

# Optimal Care Referral Pathway Position Statement



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## Statement

Currently, people with ME/CFS and post infection diseases, such as Long COVID, do not routinely receive appropriate, coordinated shared care. Further, they face barriers accessing evidence-based information and integrated non-clinical support, all of which can inhibit symptom management and quality of life. It is critical that ME/CFS and other post infection disease patients are empowered to understand their unique needs and become partners in their own care.

Every person who lives with ME/CFS and post infection disease deserves the best care and medical treatment, regardless of financial status or location in Australia. A national, Optimal Care Referral Pathway (OCRP) will provide all people with ME/CFS consistent care across Australia, using an evidence-based, best practice pathway that empowers patients and clinicians to navigate support of complex, multi-system conditions such as ME/CFS, and other post infection diseases, such as Long COVID.

Emerge Australia recommends OCRP should be developed through a multi-disciplinary clinician consensus process that includes people with ME/CFS, carers and allied health professionals to establish the elements of quality care that should be offered. A thorough monitoring and evaluation process would similarly ensure the OCRP is delivering efficient, appropriate and equitable care.

A ME/CFS OCRP will:

- **Improve patient outcomes:** with evidence based best practice pathways of care with constant principles and expectations of optimal care.
- **Prevent worsening of symptoms:** While it is not possible to prevent someone from developing ME/CFS, it is possible to prevent their symptoms getting worse. Initial care can be implemented, including pacing, while ruling out other conditions. For people with Long COVID, it may be possible to reduce the chance of developing ME/CFS by implementing pacing and rest.
- **Enable earlier diagnosis:** by providing accurate information about how to diagnose, and prescribe safe management techniques
- **Support access to social services:** by educating healthcare providers about available disability supports (i.e. DSP and NDIS) and how to access them.

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*Supporting Australians Living with ME/CFS*

## Background

People with ME/CFS currently attempt to navigate a health care system that does not understand their disease, and is known to use outdated treatments, including graded exercise therapy and cognitive behaviour therapy.

People with ME/CFS can have wildly varying experiences of care depending on where they live, how much money they have, their ethnicity and the GP they see. This is due to a combination of factors, which include:

- Out of date clinical guidelines
- Lack of education and understanding of ME/CFS for and by health professionals
- Income (access to multi-disciplinary health care is expensive)
- Stigma and associated negative experiences with health care systems
- Poor access to Disability support, both financial and practical

The standardised treatment pathway that an ME/CFS Optimal Care Referral Pathway would provide will assist in neutralising many of these factors. This will result in equality of care, which is not determined by the factors above.

Optimal care pathways are developed with clinicians, patients and carers, ensuring that the patient remains at the centre of care.

## Evidence

Optimal Care Referral Pathways (OCRPs) support integrated shared care across the entire health system. Key features of OCRPs:

- Describe key stages in a patient's journey and expected standards of care at each step.[1]
- Draw from standards, guidelines, research and clinical consensus, in addition to consumer engagement.
- Provide the framework to ensure consistent, high quality care across the health system.

OCRPs differ from a protocol because they do not provide a proscribed, mandatory process for care. They also differ from a clinical guideline because the aim is to map the patient journey across the health system. Please see Emerge Australia's position about the need for updated clinical guidelines which would mandate safe, up to date clinical care.

Innovative approaches to the coordination of service delivery have achieved improved outcomes for patients in other settings. For example, shared care, in which care is shared between specialist and primary care or other health professionals, has been implemented successfully for a range of health conditions, including diabetes, cancer, paediatric oncology and obstetric care.[2] Shared care enables multidisciplinary collaboration between specialist/ hospital care and primary care clinicians.

An Optimal Care Referral Pathway aims to address seven, key areas of care.

These areas are:

1. **Patient-centred care:** healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and carers.
2. **Safe and quality care:** provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care
3. **Multidisciplinary care:** an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient
4. **Supportive care:** an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer.
5. **Care coordination:** a comprehensive approach to achieving continuity of care for patients.
6. **Communication:** the responsibility of the healthcare system and all people within its employ, in order to ensure the communication needs of patients, their families and carers are met.
7. **Research and clinical trials:** participation opportunities should be offered to patients where practical, at any stage of the care pathway.[3]

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stage of the care pathway.[3]

An OCRP for ME/CFS and post infection diseases like Long COVID would ensure each patient receives equitable and safe care from a breadth of healthcare professionals. Allied health professionals like physiotherapists, exercise physiologists, occupational therapists and psychologists can provide critical support with symptom management. Similarly, specialists including cardiologists, gastroenterologists and rheumatologists can help with symptoms of ME/CFS and Long COVID and common comorbid conditions, like postural orthostatic tachycardia syndrome, irritable bowel syndrome and fibromyalgia.

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  3. National Cancer Expert Reference Group. (2015). 'A Framework for Optimal Cancer Care Pathways in Practice: supporting continuous improvement in cancer care.' Available at: [https://www.nemics.org.au/icms\\_docs/252502\\_A\\_Framework\\_for\\_Optimal\\_Cancer\\_Care\\_Pathways\\_in\\_Practice.pdf](https://www.nemics.org.au/icms_docs/252502_A_Framework_for_Optimal_Cancer_Care_Pathways_in_Practice.pdf).