INTRODUCTION TO PALLIATIVE CARE

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PALLIATIVE CARE

- ‘Palliative care is an **approach** that improves the **quality** of life of **patients and their families** facing the problem associated with **life-threatening illness**, through the **prevention and relief** of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, social, psychosocial and spiritual.’

Cancer pain relief and palliative care. Geneva; World Health Organization: 2002

SKILLS USED IN PALLIATIVE CARE

- Knowledge of diseases and their progress
- Symptom Management
- Communication skills (listening)
- Empowerment
- Self-knowledge
- Team membership
- Reflection
- Empathy
- Patience
- Courage

PALLIATIVE MEDICINE

Specialist	Hospices, Palliative care teams, In-patient Units, Domiciliary Advice
Generalist	Community and Hospital *Every healthcare professional*

PALLIATIVE MEDICINE

- Assessment
- Symptom Management
- Rehabilitation
- Respite
- Psychological, Social, Emotional and Spiritual Support
- Terminal care
- Bereavement

GLOBAL PERSPECTIVE

- High Income countries:

  - Modern Hospice movement started in United Kingdom (St Christopher Hospice)

  - Well-established in many western countries

  - In form of Hospital, Hospice and Community Palliative care teams

GLOBAL PERSPECTIVE

- Middle Income countries:
  - Growing Palliative care initiatives
  - India, Brazil, China
  - Access still remains limited

GLOBAL PERSPECTIVE

- Low-Income countries:

  - Minimal or non-effective in many African, South Asian and Latin American countries
  - Lack of funding
  - Lack of trained professionals
  - Limited Opioid access

BARRIERS TO PALLIATIVE CARE WORLDWIDE

- Lack of awareness
- Limited healthcare policies
- Shortage of trained professionals
- Opioid access restrictions

AMBITIONS 2021 – 2026

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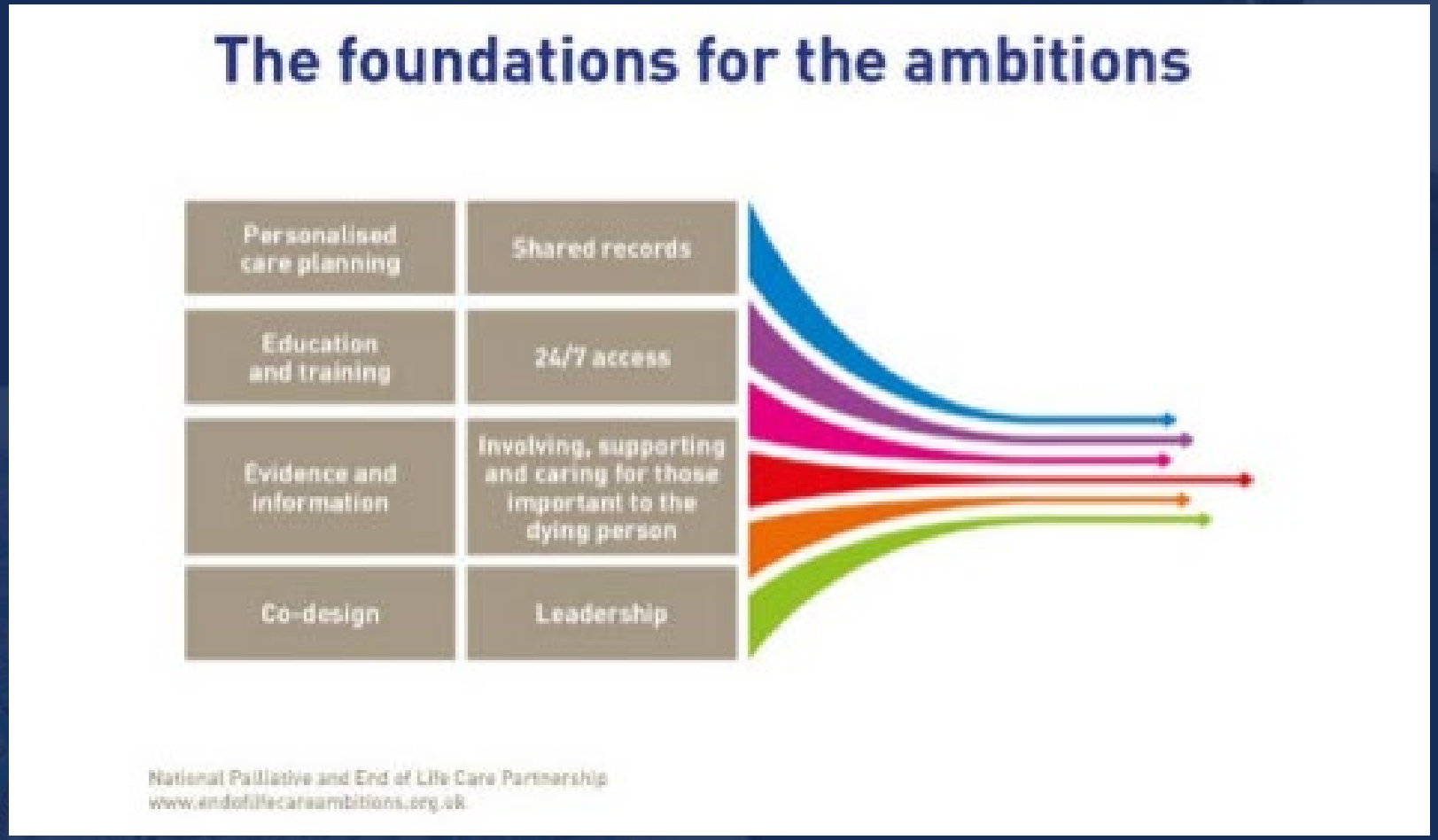
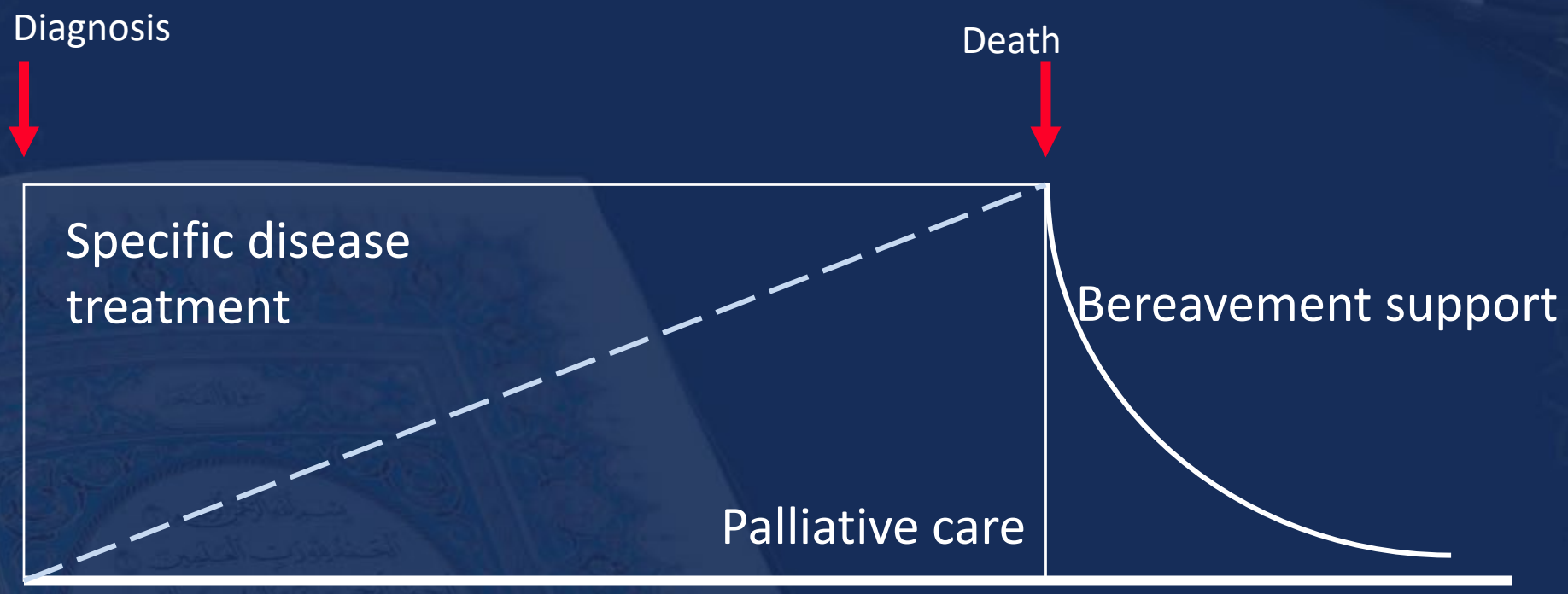


