



**Myalgic  
Encephalomyelitis  
Group Australia**

## Severe ME Day 2024 Webinar Event

### Lived Experience Forum

**Saturday, 10 August 2024**  
12:00 pm (Qld time)

### Expert Presentations

**Saturday, 17 August 2024**  
12:00 pm (Qld time)

### Event Booking



**SEVERE ME AWARENESS DAY 2024**  
LIVE WEBINAR

<b>LIVED EXPERIENCE FORUM</b> Saturday 10 August 12pm to 2pm	<b>EXPERT PRESENTATIONS</b> Saturday 17 August 12pm to 3pm
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**REGISTER NOW**

To register scan the QR code or email  
info@megroupaustralia.org.au

 **Myalgic  
Encephalomyelitis  
Group Australia**

Join us via Zoom: <https://us02web.zoom.us/j/83427404700>


## Programme

### Lived Experience Forum

Saturday, 10 August 2024: Start at 12:00 pm (Qld time)

Presenter	Time	Length	Topic
<b>Opening</b>			
Justin Hogg	12:00 pm	10 min	<b>Welcome.</b> <b>Acknowledgement to country.</b> <b>Megan and Angus' story by ME/CFS South Australia</b>
<b>Lived Experience Forum</b>			
<b>Chair:</b> Nicole Roudenko	12:10 pm	120 min	<b>Panel:</b> Helen Sandra Ketra

## Presenters

Presenter	Bio
<b>Host</b>	
<b>Justin Hogg</b> 	<p>Justin Hogg is a governance professional that has worked across a diverse range of industries that has included overseeing teams responsible for billion-dollar business ventures through to working with charities to further their goals. For the past 7 years, Justin has established Right Source, an organisation focussed on providing governance and strategic support to the not-for-profit sector.</p> <p>He is currently a Director of Myalgic Encephalomyelitis Group Australia who's aim is to support those with Myalgic Encephalomyelitis and ultimately establish specialty clinics to provide holistic services for those with ME.</p> <p>As part of Right Source, Justin holds Company Secretary positions with various not-for-profit organisations.</p>

**Lived Experience Panel**

**Nicole Roudenko**



Nicole is an Immunology specialist, worked as a senior scientist in diagnostic pathology and research at several hospitals, focusing on immunophenotyping hematopoietic malignancies, HIV, and immunodeficiencies.

After 20 years in science, she retrained in occupational therapy, graduating with first-class honours in 2023, and now works at OccAssess Pty Ltd.

Her honours research on severe ME inspired her to enhance healthcare services for individuals with ME. Nicole is dedicated to destigmatizing ME through education for patients, families, healthcare professionals, and the community, advocating for timely diagnoses and meaningful support for those affected.

**Ketra Wooding**



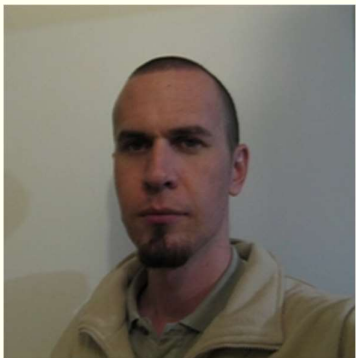
Ketra Wooding is a former professional yachting who in 2011, was diagnosed with severe Myalgic Encephalomyelitis (ME).

She spent 10 years living in aged care - which she credits with saving her life.

Now as an ACA-registered counsellor, Ketra founded 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.

**Helen Donovan & Alem Matthees**



Alem before Severe ME onset.

Helen is Alem's fulltime carer since 2016.

She has watched his weight plummet and due to his sensory sensitivities, she is unable to give her son a cuddle. She can only communicate with Alem with short conversations, and together they have developed their own sign language.

As a mother of a child with severe ME she experiences daily agony witnessing Alem suffer beyond comprehension. She is frustrated at the lack of support Alem has received from some medical professionals.

Alem is 44 years of age, and he is now bedridden.

After catching chickenpox at 15, he never fully recovered and developed chronic fatigue syndrome (CFS). Despite years of tests and treatments, no effective treatment was found.

In 2011 he started on the PACE trial. Along with other ME patients he worked under the FOI to get the Queens University to access the true findings of the PACE trial for which they were successful. During that time some people with ME had committed suicide and others had passed away from the condition.

By February 2016, Alem became extremely sensitive to light, sound, and touch and could only consume smoothies. He had to move back home with his parents who provided fulltime care. For a few years Alem wanted to know any news either about ME or news in general. Today he lives in a dark room, unable to talk or engage with the world.



Alem now.



Alem exists in a dark room.

**Sandra & Chantal**



Kilcare lookout (Sandra tiedie and Chantal in green)

Sandra developed Moderate ME in 2012 & could not return to work. Focus is on managing ME symptoms by pacing, dietary choices, GP guided use of supplements, LDN, gentle yoga, regular acupuncture & Bowen Therapy treatments.

The online ME community brought awareness of millions of other sufferers which fuels her to share “the information she wished she’d known earlier”. A good day may allow up to four carefully used hours for all tasks of daily living.

Chantal is a friend from healthier days. She had Mild ME when a series of housing stressors caused her to decline into Severe ME & is now mostly bed bound.

Recent picture inside Chantals flat.



