



**TEESSIDE HOSPICE
CARE FOUNDATION**

Teesside Hospice Care Foundation

Briefing Paper for Middlesbrough Health Scrutiny Panel

Thursday 16th September 2010

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Section 1

1. Background

Teesside Hospice Care Foundation was formed in 1982 as a response to the shortfall in specialised care for those suffering from a life limiting illness in the Tees Valley and North Yorkshire region.

Our primary aim is to act as a resource to the local community to provide **holistic specialist palliative care** at any point during a life-limiting illness.

1.1 Teesside Hospice Services

1.1.1 Teesside Hospice's 10 bedded Inpatient Unit provides specialist palliative care to patients for four main reasons:

- To **Control Symptoms** relating to a patients illness such as pain and nausea
- For **Respite Care** to give families and carers the opportunity to have a break from nursing
- For **End Stage Care**: Some patients choose to spend their last days in the unit, being admitted during the very late stages of their illness
- To **Rehabilitate** patients who may have had a long stay in hospital to allow them to return home to their families if that is possible or another care provision when home is not an option

1.1.2 The **Edward & Glenis Guy Day Centre** - offers professional advice and rehabilitation from our multidisciplinary team. Sixteen guests a day enjoy day care from Monday to Thursday at Teesside Hospice and on Friday's at our satellite day care centre at East Cleveland Hospital in Brotton.

Patients visit the day care centre for one day per week for a period of 3-4 months enabling them to use our services in a welcoming and homely environment. It is often referred to as the "getting on with living department" where a sense of normality is promoted at all times.

1.1.3 The **Bereavement Counselling Services** provide support to both **adults and children** (via 'Forget-Me-Not' children's and young adults' bereavement counselling service) and enables people to work through their grief and accept what has happened helping them move forward in their lives.

1.1.4 Teesside Hospice offers a number of **outpatient clinics** especially designed to manage symptom control. Our Consultant-led team sees new patients, reviews the management of existing patients and assesses the needs of Day Care guests.

As well as running our outpatient clinics, our consultant also offers a **domiciliary service** visiting patients too ill to travel to the Hospice, either in their **own homes** or local **hospitals** to help increase their comfort and quality of life.

1.1.5 Lymphoedema Service

Teesside Hospice offers specialist care and symptom management to patients with lymphoedema - a condition where swollen limbs result from illness or treatment. The clinic at Teesside Hospice sees people with both primary and secondary lymphoedema. The clinic is run to instruct people how to manage their lymphoedema effectively, as there is no cure for the condition, although the earlier it is diagnosed, the more effectively the condition can be managed.

1.2 Teesside Hospice Care Foundation (THCF) - Mission Statement

"Teesside Hospice Care Foundation exists to enhance the quality of life for those suffering from a life-limiting illness. It offers specialist palliative care and support to patients and carers, in the belief that each person is entitled to dignity and choice within the best provision of care".

1.3 Vision

To provide a Consultant led Specialist Palliative Care service free of charge at the point of delivery for the population of Teesside.

1.4 Principles

Service provision and development must continue to be needs led. It is recognised that, in practice specialist palliative and end of life care needs may be difficult to identify, assess, quantify and prioritise.

Sources used to identify needs include:

- National policy
- Local policy
- The views of patients and carers
- Help the Hospice's minimum data set questionnaire – which enables the performance of THCF to be compared with national data
- THCF audit programme

1.5 Who Do We Work With?

Teesside Hospice works closely with local Acute Hospital Trusts, Primary Care Trusts, Macmillan Nurses, Community Nursing Teams and General Practitioners to deliver specialist palliative care services and expertise to patients, families and carers.

1.6 Who Provides The Care At Teesside Hospice?

We have a skilled multidisciplinary team, which offers our patients holistic care, ensuring that their physical, emotional, social and spiritual needs are cared for. The team includes: **Consultants in Palliative Medicine, Hospice Medical Team, Specialist Nurses, Occupational Therapists, Dietician, Social Worker, Physiotherapist, Complementary Therapist, Chaplaincy and Counselling Services.**

1.7 Definitions

The terms **palliative, end of life, supportive care and a good death** are used interchangeably by professionals, the media and others and cause confusion to many people.

