St Andrew's Hospice

Wellbeing Services Referral Criteria

The following is intended to provide guidance to health professionals to enable appropriate patient referral to St Andrew's Hospice Adult Services. The criteria varies depending on which element of the service is required by the patient. It is, of course, not comprehensive, and the clinical team are happy to advise further in uncertain situations.

The services are available to people who have life limiting, malignant and/or non-malignant disease.

St Andrew's Hospice provides interventions at different levels, according to the needs of the individual patient:

- Symptom Control of difficult to manage symptoms
- Psychological and/or Spiritual Support
- Palliative Rehabilitation
- Care of the Dying Patient
- Respite Care both - planned and emergency.

St Andrew's Hospice Adult Wellbeing Services Criteria

About the Wellbeing Service

The aim of the service is to help and support patients to live well by being as in control of their condition as possible and, where appropriate, achieve the things that are important to them. The design of this service enables patients to be discharged when they are doing well and re-referred when needed rather than an ongoing service.

To achieve this each person will be offered a thorough assessment of their needs. This will then lead to a personalised plan of care based on individual needs to improve their emotional, physical and social wellbeing in order to enhance their independence and quality of life. Programmes vary in length dependent on individual patient's needs. Patients are reviewed three monthly or sooner if required, to ensure the identified need has been met and the patient may be discharged or referred into another service.

Who delivers the Wellbeing service?

The Wellbeing Service comprises of the Wellbeing team, Complementary Therapy team, Physiotherapy team and Therapeutic Activities Assistants, as well as support from the Living With and Beyond Cancer, Family Support and Spiritual Care teams.

Wellbeing Service criteria

Referrals will be accepted from all health professionals, patients, relatives and carers for any patients who live in North East Lincolnshire who have a diagnosis of a progressive

life limiting condition, whether that be malignant or non-malignant, or be a patient known to the Living With and Beyond team.

How to refer to the Wellbeing Service

All referrals for Wellbeing Services can be made by ringing the hospice on 01472 350908. Either a member of the Wellbeing Team or Clinical Administration will take the referral. It is essential on referral that the referrer communicates accurate and up to date information, the identified reason for referral and the current problems requiring wellbeing services input. The patient will be contacted within 72 hours to invite the patient into the hospice at a convenient time for the assessment to be undertaken.

Appendix 1 – Specific Disease Related Indicators

More details of Indicators – the intuitive surprise question , general and specific clinical

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) 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
- Considered eligible for DS1500 payment

Functional Assessments

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc .

PULSE 'screening' assessment - P (physical condition); U (upper limb function);
L (lower limb function); S (sensory);
E (environment).

Karnofksy Performance Status Score
0-100 ADL scale .

WHO/ECOG Performance Status
0-5 scale of activity.

Step 3 Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

a) Cancer – rapid or predictable decline

Cancer

- 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

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 o confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistan organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

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

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.

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 – 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/Karnofksy
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression.

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.