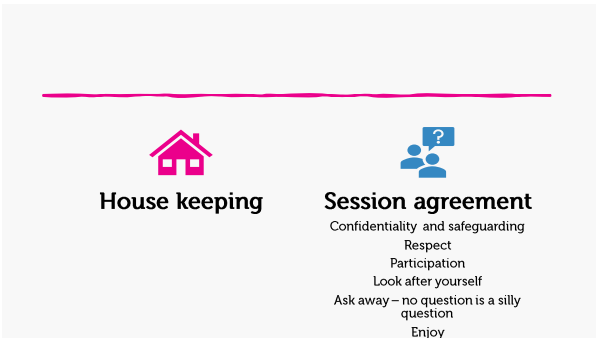

Social Prescriber Link Workers
Personalised Cancer Care in the Community
Welcome
Education Event 6th June 2022

1

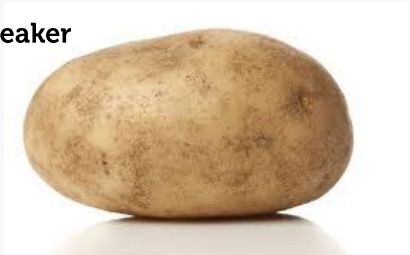

House keeping
Session agreement
Confidentiality and safeguarding
Respect
Participation
Look after yourself
Ask away – no question is a silly question
Enjoy

2


Confidence to Care
Agenda for the day
• Welcome and Ice breaker
• Palliative and End of Life Care and Priorities of Care of the Dying Person
• Break
• Feedback and problem solving
• Support
• Education and training offer
• Communications
• Other ideas or requests
• Evaluations and close

3

Ice Breaker



Divide into teams and take two minutes to make a list of how many things you can do with a potato.

4

Palliative and End of Life Care and Priorities of Care of the Dying Person

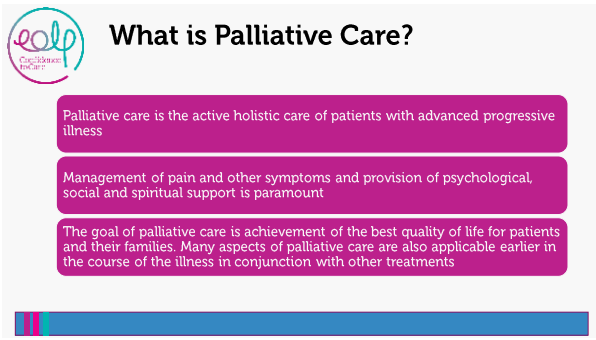
Mary Buttle
June 2022

5

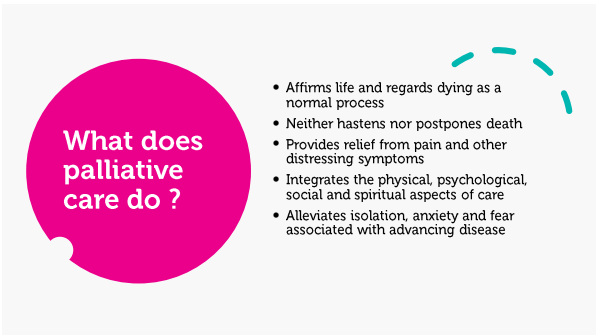
Aims and objectives

- To increase your awareness of palliative and end of life care
- To raise your awareness of the 5 Priorities for the Care of the Dying Person
- To consider the four domains of holistic end of life care

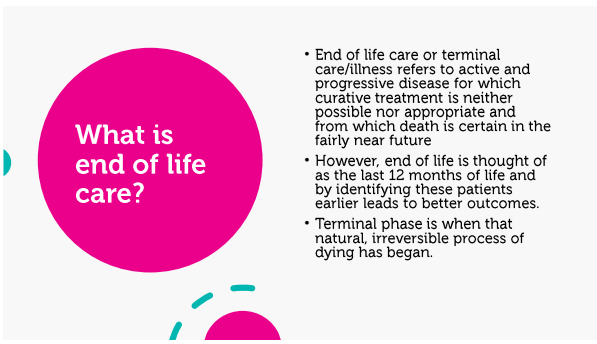
6


What is Palliative Care?
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

7


What does palliative care do ?
Affirms life and regards dying as a normal process
Neither hastens nor postpones death
Provides relief from pain and other distressing symptoms
Integrates the physical, psychological, social and spiritual aspects of care
Alleviates isolation, anxiety and fear associated with advancing disease

8


What is end of life care?
End of life care or terminal care/illness refers to active and progressive disease for which curative treatment is neither possible nor appropriate and from which death is certain in the fairly near future
However, end of life is thought of as the last 12 months of life and by identifying these patients earlier leads to better outcomes.
Terminal phase is when that natural, irreversible process of dying has began.

