

Deterioration in Parkinson's Disease

When to refer to Specialist Palliative Care



SMRPCC

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Background

This document has been written for health professionals who are caring for a person with Parkinson's Disease (PD) living in the community. It may also be applicable for other progressive neurological conditions (PNC).

The guide aims to highlight symptoms the patient may exhibit which could be an early indicator of the transition to the palliative stage of the person's life.

A progressive neurological condition is a life-limiting diagnosis, however compared to (for example) a cancer diagnosis, there may be many years before the terminal stage. Furthermore, patients may develop co-morbidities that will either cause death prior to the PNC or contribute to deterioration of the patient. The palliative approach to care for persons with a PNC aims to maximise quality of life through the provision of needs-based care to address physical, psychological, spiritual and social needs.

The 'Triggers' identified in this document are intended to assist health care professionals in identifying when and how to refer to specialist palliative care services.

How palliative care can help

To palliate means to relieve suffering without curing, by managing the symptoms.

Palliative care is designed to maximise quality of life for people with life-limiting illnesses; to provide support, bring comfort and maintain dignity throughout the course of the disease.

Palliative care discussions may give the patient/client a sense of control when they are able to make care decisions about their future. Palliative care discussions include the discussion of Advance Care Planning and goals of care which are an important way for people and their families to have a sense of control over their journey.

Differences between a palliative approach and specialist palliative care

The goals are the same for comfort and quality of life with similar treatment issues, but there are some differences.



Palliative approach

The palliative approach — care of the dying in their place of choice with generalist services involvement e.g., aged care facility with GP and nursing staff.

Many needs may be met by community services without referral to specialist palliative care services provided the patient/client is comfortable and has a care treatment plan that is meeting their needs. They may be managed by their GP and may not need to involve specialised services unless symptoms are not stable or creating issues for the patient/client/family/carer/treatment team. This is called a palliative approach.

If symptoms are stable, and patient/client/family/carer are comfortable, there may be no need for the involvement of specialist services. It may be enough to have regular meetings with the GP, clear goals of care established by the family and anticipatory medications in place to enable symptom relief when the patient/client develops distressing symptoms.

Specialist palliative care

A specialist palliative care service offers specialist advice and intervention for symptom management and complex needs for such things as pain, psycho-social needs and carer respite.

Specialist palliative care can assist with management of pain and symptoms when symptoms cannot be managed by non-specialist services. It includes specialist nursing, medical and allied health services, including psychological support, spiritual care, creative wellbeing therapies and volunteer support. Where the GP or other health professionals require additional support to manage complicated and complex symptoms then referral to specialist palliative care is an appropriate path for ongoing care and support.

Palliative care staff work in conjunction with other services, including GPs and neurologists, to form a team of people providing support and services. There are several types of palliative care service options available, depending on where the patient/client may choose, and depending on what is available within their local area.

Palliative care services do not provide round-the-clock nursing care in the home, although they may provide in-patient respite care for the family/carer with volunteer support or other agency involvement, as appropriate. Many community services provide 24-hour access via an after-hours service.

Benefits of having an advance care plan

Advance care planning gives a person the opportunity to think about, discuss and record in a document, their preferences for the type of care they would or would not like to receive. Advance care planning helps to ensure family and health providers know what matters most to their patients and respect treatment preferences.

Advance care planning also involves appointing a substitute decision-maker to help ensure a person's wishes and preferences are respected in the event they are no longer able to do so themselves. Advance care planning can happen at any stage of life and is most helpful early in the trajectory of an illness with regular reviews.

Settings in which palliative care can take place

Community palliative care

- Palliative care in the community provides specialist medical, nursing and allied health support, as well as information, medications, and the management of complex symptoms and pain management for people being cared for at home or aged care facilities. Community palliative care services provide services to all areas across Victoria and accept referrals based on a person's place of residence. Services are provided to people of all ages. The services are free of charge.
- Services vary from agency to agency, but most provide nurses, medical consultancy, counseling, allied health, OT and PT, pastoral care, bereavement support, telehealth support and some also offer creative health therapies such as art and music therapy.
- Community palliative care may also have trained volunteers who are an integral part of the community palliative care service and may be involved in many different aspects of care to support patients/clients.
- Community Palliative Care services provide planned visits Monday to Friday with weekend visits scheduled as required. A 24-hour on call phone support nursing service is available in most areas, however, the family and carers provide the bulk of the day-to-day care in the home Inpatient Palliative Care.

