Supportive housing for people with severe Myalgic Encephalomyelitis

Myalgic Encephalomyelitis Group Australia

Your OT Tutor
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Session take-aways...

- 1. What housing features and assistive technology people with severe ME require
- 2. How to collect evidence without causing harm
- 3. How to clearly describe the person's function in NDIS reports
- 4. Where to go for more guidance

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Disclaimer

- These tips aren't endorsed by specific funding bodies, but they are supported by many other experienced clinicians and people with lived experience of ME.
- This is general advice only! Further professional development and supervision is recommended.

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Impairments associated with severe ME

- **System** – Gastrointestinal disturbances, orthostatic intolerance, sleep dysfunction
- **Physical** – Profound weakness, reduced ability to speak or swallow, pain (headaches, hyperesthesia)
- **Sensory** – Hypersensitivity to light, sound, touch, chemicals and odours
- **Cognitive** – Brain fog, word-finding difficulties, slowed information processing and difficulties with decision-making and executive functioning BUT still able to actively participate with the right support
- **Psychosocial** – loss of occupations and roles, social isolation, gaslighting
- *Plus: extreme intolerance to small amounts of physical, mental, emotional or orthostatic stressors, such as sitting, bathing, toileting, eating and speaking. These can trigger Post-Exertional Neuroimmune Exhaustion (onset 12-48hrs post activity)*

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A week in the life of someone with severe ME...

Fluctuations	Individual differences	Reduced ambulation; wheelchair needed
Assistance and AT needed for self-care	Domestic tasks delegated to others	Slowed information processing
Difficulty engaging in conversations	Energy expenditure needs planning	PENE can hit without warning

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1. What housing features and assistive technology people with severe ME require

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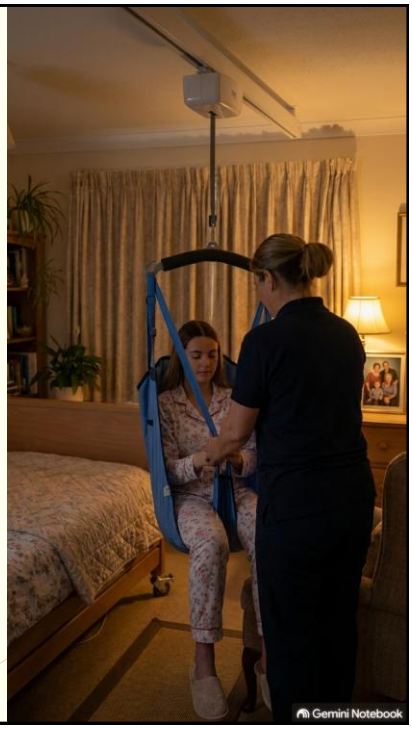
Physical accessibility

- Wheelchair accessible
- Able to have ceiling hoists fitted
  - Reduces carers = better value for money and more favourable for people with severe ME (decreased interactions with people)
- Enough bedroom space to accommodate equipment like an adjustable bed, wheelchair, commode
- Bathroom big enough for commode including tilt commode as often need to be semi-reclined
- Backup power solutions for all the powered AT



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Home automation

- *Why?* Many spend long periods in bed, and it assists with conserving energy
- *What will it control?*
  - Doors/access
  - Curtains/blind control
  - Lights
  - Heating/air con control
  - Television/music/devices
- Activate via voice, switches, timers
- *Watch webinar featuring Jon from Smart Places Australia for more details*

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Living with others

- Shared living difficult due to:
  - Hypersensitivity and sensory overload (noise, smells, lighting, chemicals, movement) means a highly controlled environment is needed
  - Compromised immune function
  - Disrupted and reversed sleep patterns
- Shared housing creates issues for the person with severe ME AND creates restrictions and challenges for the housemate
- Generally single-resident accommodation is required
- ***We need to spell out these challenges in our report when recommending single-resident accommodation***

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Formal support workers

- **1:3 ratio generally unsuitable**
  - Complexity of support needs
  - Unable to live with others (so can't share)
- **24/7 support required,** but not someone physically present at all times
  - Planned short sessions with scheduled breaks alone
  - Stand-by/on call support at all other times for needs that don't happen on a schedule (symptoms, toileting) – *Onsite shared support*
  - Separate space/room for support worker away from person with severe ME
- ***Important to state the ratio required for each activity in your reports***

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2. How to collect evidence without causing harm

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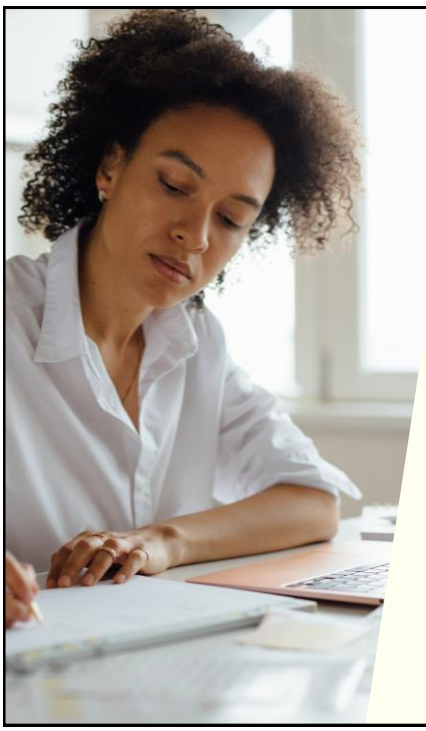

