Federal Government's focus on individual capacity building for people with ME/CFS or long COVID?

There was a mixed response to the idea of individual capacity building for people living with ME/CFS or long COVID. While some acknowledged potential benefits, particularly in fostering peer support and social connections, many felt that focussing on individual capacity building demonstrated a lack of understanding of the unique challenges faced by individuals with ME/CFS and long COVID.

Respondents emphasised that practical and physical support, such as cooking, cleaning, shopping services was their primary need. For many, the focus on skill-building was seen as inappropriate, as it assumes a skill-deficit which they don't have.

*“I don't need to be taught how to do things. I need someone to do them for me.”
(emphasis added)*

Respondents also highlighted the need for services which would meet the needs of those who were house or bedbound, to improve both the quality of life and capacity of these individuals would be to provide services, either online or in-home, which are accessible to them.

Other respondents mentioned the need for tailored professional advocacy services that reflect an understanding of both the needs of people living with energy-limiting conditions and disability services which are available, and which are accessible to people living with these conditions.

Overall, while some could see the value of individual capacity building to improve social connections, most felt this didn't address their needs and reflected a lack of understanding of their condition. Respondents felt that government should prioritise practical support and advocacy services tailored to the specific needs of individuals with energy-limiting conditions such as ME/CFS and long COVID, rather than generalised capacity-building initiatives.

What individual and family capacity building supports have you accessed that have been helpful? What was helpful about these supports?

Respondents shared varied experiences regarding individual and family capacity-building supports. Many had not accessed any such supports or expressed confusion about what these supports entail, highlighting a gap in information awareness.

For those who did access resources, the beneficial aspects of support groups were noted, particularly for reducing feelings of isolation and developing a sense of community and connection. Feelings of isolation are common among people living with ME/CFS and long COVID because most, if not all, of their energy is used on tasks of daily living.

Social activities can also be a high-energy activity, emotionally and physically – particularly if delivered in person. Consequently, most of the support groups accessed by respondents operate

online, often through Facebook or through specific online communities, such as Emerge Australia's online Community Forum. Many valued the opportunity to interact with others at a time that suited them and with people who understand their condition. Organisations like Emerge Australia were frequently cited as providing both community connections and reliable information.

*“Online peer support group initially through Emerge Australia. Half a dozen of us have **remained in contact for several years now**, and provide each other with **ongoing companionship, information, laughter and support. Invaluable.**” (emphasis added)*

Some respondents also accessed practical assistance through services such as Carer Gateway and Care Australia. These organisations provided tangible help, including transport to medical appointments and shopping vouchers. However, accessing these supports often required persistence and advocacy, which is particularly challenging for individuals with limited energy or cognitive capacity. Despite these challenges, these services were appreciated for addressing short term, practical needs.

What challenges have you experienced when accessing individual capacity building services? How could existing supports be improved for you, or what new supports should be developed?

Access and eligibility issues

A common concern was the lack of awareness about available supports or the inaccessibility of existing services. Many respondents noted difficulties navigating complex systems, lengthy wait times, and rigid eligibility criteria, particularly with government programs like the NDIS and DSP, which often excluded people with ME/CFS or long COVID, despite significant disability. Some expressed frustration at the need to repeatedly "prove" the severity of their condition, describing this process as burdensome and degrading. Additionally, many services followed a "one-size-fits-all" approach that failed to address individual needs and varying levels of disability.

Emotional toll

The process of seeking help often carried a significant emotional burden. Respondents shared feelings of distress, shame, and reluctance to request support due to negative past experiences. People with energy limiting conditions need services to be more empathetic and person-centered, to reduce stigma and build trust.

Lack of available services

A critical challenge highlighted by respondents was the scarcity of services, particularly in regional and remote areas, as well as Tasmania as a whole. Many had not accessed any supports because

they were unaware of their existence or because local resources were unavailable. This reflects gaps in both service provision and the dissemination of information about existing supports.

