lake taupō hospice

CLINICAL POLICY CP-039

LAKE TAUPŌ HOSPICE COMMUNITY SPECIALIST PALLIATIVE CARE SERVICES REFERRAL, TRIAGE AND ADMISSION PROCESS

REFERRAL PROCESS

Lake Taupō Hospice accepts referrals from GPs, medical specialists and other healthcare professional agencies or directly from patients or their family/whānau.

Referrals from GPs, medical specialists and other health care professionals must be submitted on either a "Hospice & Specialist Palliative Care Referral Form" (available on the Lake Taupō Hospice website) or electronically via the 'Health Share Best Practice" (BPac) system. BPac was created for the purpose of assisting in the transfer of electronic referrals (e-referrals) and helping to manage the exchange of information between health care providers in the Midland region. A username and password are required to access the BPac e-referral system.

Verbal referrals from patients or their family/whānau should be directed to the Clinical Manager.

Paediatric palliative care referrals must be discussed directly with the Clinical Manager.

Referrals to hospice must include confirmation that the patient (if competent) or their named advocate has consented to the referral. Referrals should be accompanied by all available supporting patient information e.g., hospital discharge summaries, specialist letters, Advanced Care Plans, EPOA status, medication summaries, Community Authority for Medication Administration if on a syringe driver etc.

Lake Taupō Hospice is a community-based specialist palliative care service. When patients require referral(s) to non-specialist palliative care primary care service providers, the original referrer is responsible for sending these. Non-specialist palliative care referrals include:

- Domiciliary oxygen supply
- Wound Care
- Ostomy care and supplies
- Indwelling catheter or supra-pubic catheter management and supplies
- NASC referrals for those with a life expectancy > six months
- Community Occupational Therapy and Physiotherapy assessments / equipment

Lake Taupō Hospice is not funded to provide equipment, but does have limited supplies of some items more commonly needed by hospice patients whose performance status is deteriorating e.g., electric recliner chairs, hospital beds, air mattresses, commodes etc.

Please note that a referral to Lake Taupō Hospice does not mean automatic acceptance. Please see over for "Referral Criteria for Adult Palliative Care Services in Midland Region. To discuss or clarify referrals Mon – Fri 0830-1700hrs, phone the Clinical Manager on (07) 377 4252.

For **urgent referrals after-hours and weekends** contact the on-call hospice nurse on **0800 920044** to provide a verbal handover prior to sending the written referral via email to: info@laketaupohospice.co.nz

If the advice of a Palliative Medicine Specialist is required, contact Dr Denise Aitken Mon-Fri 0900-1600hrs via the Rotorua Hospital switchboard (07) 348 1199. If Dr Denise Aitken is unavailable to discuss the referral and/or it is after-hours or a weekend, call the Waikato Hospital switchboard on (07) 839 8899 and ask for the Palliative Specialist on duty/on call.

TRIAGE AND ADMISSION PROCESS

All referrals are triaged by the Clinical Manager as per 'Referral Criteria for Adult Palliative Care Services in Midland Region'.

The Clinical Manager completes an 'Acknowledgement of Referral' form (CS-004 in Clinical Documents) advising whether the referral has been accepted or declined. This form is then emailed to the referrer by hospice admin staff.

E-referrals received via BPac go to both info@laketaupohospice.co.nz and the Clinical Managers email address. BPac referrals are accepted or declined by the Clinical Manager clicking the 'reply' tab and typing in the response. The reply message will automatically go back to the referrer and the triage status in BPac will show as "replied". The BPac User Manual MG-029 is saved in User Manuals & Guidelines.

Once accepted, patient details are entered into PalCare by hospice admin staff and the referral is uploaded into the 'Correspondence' section of the patient's PalCare notes.

The Clinical Manager accesses the patient's PalCare notes and clicks the "accept" then "admit" tabs and allocates a hospice nurse.

The hospice nurse contacts the patient and/or family/whānau to book an Initial Assessment to introduce Lake Taupō Hospice service as soon as is practicable.

A Family Support Team member then contacts the patient or family/whānau within 2-3 days of the first nursing visit to introduce Lake Taupō Hospice family support services.

All new patients are presented at the next patient handover meeting to coordinate their ongoing care.

REFERRAL CRITERIA FOR ADULT PALLIATIVE CARE SERVICES IN MIDLAND REGION

Based on the Leeds Eligibility Criteria for Specialist Palliative Care Services (Bennett, et al., 2000) Midland region includes Bay of Plenty, Lakes, Tairawhiti and Waikato

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,
- specialised 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 area.
(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 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 Guidance (Thomas, et al., 2011).

1 **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?

2 **Are there increasing needs and/or general indicators of decline?**
Refer to Step 2 in Appendix A below

3 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 Guidance aims to help health professionals in the earlier identification of adult patients nearing the end of their life who may need additional support (Thomas, K., et al., 2011).

Appendix B provides an additional tool, the Supportive and Palliative Care Indicators Tool (SPICT), which was developed as a practical, clinical tool to help multidisciplinary teams identify patients at risk of deteriorating and dying in all care settings (Highet, et al., 2014).

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 in 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.

GOVERNING LEGISLATION AND ASSOCIATED DOCUMENTATION

Associated Documents

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

Highet, G., Crawford, D., Murray, S.A. & Boyd, K. (2014) Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Supportive and Palliative Care, 4(3): 285-290.