Key principles of information gathering

- Don't go ahead with your autopilot approach!
- Planning is crucial to avoid causing harm on your first visit
- Consider your client's communication preferences
- Prioritise which questions to ask in an interview, how to ask them and consider alternatives for getting the information
- Consider appropriateness of standardised assessments and whether they capture during and AFTER challenges

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Preparation for assessments

Build your NDIS knowledge!	Understand ME presentations	Understand communication preferences
Be flexible with time of day	Would they like carers present?	Map out a plan using the PEO

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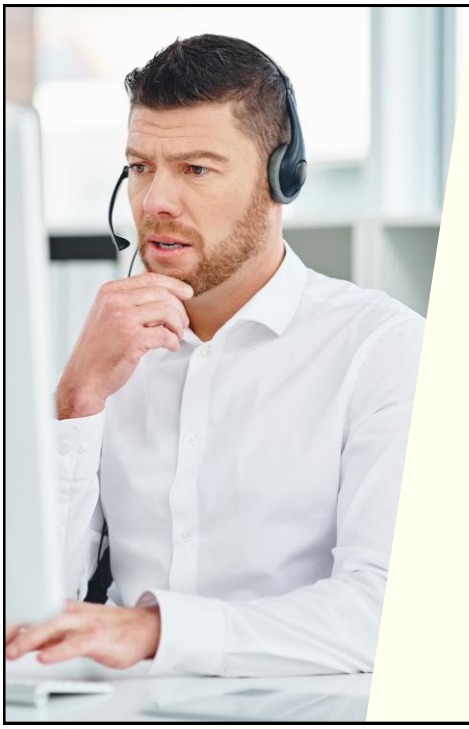

Interviews

- Consider telehealth or written format (so they can answer in their own time)
- Two hours is usually too much – can you split your assessment?
- Prioritise what questions you ask – do you need to ask them all?
- Slow the pace – give them space to think and respond
- Include caregivers – can they be a proxy?
- Capture their worst day – being stoic doesn't help!

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Functional observations

- Hard work, but ESSENTIAL!!
- Conduct observations across the NDIS functional domains but focus on tasks where support will be required
- Consider timing – observe tasks when they naturally happen to avoid unnecessary energy expenditure
- Use videos and logs as an alternative
- Capture details for your report – timeframes, frequency, support needs and risks

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Standardised assessments

Only include if they add value

Focus on function not symptoms

NDIS preferred assessments

Consider psychometrics for validity

Consider clinical utility to save energy

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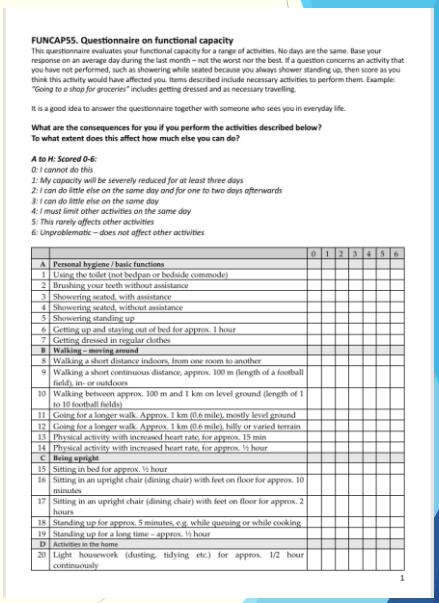
Standardised assessments

- FUNCAP – measures impact of doing activities on the ability to do other activities (PENE)
- Good Day/Bad Day Questionnaire (Bateman Horne Center)
- WHODAS 2.0
- Community Integration Questionnaire – Revised (compare with norms)
- Sensory Profile
- Modified Barthel Index or FIM



FUNCAP55. Questionnaire on functional capacity

This questionnaire evaluates your functional capacity for a range of activities. No days are the same. Base your response on an average day during the last month – not the worst nor the best. If a question concerns an activity that you have not performed, such as showering while seated because you always shower standing up, then score as you think this activity would have affected you. Items described include necessary activities to perform them. Example: *"Going to a shop for groceries"* includes getting dressed and as necessary travelling.

It is a good idea to answer the questionnaire together with someone who sees you in everyday life.

What are the consequences for you if you perform the activities described below?
To what extent does this affect how much else you can do?