END OF LIFE CARE

Transition to palliative care



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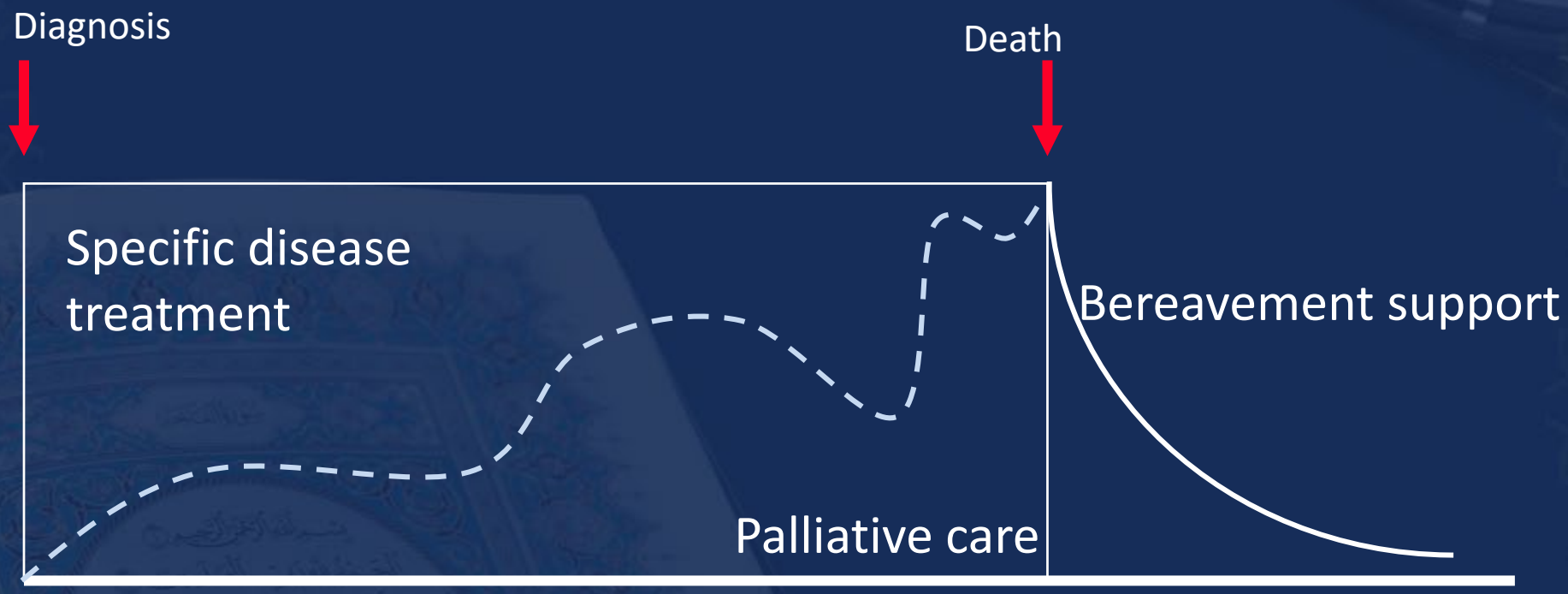

TRANSITION TO PALLIATIVE CARE

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PROGNOSTICATION AND TRANSITION

- Will you be surprised if the patient dies within a year?

