BACUP/WATERFOOT DISTRICT NURSING TEAM

TASK
Devise a pathway for palliative care.

PURPOSE
To contribute to giving commissioners a clear view of the services we can provide and ultimately to enhance patient care by standardising services across ELPCT.

DEFINITION OF PALLIATIVE CARE
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 the 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 their treatments. (World Health Organisation. 2002)

TYPES OF PALLIATIVE CARE (NICE, 2004)

<table>
<thead>
<tr>
<th>General Palliative Care</th>
<th>Specialist Palliative Care</th>
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<tbody>
<tr>
<td>○ Delivered by all health and social care provider</td>
<td>○ Delivered by those with additional training and expertise.</td>
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<tr>
<td>○ Competent in non-specialist care.</td>
<td>○ Multi-disciplinary teams.</td>
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<td>○ Need to recognise when referral is required.</td>
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MODELS OF PALLIATIVE CARE

<table>
<thead>
<tr>
<th>A) The Wedge</th>
<th>B) The Wave</th>
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<tbody>
<tr>
<td>Palliative Care</td>
<td>Bereavement Support</td>
</tr>
<tr>
<td>Curative Treatment</td>
<td>Death</td>
</tr>
<tr>
<td>Bereavement Support</td>
<td>Supportive and Palliative Care</td>
</tr>
<tr>
<td>Death</td>
<td>Curative Treatment</td>
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The wave model is the one that the team adopts – supporting patients right through their journey.

This model best fits the W. H.O. definition of Palliative care.
REFERRAL

Assessment
(Experience primary Nurse Band 5 or 6)
Outcome = get baseline information. Begin to plan and co-ordinate. Be aware of patient choice/preference
(Please see assessment framework)

Planning

Outcome
An agreed plan of care with patient. Involve other agencies and usually D/N (band 5 or 6) takes on role as key worker.
Possible introduction of P.P.C. document. See sheet on ASSESSMENT. May have several PPC’s over a course of time e.g. MND pt – palliative for a long time.

Referral to other agencies – may be active or just for information at this stage i.e. informing OOH nursing services of a potential patient at this stage or hospice that someone has nominated this as their PPC for E.O.L.

Include on GSF register. Outcome = equity of Care. Numbers and frequency of visits – can’t quantify this as each person will have individual needs. Outcome = Individual care. Can range from 3-4 visits daily to a monthly support visit or telephone call.

Information Giving
All these will be given at various stages as appropriate
• Contact telephone numbers
• What to do if….
• Advise GP’s to complete special cautionary notes for GP Ooh service when near EOL.
• Specific advice leaflets on particular conditions and what to expect.
• Diagnosed with cancer leaflet
• Copying with dying leaflet
• Dep. of Work & Pensions what to do after a death.
• Care pathway leaflet.
• Outcome = Patients/Carer can make informed choice and are supported.
**VISITS**

These could arrange from

<table>
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<tr>
<th>Support Visit</th>
<th>Clinical Activity</th>
<th>Multi –Discipline Meeting</th>
<th>Visit to Confirm Death</th>
<th>Bereavement Visit/Attending Funeral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion, listening, basic counselling, introducing PPC, evaluation plan of care and adjusting to meet needs.</td>
<td>To carry out a clinical activity. This could be:- Line flush; taking bloods; care of PEG site – assist with feeds; dressing; syringe driver (setting up, routine change, problem shooting) bowel care; helping with nebuliser; changing a chemo – pump; sub cutaneous fluids; administering a supplementary medicine; assisting/supervising formal carers with basic hygiene needs in the very last days of life.</td>
<td>Held at patient’s own home. This is done in the case of applying for C.H.C. funding. (Band 6 or experienced Band 5).</td>
<td>This is restricted to those nurses on the OOH/night team who have undergone specific training. But often the day staff are asked to attend and then they request the GP to visit. Special skills required here to deal with loss, anxiety and fear of the relatives. Need to be knowledgeable about the procedure to be followed after death. Can be a long visit – might not be able to leave the relatives alone.</td>
<td>Some families specifically ask D/N’s to attend the funeral (this isn’t always possible, but it does happen occasionally). A bereavement visit is always offered BUT not always accepted. Usually by the primary nurse that has had most dealings with the family.</td>
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Outcome = The D/N Team “will deliver comprehensive end of life care services which will provide choice, quality, equity and value for money.” (Operating Framework 2007/08 PCT Baseline review of services for end of Life Care).
Need to qualify that this assessment is holistic and therefore becomes the lynch pin in determining the care given. It can be a springboard from which many other services will become involved. Therefore it must be viewed as a specialist assessment.

**ASSESSMENT + PUT ON GSF**

**PHYSICAL SYMPTOMS**
- Pain, nausea, vomiting, hair loss, constipation, insomnia, depression, fatigue, muscle wastage, shortness of breath, swallowing difficulties, etc.
- Introduction of I.C.P. when approaching EOL.

