

Functional Capacity Assessments for people with Myalgic Encephalomyelitis

A Guide for Occupational Therapists

Clare Batkin (Your OT Tutor) with Julie Hughes (ACU), Chelsea Bartlett (MLEA), and ME Group Australia

PREPARATION PHASE

- Have a clear understanding of the purpose of the report – is it for NDIS access, or to request additional funding? Tailor the information gathering and report writing to meet the purpose.
- *NB If the FCA is for an NDIS access request, it is essential the person has strong medical evidence of previous treatment and the permanency of their diagnosis.*
- Ensure you have a good understanding of common presentations and symptoms associated with ME. Every person is unique; however, some common symptoms include:
 - PENE (Post-exertional Neuroimmune Exhaustion), also known as PEM (Post-exertional Malaise), pain, gastrointestinal issues, postural orthostatic tachycardia syndrome (POTS), chemical and other sensitivities, joint stiffness and temperature dysregulation.
 - Cognitive issues, or 'brain fog,' including difficulties with memory, word-finding and concentration.
- Be aware people with ME may have experienced social isolation due to difficulty in accessing the community, previous trauma and stigma, misunderstanding and poor interactions with healthcare professionals, and carer compassion fatigue.
- Check your client's preferences for assessment timing and format, communication, and what support people or carers may need to be present. Send through questions prior to a visit so they can prepare.
- Consider asking the person or proxy to complete an activity diary to gain an idea of how the person spends their time and what activities may be important to assess.

PREPARATION

INFORMATION GATHERING PHASE

- Utilise a variety of methods to accommodate the person's preferences and needs; this will also strengthen the quality of the evidence you collect.
- *Interviews*
 - Complete shorter sessions – a 2-hour session is too much.
 - Symptoms can fluctuate so describe the 'worst days' and include percentages if possible (e.g. "50% of the time Mary can walk to the bathroom, 50% of the time she is unable to walk.")
 - Prioritise what questions you ask – do you need to ask them all?
 - Slow the pace – give the person space to think and respond.
 - Include caregivers – can they answer some questions on the person's behalf?
 - Consider written format – so they can answer in their own time.
- *Observations*
 - They can be hard work, but they are ESSENTIAL!!
 - Complete observations across the NDIS functional domains; Focus on tasks requiring supports.
 - Observe tasks when they naturally happen to avoid unnecessary energy expenditure.
 - Use videos and written logs as alternatives and to capture specifics.
 - Capture details and numbers for your report – distances, timeframes, frequency.
 - Capture the delayed impact of exertion: can they do the activity, but this triggers PEM and so they can't complete other activities in the following days.
- *Standardised assessments*
 - Only include if they are adding value!
 - Focus on functional impacts, not the symptoms themselves.
 - Be aware of the NDIS preferred assessments
 - Consider psychometrics – clinical utility (length, delivery format) is essential to consider!
 - Recommendations: WHODAS 2.0, Modified Barthel Index (MBI) or Functional Independence Measure (FIM), Care and Needs Scale (use with caution, not validated for ME), Lawton's IADL Scale or Community Integration Questionnaire Revised, Adult Sensory Profile, FUNCAP.

INFORMATION GATHERING

REPORT WRITING PHASE

- *Language is important*
 - Be deficit-focused (but strengths focused when not writing the report).
 - Include NDIS terminology and plain language.
- *Formatting is important*
 - Increase clarity with sub-headings, dot points and footnotes.
 - If your report is long, include an executive summary on the first page so the reader can quickly get an overview of the person and their situation.
- *Content is important*
 - Highlight risks to the person with ME and/or their carers.
 - Back yourself with evidence from literature.
- *Double-check your facts*
 - Review your draft report with your client/carer prior to submission.

FOLLOW-UP PHASE

- Expect delays for decisions
- Prepare for rejection - if it comes, request the NDIA provide reasons in writing.
- Refine your report, specifically addressing the NDIA reasons for rejection.
- Seek supervision for an outside opinion - is there anything you may have missed?

There is hope, but it can be a fight, so don't give up straight away!

MORE RESOURCES

Websites and documents:

- **ME Group Australia:** <https://megrouppaustralia.org.au/>
- **Emerge Australia:** <https://www.emerge.org.au/>
- **The ME Association (UK):**
<https://meassociation.org.uk/>
- **Nice Guidelines:**
<https://tinyurl.com/niceguidelinemecfs>
- **ME International Consensus Primer for Medical Practitioners (ME-ICP):** <https://tinyurl.com/meicp2012>

Journal Articles:

- Bartlett, C., Hughes, J.L., & Miller, L. (2022). Living with myalgic encephalomyelitis/chronic fatigue syndrome: Experiences of occupational disruption for adults in Australia. *British Journal of Occupational Therapy*, 84(4), 241-250. <https://doi.org/10.1177/03080226211020656>
- Montoya, J. G., Dowell, T. G., Mooney, A. E., Dimmock, M. E., & Chu, L. (2021). Caring for the patient with severe or very severe myalgic encephalomyelitis/chronic fatigue syndrome. *Healthcare*, 9(10), 1331. <https://www.mdpi.com/2227-9032/9/10/1331>

Watch the FREE webinar on FCAs for people with ME here:



Find out more about Your OT Tutor NDIS courses here:



Clare Batkin
Your OT Tutor



Julie Hughes
Australian Catholic University



Chelsea Bartlett
MLEA



ME Group Australia