QUESTION

- What are the commonest barriers in diagnosing that someone may be in last year of life?

BARRIERS

- Hope that the patient may get better
- No definitive diagnosis
- Pursuance of unrealistic or futile interventions
- Disagreement about the patient's condition
- Failure to recognise key symptoms and signs
- Lack of knowledge on how to prescribe

BARRIERS

- Poor ability to communicate with patient and carers
- Concerns about withdrawing or withholding treatment
- Fear of foreshortening life
- Concerns about resuscitation
- Cultural and spiritual barriers
- Medico-legal issues

LAST OPPORTUNITY

- Finish our business
- Create final memories
- Give final gifts
- Achieve spiritual peace
- Say good-bye

IF NOT DONE WELL

- Patient and carers unaware that death is imminent
- Patients loses trust as their condition deteriorates
- Patient and carers get conflicting messages
- Uncontrolled symptoms leading to distressing death
- Dissatisfaction
- CPR may be inappropriately initiated
- Cultural and spiritual needs not met
- Issues in bereavement

QUESTION

- What can be markers that patient is in last year or few months of life?

INDICATORS TO IDENTIFY A PALLIATIVE CARE PATIENT

- Progressive deterioration in performance scale (ECOG Scale 3 or 4)
- Dependence in 3 or more activities of daily living
- Multiple co-morbidities
- Symptoms that cannot be alleviated by treating underlying disease

INDICATORS TO IDENTIFY A PALLIATIVE CARE PATIENT

- Signs of malnutrition due to illness – cachexia; albumin <25g/l
- Severe progression of illness over recent months

TRANSITION

- Identifying curative vs Palliative intent
- Improve communication skills
- Enhance participation of patient/relative in medical decision-making
- Integrative model of healthcare system ranging from active treatment modalities to palliative care setup
- Identify medical, social, cultural, and geographic hurdles in developing palliative care

COMMUNICATION SKILLS IN PALLIATIVE CARE

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QUESTION

- What are the biggest barriers to have good communication with patients or colleagues or even you family members?

EFFECTIVE COMMUNICATION

- you must make your message understood
- you must receive/understand the intended message sent to you
- you should exert some control over the flow of the communication
- Thus *you must learn to listen as well as to speak*.

AMBIGUITY

- Words mean not what the dictionary says they do but rather what the speaker intended.
- The word has multiple meanings, it might not be the one intended, and you may have misheard it in the first place - how do you know what the speaker meant?
- Look at body language

Palliative Care CPD Day

2025: Year of Mulla Asghar

- “As we know, there are known knowns; there are things we know we know. We also know there are known unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns -- the ones we don't know we don't know."

(Donald Rumsfield – US Secretary of Defence 2005)

- “We do know of certain knowledge that he [Osama Bin Laden] is either in Afghanistan, or in some other country, or dead.“

- "I believe what I said yesterday. I don't know what I said, but I know what I think, and, well, I assume it's what I said."

AMBIGUITY

- ‘What they said:
- ‘Vaccines need to go through safety trial, which can take years’ (May 2020)

- What they meant:
- We need to be cautious as we do not know if we can develop all data within months.

- What some people concluded:
- How can vaccines be developed so quickly. It must be a lie that the vaccines are safe.

QUESTION

- What are you worried about in terms of patients'/their families' reactions when you are breaking bad news or discussing poor prognosis?

HOSTILE REACTIONS

- Anger
- Crying
- Irrational reasoning
- Body Language
- Showing unnecessary vulnerability
- Harassment
- Refusal to communicate

COMPOSITION OF A COMMUNICATION

- Perception of an idea
- Finding vocabulary
- Arranging mode (tone of voice/environment/body language)
- Uttering words

- Receiving message
- Reflecting on it
- Acting on it

Palliative Care CPD Day

2025: Year of Mulla Asghar

SPIKES - S

- Step 1: S – SETTING UP:

- Prepare in your own mind what words and tone you are going to use.
- Collect right information about patient.
- Arrange for some privacy. Have tissues ready in case the patient becomes upset.
- Involve significant others. Ask the patient to choose one or two family representatives.
- Sit down. Sitting down relaxes the patient and is also a sign that you will not rush. When you sit, try not to have barriers between you and the patient.
- Make connection with the patient. Maintaining eye contact may be uncomfortable but it is an important way of establishing rapport. Touching the patient on the arm or holding a hand (if the patient is comfortable with this) is another way to accomplish this.
- Manage time constraints and interruptions. Inform the patient of any time constraints you may have or interruptions you expect.

SPIKES - P

- STEP 2: P - Patient/Carer's PERCEPTION

- Ask: 'What do you think is going on?'
- 'Do you feel things are getting worse or better?'
- 'How does that make you feel?'
- 'What is your biggest fear/concern?'

SPIKES – I

- STEP 3: I - Obtaining patient's INVITATION

- 'How can I/we help you?'
- 'Do you want me to get someone else here to be with you?'
- 'Do you think you are depressed or anxious?'

SPIKES - K

- STEP 4: K - Giving KNOWLEDGE and information to patient
- Respond to any questions
- State how the patient's condition is
- Be honest about poor prognosis
- Repeat patient/carer's own vocabulary
- Use non-jargon language (e.g., use 'spread' rather than 'metastasis')
- Avoid excessive bluntness but be honest
- Small sentences/chunks
- Stress on positives. Explain what you can do (e.g., we can be here to make patient comfortable, we can support family, allow visiting/staying at night etc.)

