

## **PALLIATIVE CARE IN HEREFORDSHIRE**

### **Briefing Paper for the Herefordshire Health Scrutiny Committee**

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## **1. INTRODUCTION**

Palliative care is:

“... the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.” (WHO, 2002)

Palliative care is based on two core principles:

1. *It is the right of every person with a progressive life-threatening illness to receive palliative care wherever they are*
2. *It is the responsibility of all health and social care professionals to practice the principles of palliative care as an integral component of practice and to refer to specialist palliative care when needed.* (National Council for Palliative Care Services 1999).

## **2. WHO PROVIDES PALLIATIVE CARE IN HEREFORDSHIRE?**

The professionals providing palliative care fall into two distinct categories:

1. Those providing the day-to-day care to patients and carers (general palliative care, eg GP's District Nurses, hospital medical and nursing teams, social workers, allied health professionals, private and voluntary organizations, NICE, 2004.
2. Those who specialise in palliative care (e.g. consultants in palliative medicine, nurse consultants and clinical nurse specialists in palliative care, some of whom are accredited specialists).

### **2.1 EXISTING PALLIATIVE CARE RESOURCES IN HEREFORDSHIRE**

Services within Acute Hospitals including:

- Hospital Palliative Care Team - One Macmillan Palliative Care Nurse Specialist and sessions from the Medical Consultant in Palliative Medicine
- Lead Cancer Nurse
- Two Breast Care Nurses Specialists
- One Urology Nurse Specialist
- Psychology services
- Age care services
- Oncology Services
- Haematology Services

Services within the community including:

- St Michael's Hospice
- Macmillan Nurse Consultant
- Macmillan Community Palliative Nursing Service
- Marie Curie Nursing Service
- Palliative care psychology service
- Lymphoedema Service
- Primary Health Care Teams
- Bereavement co-ordinator and trainer
- Community pharmacy scheme
- Community hospitals and PCT in patient units
- Care Homes
- ICCP project
- Voluntary and private providers including Carers Action Carers and Pathways scheme

## **2.2 CORE COMPONENTS OF SPECIALIST PALLIATIVE CARE**

The core components of specialist palliative care services as set out by NICE (2004) are:

- Specialist in-patient facilities (such as hospice beds) for patients with complex problems which cannot be managed in other settings.
- Multi-professional specialist palliative care teams providing assessment, advice and care for patients in all locations (ie community and hospital teams)
- Hospice at home services
- Day therapy / Day Hospice
- Out-patients
- Bereavement services.
- Education and training in palliative care.

The majority of these are available in the county. Set out below is a brief description of each specialist service:

### **2.2.1 Herefordshire Specialist Palliative Care Services**

The Specialist Palliative Care Services in the county comprise of:

- St Michael's Hospice
- The Macmillan Community Palliative Nursing Service
- Hereford Hospital NHS Trust Palliative Care Team

Patients and carers are likely to need specialist palliative care if there are:

- Unresolved symptoms
- Complex end of life issues
- Complex bereavement issues
- Complex psychosocial issues (NICE, 2004)

## 2.2.2 St Michael's Hospice

St Michael's Hospice was established by the Freda Pearce Foundation and opened in 1984. The continuing aim is to provide holistic care to people who have a life limiting illness and to support their families, friends and carers. No charge is made for Hospice services. Last year it cost over of £2.5m to provide all Hospice care and as a registered charity it relies entirely on voluntary giving for more than 80% of its income.

The Hospice supports adults aged 16 years and above from Herefordshire and the surrounding areas. It has 16 beds with a county-wide medical on-call service 24 hours a day / 7 days a week, and accepts admissions for symptom control, emergency respite care, assessment, and care of the dying. 14 day care places are available Tuesday – Friday and there is a dedicated social care team and bereavement service. Limited accommodation is available on site for visitors who have traveled from outside the area.

The Hospice also provides Lymphoedema care and operates a variety of outpatient sessions including medical, social care, psychology, spiritual care and complementary therapies. During 2005 / 2006 the 24 hour telephone advice service (not including bereavement) answered a large number of calls from professional staff, carers and patients. Activity for 2005 / 2006 is detailed in the table below.

### Activity for 2005/2006

Admissions	335
Average length of stay	13 days
Number of deaths	182
Day Hospice attendance	1109
Lymphoedema attendance	178
Domiciliary visits	
• Medical	26
• Occupational therapist	149
• Social worker	5
Telephone advice provided by the following staff at St Michael's	
• Medical	475
• Nursing	1861
• Social Worker	261

Of the 335 admissions in 2005/06, 94% were Herefordshire residents and 3.5% from - Shropshire, Worcestershire, Gloucestershire and Monmouthshire with 2.5% from Powys.