Ministry of Health (2013). Resource and capability framework for integrated adult palliative care services in New Zealand. Wellington, Ministry of Health. 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

APPENDIX 1 **CP-039**

PROGNOSTIC INDICATOR GUIDANCE (PIG) 4TH EDITION SEPTEMBER 2011

Step 1: The Surprise Question

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?

Step 2: General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score, Karnofsky Performance Status Score or Palliative Performance Scale), 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 albumin <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:

- New York Heart Association (NYHA) Functional Classification for Congestive Heart Failure 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)
- 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; Hepato-renal 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 / Cerebral Vascular Accident (CVA) - gradual decline

Any person who fits within this category of diseases should already have had a referral to, and assessment by, a District Health Board funded Needs Assessment Service. This will ensure that both the patient and their family/carers have access to DHB funded supportive care programmes and funding appropriate to the patient's disease and identified needs. Specialist Palliative Care Services are not equipped to provide all of the service components necessary to care for those with frailty, dementia or the consequences of a severe cerebral vascular accident.

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/Karnofksy
- 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

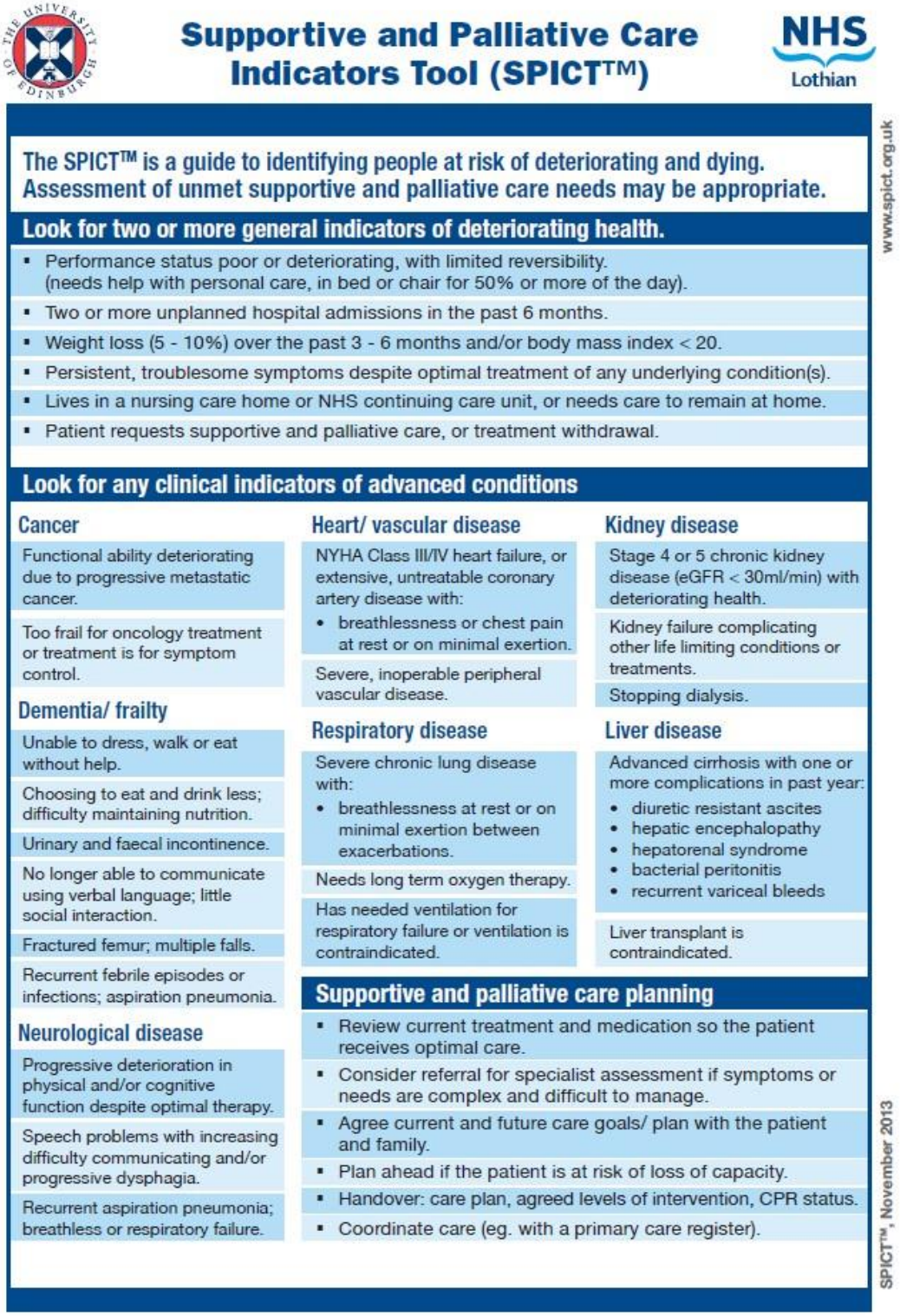
Plus any of the following:

- 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.

SUPPORTIVE AND PALLIATIVE CARE INDICATORS TOOL (SPICT)

(Highet, et al., 2014)



Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

www.spict.org.uk

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assessment of unmet supportive and palliative care needs may be appropriate.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Supportive and palliative care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

SPICT™, November 2013