Severe ME Month 2025 Webinar Event

Lived Experience Forum

Saturday, 31 May 2025
Start at 3:00 pm (Brisbane/Qld time)

Program

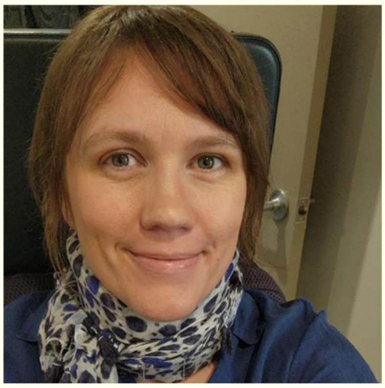
Forum	Time	Length	Topic
Opening			
Julie Hughes - Occupational Therapy Advisor to MEGA Board - Lecturer in Occupational Therapy at Australian Catholic University (ACU)	03:00 pm	20 min	**Welcome.** **Acknowledgement to country.** **Housekeeping** **Introduction to Panel**
Lived Experience Forum			
Q & A with Special Guests	03:20 pm	40 min	**Panels ask questions about Assistive Technology (AT) with Special Guests**
Panels share their Lived Experience	4:00 pm	55 min	**Focus Topic: Assistive Technology (AT)**
Closing			
Julie Hughes	4:55 pm	5 min	**Closing**

Participants

Participants	**Bio**
Moderator	
Julie Hughes 	Julie Hughes has been an occupational therapist for over thirty years. She has a long standing interest in ME and has worked in this area as both a clinician and researcher. She studied in Brisbane but then lived and worked in the UK for many years before returning to live in QLD in 2017 where she commenced as a Lecturer in Occupational therapy on the Australian Catholic University (ACU) campus in Brisbane. She is the occupational therapy advisor for MEGA. She also provides Telehealth Occupational Therapy service called ME Exhaustion Management by Telehealth.
Special Guests	
Clare Batkin 	Clare Batkin is an occupational therapist, clinical educator, sessional academic and founder of the clinical education business Your OT Tutor. Clare has over 15 years' experience as an OT working with adult clients across public and private sectors with her most recent work focusing on completing Functional Capacity Assessments for adult NDIS participants. She is a self-proclaimed "OT Nerd" who loves sharing her enthusiasm for learning and evidence-based practice with other therapists to help them become better OTs who love what they do.

Joanne Mak 	Joanne Mak, founder of My Rehab Team, is passionate about enabling people to be excited about their potential through rehabilitation. Working in community rehabilitation for many years in the UK has grounded her strong belief in the significant benefits of community based service. The completion of a Masters degree in Rehabilitation further consolidated her view and understanding. In 2010, she returned back to Brisbane to be closer to her family. She worked briefly for MS Queensland. Subsequent to that, she worked in the outpatients rehabilitation service at the Ipswich Hospital. It was during those months that she noticed a need for a neurological service which is delivered in a mobile, multi-professional manner and is being made efficient and seamless by the sharing of skills between professionals – trans-disciplinary practice. The service also needs to respond to the changing needs by being patient-driven in design. This gave birth to My Rehab Team. The journey of re-learning about M.E. and the invaluable experience gained are the reasons that Jo agreed to the invitation to share at the Severe M.E. Webinar.
Jon Mitchell 	**Jon Mitchell** Jon Mitchell is the co-founder and NDIS specialist at Smart Places Australia, a pioneering provider of smart home solutions tailored for people with disability. With a background in rehabilitative equipment and occupational therapy studies, Jon brings deep insight into accessibility needs. He works closely with occupational therapists and healthcare professionals to deliver customised automation—smart lighting, locks, climate control, and more—that enhances independence and safety. Passionate about inclusive design, Jon leads with empathy and innovation, ensuring every solution supports real-life functionality. His commitment to improving everyday living through technology has made Smart Places a trusted name in Australia's disability support landscape.

Panels	
Sandra 	Sandra has a background in IT, Complementary Therapies and Vocational Training. Life was vital before ME developed in 2012 after a virus. An attempt to return to work faltered, social activities and hobbies fell away. With no education of PENE and appropriate pacing, her health worsened. It took five years to a clear diagnosis then living within her energy envelope became her goal. She slowly stabilised but has remained in the moderate spectrum. Understanding the history of ME and following the biological science (with preference for the International Consensus Criteria) are very important to her. Sandra is passionate about learning from mistakes of the past and forging new care pathways. She is excited by MEGA's vision for a multi disciplinary clinic and supports the organisation as energy levels allow.
Tracey 	Tracey has lived with ME for 19 years but was only diagnosed in 2022 and spent the next 2 years house and bed-bound with severe ME. Over the past 9 months Tracey has managed to find some treatments that have given her small but significant improvements in capacity. She now prioritises spending time with her family, learning to paint with watercolour, and advocating for people living with ME, mainly via her blog 'Not Just Tired' on Facebook. Prior to having severe ME, Tracey worked in leadership roles at TAFE NSW, loved long walks in nature, yoga, tennis, netball, and swimming, as well as reading and weeding the garden.
Adrienne 	Adrienne comes from a family profoundly impacted by myalgic encephalomyelitis (ME), particularly on my maternal side. Severity ranges from relatives who are 100% bedbound—living in silence and darkness, unable to speak or eat unassisted—to those who can work but must strictly manage activity to avoid post-exertional neuroimmune exhaustion. Our lives have been transformed by the research and guidance of the WorkWell Foundation, whose science-based approach has helped us manage our illness, halt further decline. I'm honoured to be part of this panel and especially grateful to Dr. Todd Davenport for his critical work.

Ketra Wooding 	Ketra Wooding is a former professional yachtie who in 2011 was diagnosed with severe Myalgic Encephalomyelitis (ME). She spent 10 years living in aged care - which she credits with saving her life. Now as an ACA-registered counsellor, Ketra has started her own counselling business to support those dealing with chronic illness. She also volunteers with Lifeline, finding purpose and connection in giving back when she can. Ketra still needs to spend most of her time resting to avoid relapsing and she needs a lot of daily support, but things are looking brighter with the help of her toy poodle Bindi and careful heart-rate pacing.
Shelley-Lee Waller 	Shelley-Lee Waller is a passionate ME advocate and carer for her young adult son, who has improved from severe as a teenager to moderate ME. She also lives with ME and other comorbidities, giving her a dual perspective that deeply informs her advocacy. She is committed to amplifying the voices of parents caring for children with severe ME, navigating both the medical system and the practical demands of caregiving with resilience and clarity. A former journalist now working in health promotion, she blends storytelling with strategic insight to drive change. Her work centres on improving care, visibility, and support for affected families

Myalgic
Encephalomyelitis
Group Australia

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