

**GUIDELINES: Referral Guidelines to Nelson Tasman Hospice Service including Clinical Criteria for Patients**

**Overview**

Admission to the hospice service is NOT diagnosis specific and includes all patients with a life limiting condition whose care is complex and cannot be fully met by a generalist provider. The patient does remain under the care of their general practitioner with the wider care and support of the NTH.

Most referrals to specialist hospice 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 Nelson Tasman Hospice.

**Scope**

This guideline is for both generalist providers of palliative care and the clinical staff of Nelson Tasman Hospice.

**General Criteria for Referral to Hospice Service for all Diagnoses**

**All of below:**

- The patient has active, progressive and advanced disease and they are reasonably expected to die within twelve months (this time-frame may be longer if they are children or young adults, and those with non malignant diseases) the focus of care is quality of life. .
- The patient or family/ whanau have complex palliative care needs that can not be met by generalist providers of palliative care e.g. primary care or hospital care providers. These may be symptom management issues, psychosocial issues, spiritual or cultural issues.
- The patient agrees to referral to Nelson Tasman Hospice.
- The patient is currently residing in the catchment area.
- The patient is registered with a local primary health care provider

**Additional Groups** - may be referred and discussed individually with the hospice team:

- The patient is imminently dying and has requested to die in the hospice.
- Some patients who have a progressive terminal disease with a longer prognosis but have complex needs.

Patients may 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 will 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.

**Inappropriate referrals include:**

- Patients with chronic stable disease or disability with a life expectancy of greater than 1 year.
- Patients with chronic pain problems not associated with a progressive terminal disease.
- Competent patients who decline referral or who are unaware of their underlying disease.
- Patients whose problems are principally psychiatric and need specialist psychiatric referral, whether or not they have declined such help.

**Specialist Palliative Care Advice**

Palliative care advice is available at all times, whether or not the patient is on the Hospice service (Tel 03 546 3950). Information is also available on the Health Pathways website.

<http://nm.healthpathways.org.nz/>

**Some examples of reasons for referral include:**

- Complex care coordination and requirement for patient advocacy.
- Complex symptoms which have not responded to simple measures e.g. pain, nausea/vomiting, breathlessness etc.
- Psychological/spiritual distress associated with approaching death for the patient or their family/whanau e.g. severe anticipatory grief.
- Complex social issues associated with failing health.
- Complex communication issues, including advanced care planning, wills and funeral issues, distress associated with requests for euthanasia or physician assisted suicide.
- Wish to avoid hospital admissions and likely need for support out of hours.
- Symptom management and end of life care and co-ordination of care when a patient chooses to withdraw active management of their illness e.g. dialysis.

## Disease Specific Clinical Indicators to Guide Referral to Hospice

**All patients should meet the criteria above** and have symptoms and/or psychological, spiritual, social or cultural issues that can not be managed by generalists. However there are a number of disease specific clinical indicators here to guide appropriate referral of non-cancer patients as it can be much harder to define an accurate prognosis for this group of patients. Admission to Hospice service may be episodic.

### Cardiac Disease/Heart Failure

#### All of below:

- Advanced heart failure (New York Heart Association class 4 - see appendix 1).
- Recent review by cardiology team to ensure maximum tolerated therapy.
- Heart transplantation and mechanical circulatory support ruled out.
- Patient does NOT want CPR in the event of a cardiac arrest.

#### Other prognostic factors suggesting limited life expectancy include:

- Poor renal function
- Low sodium
- Refractory hypotension necessitating withdrawal of medical therapy
- Multiple admissions to hospital in last 12 months with symptoms of heart failure despite optimised treatment
- Diuresis resistance
- Cardiac cachexia
- Physical or psychological symptoms despite optimal tolerated therapy
- Patient has had life saving therapy and/or an internal cardiac defibrillator turned off

The hospice service will liaise with the cardiology team where appropriate to maximize symptom management. Admission to service may be short term e.g. 6 weeks and then reviewed.

### Pulmonary Disease

#### All of below:

- Short of breath at rest (MRC grade 4 – see appendix 1)
- Very severe airflow obstruction – FEV<30% predicted
- 2 or more hospital admissions for severe exacerbations in the last year
- Patient no longer wishes hospital admission for treatment with IV antibiotics/ventilator support for infective exacerbations

### **Other prognostic factors suggesting limited life expectancy:**

- Housebound by disability
- BMI<20 and weight loss
  
- Receiving long term O2 therapy
- Documented progressive disease
- Symptomatic right heart failure/cor pulmonale

### **Renal Disease**

- Stage 5 renal failure or Stage 4 chronic kidney disease **and** significant comorbidities (see appendix).
- Not able or willing to undergo dialysis or transplant.

