

in brief

PARKINSON'S AND PALLIATIVE CARE



Parkinson's is a progressive neurological condition and the term Advanced Parkinson's usually refers to a time when symptoms are more complex and have more of an effect on day to day life. The effects of medication may be less reliable and may cause side effects at this stage.

Palliative care is not just for the end of life. The principles of palliative care are applicable to all stages of the condition and early discussions with family and/or carers about future care needs and wishes are encouraged.

Palliative care has traditionally been associated with the care of cancer patients but it is also increasingly applied to the care of other advanced chronic conditions.

Palliative care is defined as:

The active total care of patients whose condition is not responsive to curative treatment.

Palliative care offers a support system for the person and their family to manage symptoms and promote comfort and quality of life as Parkinson's advances. In addition, palliative care may positively influence the course of the condition.

Palliative care aims to:

- Provide relief from distressing symptoms such as fatigue, bladder and bowel problems, swallowing difficulties, communication problems, relieve pain and manage any other aspects of advanced Parkinson's.
- Consider the psychological, social and spiritual needs of the person and family by promoting holistic care
- Enhance quality of life.

Recognising the palliative phase in Parkinson's:

Each case of Parkinson's presents with a unique set of symptoms and treatment. Because Parkinson's follows a less predictable course than other advanced conditions, recognising the palliative stage can be difficult. It may be a long stage and the condition can continue to change and progress within this time.

There are limited therapeutic options in the advanced stage and as a result many people require additional care and support alongside regular treatment in order to manage other difficult symptoms. Palliative care provides a framework to guide and plan healthcare.

Indications the palliative stage is approaching:

- Unpredictable efficacy of Parkinson's medications
- Associated cognitive decline or dementia
- Presence of advanced co-morbidities and other issues such as recurrent infections

Support and planning ahead:

The advantages to early discussion and planning for end of life are:

- Being prepared emotionally and practically brings peace of mind
- Increased control and choice around treatment options and where that treatment will take place
- Advice and support will be available to all involved
- Open communication helps guide informed decision making and realistic goal setting. Ongoing family and carer support is important.

Each Australian state and territory has a legal framework for individuals to formally appoint alternative or substitute decision makers to uphold their wishes for future care needs if their own decision making capacity is lost. Enduring Powers of Attorney enable nominated persons to carry out financial matters. Advanced Care directives and Enduring Guardianship allow the person's preferences regarding accommodation, lifestyle, medical and end of life choices to be respected.

This planning reassures the person with the diagnosis that they are involved in their future. It can also ease the burden on the family when personal wishes have been discussed and recorded. These decisions may change over time.

Parkinson's Nurse Specialists and Movement Disorder Nurses may be available in both community and hospital settings and are well placed to offer emotional support from the time of diagnosis to the palliative stage. It is also recommended that these matters are discussed with the treating neurologist, physician or general practitioner.

These professionals can provide guidance on when it is appropriate to access palliative care and where it is available. Palliative care services are available in hospitals, aged care facilities and in the home.

This brochure aims to introduce the concept of palliative care in Parkinson's and is not intended to be used as an end of life guideline.

For further information on palliative care and end of life issues please visit

www.palliativecare.org.au

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Prepared in collaboration with:

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