St Michael's is the major provider of palliative care education and training within Herefordshire. It holds a programme of courses in the Education Centre at the Hospice and offers bespoke training to organisations off site.

St Michael's is a charity governed by a Board of Trustees whose members live in the community it serves. It is supported by just under 600 committed volunteers who work in all aspect of the organisation, either in Hospice supporting staff, or in the community in the 12 support groups or 13 charity shops. It is estimated that these volunteers save the Hospice around £450,000 per annum.

### **2.2.3 Community Macmillan Palliative Nursing Service**

The Macmillan Community Palliative Nursing service provides specialist palliative nursing to patients with life threatening illnesses and their families. The service is complementary to services already available to patients and their families. Macmillan Palliative Care Nurse Specialists are first-level registered nurses who have undertaken specific clinical and educational preparation to practice as specialists in palliative care.

The team is based at St Michael's Hospice. Patients are seen in their own homes, Community Hospitals and Nursing Homes. The team works closely with all members of the specialist palliative care service at St Michael's Hospice and Hereford Hospital Palliative Care Team to support the transfer of care between settings.

The service is available Monday – Friday 9-5 pm. There is 1 full time Nurse Consultant and 3.8 WTE Nurse Specialists. The Nurse Specialists work in two teams, Herefordshire North and South. Each team works with designated practices. The nurse consultant manages the Macmillan Team and works two clinical days a week largely in the Community Hospitals to support the development of palliative care in this arena.

Referrals are accepted from any health or social care professional, patient or family member and are appropriate for any patient with a progressive life threatening illness registered with a Herefordshire GP. The GP is always informed of the referral and the case regularly discussed with relevant members of the Primary Health Care Team involved in the patient's care. A weekly multi disciplinary meeting with the hospital palliative care team, the consultant clinical psychologist and staff at St Michael's takes place to enhance care.

The nurses have responsibility for a caseload, provide specialist assessment, clinical advice, information and support to patients and families, participate in discharge planning, provide bereavement care, regularly audit, and evaluate standards of care and provide education.

Activity for 2005/2006

Total number of patients referred	346
Face to face contacts	2521
Telephone contacts	5026

### **2.2.4 Hereford Hospital NHS Trust Hospital Palliative Care Team**

The Hospital Palliative Care Team consists of 1 Medical Consultant and 1 WTE Macmillan Palliative Care Nurse Specialist. Duties and responsibilities of the Medical Consultant post include sessions in Hereford Hospitals NHS Trust including a monthly outpatient clinic in Builth Wells, designated beds in St Michael's Hospice, and duties associated with Herefordshire PCT, which includes advice to the Community Macmillan Team, PCT inpatient units and development of appropriate new services.

Activity for the Hospital Team 2005/6:

Total number of patients referred	312 (new patients = 278) 218 with malignant diagnoses. 56 with
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	non-malignant diagnoses (i.e. 20%)
Total no. of inpatient patient contacts	975
Mean length of hospital support care	7.86 days
Number of patients who died whilst under the care of Hospital Palliative Care Team	70
Total number of outpatient attendances	155

### **3. STRATEGIC DEVELOPMENT OF PALLIATIVE CARE AND INVESTMENT**

Herefordshire forms part of the 3 Counties Cancer Network (3 CCN). Cancer Networks are the organisational model to implement the Cancer Plan (2000) and Supportive and Palliative Care Guidance for Adults with Cancer (NICE 2004). The 3 Counties Cancer Network Palliative Care group reports to the Network board and key individuals from Herefordshire participate at this group. All 3 counties participate at network level and work is in place to establish increased working as a network.

Along with the 3 CCN the strategic development of palliative care is the responsibility of The Herefordshire Supportive and Palliative Care Directorate (SPCD). The Directorate is serviced by the PCT IMPACT team and the current Chair is the Lead Cancer Nurse who has a PCT and HHT role. At the present time the SPCD has limited direct commissioning role.

The SPCD has made significant headway in developing palliative services through implementation of "*Setting the Strategic Direction for Palliative Care in Herefordshire 2002 – 2005*". This review of the first Palliative Care Strategy (1999) and publication of the Herefordshire Palliative Care Needs Assessment (2004) was led by a Lead Nurse at Herefordshire Health Authority – a project post funded by Macmillan Cancer Relief.