*“...the number one biggest impact on any support is the **lack of community education and acknowledgement around ME/CFS**. If we could shift community knowledge and service delivery knowledge, **we would suddenly open doors**.”*
(emphasis added)

Respondents suggested how services could be improved:

- **Increased awareness and accessibility:** Improve public awareness of available supports and develop home-based or online services to accommodate those who are house or bedbound. Services should be flexible and able to be delivered at times that align with the energy levels of people living with ME/CFS or long COVID, to accommodate these disabilities.
- **Empathetic service delivery:** More compassionate service delivery to reduce the emotional toll of seeking help, ensuring support systems are person-centered.
- **Practical support systems:** Expand service offerings to include practical assistance such as home cleaning, cooking, and gardening. This would address the primary needs of individuals with ME/CFS and long COVID, and allow them to conserve energy and potentially engage in other activities.
- **Community education and training:** Increase community awareness through education and training initiatives to reduce stigma and improve societal acceptance and support for those living with energy limiting and invisible illnesses such as ME/CFS and long COVID.

3. Community capacity building

What community, non-government, or other organisations have you used that were helpful to you? What made it easy to access them, or what was helpful about their support?

Respondents identified a range of community, non-government, and other organisations that provided support. Organisations that fostered social connections and provided inclusive activities were seen as most useful. Among the most frequently mentioned was Emerge Australia, noted for our targeted resources and advocacy for individuals with ME/CFS and long COVID. Other organisations mentioned as being helpful include:

- Victorian Actors Benevolent Trust
- Rivendell Trauma Recovery Centre
- WellWays
- Safe Haven

- GLBTI Rights in Aging (GRAI)
- Sexual Assault Support Service (SASS)
- Riding for the Disabled
- Lachy Foundation
- Church groups

Non-traditional avenues, such as local dance schools, churches, and Riding for the Disabled, were appreciated for their ability to reduce isolation and enhance emotional wellbeing. The helpfulness of these organisations often stemmed from their accessibility and flexibility. Online options were particularly valued. Respondents noted that organisations providing financial support or tailoring their services to individual needs were especially impactful.

*“Local dance school has been **completely inclusive and supportive** of reduced attendance and energy. It has helped **maintain social connections** and made **major difference to my child's outlook.**” (emphasis added)*

What would help to provide disability-inclusive and accessible services for people who live with ME/CFS or long COVID?

The most frequently mentioned suggestion for increasing the accessibility of services for people living with ME/CFS was to increase virtual, online access. These services should provide the option of short appointments, and be available in sensory and energy-friendly formats, such as audio-only, the ability to pause and come back to the information, or participate via text.

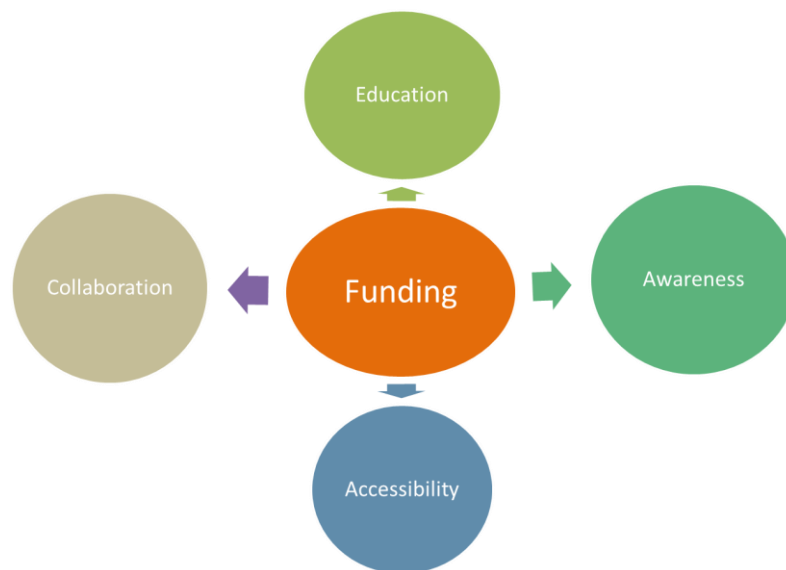
Our collection of responses highlights the need for a holistic approach to service provision, one that considers physical, sensory, and cognitive needs to make services more inclusive and accessible.