1.7.1 Palliative Care

The World Health Organisation defined palliative care in 2002 as:

“An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment”.

They go on to state that: “Palliative care

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness;
- Applies early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

1.7.2 Specialist Palliative Care

The National Council for Hospice and Specialist Palliative Care Services in 1999 defined specialist palliative care as:

“The total active care of patients with progressive, far advanced disease and limited prognosis, and their families, by a multi-professional team who have undergone recognized specialist palliative care training. It provides physical, psychological, social and spiritual support, and will be given by practitioners with a broad mix of skills, including medical, nursing, social work, pastoral/spiritual, physiotherapy, occupational therapy, pharmacy and related specialties”.

Patients referred to these services would have complex needs, for which the generalist teams require specialist advice and support.

1.7.3 End of Life Care

It is crucial to develop an understanding about the term ‘end of life care’ and to relate that meaning to the established definitions of supportive and palliative care. Without such understanding it may not be possible to define either the client group or their ‘end of life care’ needs in a way which is complementary to existing well-established definitions. **Furthermore, it might also result in some confusion on the part of commissioners as to whether a strategy for end of life care constituted a shift of focus to the exclusion of supportive and palliative care that may be needed earlier in the patient journey.**

It is clear that the beginning of the phase is variable according to the following factors:

- Variation according to condition e.g. cancer, organ failure, frail elderly/dementia
- Variation according to the perspective of individual patients
- Variation according to the clinical/prognostic judgement of individual professionals

It may be that the key factor is professional judgement. There may nevertheless be criteria that are commonly used by professionals in exercising their judgement. In response to that the Gold Standard Framework (GSF) Team has recently produced a set of prognostic indicators that may help in making decisions about when 'end of life' begins. In summary they are:

- **The Surprise Question** – Would you be surprised if this patient were to die in the next 6-12 months?
- **Patient Choice/Need** – The patient with advanced disease makes a choice for comfort care only (not curative treatment) or is in special need of supportive or palliative care.
- **Clinical Indicators** – General predictors of end stage illness (multiple co-morbidities, weight loss, general physical decline, serum albumin level, reduced performance status, dependence in most activities of daily living) and condition specific indicators.

The Liverpool Care Pathway (LCP) also includes guidance on when diagnosis of dying may be made. However the LCP is concerned with the last days of life rather than the last weeks or months.

In essence, the focus on end of life has the aim of ensuring that at the point of entering the last phase of life a comprehensive assessment is undertaken of the individual's supportive and palliative care needs. The search is therefore for a recognisable trigger point for that assessment. Given the variations due to condition, patient perspective and professional judgement, it is clear that there is no common trigger point. In consequence, the trigger is likely to be determined, as discussed above, mainly by professional judgement.

Given that the period called end of life has so many variations, it may be that the term can have no formal definition. Nevertheless it would still be important to attribute a general meaning to it that is embedded in and reflective of currently accepted definitions of supportive and palliative care. That would suggest that the following may be acceptable:

“End of life care is simply acknowledged to be the provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life”.

Section 2 - Questions from the Scrutiny Panel

2.1 What proportion of funding for your organisation comes from the statutory sector?

Work was undertaken in 2006 by the Department of Health in respect of the current costs of **specialist palliative care services** and their sources of funding. This showed that the estimated total costs of services for adults was between £418 and £440 million of which £326 million was expended by the voluntary hospices and the remainder by NHS managed services. It was also estimated that the NHS contributed £119 million to the costs of voluntary hospices. **The remaining £208 million was funded from charitable sources (NCPC, 2006).**

Teesside Hospice helps over a 3,000 people every year, from Tees Valley and North Yorkshire.

Teesside Hospice running costs are in the excess of £2.1 million per year (2009) and the local Primary Care Trusts contribute to around **a third of these costs which equates to £635,592**. We must therefore raise £4,100 per day, every day of the year through our own resources. Teesside Hospice Trading Company is the fundraising arm of the Hospice which currently has **14 charity shops**, a weekly subscription **lottery** with 12,500 players and a **fundraising department**. The total profit from the Trading Company is transferred to the Hospice's income.