SPIKES - E

- STEP 5: E - Addressing the Patient's EMOTIONS with Empathic Responses
- Observe for any emotion on the part of the patient. This may be tearfulness, a look of sadness, silence, or shock.
- Identify the emotion experienced by the patient by naming it to oneself. If a patient appears sad but is silent, use open questions to query the patient as to what they are thinking or feeling. (“Are you feeling sad/angry?”)
- Identify the reason for the emotion. (Is it because…?)
- After you have given the patient a brief period of time to express his or her feelings, acknowledge the feelings. (Usually not straight away)

SPIKES - S

- STEP 6: S - STRATEGY and SUMMARY
- Discuss future/management plan
- Share responsibility for decision-making with the patient
- Check the patient's understanding of the discussion (any misunderstanding can prevent desirable response)
- Acknowledge uncertainty for patients but also for professionals
- Accept that it is hard for professionals to make a definite prognosis but always help with future/advance care planning
- Close the discussion with a plan and offer to talk again

PITFALLS: IGNORED OBVIOUS

- Misunderstanding of the question
- If you are unprepared for the question
- If you are uncomfortable with the question
- Acknowledge the refusal to speak
- Is a clear answer difficult?

ADVANCE CARE PLANNING

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ADVANCE CARE PLANNING

- Advance care planning (ACP) is a voluntary process where individuals with mental capacity discuss and document their preferences for future healthcare, including medical treatment and care decisions.
- This planning helps ensure that a person's wishes are followed even if they are later unable to communicate or make decisions for themselves.

KEY FEATURES

- Person-centered
- Communication
- Documentation
- Ongoing process
- Mental capacity
- Legal considerations

BENEFITS

- Ensures care aligns with wishes
- Reduces burden on families
- Supports healthcare providers
- Promotes informed decisions

ELEMENTS OF ACP

- Treatment Escalation Plan:
  - DNACPR
  - Withholding and Withdrawing Treatments
- Advance decisions to refuse treatment
- Powers of attorney
- Advance statements:
  - Preferred priorities (Place) of Care
  - Organ Donation

DEATH

- Historically, Cardio-Pulmonary Death
- Brain Death: Irreversible cessation of all brain activity
  - USA – Uniform Determination of Death Act
  - UK – Academy of Royal Colleges
  - Canada, France, Germany, Italy, Spain, Netherlands, Sweden, Japan, India, Australia, New Zealand
  - Legal but Limited: Saudia Arabia, China, Russia

TREATMENT ESCALATION PLAN

- DNACPR
- Withholding and Withdrawing Treatments

Principles:

- Medical futility
- Patient choice
- Prevention of harm

LASTING POWER OF ATTORNEY

- Health and welfare
- Financial

- Principles:

  - To act as patient to inform system of patient's choices / interests

ORGAN DONATION

- From living donors:
  - Blood
  - Kidney
  - Liver (part)
  - Lung (part)
  - Intestinal (part)

ORGAN DONATION

- From deceased donors:
  - Heart
  - Lungs
  - Liver
  - Kidneys
  - Pancreas
  - Intestines
  - Cornea
  - Skin
  - (ETC.)

DIAGNOSING DYING IN PALLIATIVE CARE

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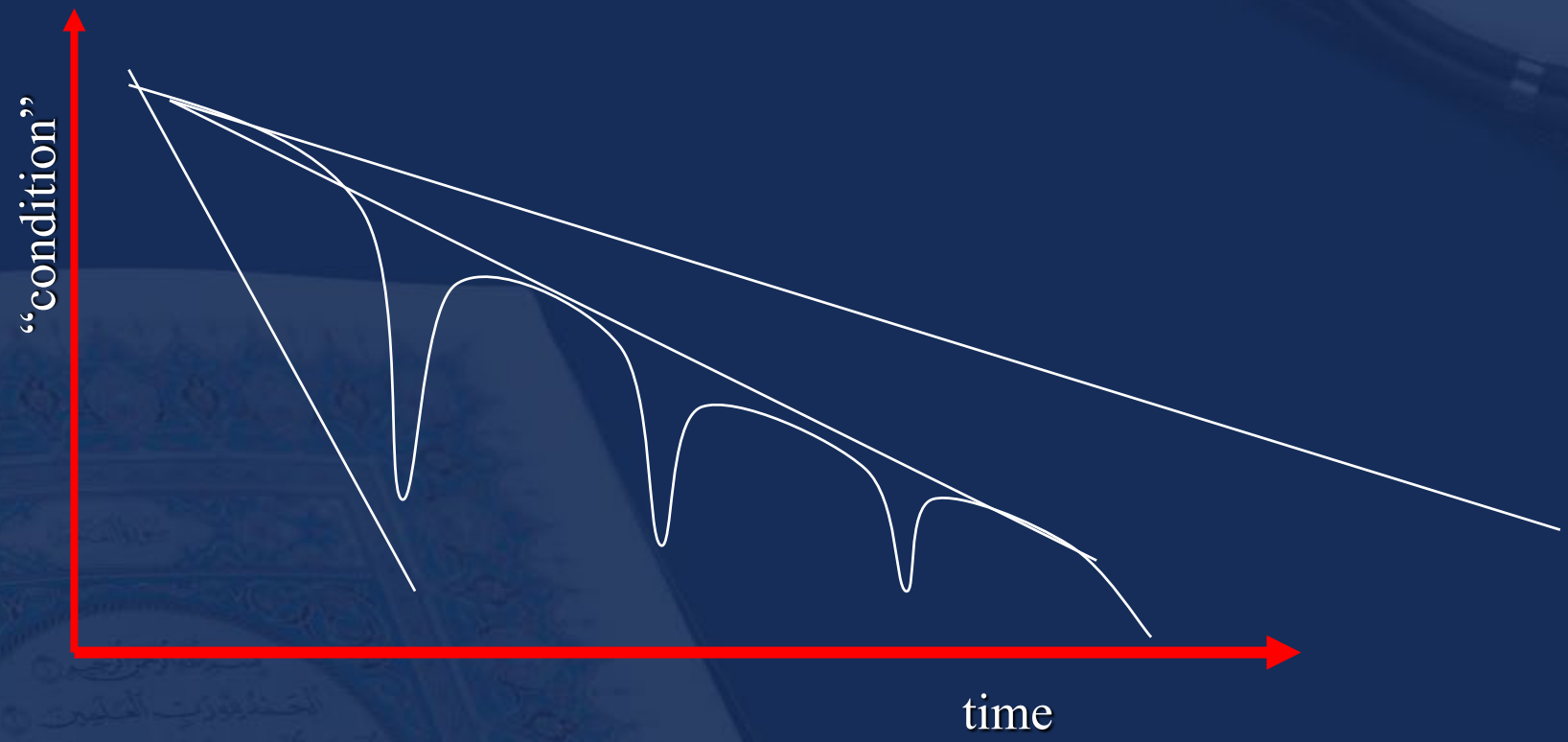
‘How people die remains in the memory of those who live on’