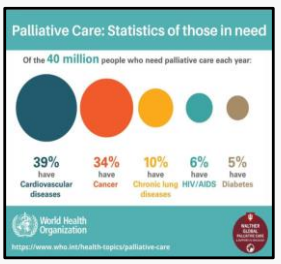
9

Who is responsible?

Everyone is responsible for palliative and end of life care

- Assess the care needs of each patient and their families across the domains of physical, social, psychological and spiritual
- Meet those needs within the limits of your knowledge, skills and competence.

10



11

North West Model for Life Limiting Conditions

12

13

One Chance to Get it Right – Priorities for the Care of the dying person

This document was been developed by the Leadership Alliance for the Care of Dying People (LACDP), which was established following an independent review of the Liverpool Care Pathway for the Dying Patient (LCP).
The LACDP is a coalition of 21 national organisations that was set up to lead and provide a focus for improving the care of people who are dying and their families.

14

Priority One – Recognising Dying

The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

15

BBC Radio 5 live - You, Me and the Big C: Deborah James' Last Dance | Facebook

16

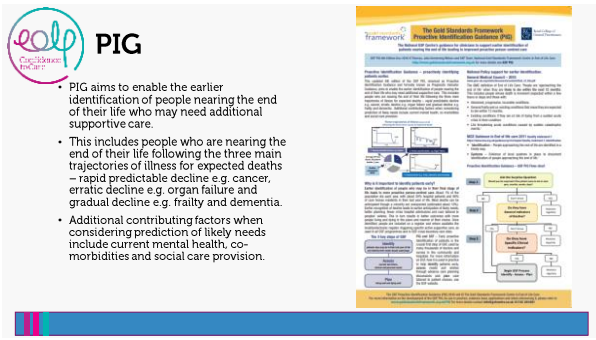
Recognising end of life- Why it is important?

- People want to be dealt with honestly and sensitively
- To consider if there are particular treatments they don't want to have or are no longer appropriate
- Opportunity to plan in accordance with patient and family preferences e.g, place of care, chaplain visit
- Complete unfinished business e.g., make amends, write a will, create a lasting power of attorney
- Planning for loved ones
- Suitability for the Gold Standard Framework (GSF)
- Fast tracking of CHC funding, DS1500,

17

How do we recognise when someone is dying ?

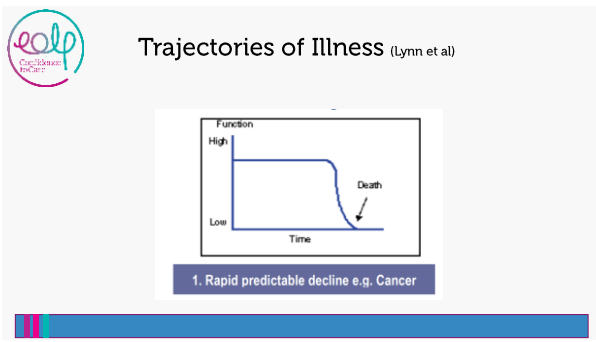
18



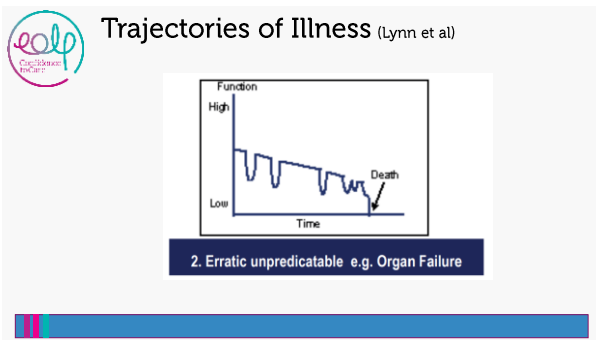
PIG

- PIG aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care.
- This includes people who are nearing the end of their life following the three main trajectories of illness for expected deaths – rapid predictable decline e.g. cancer, erratic decline e.g. organ failure and gradual decline e.g. frailty and dementia.
- Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.