The table below includes respondents’ suggestions about how services could be made more inclusive. While these accommodations are designed to specifically address the needs of those living with energy limiting conditions like ME/CFS and long COVID, they would make services more accessible to all Australians.

Physical	Sensory	Cognitive
Online options/ Home visits	Temperature control measures	Single point of information and access
Wheelchair access	Options for visual or auditory resources	Short appointments
Flexible times	Dark and quiet rooms	Support to recognise what you need help with most
Rooms with recliner chairs	Self-paced	Appointment followed up with summary in individual’s preferred format

Do you have any ideas about how government and non-government sectors can work together to better support all people with disability, their families and carers in the community?

Survey responses highlighted a strong desire for greater awareness, understanding, and tailored support for Australians living with ME/CFS and long COVID. Respondents noted the importance of collaboration between government and non-government sectors to address these needs effectively, and the need for greater levels of long-term funding to ensure such collaboration occurs effectively.



*“The government can NOT expect organisations to run with 0 funding. If there was better funding, and organisations knew that funding wouldn't cease pending the elected parties whims, organisations could **properly staff themselves** and then, only then, would **networking and inter-agency cooperation** be possible to provide **better outcomes for people with disability.**” (emphasis added)*

Education

Education and training for healthcare professionals, disability assessors and support service providers would ensure a better understanding of the unique challenges faced by people with ME/CFS and long COVID. Education would also assist to create equitable access to services, and enable services to be more responsive and appropriate.

Accessibility to support and resources

Expanding access to disability support services and advocates is seen as critical to improving outcomes for people with energy limiting conditions. Respondents also recommended increasing the availability of public and social housing options.

Collaborative efforts for accessibility and quality of life

Respondents highlighted the importance of fostering collaboration between government and non-government sectors to improve accessibility, raise public awareness, and provide comprehensive resources. By working together, these sectors can address systemic gaps and enhance the quality of life for individuals with disabilities, their families, and carers.

Healthcare and financial support

Increased Medicare rebates for individuals on pensions, additional rebates for allied health services and improved access to Medicare rebates for telehealth services were recommended. Respondents also suggested creative ways to improve the quality of life of people living with ME/CFS, such as subsidised meal delivery services for people on DSP, to address both health and wellbeing, and financial challenges.

What could the Government measure to help show that life was improving for people with disabilities, especially those living with ME/CFS or long COVID?

Respondents suggested several indicators the government could measure to demonstrate improvements in the lives of people with disabilities, particularly those with ME/CFS or long COVID. These metrics aim to capture both tangible outcomes and overall quality of life.

Access to financial support

One key metric would be an increase in the percentage of individuals successfully accessing the Disability Support Pension (DSP) or the National Disability Insurance Scheme (NDIS), and the number of people engaged in employment. This would reflect improved eligibility processes and greater support for those in need.

Research and data collection

Investing in research that reaches communities directly, and over a period of time (longitudinal) were recommended as crucial steps toward understanding the long-term needs of people living with these conditions. In particular, quality of life indicators were suggested including:

- overall health and well-being
- attendance at education, work, and social activities
- physical activity markers such as daily walking time or hours of upright activity (HUA) should be measured. HUA is used in ME/CFS and long COVID to measure functional capacity and illness severity
- healthcare accessibility, such as reduced time to diagnosis and increased availability of tailored medical care.

Paid participation in surveys was also suggested by a number of respondents as an important way to recognise the value of individuals' time and insights informing policy and service delivery.

Expert organisations, such as Emerge Australia, could be used to undertake this research, especially as often they have their own ongoing research which could be expanded to incorporate government measures. For example, Emerge Australia's Health and Wellbeing Survey (HWS) is a longitudinal study that has measured income, formal and informal supports, access to healthcare and financial

support, and workforce participation data in Australians with ME/CFS since 2015. Our next HWS will include Australians with long COVID. Our AusME patient registry also tracks illness severity in Australians with ME/CFS and long COVID over time.