2.2 Is the income from the statutory sector from contracts of a given length or on a spot purchasing basis?

In previous years we have benefited from a 3 year contract however 2010/11 the PCT commitment is for 1 year only which includes a review of Hospice services.

2.3 How well does the Tees area, as a health and social care system, deal with End of Life care currently?

The provision of care across the Tees area is variable in terms of resource and quality. There appears to be confusion regarding the clarity of role and function in terms of the District/Community Nurse role, Clinical Matrons and Specialist Palliative Care Nurses (Macmillan Nurses) in terms of delivering palliative and end of life care.

Also, various models of health and social care delivery appear to be in operation with some localities having integrated health and social care and others having a more fragmented service. Community Hospital's provide a significant amount of general palliative and end of life care and are less accessible in Middlesbrough compared to Redcar & Cleveland.

Furthermore, there are 10 Specialist Palliative Care beds for adults in the Middlesbrough, Redcar & Cleveland population (278,100) compared to 20 beds for the population of Hartlepool and Stockton (281,600).

The data usually quoted about people's preferences for place of death is derived from a telephone survey of a random selection of the **general public** undertaken by the National Council for Palliative Care (NCPC) in 2006. **The findings do therefore have to be treated with some caution since it cannot be assumed that the preferences of those who are in the last phase of life would match those of the survey sample.**

The findings are quoted below:

| Preferred Place of Death | % |
|---------------------------------|----------|
| Home | 56% |
| Hospital | 11% |
| Hospice | 24% |
| Care Home | 4% |
| Elsewhere | 5% |

It is clear that substantially more people would prefer to die at home or in a hospice than actually do and consequently many fewer people would prefer **not** to die in a hospital or care home. **The survey suggests that 24% of people would prefer to die in a hospice. Currently only 4% do so.** To meet such a preference level would require a six fold increase in hospice beds.

This one simple example demonstrates that patient choice is a challenge and in palliative care this choice is not clear for patients, carers and professionals. Does choice in palliative care include choice of provider and, if so, between what options – hospice, hospital, community hospital, care home? And how will informed choice be ensured?

Previously, palliative care was used as the only option for a patient when active treatment had failed – ‘terminal care’. It is now appreciated that some aspects are applicable from much earlier in the patient's illness and can be used in combination with stabilising or curative treatments. Often it is difficult to predict a time point in the course of a disease which marks the move from curative to palliative care. This is often a gradual process when the aim alters from prolonging life at all costs to preserving the quality of life and balancing the benefits of treatment with its burden or side effects.

At Teesside Hospice we believe that maximising the quality of life for patients and their families through the use of **symptom control and good supportive care is relevant at any or all points along the disease pathway – from diagnosis and treatment, to recovery or death.**

2.4 In your view does the health & social care system have sufficient capacity to deal with the demand around End of Life Care?

It should be acknowledged that a great deal of end of life care is delivered by families and lay carers. Resources are not available currently to provide 24 hour care at home with even the most comprehensive care packages providing a maximum of 4 visits per day (30minutes – 1 hour each) supplemented by Community Nursing support.

Furthermore, the Out of Hours Palliative Care Service is provided for patients in Redcar & Cleveland PCT areas and is **not** available to patients in the Middlesbrough PCT area.

Access to specialist palliative care telephone advice out of hours for patients, carers and professionals is provided by Teesside Hospice nurses and doctors and through them occasionally to the Consultant in Palliative Medicine on call for the Tees locality. **This service is not funded by the NHS despite requests by NHS Commissioners for business cases to be prepared to support further development and raising awareness of this advice for the benefit of the population.**

Teesside Hospice provides the specialist palliative care service for the locality with **patients being transferred from the acute hospital palliative care service for complex symptom management and end of life care.** Because of this rising trend over the last 5 years an increasing proportion of patients cared for at Teesside Hospice have complex needs. **This in turn has reduced the capacity for 'straight forward' end of life care and respite care to be delivered here given that there are a maximum of 10 Inpatient beds available.**

The knock on effect is that more patients will be dying in hospital (acute or community) if home/care home is not an option. The capacity for generalist staff (Ward and Community Nurses, GP's and Nursing/Care Home staff) to care for these patients is a concern with a substantial need for training and education regarding symptom management and end of life care.

