What is Hospice Palliative Care?

2015
Aims of Sessions

• Provide an overview of hospice palliative care.. Whatever the setting..
  ☐ What it is a Hospice For?
  ☐ What does palliative care mean?
  ☐ Who needs it?
  ☐ Why?
  ☐ Caring skills and competencies
  ☐ Stories
Myths and Misconceptions about Hospices

• You have to be religious
• Hospices are where people go to die
• Palliative Care is synonymous with dying
• You must have cancer to get into a hospice
• If you go to a hospice..you have given up/in
• Hospices are only for rich/middle class whites
• Hospices are depressing places for old people
• Hospices are no different from hospitals
So what is a Hospice for...

- Everyone and Anyone who needs palliative care, symptom control, or dying,
- Patient or Carer
- 24/7 Access
- Straddles community/NHS Service divides
- Fills the NHS gaps
- Open referral system
- Assists with benefits/allowances
Some Facts and Figures

The figures are from the National Audit Office and Hospice UK

- 33% of those who die in hospital have no clinical need to be there
- Only 21% of Hospitals have 24/7 face to face palliative care
- Only 30% of patients think the coordination of their care between organisations is good
- 20% of hospital beds are taken up with patients at end of life
- By 2030 44% of all UK deaths will be people over 85 years
- 500,000 Deaths in UK each year
- Of the 50% of people who die in hospital...
- 80% of people would prefer to die at home
• Help the Hospices UK plan to reduce the number of Hospital deaths by 50% by 2017/18
• They suggest this could save the NHS £160m/year
• A net saving for the Government of £80m
• 1% of GP lists should be those on the national End of Life register
• Currently just 27% of this target has been achieved.
• The plan is to increase this to 80%
• For every 20 deaths in a GP practice 5 would be cancers; 6 would be Organ Failure; 8 would be dementia and Frail Elderly; 1 would be sudden and unexpected.
• In 2013/14 Hospice in the Home saw 891 New Referrals ...the plan was to increase by 15% to 1025 at the year we had seen 1141 an increase of 28%
What is Hospice Palliative Care?

• Focuses away from medicalization of illness
• An approach that improves the quality of life of patients/residents and their families and carers facing the problems associated with a life limiting illness.
• It is a philosophy of care that is applicable from diagnosis until death and into bereavement care for the family.
Holistic Care

• Is the provision of comprehensive care with the patient at the centre of care.

• A philosophy that can be applied anywhere across a range of skills and settings and diseases.

• Focused on the needs of the patient/resident, carers and family.
Too many people dying without dignity

- 20 /5/2015 Ombudsman service report finds 355,000 people who need better care.
  - Poor communication
  - Poor Planning enabling death at home
  - Inadequate Out of Hours
  - Poor pain management

- We only have one chance to get it right!
Components of Palliative Care

- Symptom relief
- Teamwork & partnership
- Psychosocial & spiritual
WHO Definition of Palliative Care
(updated 2002)

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor 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/carers cope during the patient’s illness and in their own bereavement.
• Uses a team approach to address the needs of patients and their families including bereavement counselling if appropriate.
• Will enhance quality of life and may also positively influence the course of the illness.
Why do we need it?

Professional

CONSEQUENCES OF CARE

PROVIDED AND ENABLED

Laboratory

INTERACTIVE & EMOTIONAL CARE

Compassion

Personal & Unique

Respect

Spiritual and Social

RESTORATIVE, RENEWAL, REFUGE
Group Work

• What are the caring skills you would want if you have a life limiting illness? Such as Dementia, Organ Failure, Cancer, Frailty,

• As a patient

• As a relative of the patient

• In your role as a carer
Stories

Jane and Rose
DELIVERY OF PALLIATIVE CARE

• Remember that people with life limiting illnesses and their families become experts in their own conditions.

• Team working is essential
CISP

**CONTEXT**
Why is the person needing help? What are their expectations?

**ISSUES**
Their concerns – person centred then Health Care Worker questions

**PLAN**

**STORY**
Person or families unique narrative of their illness
So what about Patients... with Dementia?

• “How did all this begin?”
• “What should I know about you as a person to provide the best possible care”

Plan – Refer, Review, Investigate, Treat
This is me..