Dame Cecily Saunders

Palliative Care CPD Day

2025: Year of Mulla Asghar

End of Life Care



LAST YEAR OF LIFE

- Three triggers:

1. The Surprise Question: ‘Would you be surprised if this patient were to die in the next few months, weeks, days’?

2. General indicators of decline - deterioration, increasing need or choice for no further active care.

3. Specific clinical indicators related to certain conditions.

GENERAL INDICATORS

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden

GENERAL INDICATORS

- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

GOLDSTANDARD FRAMEWORK

- https://www.goldstandardsframework.org.uk/

PATHO-PHYSIOLOGY OF DEATH

- Cachexia
- Hepatic failure
- Renal failure
- Hypoproteinaemia
- Cytokines e.g., TNF, IF etc.
- Loss of adipose tissue
- Deranged electrolytes

Stevenson et al *BMJ 2004;329:909-912*

PATHO-PHYSIOLOGY OF DEATH

- **Cachexia** – last months of life
  – Discuss advance care planning - Communication with right people
- Hepatic failure
- Renal failure
- Hypoproteinaemia
- Cytokines e.g., TNF, IF etc.
- Loss of adipose tissue
- Deranged electrolytes

PATHO-PHYSIOLOGY OF DEATH

- Cachexia
- **Hepatic failure**
- **Renal failure**
- **Hypoproteinaemia**
- Cytokines e.g., TNF, IF etc.
- Loss of adipose tissue
- Deranged electrolytes

Last short number of months

DNACPR, complete advance care planning, Preferred Place of care, Anticipatory medications

? Need of other medications

QUESTION

- How do you diagnose last days of life?

PATHO-PHYSIOLOGY OF DEATH

- Cachexia
- Hepatic failure
- Renal failure
- Hypoproteinaemia
- **Cytokines e.g., TNF, IF etc.**
- **Loss of adipose tissue**
- **Deranged electrolytes**

Short number of weeks – days

- Withhold unnecessary medications

- Care in bed

- Arrange care appropriately

- Spiritual / cultural issues

- Review medications route (syringe driver)

STRATEGIES FOR SELF CARE

- Extended supervision / mentoring / coaching
- Reflective practice (monthly—alternating fortnight with the above)
- Access to on-the-spot debriefs (individual request)
- Creating self-care in healthcare environments (ongoing)
- Look after self:
    - Get regular exercise
    - Eat healthy
    - Make sleep a priority
    - Try a relaxing activity
    - Set goals and priorities
    - Practice gratitude
    - Focus on positivity
    - Stay connected

CARE OF THE DYING IN PALLIATIVE CARE

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ORGANISING DEATH!

- Open discussion
- Discuss place of death
- Explore fears, concerns, beliefs
- Respect
- Family issues and involvement
- Multi-disciplinary approach
- Pre-bereavement support

PHYSICAL CARE

- Anticipate symptoms and treat
- Consider Total pain
- ‘Rescue medicines’

QUESTION

- What are the commonest symptoms which concern people in last days of life?

COMMON SYMPTOMS

- Pain
- Nausea & Vomiting
- Breathlessness
- ‘Death rattle’
- Restlessness
- Urinary problems

PAIN

- Oramorph® (Oral morphine solution 10mg/5ml)

  5mg to 10mg every 4 hours PRN.

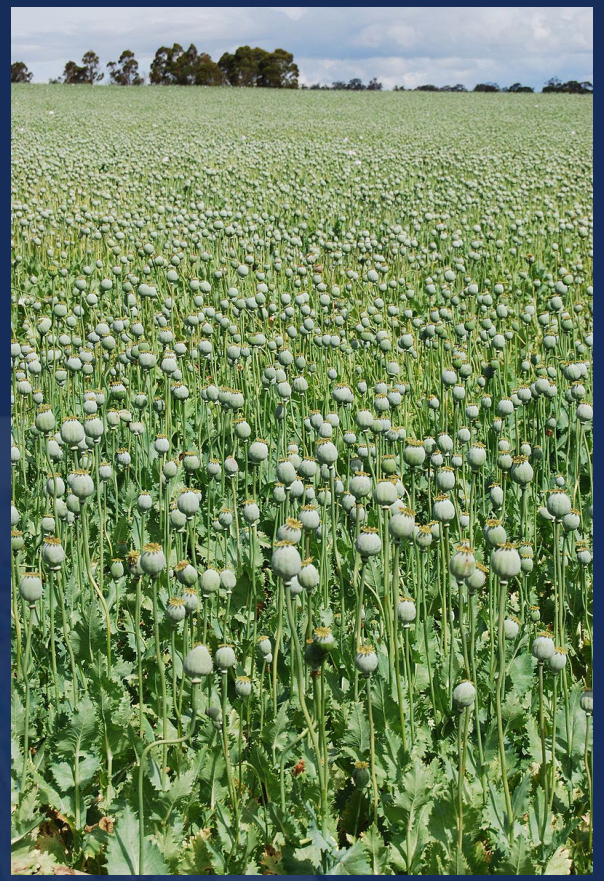
- Morphine sulphate inj (10mg/1ml, 30mg/1ml amps) 2.5mg to 5mg SC PRN up to every 1 – 2 hours. (Maximum 6 doses in 24 hours. However seek specialist advice after 3 doses in 24 hours).