2.5 The panel has heard in evidence that the majority of hospice places (In patient and Day Care) are used by cancer patients – is this consistent with your experience?

Teesside Hospice cares for any patient requiring specialist palliative care at any stage of a life-limiting illness. Our referral criterion does not discriminate against any condition.

The table below is the most recent data comparing Teesside Hospice non cancer patient activity with the national median.

| % new patients with non cancer diagnosis (National Council for Palliative Care, Minimum Data Set, 2008-09) | | | | | |
|---|-----------------|------------------|-----------------|---|-----------------|
| In Patient Unit | | Day Care | | Out Patients (including Lymphoedema) | |
| Teesside Hospice | National Median | Teesside Hospice | National Median | Teesside Hospice | National Median |
| 9.2% | 6.8% | 12.8% | 11.2% | 57.6% | 7.9% |

2.5.1 Is it the case that people with other conditions have less access to hospice facilities?

Whilst the patients that are referred predominantly have cancer we do also care for non-cancer patients. Historically hospice care and expertise regarding symptom management has evolved from this background, however, this is changing with the recognition nationally and amongst clinicians that palliative care is appropriate for patients with other progressive life limiting illnesses although the progression of the disease may be more difficult to predict e.g. Motor Neurone disease, Heart & Lung disease. In our experience patients who access our services early obtain the greatest benefit as they are monitored by experienced staff and problems are anticipated and managed.

Teesside Hospice is also committed to providing a complete range of Bereavement Services to adults and children (via 'Forget-Me-Not' children's and young adults' bereavement counselling service). This service is open to the public and not exclusively for people who have had care at Teesside Hospice. The counselling team is lead by a small team of paid staff who are supported by a large number of specially trained volunteer counsellors who are professionally supervised.

'Forget Me Not' Children's Bereavement Service was launched in 1998 to bridge the gap in support to youngsters under the age of sixteen who have lost a parent or loved one. The Bereavement Service enables people to work through their grief and accept what has happened helping them move forward in their lives. This is achieved by positive counselling work consisting of a variety of unique methods, including one to one sessions and group work. In recent research and in the experience of professionals working with children, it has been indicated that the emotional health, social and educational needs of children and young people are adversely affected by unresolved grief. In a relationship of trust, the counsellor works creatively with the young person using appropriate aids such as play, art, writing and drama. The methods enable the young person to explore and understand their uncomfortable feelings and emotions and take out anger, aggression, hate or resentment in a safe, controlled fashion.

Teesside Hospice offers a range of education courses in Bereavement, Counselling Skills and Communication Skills which are held regularly at the Hospice with some accredited by Teesside University.

2.6 Where should End of Life Care go from here? What developments are required?

2.6.1 Positive communication about the value and role of hospice care

Some patients and their families may associate hospice and palliative care with imminent death and 'hopelessness' so its role should be explained carefully. Likewise, hospices may be seen as places for people to die and patients may turn down referral for intensive symptom control or respite. Whilst some patients have expressed these concerns at the time of referral to Teesside Hospice they often report that they wish they had accessed services sooner and have gained a great deal by attending. **Along with supporting conversations about 'a good death' and end of life care we believe that some of the myths about hospices and palliative care should be challenged.**

2.6.2 Education & Training

It is already recognised that to achieve the objectives of developing palliative care for all patients regardless of diagnosis and of enabling patients to receive care in their place of choice that tools and training are required. It is essential that local expertise and resource is utilised to produce local network and national solutions. The Specialist Palliative Care (SPC) workforce can form this resource as they work across local health communities, and by so doing sit outside the traditional organisational boundaries. At Teesside Hospice we encourage professional staff involved in the care of patients through education and placement experience to promote the capacity of hospice services and palliative care to alleviate suffering and improve quality of life.

2.6.3 Out of hours palliative care services for Middlesbrough need to be commissioned in the form of a dedicated home care service and a robust and funded telephone advice service.