#### ***AND at least one of the following:***

- Patient wishes to stop dialysis
- Signs and symptoms of renal failure (e.g. severe nausea, pruritus, restlessness and altered consciousness)
- Intractable fluid overload
- Rapid deterioration anticipated by renal team

### **Neurological Disease**

- Significant progressive decline in overall function

#### ***AND at least one of the following:***

- Complex discussion around treatment options e.g. BIPAP/PEG placement and end of life advanced care planning for MND.
- Barely intelligible speech or difficult communication issues
- Difficulty eating/drinking, associated cachexia and feeding/PEG issues
- Significant dyspnoea
- Major psychological issues associated with the disease process

### **Liver Disease**

#### ***At least one of the following:***

- Ascites despite maximum tolerated diuretics
- Spontaneous peritonitis
- Jaundice and hepato-renal syndrome
- Encephalopathy
- Recurrent variceal bleeding if further intervention is inappropriate

#### ***AND:***

- Liver transplant is not indicated

## **Dementia**

- Inability to dress and/or walk without assistance and
- Urinary and faecal incontinence and
- No consistent meaningful verbal communication

### **AND at least one of:**

- Difficulty swallowing/eating; weight loss (>10% loss over 6 months)
- Recurrent urinary and/or respiratory infections
- Multiple stage III or IV decubitus ulcers
- Symptoms causing distress

## **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

## **FRAILITY**

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

## Other Situations Include:

- Multiple co- morbidities with no primary diagnosis
- Patient medically unfit for surgery for life threatening disease
- Failure to respond to Intensive Care and death therefore inevitable

## References

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These guidelines will be reviewed 2 yearly.

Date Initiated:		Name: Frans Dellebeke		Clinical Policy and Guidelines Manual	
Last Review Date: May 2015		Position: CEO		Guidelines – Appropriate referral to NTH with specific clinical criteria	
Next Review Date: May 2017		Signature:			
Reviewed By: (Initials)	QI	CNL	SMO	ED	

## Appendix 1

The New York Heart Association Functional Classification	
Class 1 (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation or dyspnoea.
Class 11 (mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical exertion results in fatigue, palpitation or dyspnoea.
Class 111 (moderate)	Marked limitation of physical activity. Comfortable at rest but less than ordinary activity causes fatigue. Palpitation or dyspnoea
Class 1V (Severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. Physical activity increases symptoms experienced.

Medical Research Council Dyspnoea Scale	
Grade 1	'I only get breathless with strenuous exercise'
Grade 2	'I only get short of breath when hurrying on the level or up a slight hill'
Grade 3	'I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level'
Grade 4	'I stop for breath after walking 100meters or so or after a few minutes on the level'
Grade 5	'I am too breathless to leave the house'

Stages of Chronic Kidney Disease		
Stage	eGFR	Description
1	90+	Normal kidney function but urine findings or structural abnormalities or genetic trait point to kidney disease
2	60-89	Mildly reduced kidney function, and other findings (as for stage 1) point to kidney disease
3A 3B	45-59 30-44	Moderately reduced kidney function
4	15-29	Severely reduced kidney function
5	<15/on dialysis	Very severe, or end stage kidney failure

<b>WHO Performance Status Clarification</b>	
0	Able to carry out all normal activity without restriction
Grade 1	Restricted in physical strenuous activity, but ambulatory and able to carry out light work
Grade 2	Ambulatory and capable of self care but unable to carry out work; up and about for more that 50% of waking hours
Grade 3	Capable only of limited self care; confined to bed more than 50% of waking hours
Grade 4	Completely disabled; cannot carry out any self care; totally confined to bed or chair

<b>Palliative Performance Scale (PPS)</b>					
<b>%</b>	<b>Ambulation</b>	<b>Activity Level Evidence of Disease</b>	<b>Self-Care</b>	<b>Intake</b>	<b>Level of Consciousness</b>
100	Full	Normal <i>No Disease</i>	Full	Normal	Full
90	Full	Normal <i>Some Disease</i>	Full	Normal	Full
80	Full	Normal with Effort <i>Some Disease</i>	Full	Normal or Reduced	Full
70	Reduced	Can't do normal job or work <i>Some Disease</i>	Full	As above	Full
60	Reduced	Can't do hobbies or housework <i>Significant Disease</i>	Occasional Assistance Needed	As above	Full or Confusion
50	Mainly sit/lie	Can't do any work <i>Extensive Disease</i>	Considerable Assistance Needed	As above	Full or Confusion
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion
30	Bed Bound	As above	Total Care	Reduced	As above
20	Bed Bound	As above	As above	Minimal	As above
10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	--