**SUPPLY OF MEDICATION**
- Arrange collection/delivery service from chosen pharmacy. G.P. to organise exemption for prescription charges if possible.

**PHYSICAL HELP TO ACHIEVE DAILY LIVING**
- Package of care – possibly from social services but could be Hospice Social Care/Hospice at Home.
- In end stages may be a combination of D/N service meeting up with carer/hospice staff.
- Respite Care (vouchers/? hospice)
- Day hospice and complimentary therapies.
- Night sitters – (hospice or Marie Curie)

**INFORMATION GIVING**
- Contact numbers. Various leaflets (see sep. page)
- Informing G.P. 00H (special cautionary notes).
- Informing 00H D/N.
- Support groups.

**EMOTIONAL SUPPORT**
- May need support visit from D/N or may need CNS Macmillan support. Counselling. Look at family dynamics – support for carer/family – sep. Carer’s assessment. PPC Document. Clergy/Priest/Religious Minister. Cultural beliefs/Traditions

**FINANCIAL**
- DS1500
  - ?main wage earner
  - Benefits – social services. Macmillan Grant Continuing Care Funding.

**TRANSPORT DIFFICULTIES**
- Arrange for transport to OPA. Use voluntary sector. ?help with travel costs. May need someone to go with them.

**DETERMINE PLAN OF CARE**
- In agreement with patient/family/carer, devise a personalised, realistic plan of care.
  - N.B. Frequency of visits will be agreed but as needs change this will alter.
  - Always open access 24 hrs to D/N service, therefore the potential is there for a vast range of visits throughout the 24 hours dependant upon individual circumstances.

**HOME ENVIRONMENT**
- Any equipment needed?
- Re-arrange furniture. Any adaptations. Moving and handling.

**ASSESSMENT**

CPM 2007
## RESOURCES TO BE CONSIDERED AT AN OPERATIONAL LEVEL, IN ORDER TO FOLLOW THE PATH WAY FOR A PALLIATIVE CARE PATIENT

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<th>Training</th>
<th>Resource</th>
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<tr>
<td>1</td>
<td>All primary nurses (5 and above) will be knowledgeable about the EOL Tools I.E. Preferred Place of Care, Gold Standards Framework Integrated Care Pathway.</td>
<td>E.O.L. Team have done various training events over the last 12 months. Will continue to support staff. Modern Matrons to ensure staff are using the tools and highlight difficulties/training needs. Support and work with teams.</td>
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<tr>
<td>2</td>
<td>Enhanced Communication Skills Resource</td>
<td>All band 5 and above will have accessed this course, facilitated by Cancer Help. (3 days out of practice)</td>
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<td>3</td>
<td>Gold Standard Framework Resource</td>
<td>Monthly GSF meetings (usually one hour in total), attended by Band 6 or Band 5.</td>
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<td>4</td>
<td>Syringe Driver Training Resource</td>
<td>All nurses Band 5 and above must attend annual syringe driver training. This will be made MANDATORY. This will encompass the practical skills of setting up a syringe driver and mixing the drugs. Plus an overview of symptom control and commonly used drugs.</td>
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<tr>
<td>5</td>
<td>Specific Training – Chemo, Pumps, Line flushes etc. Resource</td>
<td>All Band 5 and above will be competent to carry out these procedures.</td>
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<tr>
<td>6</td>
<td>Palliative Care Modules Resource</td>
<td>Staff who have undergone Palliative Care Modules</td>
</tr>
<tr>
<td>7</td>
<td>Shadowing /spending time with hospice/Macmillan CNS as part of personal development plan.</td>
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TIME

This will be the costliest factor in providing care for this patient. The amount of time spent with each patient is totally **UNPREDICTABLE** and will **VARY IN THE INTENSITY** of care dependant upon what stage the patient is in their illness.

- Time required on an individual basis to do the first assessment (see separate sheet for what this involves)
- Subsequent visits (see under visits to qualify this). Also tied by policy – 2 nurses to set-up syringe driver. Should be checked twice daily.
- Training needs of D/N Team (see under training)
- D/N being keyworker – therefore all telephone calls, discussion with G.P.’s etc.
- Attending MDT/GSF meetings etc. re patient E.O.L. Link Group (designated rep from each team)
- Reflective practice/debrief – time to go through experience, share anything we have learnt (IPR/best practice). Work with mentor/preceptor.

CPM 2007  6
GOVERNANCE

1. To follow NICE guidance for specific conditions.

2. To consider those elements that should be provided as a baseline by the PCT in its end of care and to endeavour to build on these.

3. To follow the ELPCT Palliative Care Policy

4. NSF for COPD

5. National E.O.L. strategy (expected later this year).