19

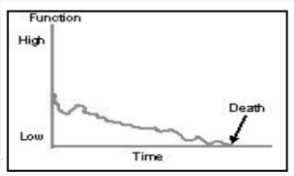


20



21

Trajectories of Illness (Lynn et al)



3. Gradual decline e.g. frailty, dementia, multi-morbidity

22

Priority One - Recognising Dying

- The natural process of dying is generally a progressive not a simultaneous failure of vital organs
- Death itself is not physically painful but aspects of the terminal disease / illness may be
- In the majority of cases there are warning signs that death is approaching
- It is important to recognise these signs if we are going to manage the last days of a person's life appropriately

23

Signs of the active phase of dying

- Increased restlessness, confusion, agitation
- Beginning to show periods of pausing in the breathing (apnoea) whether awake or sleeping
- A staring, glazed, hollowed appearance to the eyes
- Inability to rouse patient at all (coma) or, ability to only rouse the patient with great effort but patient quickly returns to severely unresponsive state (semi-coma)
- Urinary or bowel incontinence in a patient who was not incontinent previously

24

Signs of the active phrase of dying

- Marked decrease in urine output and darkening colour of urine or very abnormal colours (such as red or brown)
- Pulse becomes weak or 'thready' and/or slow/rapid
- Drop in body temperature
- Blood pressure dropping dramatically ***from patient's normal*** blood pressure range (more than a 20 or 30 point drop)
- Systolic blood pressure below 70, diastolic blood pressure below 50
- Patient's extremities (such as hands, arms, feet and legs) feel very cold to touch

25

Signs of the active phrase of dying

- Cyanosis, or a bluish or purple colouring to the patients arms and legs, especially the feet and hands)
- Extreme pallor, waxy, jaundice
- Mottling – 'port wine staining'
- Patient's body is held in rigid unchanging position
- Jaw drop; the patient's jaw is no longer held straight and may drop to the side their head is lying towards
- Breathing becomes shallow, periods of pausing in the breathing (apnoea), 'rattley' breathing, Cheyne stokes breathing.

26

Dying isn't as bad as you think it is

https://www.youtube.com/watch?v=CruBRZh8quc

27

Priority Two – Communication

- Sensitive communication takes place between staff and the dying person, and those identified as important to them.

28

What does the document say?

- Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care.
- Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them.
- If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met.
- Communication must be regular and pro-active,
- It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information.
- It should be conducted in a way that maximises privacy.
- Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time.
- Staff must check the other person's understanding of the information that is being communicated, and document this.

29

How do we achieve this? What skills do we need to employ?

30

31

Silence

It gives the person time to think about what to say

It gives space to experience their feelings

Allows them to precede at their own pace

Provides them with time to deal with mixed feelings about sharing

Gives them freedom about whether or not to continue

32

Summarise

Brief statements that pull together, clarify and reflect back, should be used throughout the consultation.

A summary of the discussion of the with the person.

"you have mentioned a few things to me, pain, your daughter, going home, which of these is the most important at this time"

"you have mentioned a few things to me, pain, your daughter, going home, is there something else worrying you?"

33

Language

- Non – medical
- Avoid acronyms
- Unambiguous
- Use your "D" words – not euphemisms

"Fear of a name increases fear of the thing itself"

J.K Rowling

Death, Dying, Deceased and Dead.
Use these words.
Deliver them with a gentle tone and at a slow pace, remember to be warm, compassionate and empathic.

There are not better words

34

35

Priority Three - Involve

- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

37

What is important to me?

What is a good death?

When I am dying, I would like…

When I am dying, I do not want…

After death I hope ….

38

What is important to me?

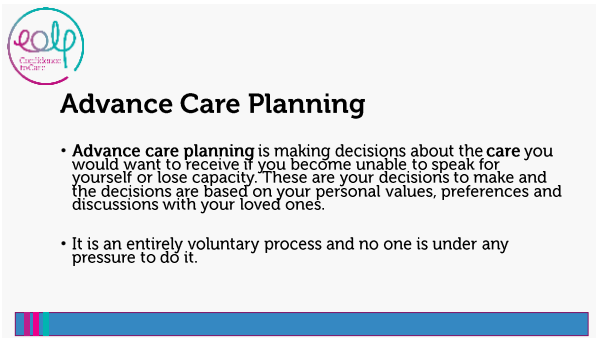
- being pain-free – pain control on tap, administered by experts
- being peaceful and calm, with those chosen by the dying person to be present
- having the role and emotional needs of carers (and wider family) recognised and respected
- a feeling of control over the process (for the terminally ill person and family)
- a private space for family being available
- being in a hospice (for some)
- being at home (for some)
- knowing what to expect, and who does what
- being able to summon help 24/7
- an appropriate level of physical , spiritual and personal care that respects dignity and choice

39

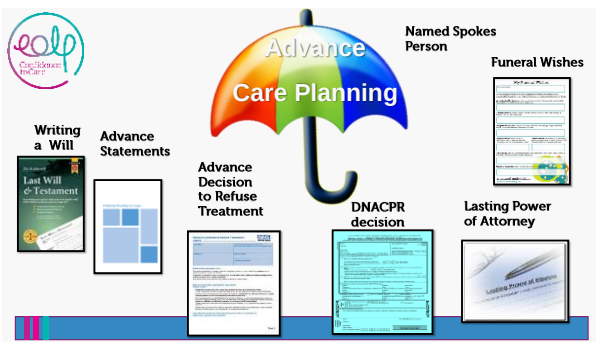
40


How do we involve dying patients in their care?

