

## section 2.6: palliative care for non-malignant diseases

### what is the context of care for these patients?

Patients diagnosed with a non-malignant condition face the difficulty of chronic disease which may span decades of slow and relentless loss of function and sometimes of their sense of self. Even in this setting there is frequently an unpredictable trajectory of disease with long periods of stability between hospital admissions, though these may be at a lower functional level following an acute event. Advanced illness may seem like a rollercoaster ride for patients and family and judging of prognosis for medical staff is often more difficult than in malignant conditions.

Although these patients are, on average, older than their cancer counterparts, they may have a similar symptom load, with an unintentional weight loss<sup>1</sup> and progressive loss of functional status and quality of life.<sup>2</sup> Progressive disease is usually characterised by increasing symptoms despite optimal use of pharmacologic and non-pharmacologic treatments and precipitous exacerbations which may require intensive care level interventions. A crucial aspect for consideration is the pivotal place of the caregiver and the duration and impact of the caring role.

### important patient- centred goals to consider

- encouraging a focus on wellness can be a positive approach for patients and the balancing of realistic expectations with promoting hope as many chronic conditions depend on self-management strategies<sup>3</sup>
- involvement in decision making processes:
  - patients often understand that they are dying based either on information provided by health professionals or they have worked it out for themselves
  - many patients welcome open and frank discussions about death and dying and want to be involved in directing care priorities
  - these types of discussions need to be carefully planned to allow time for adjustment to progressive disease and declining function and consideration of risks and benefits
  - involvement of key family members is critical

### practical management strategies

- assessment and reassessment allows an appropriate and timely response to the level of patient and caregiver needs
- planning early for changing needs gives some flexibility as supports may take time to put in place
- active symptom management takes priority – patients with end stage respiratory, liver or kidney failure may suffer from severe symptoms in the last year/s of their life and pain is more common in the terminal stages<sup>4</sup> – consider whether a referral to the specialist palliative care team for assessment and optimising symptom management would be of benefit
- exploring quality of life for the patient is critical to overall management and can be easily overlooked – a key family member or caregiver may be able to provide valuable insights in this area
- frequent hospital admissions and medical crises, coupled with an associated loss of functional status and disease which does not respond to therapeutic interventions, may prompt an opportunity for frank and sensitive discussions about future care planning and management decisions

- caregivers require assessment of their specific needs:
  - many family and caregivers willingly provide care for long periods, which may be at personal sacrifice of their physical, psychological or emotional health
  - regular review of caregiver burden by a trusted health provider is required – this may be the GP or staff in the acute setting with whom there has been a lengthy relationship
  - caregivers may be waiting for clinicians to initiate these conversations rather than prompt requests themselves – questions such as “How much sleep did you have last night?” may be a good starting point
  - encouraging caregivers to share the load is essential but may be difficult to accept when they may have “done it all myself for years”
  - the loss of the person either through chronic illness or a dementing process is a particularly distressing and confronting issue that can make the caring role even more difficult – support is critical

Adopting a palliative approach to all aspects of management of end stage non-malignant disease is required (see Section 1 – *About palliative care*) with input from the specialist palliative care team for initial assessment when symptoms for the patient or caregiver become complex. Ensuring that staff with particular skills in chronic disease management (eg specialist respiratory nurses, heart failure nurses, practice nurses in the GP surgery) are involved in the team and that medicines review teams, if available, are utilised to review complex medication regimens, promotes a broad-based approach to care planning across settings.

## **related resources and information:**

Relevant resources are located at the completion of the section containing specific non-malignant conditions.

## **references**

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- <sup>1</sup> Murden R, Ainslie N (1994) Recent weight loss is related to short-term mortality in nursing homes. *J Gen Intern Med* 9:648 – 650.
  - <sup>2</sup> Goodlin S, Jette A, Lynn J, Wasson J (1998) Community physicians describe management issues for patients expected to live less than 12 months. *J Palliat Care*, 14:1, 30-35.
  - <sup>3</sup> Davidson T Preparing for the worst, while hoping for the best: An Integrated Palliative Approach in Cardiovascular Disease. Newsletter, June 2006.
  - <sup>4</sup> Addington-Hall J, Fakhoury W & McCarthy M (1998) Specialist palliative care in non-malignant disease. *Palliative Medicine*, 12:417-427.