Do you have any other feedback about General Supports and how supports might be delivered?

A key theme in other feedback about General Supports was the need for holistic support that addresses both the practical and emotional needs of individuals. Respondents reiterated points made earlier in this submission:

- support should be genuine and practical, such as help with household tasks.
- the need for more streamlined processes for accessing support programs.
- application processes should be quick, simple, and well-staffed, to reduce barriers to entry and avoid unnecessary delays.

*“Once you’ve worked out what the supports are, please make sure you **actually tell people they are eligible**. Make the application process **quick and simple**. Make sure there is **sufficient staff**. Please make them **include practical support in the home**.” (emphasis added)*

Many respondents also called for greater equity in healthcare access, enabling all individuals to receive the care they need without discrimination or barriers. This includes implementation of COVID-safe practices, particularly in healthcare settings, to ensure individuals with compromised health or severe symptoms can access care while minimising additional risks.

Finally, respondents emphasised that General Supports should not replace access to the National Disability Insurance Scheme (NDIS) for those who are eligible, and that equitable access to the scheme should be ensured for all Australians with disability, including those with ME/CFS and long COVID. The NDIS remains the key support people wanted greater access to through this reform process.

Conclusion

Current healthcare and support frameworks often fail to fully address the needs of those living with energy limiting conditions such as ME/CFS and long COVID. Many existing policies and strategies are not designed with these conditions in mind, and as a result, the specific challenges faced by individuals with these conditions are overlooked. Furthermore, the success measures used in these frameworks often reflect those with visible disabilities, which are often not applicable to people living with invisible disabilities.

*“I feel like lots of gov[ernment] disability is **based on intellectual disability** e.g. face to face, build skills slowly. And that may be ideal for that cohort. But I feel like we're all being forced into that model and that **does not represent my needs.**” (emphasis added)*

A different lens must be adopted when planning and delivering services for people living with ME/CFS and long COVID. Four key themes from the community from this consultation are:



- 1. Practical support:** Respondents consistently highlighted the need for more practical help to complete essential activities, such as cooking and cleaning. Although this is outside the scope of General Supports, this is the kind of support most respondents were lacking and that would make the most difference to their quality of life. Additionally, understanding and accessing financial rebates, subsidies, and aids like parking permits can reduce strain on patients and carers improve their quality of life.
- 2. Education and awareness:** across service providers, organisations, and the broader community and advocacy. Such education will reduce stigma and discrimination, as well as reduce the burden on patients to educate others about their condition.

- 3. Information and access:** access to reliable and accurate ME/CFS and long COVID-specific information, and ME/CFS and long COVID-aware services, both online and trained service professionals and staff. Respondents particularly value resources that are clear, concise, and tailored to their needs. Organisations like Emerge Australia, which provides evidence-based, relevant information, are highly regarded and seen as crucial in helping people navigate their conditions effectively and link to available support in the community. Further, centralised, sensory-friendly, understanding services and support would reduce the energy required to access such information and services.
- 4. Increased, long-term funding:** The most pressing critical and immediate sector capacity challenge is funding, for organisations like Emerge Australia and others, to enable sustainable and widespread education, specialisation and service provision for people living with energy-limiting conditions. Without sufficient financial resources, the ability to provide the essential services and support appropriate to the needs of people with ME/CFS and long COVID, is limited. We are not able to help as many people as we need to help, nor with the depth of services required due to lack of secure funding.

As documented throughout this submission, the needs of people with energy-limiting conditions like ME/CFS and long COVID have been overlooked and forgotten for too long. 'A different lens' is required to ensure that the proposed Foundational Supports cater to people with all disabilities, including those with energy-limiting conditions, and their carers. Many people, not just those living with energy-limiting conditions, can be more effectively supported if proposed Foundational Supports are developed in consultation with our community, include education for service providers and tailor delivery to accessibility requirements.

"A lot of people have this illness, the government and community need to get moving. People are deeply suffering, often alone." (emphasis added)