Patients may be admitted to a hospice or hospital palliative care unit:

- For treatment of complex symptoms and/or carer burden. While in hospital a plan of care is established providing patient and family choice prior to returning home

- For family/carer respite or because continuing to be at home is not an option
- This can be a short-term placement to stabilise or improve quality of life and to control symptoms
- For end-of-life care if there is a rapid deterioration and care cannot be facilitated in the home setting

Hospice has much more flexibility in terms of visiting and pets and is a more home-like atmosphere compared to a hospital setting.

Hospital palliative care consultancies

- Palliative care consultancy services are located within acute care hospitals.
- The consultancy team consists of nursing and/or medical and allied health professionals who provide specialist palliative care skills and education to hospital staff, patients with a life-limiting illness and their families/carers.

Signs of deterioration: triggers

Whilst not all changes listed below are confirmed triggers for impending palliative stage illness, when appearing in combination should be seen as indicators for further discussion with the patient, their family, and the treating medical practitioners.

Changed symptoms on their own can indicate a temporary deterioration, perhaps due to an acute treatable condition such as infection.

The 'Surprise' question should be considered here: "Would you be surprised if this patient were to die in the next 12 months?"

Pain

- Requesting more frequent pain relief, or refilling scripts before they are due
- Prescribed pain relief not adequately managing pain levels
- Non-verbal cues of pain:
 - Facial expression e.g., grimacing, pursed lips, furrowed brow
 - Changed breathing
 - Guarding part of the body
 - Agitation

Respiratory failure

- Abnormal breathing too high or too low — decreased O₂, raised CO₂ sats (although rapid respiratory rate can be a drug induced dyskinesia in Parkinson's and Huntington's Diseases)
- Use of accessory muscles
- Shortness of breath
- Headache, especially on waking
- Poor sleep — needing to sleep upright or in recliner chair
- Increasing or persistent fatigue

Nausea and vomiting

- Decreased appetite
- Dehydration
- Potential for aspiration


Nutrition

- Decreased food and fluid intake
- Dehydration
- Malnutrition
- Weight loss
- Need to change consistency of food and fluids
- Need to change amount of intake — less food more often
- Unable to absorb medications

Cognition, agitation, delirium, hallucinations

- Altered mental status
- Confusion
- Delirium due to infection/ dehydration

Bladder and bowel

- Incontinence
 - Urinary retention
 - Bladder infection
 - Constipation, with or without overflow
- 

Dysphagia and / or secretions

- Aspiration pneumonia
- Choking episodes
- Coughing and clearing throat
- Dehydration
- Drooling
- Dry/ ulcerated mouth and lips

Communication

- Loss of coherent speech/ loss of speech
- Change in cognition
- Withdrawal from social settings

Mobility

- Increasing number of falls
- Increasing number of episodes of care
- Spending more time in bed/ withdrawing from activities and not attending medical appointments
- Orthostatic hypotension
- Increasing assistance with ADL's, PADL's
- Increasing fatigue

When to refer to palliative care

When in doubt as to when to refer, ask the question: "Would I be surprised if this patient died in the next 12 months?" If the answer is yes, consider making a referral. Also, you could contact your local palliative care service to check if a referral would be appropriate.

It is important to assess symptoms for signs of deterioration on an ongoing basis to allow for timely referral to palliative care.

There is no clear answer to the question of when to refer. Evidence suggests that earlier referral to specialist palliative care services can improve the management of symptoms which include physical, social, emotional, or spiritual needs. As palliative care is based on the individual's needs, some people may require periodic referrals to

specialist palliative care services, especially at times of particular symptoms or psychosocial issues.