  (CSCI 10mg to 30mg/24 hours)

ROLE OF OPIOIDS

- An opioid is any chemical such as morphine that resembles opiates in its pharmacological effects.
- Opioids work by binding to opioid receptors, which are found principally in the central and peripheral nervous system and the gastrointestinal tract.
- Opiates belong to the large biosynthetic group of benzylisoquinoline alkaloids, and are so named because they are naturally occurring alkaloids found in the opium poppy. The major psychoactive opiates are morphine, codeine, and thebaine.

MORPHINE



MORPHINE

MORPHINE

MODE OF ACTION

- Opioids primarily act by binding to specific receptors in the brain, spinal cord, and other parts of the body, specifically those related to pain and pleasure
- Opioids act by:

- Binding to Opioid Receptors located on nerve cells in the brain, spinal cord, and other areas. These receptors are key components of the nervous system, involved in pain perception and the regulation of other bodily functions.

- Blocking Pain Signals by interfering with the transmission of pain signals from the body to the brain, reducing the intensity of pain experienced.

- Influencing Neurotransmitters

- Modulating Spinal Cord Activity

BREATHLESSNESS

- Oramorph® (oral morphine sulphate solution 10mg/5ml)
  5mg to 10mg every 4 hours PRN.
- Morphine sulphate inj (10mg/1ml, 30mg/1ml amps)
  2.5mg to 5mg SC PRN up to every 2 to 4 hours. Maximum 6 doses in 24 hours. However seek specialist advice after 3 doses in 24 hours. (CSCI 10mg/24 hours)

- Midazolam (10mg/2ml amps) 2.5mg SC PRN up to every 2 hours. Maximum 6 doses in 24 hours. (CSCI 5mg to 10mg/24 hours starting dose).

- Lorazepam 500 microgram Sublingually prn

NAUSEA & VOMITING

- Haloperidol Oral 1.5mg daily PRN; increase to 3 times daily as required.

  SC 1.5mg every 8 hours PRN (5mg/1ml amps)

  (CSCI 2.5mg to 5mg/24 hours)

- Metoclopromide 10mg PO/SC PRN (10mg/2ml amps) every 8 hours (CSCI 30 to 60mg/24 hours)

RESPIRATORY SECRETIONS

- Hyoscine Butylbromide (20mg/1ml amps)

  20mg SC PRN up to every FOUR hours (CSCI 60mg to 120mg/24hours)

- Glycopyrronium bromide (200micrograms/1ml, 600micrograms/3ml amps) 200 to 400microgram SC PRN up to every SIX hours. (CSCI 600micrograms to 1.2mg/24hours).

DELIRIUM

- Haloperidol (tablets or oral solution) or SC (5mg/1ml amps) 500 micrograms to 1mg PRN 4 hourly (CSCI 2.5mg to 5mg/24hours). Increase in 500 micrograms to 1mg increments

- If patient remains agitated, it may be necessary to use a benzodiazepine:

  Lorazepam (1mg tablets)

  500 micrograms to 1mg SL PRN 4 hourly max 4mg/24hours.

  OR

  Midazolam (10mg/2ml amps) 2.5mg to 5mg SC PRN every TWO hours. Maximum 6 doses in 24 hours. (CSCI 5mg to 30mg/24 hours)

- Chlorpromazine as third line?

GENERAL MANAGEMENT

- Decrease medications
- Review route
- Consider Syringe Driver
- SOS Medications
- Review repeatedly

CARE OF THE DYING - 1

- Personal Hygiene
- Mouth care
- Pressure areas care
- Isolation vs close family visiting

CARE OF THE DYING - 2

CONSIDER (DISCUSS):

- Religious / cultural rituals
- Talk to Family

  …Fears…Feelings…Need for support…? Young children… Elderly parents
- Patient's wishes
- Respect after death

GOOD DEATH

- What makes a good death?
  - peace, location, company, pain-free, with dignity
- Lack of data on how people die
  - especially patients' perspectives
  - different conditions, cultures, ages
- Are people afraid of dying rather than death?

Kendall et al BMJ 2007

PROCESS OF DEATH AND CERTIFICATION

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MCCD

- Medical Certificate of Cause of Death (MCCD):
- A doctor, usually the one who saw the person recently, will complete the MCCD if the death was expected and from natural causes.
- In England and Wales, the MCCD is reviewed by a medical examiner, who is a senior doctor not involved in the deceased's care.
- The medical examiner's office will contact family to explain the cause of death and to answer any questions families have.
- The medical examiner then submits the MCCD to the registrar.

REGISTRATION OF DEATH

- The MCCD is sent to the registrar by the medical examiner, which triggers the 5-day statutory timeframe for registering the death.
- A representative of the deceased will be notified to arrange the registration at the registry office.
- It's important to note that the informant, who is usually a family member, should be aware of the cause of death before registration and have an opportunity to raise any concerns.

CORONER

- If the death is referred to the coroner, there will be a delay in issuing the death certificate while the coroner investigates.
- The coroner's investigation may involve preliminary enquiries and, if necessary, a full inquest.
- If the coroner decides that an investigation is not required, the attending practitioner or medical examiner will complete the MCCD.

ETHICAL DILEMMAS IN PALLIATIVE CARE

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Ethical Dilemmas

- What is Ethics?
- Case studies
- Euthanasia / Physician Assisted Suicide
- Artificial Nutrition and Hydration
- Conclusion

Do We Need Ethics?