She was Eliza for a few weeks
when she was a baby – Eliza Lily.....Soon it changed to Lil.
Later she was Miss Steward in the baker’s shop
and then “my love”, “my darling”, Mother.

Widowed at thirty, she went back to work as Mrs Hand.
Her daughter grew up, married and gave birth.
Now she was Nanna....“Everybody calls me Nanna” she would say to visitors.

And so they did – friends, tradesmen, the doctor....

In the geriatric ward they used the patients’ christian names.
“Lil”, we said, “or Nanna”,

BUT it wasn’t on her file and for those last bewildered weeks
she was Eliza once again

Wendy Cope
Case Study

• Harry was diagnosed with dementia 7 years ago when he was 80
• April his wife has been his main carer until he had a fall and his condition deteriorated
• Harry now has a twice daily care package
• From the information you have what skills do you need to provide quality palliative care?
Caring Skills in Palliative Care

- Assessment skills (able to identify changes)
- Address barriers to communication, listen and pick up on cues that people and their families want to talk about or express if unable to use verbal communication
- Show respect and be non-judgmental
- Calm attitude, compassion, empathy, sense of humour, provide hope
- Privacy and dignity
- Recognise own limitations (seek advice)
Impact of communication on patients
Impact of communication on patients

- Body Language
- Tone of voice
- Content
Objectives

• To gain an understanding of the priorities, tools and partnership working for providing palliative care to terminally ill people, their families and carers

• To identify the best ways of providing person-centred care and support at the end of life
When is the End of Life?

- Advancing disease: 1 year +
- Increasing decline: 6 months
- Last days of life to death: Bereavement
End of life care (EOLC) is the care experienced by people who have an incurable illness and are approaching death. Good EOLC enables people to live in as much comfort as possible until they die, and to make choices about their care. It is about providing support that meets the needs of both the person who is dying and the people close to them, and includes management of symptoms, as well as provision of psychological, social, spiritual and practical support.

End of Life Care covers the care received by people who are likely to die in the next 12 months, as well as care in the last days and hours of life, and care after death, including bereavement support for families and loved ones.
Needs based coding

- **BLUE** = ‘ALL’ from diagnosis with prognosis of last year of life, STABLE condition
- **GREEN** = Benefits ‘DS 1500’ UNSTABLE, advanced disease, months prognosis
- **YELLOW** = ‘Continuing Care’ DETERIORATING, weeks prognosis
- **RED** = ‘Days’ FINAL DAYS, Terminal Care
- **NAVY** = ‘AFTER CARE’
What would you want if you knew you had less than 6 months to live?

Discuss
Examples

• To enjoy the time left – travel, music, shopping, love etc.
• To eat all the things I have been denying myself
• To spend time with those I care for – family, friends
What is a good death?

“Good”

• Pain free—pain control administered by experts
• Peaceful and calm—not alone
• Private space for family
• Knowing what to expect and who does what
• Being able to summon help 24/7
• Appropriate level of physical and personal care with dignity
• Accepting diagnosis and being at peace

“Bad”

• Poor or inadequate pain relief administered by those not use to dealing with death
• Chaos and being alone
• Carers and family kept in the dark—not involved in decisions made not feeling in control
• Lack of privacy and dignity
• Changing shifts of carers
• Poor care
• Person in denial or negative state
There is a major mismatch between people’s preferences for where they should die and their actual place of death. Peoples final journey should be their choice.

- 22 % people die at home
- 19 % die in care homes
- 52 % die in the acute sector
- 5 % die in hospice (2% other)

Only a third of the general public have discussed death and dying with anyone

(Office for National Statistics 2013)
Why not Hospitals?

- Painful investigations sometimes daily e.g. Blood tests
- Frequent bed moves meeting new professional ‘strangers’
- Disruption of family and social support networks
- Abiding by hospital rules, family not sitting on bed, one cup of tea as given at set times, lack of privacy for discussions etc
- Vulnerable to bringing and acquiring an infection, so reducing quality & life expectancy
More or Less
Why can the end of life experience be so poor?

