Severe ME Month 2025
Webinar Event
How to Care for Severe ME

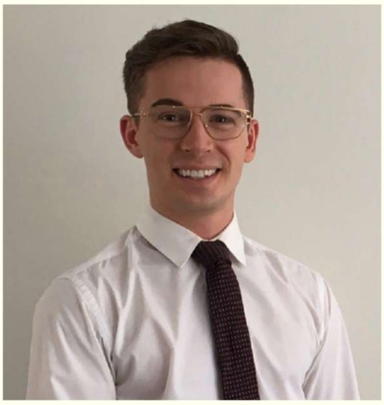
Tuesday, 26 August 2025
Start at 6:00 pm (Brisbane time)

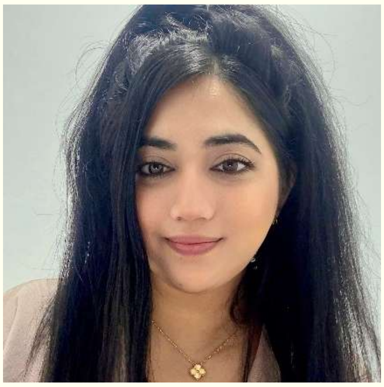
Program

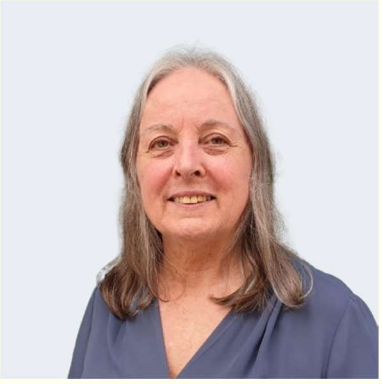
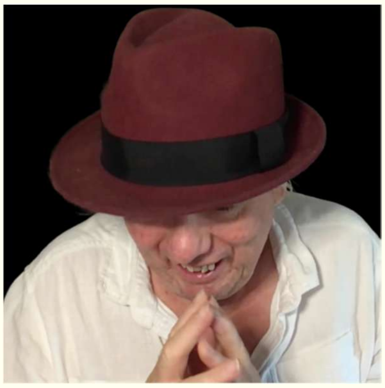
Speaker	Time	Length	Topic
Opening			
Dr Stanley Du Preez, MD, PhD	06:00 pm	10 min	**Welcome.** **Acknowledgement to country.** **Housekeeping**
Presentations			
Heenal Narsey, MSP, MSPA-CPSP	06:10 pm	30 min	**Severe and Very Severe Myalgic Encephalomyelitis (ME) in Australia: The role of Speech Pathologists in a neglected patient cohort** Heenal will share her insights into current Severe and Very Severe ME in Australia and Speech Pathologists can play important role in caring and supporting the neglected patient cohort in Australia.
Q & A	6:40 pm	10 min	

Dr M Alejandra Pinero de Plaza, PhD **Penelope Jane McMillan**	6:50 pm	30 min	**Research into frail, homebound and bedridden people (FHBP): collecting experiences and developing advocacy tools** Penelope and Dr Alejandra will present their collaborative research into the experiences of frail, homebound, and bedridden people (FHBP), highlighting how co-designed inquiry can drive meaningful advocacy and systemic change. Their session will explore: • The academic need • The community need • The evidence on consumer engagement • Designing our study • The KT engagement theories • How we implemented them • Key outputs/outcomes • Takeaways and questions
Q & A	7:20 pm	10 min	
Greg Crowhurst • An Award Winning Nurse • Staff Training & Development • Experiential Learning • Counseling & Spiritual Care • Life Coaching & Web Design • MA in Moral, Spritual and Personal Development.	7:30 pm	25 min	**Severe ME : Notes For Australia** Greg brings over 30 years of lived experience as a full-time carer for his wife, Linda, alongside deep clinical knowledge and a powerful commitment to justice for people with Severe ME. His work in the UK has shaped advocacy, training, and support resources that speak directly to the realities of those most profoundly affected. In this presentation, Greg will share: • Paralysis in Severe ME: insights from a citizen science project co-developed with Linda • The Moment Approach: a compassionate care framework outlined in his book Severe ME: Notes for Carers
Closing			
Dr Stanley Du Preez, MD, PhD	7:55 pm	5 min	**Closing Speech**

Presenters

Host	**Bio**
Dr Stanley Du Preez, MD, PhD 	Stanley is the volunteer Community Coordinator for ME Group Australia (MEGA). His commitment to patients extends into his work as a resident medical officer with Gold Coast Hospital and Health Service. He completed his PhD at the National Centre for Neuroimmunology and Emerging Diseases investigating ME. He is also involved in educating future doctors as a clinical lecturer with Griffith University School of Medicine. Stanley is passionate about improving outcomes for people with ME through clinical medicine, research, education, and advocacy. His goal is to become a specialist in immunology and engage other healthcare providers to support ME patients through safe and effective evidence-based care.

Presenter	**Bio**
Heenal Narsey, MSP, MSPA-CPSP 	Heenal is a Certified Practising Speech Pathologist who graduated with a Master of Speech Pathology from the University of Queensland in 2022. She specialises in adult neurological rehabilitation, supporting people with conditions such as Parkinson’s disease, dementia, progressive supranuclear palsy, motor neurone disease, Huntington’s disease, stroke, and traumatic brain injury. Her clinical practice focuses on the diagnosis, assessment, treatment, and advocacy for individuals with communication and swallowing difficulties. Guided by empathy, evidence-based practice, and holistic care, Heenal is passionate about optimising quality of life. Outside of her clinical work, she enjoys photography and creative writing.

Presenter	Bio
Dr M. Alejandra Pinero de Plaza, PhD 	Alejandra is a scientist committed to facilitating healthy living and better public health services through knowledge translation and health research. She is a Research Fellow at Flinders University and the National Health and Medical Research Council, Centre of Research Excellence in Frailty and Healthy Ageing. Her studies are focusing on the design, implementation, and evaluation of interventions regarding behaviour change, high-tech solutions, and partnering with end-users to ensure better access, care, equity, safety, and quality services to improve health and wellbeing outcomes. She is the Knowledge Translation and Research Advisor for MEGA.
Penelope McMillan 	Penelope has multiple chronic conditions, including severe ME, with 27 years of lived experience of frailty, being homebound, and periods of being bedbound. She has extensive local, national and global networks, both online and in person, with other people who are Frail, Homebound and Bedridden People (FHBP). Penelope actively represents FHBP, creating awareness of FHBP, and advocating for change for FHBP in the health, disability and welfare sectors. Alongside Flinders University researcher, Dr Maria Alejandra Piñero de Plaza, Penelope has helped lead a comprehensive research and innovation project to understand and change lives for FHBP, including those with severe ME.
Greg Crowhurst 	Greg Crowhurst is a nurse, author, musician, and long-time Myalgic Encephalomyelitis (ME) advocate based in Northern Ireland. He is the full-time carer for his wife, Linda, who lives with very severe ME. Together, they founded Stonebird, a website chronicling the lived experience of Severe ME. Greg has written extensively on ME, including books like Severe ME: Notes for Carers and Living in the Heart of Love. He’s also been recognized for his advocacy, placing third in the British Journal of Nursing’s “Nurse of the Year” award. His work blends compassion, creativity, and a fierce commitment to justice

Myalgic Encephalomyelitis
Group Australia

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