- Individual or societal
- Familial or cultural
- Religious or secular
- Legal or philosophical
- Good vs right
- Bad vs wrong

End of Life Issues

- Consent
- Confidentiality / Team
- Autonomy
- Truth Telling
- Life Prolonging Treatments (Hydration, withholding treatment, Resuscitation)
- Advanced Directives
- Provision of Alternative Therapy
- Research
- Assisted suicide / Euthanasia
- Conscientious objection

Aristotle *(384 BC – 322 BC)*

Moral Theories

Deontology

Ethical or not decided by the action

- Absolutism
- Prima Facie

Consequentialism

Ethical or not decided by the effects

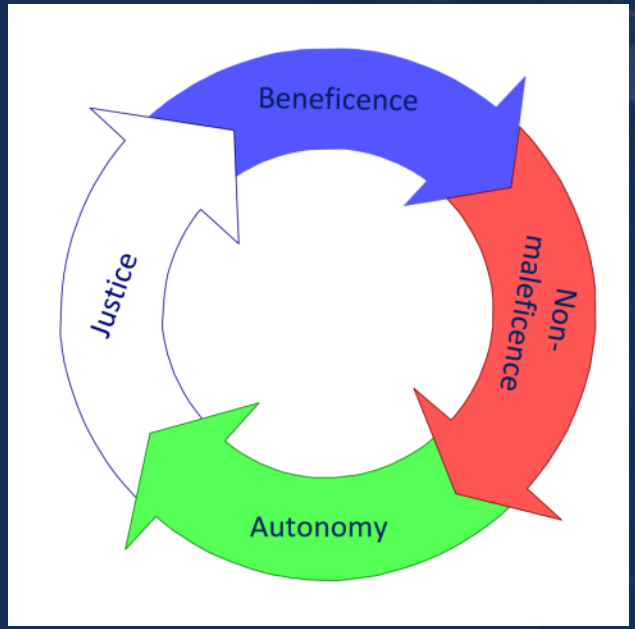
Virtue Ethics

Humans intrinsically know what is right or wrong

Ethics

Prima Facie principles:

- Beneficence – Help your patients
- Non-Maleficence - Do not harm your patients
- Autonomy – Respect
- Justice – Treat fairly



Case Study 1

Mohammed is a 65 year old man who was diagnosed to have **lung cancer**. Mohammed now has widespread metastasis and is **deteriorating.** He was admitted to hospital with a possible lung infection.

Despite antibiotics, Mohammed kept deteriorating and the medical team felt that he was in the **terminal phase of life**. He and his wife agreed but his 35 year old daughter, who is a doctor, believed that you should continue with IV fluids and antibiotics.

QUESTION

- Why is the daughter asking for these interventions?

Life prolonging treatments

- Potential benefits of treatment must balance against potential risks and burdens
- Doctors must strive to preserve life but when, burdens outweigh benefits, withdrawing or withholding such treatments and providing comfort in dying is their duty

Life prolonging treatments

Decide appropriate treatment with the patients, keeping in mind:

- The patient's biological prospects
- The therapeutic aim and benefits of each treatment
- The adverse effect of treatment
-
- The need not to prescribe a lingering death

Life prolonging treatments

- Parenteral hydration or medications
- Medications for concomitant diseases
- Cardiopulmonary Resuscitation

Case Study 1

Jannat is a 45 year old female who has **breast cancer** with **lung and brain metastasis**. Jannat is slowly getting weaker but is still able to manage her affairs and go out. Doctors have told Jannat's husband Karim that Jannat's disease is advanced. Karim was very angry and asked doctors not to tell patient this. Jannat keeps on asking doctors, what is wrong with her?

Collusion?

- In conversational English, collusion denominates a secret agreement and cooperation for an illegal or deceitful purpose between two or more persons who share an unvoiced and complicit intention
- n Psychology, collusion is defined as an unconscious bond: the associated persons take part in a plot without knowing the script of the play (the Latin root of collusion, “colludere,” signifies “to play together”).

SHAHEEN PALLIATIVE CARE PROJECT

What is Collusion ?

- Collusion: This usually occurs at the family's request and is the default practice in many Asian cultures
- It is contributed to, both by the widespread practice of physicians disclosing a diagnosis to a patient's family members before revealing it to the patient and by clinicians' underestimation of the information needs of patients.
- Clinicians may also regard collusion as an easier option than telling the truth because it reduces their own stress and anxiety
- Collusion, an unconscious dynamic between patients and clinicians, may provoke strong emotions, un-reflected behaviours, and a negative impact on care

SHAHEEN PALLIATIVE CARE PROJECT

Survey in a palliative care unit in Singapore Hospital in 2004

- Patients:
- Unaware of their diagnosis at time of referral: about 70%.
- Would like to know about their illness: 67%
- Would like to know whether the illness is life-threatening: 54 %
- Would choose to know the prognosis in terms of their remaining life expectancy: 46%.

- Families: the overwhelming majority of family members would rather not have patients be aware of the life-threatening nature of their illness (91.4%)

- Or of the prognosis in terms of the life expectancy (95.7%).

SHAHEEN PALLIATIVE CARE PROJECT

Do cancer patients want to know the truth?

- "The news would kill him – you must not say anything".
- This is a commonly expressed belief that what people do not know does not harm them.
- 'No news is not good news, it is an invitation to fear'
- Evidence from research studies showed that although truth hurts, deceit may well hurt more.

Reasons families choose to keep a diagnosis from a patient

- Disclosure causes the patient to lose hope
- Disclosure leads to depression
- Disclosure hastens the progression of the illness and death
- Disclosure increases the risk of patient suicide
- Disclosure may cause psychologic pain for the patient
- Family members themselves may not be aware of the nature and severity of the illness
- Family members may be in denial
- Family members may be in conflict

SHAHEEN PALLIATIVE CARE PROJECT

Do cancer patients want to know the truth?

China

- For example Fielding and Hung challenged the notion that Asian patients with cancer and their families want less information than their western counterparts in a series of well conducted studies.
- In some Chinese culture filial duties and obligations form the basis for non-disclosure.

