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# Self-Management: Parkinson's as a Chronic Condition

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## Setting

Parkinson's is cited as a chronic disease which is a "disease... of long duration and generally slow progression"<sup>1</sup>. The burden of chronic, neurodegenerative diseases, including Parkinson's, is a growing problem worldwide, and it is necessary to find ways to support People Living with Parkinson's (PlwP) and their carers world-wide.

## Objective

This poster presents the results of a systematic review of the existing literature relating to self-management in PlwP.

## Methods

The Cochrane Database of Systematic Reviews, PsycINFO, CINAHL and Embase were used to identify evidence such as randomised controlled trials and original literature, as well as evidence-based guidelines, evidence-based review articles and meta-analysis relevant to the topics reviewed. 3532 studies were found in total, of which 49 were appropriate for review. Selection was based on quality of evidence and relevance to the topic (table 1). Five studies were judged as meeting the inclusion criteria and included in the initial review. Data was extracted, summarised, coded and critiqued.

## Findings

Five studies<sup>2,3,4,5,6</sup> provided evidence related to the effectiveness of self-management (Table 1). Four of the studies demonstrated beneficial impact<sup>2,3,4,6</sup> but one study<sup>5</sup> showed negative impact, namely worsening in fatigue scores.

Evidence Class	Author(s)	Date	Population	Intervention	Randomised	Blinded	Outcome
II	Tickle-Degnen et al. <sup>6</sup>	2010	Idiopathic Parkinson's	Self-management rehab – increasing hours	Y	Y	Improved self-help efficacy
II	Lorig et al. <sup>4</sup>	2012	One or more chronic conditions	Online chronic disease self-management program	N	N	Improved health indicators and health behaviours. Reduced use of health services
III	Ghahari et al. <sup>2</sup>	2012	Multiple sclerosis, Parkinson's or post-polio syndrome	Fatigue self-management program	Y	N	Improved self-efficacy and satisfaction. Reduced stress.
IV	Nelson et al. <sup>5</sup>	2011	Parkinson's	Chronic disease self-management program	N	N	Worsening in fatigue score
IV	Kennedy et al. <sup>6</sup>	2007	Self-defined long-term condition	Chronic disease self-management program	Pragmatic randomisation	N	Improved self-efficacy and health status; reduced health service use

## References

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## Emerging Themes

**Experience of illness:** Three areas emerged from the evidence as particularly impacting on self-management. Pain and fatigue was an area that was improved by CDSMP involvement<sup>3,2,5</sup>.

Deterioration and acceptance of loss of physical and mental function was a large issue for people living with the fluctuating nature of the disorder<sup>5</sup>. Depression was positively impacted by the CDSMP, with increased sense of self-efficacy and reduced stress levels<sup>5</sup>.

**Ways of coping:** Relaxation was a key theme throughout the literature, which responded positively to mindfulness exercises<sup>3,4</sup>. Self-tailoring was shown to be highly beneficial to participants, and was a particular focus for the young onset PlwP<sup>4</sup>.

**Use of Health Services:** Many of the studies found no impact on health service use, with only one<sup>4</sup> finding any reduction in emergency room visits. It was noted that the participants had appropriate use of health services at baseline but developed better collaborative relationships with their healthcare teams<sup>3</sup>.

**Self Efficacy:** Self-efficacy was measured in the majority of studies and found to be worthwhile in most<sup>6,4,3</sup>, with benefits sustained for one year<sup>4</sup>.

Author	Average Age	Gender F/M	Post-school education	Ethnic Background	City / Rural
Tickle-Degnen et al. <sup>6</sup>	66.3	30/68	54.3%	96.6% Anglo (other unstated)	100% / 0%
Lorig et al. <sup>4</sup>	45	150/103	40.9%		0% / 100%
Ghahari et al. <sup>2</sup>	50.25	81/18	42.1%	not stated	60.6% / 39.4%
Nelson et al. <sup>5</sup>	74	7/13	85.0%	85% Anglo 15% Hisp	unstated
Kennedy et al. <sup>3</sup>	55.5	219/94	16.3%	2.0% Aboriginal	unstated

Anglo = Anglo-Saxon Hisp = Hispanic

## Overall

Self-management improves self-efficacy, despite the progressive, fluctuating nature of Parkinson's. It is limited by the health systems in which it is attempted, requiring a collaborative, flexible approach from Health Professionals. In the medical model, this becomes a source of frustration and conflict. Additionally, younger PlwP seem to have a higher desire to engage in self-management and collaborative medicine, requiring increased access and responsiveness from the services they are engaged with, a flexibility that is not possible in the current model of care<sup>7</sup>.

## Conclusion

Self-management is a valuable tool in the overall management for PlwP.. Self-management also requires that the health system be accessible, reactive and collaborative, rather than a medical model system focussed on acute issues, and that healthcare professionals acknowledge the PlwP as someone knowledgeable about their condition and able to play an expert role in their own care. Many healthcare professionals would require support and education around this manner of working. A Parkinson's Disease Nurse Specialist is well-placed to oversee and contribute a supervisory role for healthcare staff and PlwP as an element of a larger overall service for people living with the condition<sup>7</sup>

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