#### **Investment**

Implementation of major components of the Strategy was achieved through 5 specific working groups. During this period the Government and the PCT also invested in specialist palliative care resulting in the following developments:

- Psychology posts (strategic and clinical sessions)
- Community Palliative Care Nurse Specialist Post (One full time)
- Nurse Consultant (one full time – pump prime funding for 3 years from Macmillan)
- Secretary to the Nurse Consultant
- Specialist Registrar post (contribution to training costs)
- Community pharmacy scheme
- Improved funding to St Michael's Hospice
- IT developments for St Michael's Hospice
- Education and training

Slippage funds from this investment were invested in the following projects:

- Bereavement coordinator and trainer for Cruse Bereavement Care

- Home Care support (a 2 year joint project with Marie Curie and the PCT)
- Education and training in Care Homes, Social Services and Hereford Hospitals NHS Trust
- Education and training in the use of syringe driver infusion pumps
- Support to the new Lymphoedema service
- Purchase of symptom control guidelines
- Non-recurrent support to St Michael's Hospice

Additional projects that have been delivered within the last 18 months include:

- Project Manager fixed term post to implement the Gold Standards Framework in Primary Health Care Teams in Herefordshire
- Implementation of the Care Pathway for the Dying in the PCT inpatient units
- Coordinator to implement the Care Pathway for the Dying in Hereford Hospitals NHS Trust
- Strategy post to review the 2002 -2005 strategy (fixed term funding from Macmillan)
- Macmillan Lymphoedema Service (pump prime funding from Macmillan for 3 years)

### **Future investment:**

The LDP finances are not yet determined however, investment will be prioritised for developing hospice at home services.

### **Revised Strategy (2006-2009)**

A revised Strategy was published this year (Palliative Care Strategy (adults) 2006 – 2009). This work was led by IMPACT with support from Macmillan Cancer Relief. The new Strategy sets the challenge for Herefordshire Primary Care Trust (PCT) to ensure seamless care is provided for individuals diagnosed with a palliative condition (i.e. cancer and non-malignant conditions) throughout all stages of their care pathway.

The strategy has been developed by evaluation of palliative care services in Herefordshire against the NICE guidance and other NSFs eg chronic and long term conditions, diabetes, renal services, coronary heart disease and older people. The emphasis being that the provision of palliative care should be based on patient need rather than limited to those with a cancer diagnosis.

At a minimum, palliative care that is provided in Herefordshire must encompass the 13 topics/chapters highlighted in the NICE *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults With Cancer* (2004) and evidence from the Needs Assessment.

The strategy highlighted the following key issues:

- Growing elderly population
- Rural geography
- Availability of carers
- The role of allied health professionals in palliative care
- The health and social care interface
- Extending palliative care for those with non-cancer diagnoses
- Extending community hospital provision
- Care in the home and hospital environment – user perspective
- Enabling choice – in particular - palliative care home care (hospice at home) to enable more to stay at home for longer and to die at home if this is their choice

Work is underway to implement the strategy. In particular the Directorate is working on understanding and improving the health and social care interface and the development of home care services.

#### **4. NATIONAL POLICY CONTEXT**

The immediate context for the development of palliative care is encompassed in a number of government initiatives including:

- Development of an End of Life Strategy (due 2007)
- The White Paper: "Our Health, Our Care, Our Say". This emphasised the government's commitment to end of life care and to promoting choice at the end of life. It heralded a shift of care from acute hospitals to the community and specifically highlighted -
  - End of Life Care Networks
  - Hospice at Home Services
  - Extension of current initiatives to skill up generalists (eg Gold Standards Framework, Liverpool Care Pathway and Care Planning)
- The Government's programme on Dignity in Care for older people.
  - Improved funding for hospices
  - Investing in the future of community hospitals (July 2006).

Previous and current policy influencing palliative care includes:

- The NHS Cancer Plan (2000), which committed an extra £50m per annum for specialist palliative care (Herefordshire received £158,000 and the investment is outlined on p.6)
- National Service Frameworks - covering coronary heart disease, older people and long-term conditions, renal, diabetes.
- NICE Guidance on Supportive and Palliative Care for Adults with Cancer (2004).
- Building on the best (2003) End of Life Programme. This has helped to spread the use of:
  - The Gold Standards Framework (now being used in approximately 75% of general practices in Herefordshire).
  - The Liverpool Care Pathway for the dying, which is now being used in community hospitals and is currently being implemented in HHT.
  - The Preferred Place of Care: A tool being used in primary care for eliciting and documenting patients' preferences around end of life care.
- Adaptation of tools for use in care homes.
  - The new GMS contract – QOF includes palliative care outcomes.
  - The Mental Capacity Act (2005) which sets out provisions for making advance decisions and appointing Lasting Powers of Attorney (LPAs) for healthcare decisions.