**Sophie & Zac**

**\* Pre-recorded interview will be shared at our YouTube channel.**

## Expert Presentation

Saturday, 17 August 2024: Start at 12:00 pm ([Qld time](#))

Presenter	Time	Length	Topic
<b>Opening</b>			
Justin Hogg	12:00 pm	10 min	<b>Welcome.</b> <b>Acknowledgement to country.</b>
<b>Expert Presentations</b>			
Nicole Roudenko	12:10 pm	20 min	<p><b>Knowing ME – Knowing You</b></p> <p>Accessing individuals living with severe myalgic encephalomyelitis (ME) for research purposes is challenging. Most of these individuals are largely confined to their homes and beds, reflecting the high level of health and social care required by this group. Online interviewing is one approach to reach people living with severe ME.</p> <p>There is a gap in evidence-based knowledge for healthcare clinicians to reference when treating clients with severe ME. This study explores the lives of nine Australians and, through thematic analysis, uncovers significant issues that individuals with severe ME wish clinicians to understand. Participants describe living with uncertainty regarding what is possible today and in the future, as their lives are profoundly altered by ME.</p> <p>What is certain is that a multidisciplinary team can enhance the lives of people with severe ME. Findings from this study suggest that the occupational participation restrictions experienced by those with severe ME result from the lack of clear healthcare pathways in Australia. Unlike other illnesses, where a diagnosis leads to treatment options and support, individuals with ME often encounter stigma and neglect.</p>
Jo Mak	12:30 pm	45 min	<p><b>Is Neurological Physiotherapy Right for severe ME?.</b></p> <p>In her presentation, Jo will share:</p> <ul style="list-style-type: none"> <li>• Her clinical lived experience</li> <li>• Useful information for Neurological Physiotherapists</li> <li>• Neurological Physiotherapy priorities and goals</li> <li>• Physiotherapy Outcome Measures</li> <li>• Learning so far</li> <li>• Her vision for M.E.</li> </ul>



<p><b>Dr M Alejandra Pinero de Plaza, PhD</b></p> <p><b>Penelope Jane McMillan</b></p>	<p>1:30 pm</p>	<p>45 min</p>	<p><b>Title: TBC</b></p> <p>Alejandra and Penelope will present their consumer involved healthcare research into Frail, Homebound and Bedridden People (FHBP) and Telehealth Model of Care.</p>
<p><b>Clare Batkin</b></p> <p><b>Julie Hughes</b></p> <p><b>Chelsea Bartlet</b></p> <p><b>Nicole Roudenko</b></p>	<p>2:15 pm</p>	<p>45 min</p>	<p><b>Functional Capacity assessments and ME: What an occupational therapist needs to know</b></p> <p>This collaborative presentation by Occupational Therapist (OT) team outlines important considerations for health professionals to assist more pwME to access NDIS funding to improve their function, safety and participation.</p> <ul style="list-style-type: none"> <li>• Functional Capacity Assessments (FCAs) for pwME:</li> <li>• Evidence of functional impairment to clearly addresses NDIS eligibility criteria.</li> <li>• Practical ‘how-to’ strategies for information gathering (assessment process) and report writing itself, including a guide/cheat sheet.</li> </ul> <p>After the presentation, you will be able to target FCAs to include the content NDIS is looking for.</p> <ul style="list-style-type: none"> <li>• Using language they understand and that is inline with legislation,</li> <li>• Maximise the chances of pwME receiving appropriate funding through the NDIS.</li> </ul>

## Expert Presenters

**Nicole Roudenko**



Nicole is an Immunology specialist, worked as a senior scientist in diagnostic pathology and research at several hospitals, focusing on immunophenotyping hematopoietic malignancies, HIV, and immunodeficiencies.

After 20 years in science, she retrained in occupational therapy, graduating with first-class honours in 2023, and now works at OccAssess Pty Ltd.

Her honours research on severe ME inspired her to enhance healthcare services for individuals with ME. Nicole is dedicated to destigmatizing ME through education for patients, families, healthcare professionals, and the community, advocating for timely diagnoses and meaningful support for those affected.

**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.



**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 26 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.

<p><b>Julie Hughes</b></p> 	<p>Julie Hughes has been an occupational therapist for over thirty years.</p> <p>Julie has a long standing interest in ME and has worked in this area as both a clinician and researcher.</p> <p>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.</p> <p>She is the Occupational Therapy Advisor for MEGA.</p>
<p><b>Clare Batkin</b></p> 	<p>Clare Batkin is an occupational therapist, clinical educator, sessional academic and founder of the clinical education business Your OT Tutor.</p> <p>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.</p> <p>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.</p>
<p><b>Chelsea Bartlett</b></p> 	<p>Chelsea Bartlett is an occupational therapist and clinical team leader, currently working in a community-based private practice setting.</p> <p>Since graduating from Australian Catholic University in 2019, Chelsea has developed clinical experience working with adults with a variety of health conditions and disabilities, both in hospital and community settings. She currently works across the NDIS and aged care sectors.</p> <p>Chelsea obtained First Class Honours for her research on the <i>lived experience and occupational disruption of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome for adults in Australia</i>. This research was written in collaboration with co-author of this presentation, Julie Hughes, and has been published in the British Journal of Occupational Therapy.</p>

## ME Group Australia (MEGA)

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