A to H: Scored 0-6:
0: I cannot do this
1: My capacity will be severely reduced for at least three days
2: I can do little else on the same day and for one to two days afterwards
3: I can do little else on the same day
4: I must limit other activities on the same day
5: This rarely affects other activities
6: Unproblematic – does not affect other activities

		0	1	2	3	4	5	6
A	**Personal hygiene / basic functions**							
1	Using the toilet (not bedpan or bedside commode)							
2	Brushing your teeth without assistance							
3	Showering seated, with assistance							
4	Showering seated, without assistance							
5	Showering standing up							
6	Getting up and staying out of bed for approx. 1 hour							
7	Getting dressed in regular clothes							
B	**Walking – moving around**							
8	Walking a short distance indoors, from one room to another							
9	Walking a short continuous distance, approx. 100 m (length of a football field), in- or outdoors							
10	Walking between approx. 100 m and 1 km on level ground (length of 1 to 10 football fields)							
11	Going for a longer walk. Approx. 1 km (0.6 mile), mostly level ground							
12	Going for a longer walk. Approx. 1 km (0.6 mile), hilly or varied terrain							
13	Physical activity with increased heart rate, for approx. 15 min							
14	Physical activity with increased heart rate, for approx. ½ hour							
C	**Being upright**							
15	Sitting in bed for approx. ½ hour							
16	Sitting in an upright chair (dining chair) with feet on floor for approx. 10 minutes							
17	Sitting in an upright chair (dining chair) with feet on floor for approx. 2 hours							
18	Standing up for approx. 5 minutes, e.g. while queuing or while cooking							
19	Standing up for a long time – approx. ½ hour							
D	**Activities in the home**							
20	Light housework (dusting, tidying etc.) for approx. 1/2 hour continuously							

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3. How to clearly describe the person's function in NDIS reports

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What's wrong with this?

"Jim struggles to get out of bed. He is slow and unsteady and feels tired after attempting this transfer."

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What your description should include...

- HOW you got the information
- Numbers!
- Assistance and aids required
- Highlight the risks

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What's wrong with this?

- How you got the information?
- Numbers?
- Assistance/aids required?
- Risks highlighted?

"Jim struggles to get out of bed. He is slow and unsteady and feels tired after attempting this transfer."

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Let's fix it!

- How you got the information?
- Numbers?
- Assistance/aids required?
- Risks highlighted?

"Jim was observed to require heavy physical assistance and prompting from his wife to transfer into and out of his bed. When attempting to stand from sitting, 3 attempts were made over 5 minutes, with the difficulty caused by muscle weakness and dizziness when moving from lying to sitting. Jim's wife reported he has had 3 falls this year when attempting to transfer out of bed."

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What's wrong with this sentence?

"Jane can independently brush her teeth, but needs setup assistance to put the toothpaste on the brush, and on 'bad' days can also require help to brush."

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Impairment-focused language is not nice, but it's important...

"**Jane can independently brush her teeth,** but needs setup assistance to put the toothpaste on the brush, and on 'bad' days can also require help to brush."

Otherwise, the NDIA might just see this bit...

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Rewrite like this..

Jane requires setup assistance to put toothpaste on her toothbrush to brush her teeth. On 'bad' days, she requires physical assistance to perform the brushing actions due to weakness.

(*then add all the other details I mentioned in the last example!)*

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Capture impact of PENE

Pippa has experienced frequent episodes of PENE due to insufficient support. For example, if completing her own bed wash for essential hygiene, this has triggered a 'crash' or period of neuroimmune exhaustion which meant she was confined to her bed and was not able to eat her normal meals, for a period of 3 days while recovering. Episodes of PENE currently occur on a weekly basis and last for 1 to 3 days.

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Special details required

- Include a 24/7 breakdown of the person's typical day showing
  - Time (30 – 60 minute intervals)
  - Activity being completed
  - Type of assistance required – standby or active, whether it is standard care or high-intensity
  - Ratio of support for each activity
  - Risks if care not available
- Also consider breaking down good v bad day with practical examples and quantify frequency (e.g. 4 bad days per week)

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4. Where to go for more guidance

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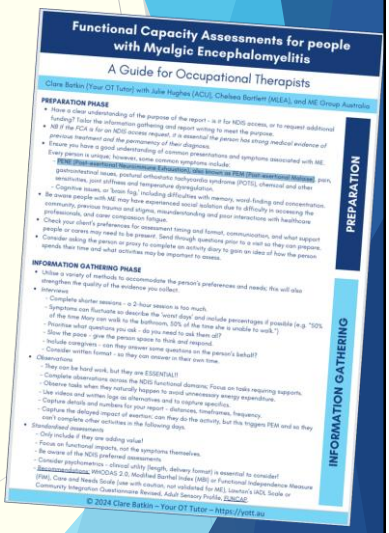
Recommended resources

- MEGA website
  - More resources coming soon via the Virtual Health Hub
  - *Get in touch if you're keen to be involved!*
- MEGA YouTube channel
  - 2025 Lived experience panel
- Facebook group: ME/CFS & Long Covid networking for health professionals
- NDIS report writing resources via **Your OT Tutor** including FCA Template (purchase) and FCA guide for people with ME (free)


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:
  - PEM (Post-exertional Neuroimmune Exhaustion), also known as PENE (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.

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 Barthal Index (MBI) or Functional Independence Measure (FIM), Care and Needs Scale (use with caution, not validated for ME), Newton's IADL Scale or Community Integration Questionnaire Revised, Adult Sensory Profile, PSRCAP.

PREPARATION

INFORMATION GATHERING

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Stop and think...

What is one thing you will do differently as a result of watching this webinar?

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