

## Referral Criteria for Adult Palliative Care Services in New Zealand

Based on the Leeds Eligibility Criteria for Specialist Palliative Care Services (Bennett, et al., 2000)

Patients must meet **all five** criteria below to be eligible for referral to Specialist Palliative Care (SPC). If there is any doubt about eligibility, the Referrer should contact the Service or Hospice to discuss further. It will be at the discretion of the Service as to whether patients who do not meet all of the criteria will be accepted.

1. *The patient has active, progressive and advanced disease.*

Patients eligible for **Specialist Palliative Care** are those with active, progressive, advanced disease for whom prognosis is limited and the focus of care is quality of life. An alternative term used is that of a life-limiting illness/condition. Prognostic uncertainty (such as exists when embarking on a trial of chemotherapy for an aggressive malignancy where the likelihood of response is low) should not necessarily be a barrier to referral; if there is a clinical need (criteria 2 below) the referral is likely to be accepted. Similarly patients may be eligible for referral to **Hospital** Palliative Care following a sudden or traumatic event in the absence of a pre-existing palliative condition (such as an intracranial haemorrhage or out of hospital cardiac arrest) if the condition is active, progressive and life-limiting.

2. *The patient has a level of need that exceeds the resources of the primary palliative care provider.*

The Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (Ministry of Health Jan 2013) states that palliative care services should “*provide direct management and support of patients, their families and whānau, where more complex palliative care need **exceeds** the resources of the primary palliative care provider.*” The Framework emphasises that the level of input is **needs-based** rather than based on diagnosis or prognosis. Stated another way, referrals to SPC are appropriate where there is an **extraordinary level of need** and examples of this include:

- uncontrolled or complicated symptoms;
- specialized nursing requirements relating to mobility, functioning or self-care;
- emotional or behavioural difficulties related to the illness, such as uncontrolled anxiety or depression;
- concern or distress involving children, family or carers, physical and human environment (including home or hospital), finance, communication or learning disability;
- unresolved issues around self-worth, loss of meaning and hope, suicidal behaviours, requests for euthanasia and complex decisions over the type of care, including its withholding or withdrawal.

3. *The patient agrees to the referral if competent to do so (or an advocate agrees on their behalf).*

4. *The patient has New Zealand residency or has reciprocal rights, and is resident within the DHB. (If the patient is not a New Zealand resident and is in hospital, discuss with the hospital SPC team. If community support is needed, the referral must be discussed with the Hospice team and approval gained from the Hospice CEO prior to the referral being made to ensure funding is authorised).*

5. *The patient is registered with a local primary healthcare provider. (Hospital inpatients without a GP must have this addressed prior to discharge if a Hospice or community palliative care referral is made).*

### **Criteria 4 and 5 are NOT a requirement for referral to a Hospital Palliative Care Team.**

- Patients who meet the above criteria should be referred for SPC Assessment; performed by a SPC Care Interdisciplinary Team. The subsequent level of involvement/intervention, treatment plan and care package will be negotiated with the patient, carer and referring team.
- If the patient is in an acute hospital with no Hospital Palliative Care Team, contact the local Hospice to assess their capacity/capability to give advice and support should that be required.

## Referral Guidance

The following clinical indicators should be assessed when deciding if a referral is appropriate or not. These general indicators are based on the Gold Standards Framework Prognostic Indicator Guide (Thomas. K et al., 2011).

- **For patients with advanced disease or progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?**

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

- **Are there increasing needs and/or general indicators of decline?**

Refer to Step 2 in Appendix A below.

- **Further guidance on referral criteria**

For further guidance on referral criteria for specific diseases and conditions, see Appendix A, which provides information from the Gold Standards Framework Prognostic Indicator Guidance. This information may be used to help determine if a referral is appropriate, and may also be provided to Referrers to inform their decision making on who to refer and when.

### Note

Most referrals to palliative care will have an expected prognosis of less than 12 months. However, not uncommonly it will either be impossible to determine prognosis with any certainty or the clinical need will be sufficient to warrant referral in the context of a life-limiting illness with a more chronic course. When in doubt, contact the Service or Hospice directly.

## Less appropriate referrals

Specialist Palliative Care is largely inappropriate for:

- Patients with chronic stable disease or disability with a life expectancy of several years.
- Patients with chronic pain problems not associated with progressive terminal disease.
- Competent patients who decline referral
- Patients who are unaware of their underlying disease (unless this is a cultural preference in which case this needs to be sensitively addressed).
- Those patients whose problems are principally psychological and need specialist psychiatric referral, whether or not they have declined such help.

Patients can stabilise following Specialist Palliative Care interventions and may no longer require input from that service with their ongoing care being managed by their primary palliative care provider. Discharge from the specialist palliative care service should be planned in collaboration with the primary team. Re-referral back to specialist palliative care can be made at any time should the need arise.

## Appendix A:

Prognostic Indicator Guidance (PIG) 4th Edition Sept 2011

© The Gold Standards Framework Centre in End of Life Care (Thomas. K et al., 2011)

### Step 1: The Surprise Question

**For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?**

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

### Step 2: General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score or Karnofsky Performance Status Score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l

### Step 3: Specific Clinical Indicators

#### A. Cancer - rapid or predictable decline

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PiPS (UK validated Prognosis in Palliative care Study), PPI, PPS etc. Prognosis tools can help but should not be applied blindly
- The single most important predictive factor in cancer is performance status and functional ability - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

#### B. Organ Failure - erratic decline

##### **Heart Disease**

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy

##### **Chronic Obstructive Pulmonary Disease (COPD)**

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)

1. Hospital Palliative Care New Zealand (HPCNZ) – August 2014
2. Sincere thanks to the Midland Palliative Care Workgroup, upon whose work the Referral Criteria are based

- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months

#### **Renal Disease**

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload

#### **Liver Disease**

- Ascites despite maximum diuretics: spontaneous peritonitis
- Jaundice; Hepatorenal syndrome
- PTT > 5 seconds above control
- Encephalopathy
- Recurrent variceal bleeding if further intervention inappropriate

#### **General Neurological Diseases**

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus the following:

##### **Motor Neurone Disease**

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties

##### **Parkinson's Disease**

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below

##### **Multiple Sclerosis**

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia

## C. Frailty / Dementia / CVA - gradual decline

### **Frailty**

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression

### **Cerebral Vascular Accident (CVA/Stroke)**

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia

### **Dementia**

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

## References

Bennett, M., Adam, J., Alison, D., Hicks, F. & Stockton, M. (2000). Leeds eligibility criteria for specialist palliative care services. *Palliative Medicine*, 14, 157-158.

Ministry of Health, New Zealand. Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand, Jan 2013.

<http://www.health.govt.nz/publication/resource-and-capability-framework-integrated-adult-palliative-care-services-new-zealand>

Thomas, K., et al. (2011). The GSF prognostic indicator guidance. (4th Edn). Available from: <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>. [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)