



**Myalgic
Encephalomyelitis
Group Australia**

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Advancing health for Myalgic Encephalomyelitis (ME) in Australia

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To everyone impacted by the debilitating condition ME

I am a young woman studying healthcare and engaged in research focusing on individuals with severe ME. Before embarking on this endeavour, I was unaware of this condition. As I read ME studies and social media blogs, the profound impact of this condition on countless lives worldwide and the numerous unanswered questions filled me with mixed emotions. My heart filled with sadness and anger, imagining the experiences of those affected and comparing them to my own long COVID journey.

Having battled COVID-19 18 months ago, I've faced ongoing respiratory, sleep, and energy issues. Waves of fatigue meant adjusting my daily schedule with pacing strategies and withdrawing from activities and events I attended in my "pre-covid life". Losing connection to social groups and activities leaves me feeling disconnected. While navigating the healthcare system has proven equally taxing as my diagnosis of long COVID met only with a disheartening prescription to "wait it out". Frustration is a companion to this journey, highlighting the shocking reality of the gap in the healthcare system.

My experience is minuscule in comparison to those with severe ME. I cannot grasp the depth of your experiences and the profound losses you have endured. You are the people who ignite the passion and determination in myself and others to advocate for ME.

Progress is undeniable, and your voices, efforts, and determination deserve credit. Although I speak from my experience, I see these positive changes extending to future therapists working in healthcare. I've noticed an increasing number of students discussing and educating themselves about ME. Within our academic community, dedicated staff, researchers, and students are driving for change to amplify your voices.

I'm sincerely grateful for your contributions and encourage you to persist.

You are not alone.

Stay resilient. Keep fighting

- Alex Bennett