Why collusion goes against the principles of best clinical practices

- **Patient factors**
- Patients may not be able to complete unfinished business and tasks prior to their deaths
- Patients who sense something amiss may come to distrust their relatives and clinicians
- Many patients suspect the diagnosis anyway, given their symptoms and physical deterioration

Why collusion goes against the principles of best clinical practices

- **Family factors**
- Family members will have to bear the burden of being untruthful or even deceptive to their loved ones, which may lead to guilt later
- A barrier to communication is erected as family members become avoidant at a time when they are most needed by patients
- Families will have no guidance in making treatment decisions, especially closer to the end of life

Why collusion goes against the principles of best clinical practices

- **Clinician factors**
- Collusion results in a breakdown of the clinician–patient relationship and a loss of trust between patients and clinicians
- Clinicians may face treatment noncompliance from patients and may be unable to provide optimal treatment, such as radiotherapy and chemotherapy

SHAHEEN PALLIATIVE CARE PROJECT

Multipronged strategy to tackle collusion in the inpatient setting

- **Family-targeted strategies**
- Ensuring that family is fully aware of diagnosis and prognosis
- Explaining the reasons and problems of collusion (reinforced with a pamphlet). Discuss value of truthfulness in all faiths
- Explaining to the family how breaking bad news is conducted (reinforced with a pamphlet)
- Offering to help break bad news on behalf of the family
- Counselling the family on possible reactions to bad news and reassuring them that the patient will be able to cope with the families' support and care
- Reassuring family members about continual care and support for the patient and for them in dealing with the terminal illness even after the diagnosis is revealed

SHAHEEN PALLIATIVE CARE PROJECT

Multipronged strategy to tackle collusion in the inpatient setting

- **Staff-targeted strategies**
- Creating awareness and addressing the issue of collusion head-on
- Making it routine to address this issue for all patients with a life-threatening or terminal illness
- Appointing clinician champions in the four major departments of the hospital who work to create awareness of collusion
- Encouraging staff to attend workshops on breaking bad news, held regularly by the hospital's Grief and Bereavement Committee

SHAHEEN PALLIATIVE CARE PROJECT

QUESTION

- What do you think is difference between Euthanasia and physician assisted suicide?

Euthanasia

- *'Good Death'*
- A deliberate intervention undertaken with the express intention of ending a life to relieve intractable suffering
- Active act (as opposed to Physician Assisted Suicide)

Physician Assisted Suicide

A doctor "*knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counselling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs*."

Euthanasia

For:

- Suffering
- Fear
- Distress
- Loss of social role
- Cost-effectiveness
- Patient's autonomy

Against:

- Basic values
- Vulnerable groups
- Religious values
- Change of social role
- Slippery slope
- Real autonomy?

Euthanasia

- Voluntary Euthanasia
- Involuntary Euthanasia
- Non-voluntary Euthanasia
- Active Euthanasia
- Passive Euthanasia

Euthanasia

Is **NOT:**

- Allowing nature to take its course
- Stopping biologically futile treatment
- Using Morphine and other drugs to relieve pain
- Using sedatives to relieve intractable mental suffering in dying patients

Euthanasia

Reasons:

- Unrelieved symptoms (esp. pain)
- Fear of future intolerable symptoms esp. pain
- Fear of being kept alive with machines and tubes at a time when quality of life would be unacceptably low
- A short-term adjustment disorder (despair)
- Depression
- Feeling a burden on one's family, friends or society
- Feeling unwanted by family, friends or society
- A fixed sense of hopelessness (Twycross – 1997)

Palliative Care

"Survey shows that a majority of respondents (82%) do not support a change in the law on assisted suicide, confirming the similar finding in a recent survey by the Royal College of Physicians (RCP). Eighty-five percent of palliative physicians who are members of the RCP opposed any change in the law and 92% opposed physician-assisted suicide."

January 2015

apm Association for Palliative Medicine

Assisted Dying Bill: The Process

Presented to UK Parliament 16 October 2024

Second reading 29 November 2024

Passed by 330 to 275 votes

Committee stage 21 January-25 March 2025

Scrutiny and amendments

Removed High Court approval & replaced with multidisciplinary 'Assisted Dying Review Panels'

Comprises senior legal figure, consultant psychiatrist & social worker

Panel would determine

- Person is terminally ill
- Mental Capacity to make decision to end their own life

Report & third stage 16 May 2025

If passed will then proceed to the House of Lords & follow the same process as above

Palliative Care CPD Day

2025: Year of Mulla Asghar

Assisted Dying Bill: Conditions

- Proposed legislation to legalise assisted dying for terminally ill adults in the UK. Applies to those who:
  - Terminally ill >18 years with less than 6 months or less to live
  - Have mental capacity to make the decision
  - Must be registered with a GP for at least 12 months
  - Must make 2 separate declarations, witnessed & signed, about their wish to die
  - Medication self-administered under medical supervision

Arguments against Assisted Dying

- Disregards sanctity of life
- Risk to vulnerable individuals:
  - Elderly, seriously ill & disabled may feel a burden to those around them & consider Assisted Dying as an 'option'
- 'Slippery Slope'
  - Once assisted dying legalised, gains acceptance, becomes normalised & eligibility criteria may be widened
- High quality palliative care can effectively alleviate distressing symptoms in the dying process
- Alters the role of doctors from 'life-sustainers' to 'hastening death'
- Difficult to attain certainty that an individual has not been coerced

Assisted Dying: France

- 27 May 2025: Parliament voted in favour of Bill to legalise assisted dying
- First reading passed by votes of 305 to 199
- Legislation would allow medical team to determine if a patient is eligible to ‘gain access to a lethal substance when they have expressed a wish’
- Eligibility criteria
  - >18 years
  - French citizenship/residency
  - Serious & incurable, life-threatening, advanced or terminal illness that is irreversible
  - Disease must cause ‘constant, unbearable physical/psychological suffering’ that cannot be addressed by medical treatment
  - Mental capacity to make decision freely & in an informed manner to end their life

Assisted Dying: European Landscape

- Austria: AD legalised 2022
- Belgium: Legalised May 2002, No legal age limit
- Germany: Right to self-determined death 2019
- Italy: Assisting a suicide not always a crime 2019
- Luxembourg: Right to Die with Dignity Law 2008
- Netherlands: Voluntary euthanasia legal since 2001 (>16 years)
- Portugal: Euthanasia legalised 2023
- Spain: Euthanasia & assisted dying legalised March 2021
- Switzerland: Assisted suicide allowed since 1942

QUESTIONS?

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