



A Descriptive study of an Innovative Patient Directed Nurse Led Model of Care to improve services for Australians Living with ME/CFS and Associated Conditions

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Aim

To present a working **Nurse-led Service Model of Care**, developed in South Australian General Practices, as a resource to improve health outcomes for patients with the multisystem conditions ME/CFS and Fibromyalgia.

Background

Australian General Practices are the front line of patient care, providing diagnosis, case management and referrals to specialists and allied health providers, as well as documentation for Government welfare and disability services.

This nurse-led model of care was developed by a South Australian ME/CFS/FMS Clinical Research Working Group of patients, researchers and clinical staff to address the barriers to medical care.

The collaboration works to prevent patients falling through service gaps, to streamline services referrals, and to increase the number of practices providing care for ME/CFS/FMS patients.

The model, based on the Australian Medicare Chronic Disease Management Frameworks, aims to address the lack of clinical guidelines and recommend standardised diagnostic measures, and treatment protocols to effectively manage patients.

Lack of management causes patients to struggle to meet disability and welfare requirements, and out of date information leads to the refusal of services and harmful treatments compound into greater illness burden.

Methods

The model was developed using a variety of methodologies (2004-2022), stakeholder consultations and data reviews were conducted including:

- Communications with Australian ME/CFS specialist clinicians
- Review of ME/CFS and Fibromyalgia clinic practice procedures
- Client call line statistical data (unpublished)
- Working groups with GP staff, nurses, doctors, allied health, patients and carers
- Collation of scattered ME/CFS related information from management and health reform stakeholder consultation projects and wider evaluations
- Participation in activities related to the upskilling of health providers including the development of the ME/CFS and Fibromyalgia primary care Health Pathways

- Collaboration with stakeholders to address barriers to Australians with ME/CFS and Fibromyalgia accessing Centrelink and NDIS.

Data reviewed included the Australian Evaluation of Chronic Disease Management Programs, Medicare Local Projects, interactive clinical databases and other rural telehealth initiatives.

Results

The findings from these activities have been developed into practice resources, and later, the Nurse-led Model of Care to accurately diagnose, manage and triage Australian patients living with ME/CFS/FMS.

The model includes practice handbooks, resources, care pathways and disease algorithms.

Stage 1: Nurse confirms diagnosis and disability levels using symptom surveys (Canadian and International Criteria, Michigan body map, disability assessments).

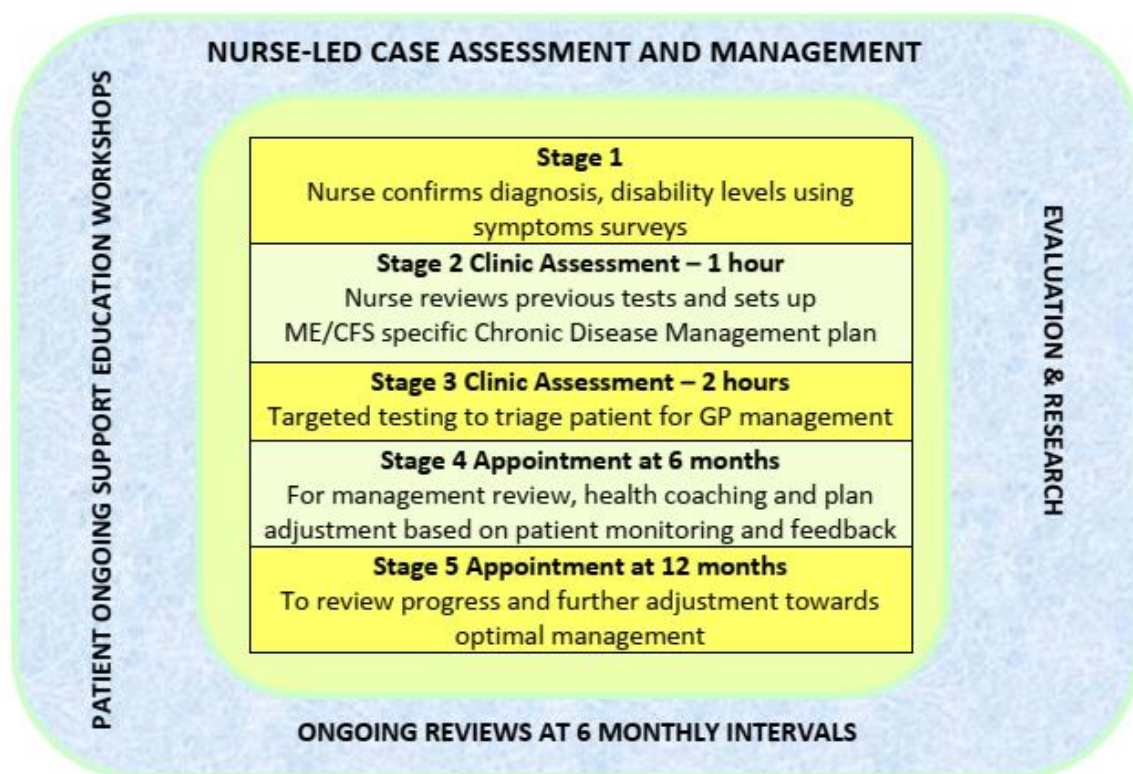
Stage 2: ME/CFS specific Chronic Disease Management plan based on Flinders Program and Medicare Care Plan funding.

Stage 3: Patient is triaged for GP management, with referral pathways tailored for patient's priorities, severity, levels of disability and disease stage.

Stage 4: Appointment at 6 months for management review, health coaching and plan adjustment based on patient monitoring and feedback.

Stage 5: Appointment at twelve months to review progress and further adjustment towards optimal management.

Stage 6: Ongoing reviews at 6 monthly intervals.



Conclusions & Recommendations

The ME/CFS/FMS Nurse-led Model of Care is a realistic and cost-effective method to address the barriers to medical care and reduce General Practice waiting lists.

We recommend it as a solution to fast-track change in healthcare and to address the barriers for patients accessing Centrelink and NDIS applications.

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