• Society does not talk about death and dying
• Families rarely talk about end of life wishes
• Staff find it difficult to initiate discussions
• Death can be seen as a failure
• Co-ordination of care can be poor
• Community resources sometimes unable to respond 24/7
How do we change this to this?
Caring for Carers

• Louise Latham
Components of the EoLC Strategy Programme 2008

- Gold Standards Framework
- End of Life Care Plan
- Advance Care Planning
Gold Standards Framework - GSF

Identify & details on register

MDT meetings
GP practices
care homes

Needs shared
and proactive
planning
Advance Care Planning

Patient Held Document → Opens conversation → Choices documented & shared
# Karnofsky Performance Scale

<table>
<thead>
<tr>
<th>AKPS Score</th>
<th>Description of Performance Status</th>
</tr>
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<tbody>
<tr>
<td>100%</td>
<td>Normal, no complaints, no evidence of disease</td>
</tr>
<tr>
<td>90%</td>
<td>Able to carry on normal activity, minor signs or symptoms of disease</td>
</tr>
<tr>
<td>80%</td>
<td>Normal activity with effort, some signs of symptoms or disease</td>
</tr>
<tr>
<td>70%</td>
<td>Cares for self, but unable to carry on normal activity or to do active work</td>
</tr>
<tr>
<td>60%</td>
<td>Able to care for most needs but requires occasional assistance</td>
</tr>
<tr>
<td>50%</td>
<td>Considerable assistance and frequent medical care required</td>
</tr>
<tr>
<td>40%</td>
<td>In bed more than 50% of the time</td>
</tr>
<tr>
<td>30%</td>
<td>Almost completely bedfast</td>
</tr>
<tr>
<td>20%</td>
<td>Totally bedfast and requiring extensive nursing care by professional and/or family</td>
</tr>
<tr>
<td>10%</td>
<td>Comatose or barely rousable, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly</td>
</tr>
<tr>
<td>0%</td>
<td>Dead</td>
</tr>
</tbody>
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# Phase of illness

<table>
<thead>
<tr>
<th>Phase</th>
<th>This is the current phase if...</th>
<th>This phase ends when...</th>
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<tbody>
<tr>
<td>Stable</td>
<td>Patient’s problems and symptoms are adequately controlled by established plan of care* and further interventions to maintain symptom control and quality of life have been planned and family/carer situation is relatively stable and no new issues are apparent.</td>
<td>The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.</td>
</tr>
<tr>
<td>Unstable</td>
<td>An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care and/or the patient experiences a rapid increase in the severity of a current problem and/or family’s/carers circumstances change suddenly impacting on patient care.</td>
<td>The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>The care plan is addressing anticipated needs, but requires periodic review, because the patient’s overall functional status is declining and the patient experiences a gradual worsening of existing problem(s) and/or the patient experiences a new, but anticipated, problem and/or the family/carer experience gradual worsening distress that impacts on the patient care.</td>
<td>Patient condition plateaus (i.e. patient is now stable) or an urgent change in the care plan or emergency treatment and/or family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td>Dying</td>
<td>Dying: death is likely within days</td>
<td>Patient dies or patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).</td>
</tr>
<tr>
<td>Deceased</td>
<td>The patient has died; bereavement support provided to family/carers is documented in the deceased patient’s clinical record.</td>
<td>Case is closed.</td>
</tr>
</tbody>
</table>
Reading

• Difficult conversations with dying people and their families: 2014. mariecurie.org.uk
• Dying for Change: Charles Leadbeater, 2010
• This is me: RCN and Alzheimer’s Society End of Life Care Strategy (2008) www.ncpc.org.uk
• Improving quality of life of patients and families www.who.int/cancer/palliative
• Sampson c et al (2014) The practice of palliative care from the perspective of patients and families. BMJ Supportive and Palliative Care, 4, 291-298
THANK YOU