41


Advance Care Planning
• Advance care planning is making decisions about the care you would want to receive if you become unable to speak for yourself or lose capacity. These are your decisions to make and the decisions are based on your personal values, preferences and discussions with your loved ones.
• It is an entirely voluntary process and no one is under any pressure to do it.

42


Advance
Care Planning
Named Spokes Person
Funeral Wishes
Writing a Will
Advance Statements
Advance Decision to Refuse Treatment
DNACPR decision
Lasting Power of Attorney

43

Advantages

- To communicate to others things that they would WISH OR wish NOT to happen
- To refuse a specific life sustaining treatment
- To put affairs into order
- To maintain control & autonomy, & reduce the decisional burden on others
- To be able to plan for future care in the event that the person loses mental capacity

44

Your life, your death, your way

45

Priority Four – Support

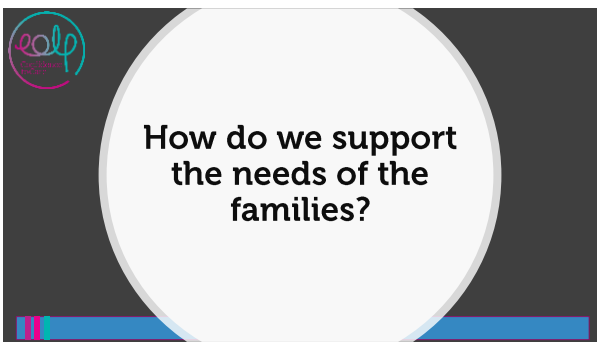
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

46

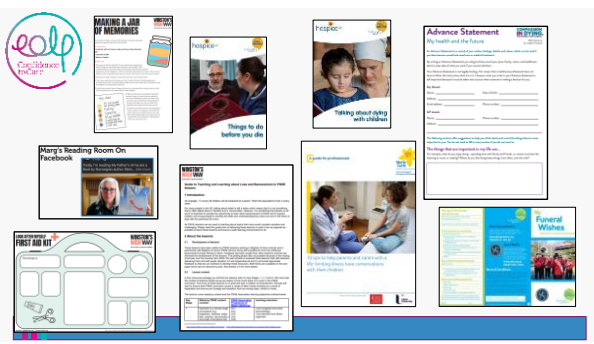
What does the document say?

- Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress.
- They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home.
- Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life.
- Where they have particular needs for support or information, these must be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help.
- If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the person and they should be involved as much as possible.

47



48



49

Priority Five – Plan and Do

- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

50

Holistic Care

It is easy to miss something you are not looking for.

Think person centered

Think holistic

- Physical
- Social
- Psychological
- Spiritual

51

Symptoms at the End of Life

Symptom	Incidence
Respiratory Tract Secretions	56%
Pain	51-56%
Agitation	30-42%
Breathlessness	22-26%
Nausea & Vomiting	12 – 14%
Confusion	9 – 12%

52

Psychological

- Loss of functional capacity, loss of independence, enforced changes in role
- Practical issues such as finances, work, housing
- Changes in relationship, concern for dependents
- Changes in body image
- Fears about dying and death
- Fears about physical symptoms
- Side effects of treatment or medication

53

Social

- When enforced change happens people are often overcome by feelings of isolation and loneliness
- Tiredness, frailty or weakness may hinder the person from being able to out and about
- Some people avoid the patient maybe due to not knowing what to say

54

Spiritual

- Existential challengesie questions about identity, meaning, death , forgiveness, hope, love and joy
- Value based consideration ie what is important to each person
- Religious consideration such as faith beliefs practices
- The important thing is that the patient tells us the form their own spirituality takes, listening carefully
- All members of the team have the responsibility for spiritual care

Spiritual Gate

https://www.openingthespiritualgate.net

55

Nutrition and Hydration

- "The offer of food and drink by mouth is part of basic care (as is the offer of washing and pain relief)an must always be offered to people who are able to swallow without serious risk of choking or aspirating food or drink"

(GMC Guidance on Treatment and Care towards End of Life: good practice in decision making 2010)

56

Taste for Pleasure

57

"How people die remain in the memory of those that live on "
Dame Cicely Saunders

58

Any questions?

59