How to refer to palliative care

Referrals to specialist community palliative care services can be made by the person, family, or any member of the treating team. Community palliative care services are available to discuss any aspect of the referral process and whether services provided are suitable for the patient/ client.

Referral to inpatient palliative care services will be made via the patient's specialist team within the hospital. Palliative care consultancy services are also located in every metropolitan health service as well as each region.

To ensure that a person's referral is not delayed or declined, it is important to understand the following:

- Admission criteria
- Person has been diagnosed with a life-limiting illness and is not currently receiving curative treatment
- Person has care needs which cannot be met by the current service such as complex symptom management, complicated end-of-life care, and more demanding carer support (**it is important to note here** that palliative care services are not funded to provide case management)
- Person is aware of their palliative status and has given consent to the referral to the palliative care agency (this may include their next of kin or person responsible)
- Person lives within the catchment area of the palliative care agency
- Specialist palliative care — referral to a specialist palliative care agency for the management of complex needs and symptoms
- Copies of relevant information is provided at the time of referral where applicable and available (client consent, medical information, hospital discharge summary, current medication list, scans and blood results, relevant specialist letters and clinical notes)
- The palliative approach — care of the dying in their place of choice with generalist services involvement e.g., aged care facility with GP and nursing staff
- If symptoms are stable and the patient, their family and carers are comfortable there may be no need for the involvement of specialist services.

Keeping in touch after referral

After referring to a palliative care service, it's important to stay in touch with the person's medical team.

- Maintain regular contact with the GP and most importantly the neurologist to discuss changing or worrying symptoms.
- Do not ignore symptoms that could be treatable.

Case study

Background

John is 80 years old, and until recently has been living independently with the support of a Home Care Package Level 3.

John's diagnosis of Parkinson's Disease was made 15 years ago after his wife noticed a tremor in his left hand. John also has a diagnosis of arthritis, particularly in his knees. Prior to John's wife's death, both she and John had spent time discussing and formalising their Advance Care Plans.



Current situation

Over the last year, John's voice and language has become unintelligible. A dietician has been involved due to over 10 kg weight loss, the dietician has prescribed a texture modified diet of Level 5 foods and Level 2 thickened fluids. A physiotherapist is involved due to the three falls John has had, the last one resulting in fractured ribs.

A continence nurse advisor has been involved to manage John's constipation, which resulted in a hospital admission where he was diagnosed with faecal overflow. Now John has a strict regime of aperients to manage chronic constipation. The continence nurse advisor has also suggested continence pads to manage urinary incontinence and monitoring for urinary tract infections, of which John has had two in the last 12 months.

John has had two hospital admissions for pneumonia, which were considered to be the result of aspiration of food or fluids. On the last admission, a social worker became involved and assisted John to review his Advance Care Plan that was written ten years ago and began the conversation about the benefits of a referral to his local palliative care service.

Outcome

John initially declined referral to palliative care. Another fall resulted in John's admission to hospital where a urinary tract infection was diagnosed. John's social worker asked herself if she would be surprised if John were to pass away in the coming 12 months, prompting further conversations with John. John then agreed to a new referral to palliative care.



The palliative care service admitted John to their service. After a few months, John's symptoms were stable after referrals were made to a community dietician, and an occupational therapy review had been completed.

Three months later, John experienced a further change to his swallowing and another episode of aspiration pneumonia. John's daughter moved in to care for John. John's care plan included his wishes to remain at home, and his desire to not continue antibiotics. The palliative care service readmitted John to their program. A week later, with his family at his bedside, John passed away at home.

References and further reading

SPICT Tool: <https://www.spict.org.uk/>

CareSearch: <https://www.caresearch.com.au/>

SMRPCC Parkinson's resources

ELDAC – Toolkits: <https://www.eldac.com.au/>

Palliative Care Victoria 1800 660 055

Palliative Care Outcomes Collaboration PCOC:
<https://www.health.gov.au/our-work/palliative-care-outcomes-collaborative-pcoc>

SMRPCC has also developed guidelines for Parkinson's Disease at the end of life. They can be found on our website www.smrpcc.org.au.

