Dealing with terminal illness and expected deaths in secure care

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Why are we here

• We are all aware of the comorbidity of physical and mental health

• Increasingly we have to deal with patients who are terminally ill

• It is important that we have a common understanding of deaths in secure care, the guidelines that deal with this, and the impact on professionals /care providers
Objectives

• Definitions
  – Expected/Unexpected/Natural/Unnatural
  – End of life

• Gold standards (LACDP-New Priorities for Care)

• Guidelines (GMC/NICE)

• Case vignettes (when things workout and when they don’t)

• SUIs and Case law

• Suggestions for future
Definitions

• EN1 Death that was expected to occur in an expected time frame (terminal illness, Palliative care)

• EN2: death that was expected but was not expected to happen in the time frame (someone with cancer or liver cirrhosis)

• EU: Death was expected but not from cause expected or timescale (drug overdose,)
Definitions (2)

• UN1: any unexpected death which are from a natural cause (cardiac, stroke)

• UN2: unexpected death from a natural cause but didn’t need to be (alcohol)

• UU: unexpected death from unnatural causes (suicide, homicide)
Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- (a) advanced, progressive, incurable conditions
- (b) general frailty and co-existing conditions that mean they are expected to die within 12 months
- (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- (d) life-threatening acute conditions caused by sudden catastrophic events.
GMC Guidance: End of Life Care (2010)

Based on following principles:

- Equalities and human rights
- Presumption in favour of prolonging life
- Presumption of capacity
- Maximising capacity to make decisions
- Overall benefit
Independent review of Liverpool Care Pathway: July 2013

• Developed from a model of care successfully used in hospices
• Generic approach to care for the dying
• Definition and terminology eg: End of Care could mean last year to last few hours; ‘pathway’ interpreted by families as decision to kill their loved one
• Lack of evidence base regarding LCP
• Documentation: LCP document meant to replace contemporaneous medical records
• Consent – patients lacking capacity, family not involved
Leadership Alliance for the Care of Dying People (LACDP)

• Coalition of 21 national organisations
• Focus on needs & wishes of the dying person and those closest to them
• Five new Priorities for Care
• Frontline health and care staff to commissioners and regulators
New Priorities for Care

• The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person’s needs and wishes, and these are reviewed and revised regularly.
• Sensitive communication takes place between staff and the person who is dying and those important to them.
• The dying person, and those identified as important to them, are involved in decisions about treatment and care.
• The people important to the dying person are listened to and their needs are respected.
• Care is tailored to the individual and delivered with compassion – with an individual care plan in place.
NICE Quality Standard (QS13)-2011

• Covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life.

• Includes adults who die suddenly or after a very brief illness.

• Does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents.
Case 1

- Detained S37/41. Schizoaffective disorder
- IO: indecent assault and false imprisonment of 13yr old girl
- Treatment resistant. Grandiose, invincible, immortal, “all women adore me and all men envy me”, leave only with young female staff. Lack of engagement with staff.
Case 1

• D&V Christmas 2015. Transferred to general hospital
• Moved between high dependency and ICU wards. IV fluids, NG feeding
• Developed complications including aspiration pneumonia for which required IV antibiotics & assisted ventilation, pneumothorax requiring chest drain
• Abdominal mass noted on clinical examination. CT revealed carcinoma of head of pancreas with biliary and gastric outlet obstruction
• Best interest meeting attended by Consultant Gastroenterologist. Palliative ERCP proposed.
• Transferred back to psychiatric ward for End of Life care
Case 1

- Reviewed by RC & Gastroenterologist to assess capacity
- Gastroenterology and Palliative Care Consultant provided guidance regarding management
- Input from MacMillan Nurses
- Regular reviews by Physical Health Modern Matron and Nurse Practitioner Physical Health
- Brother regularly updated and involved in care since transfer to general hospital until death. Happy with End of Life Care on ward
Case 2

- 75 year old man (died in 2015)
- Diagnoses: Persistent delusional disorder/ Schizoaffective disorder...
- Managed in secure hospitals since I/O in 1989
- High security in 1989 (TTK, Firearms)
- Failed Trial Leave to RSU 1995-1996.
- Progressed to Low Secure in 2001
- Returned to High Security 2004

- No siblings, Parents RIP.
- No partner (wife died)
- No next of kin (cousins-infirm/dementia)

- Extensive physical health needs (next slide)
Case 2

- Poor mobility, wheelchair bound
- **Normal Pressure Hydrocephalus (needed VP Shunt)**
- **Urethral catheter due to urinary incontinence (Needed TURP)**
- Type 2 diabetic
- IHD-Triple heart bypass surgery
- Bilateral THR
- Prostate cancer
- Dysphagia
- Haemorrhoids
- Vit D deficiency
- Poor mobility with increased risk of falls- on a wheelchair
- Recurrent UTIs
- Intermittent faecal incontinence

- Single handedly skewed the directorate budget due to sheer no. of OOGs
Case 2

- Patient developed biliary sepsis and transferred to general hospital
- Unresponsive, terminally ill
- All treatment was withdrawn
- MoJ contacted but refused to rescind Section
- Patient recovered, returned to High secure hospital with DNR and instructions by medical Consultant not to receive future treatment
- Patient had capacity, RC overturned DNR
Case 2

• Patient had respiratory arrest, successfully resuscitated
• A&E refused to admit patient on basis of previous directions from medical team
• Conflict psychiatry-medical team
• Finally treated at hospital and returned to high secure but again with DNR
• RC reviewed -> overturned DNR
• Conflict within the MDT and GP at high secure
Case 2

• New physical deterioration -> general hospital
• Unconscious, unresponsive
• Absolute discharged by MoJ.
• Issues with MHA office re informal status
• Died 2 days later in general hospital
• Executive director -> death in custody
• Coroner -> no inquest
• Hospital -> cross directorate inquiry
• Questions about DNR
Capacity v DNAR (guidance/case law)

- *Airedale NHS Trust v Bland* [1993]

- *R. (on the application of Tracey) v Cambridge University Hospitals NHS Foundation Trust* [2014]

- *Winspear v City Hospitals Sunderland NHS Foundation Trust Queen's Bench Division* [2015]
• Article 8- Right to respect for private and family life:
  – Everyone has the right to respect for his private and family life, his home and his correspondence.
  – There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law...

• Section 4(7) of the Mental Capacity Act 2005 provides:
  - “[The decision-maker] must take into account, if it is practicable and appropriate to consult them, the views of ... (b) anyone engaged in caring for the person or interested in his welfare.”

• Winspear case...Blake J:

  Although the doctor might have considered that resuscitation would have been futile, R (Tracey) v Cambridge University Hospitals NHS Foundation Trust made it plain that that did not obviate the need for consultation for patients with capacity; and section 4(7) made plain that consultation about such a decision was necessary with the carer of an incapacitated patient unless not practicable.
Challenges/Dilemmas

• MCA / GMC/NICE
• Good communication and documentation
• MoJ/Solicitor/ First Tier Tribunal/police/probation
• Coroner/ MHA commission-CQC

• Multidisciplinary approach-liaising with different agencies and encountered conflicts
  -Medical team at general hospital/Palliative care team-stigma /concerns
  -Family- conflicts of interest/IMCA/LPA
  -Court of protection
• Fair treatment at right setting/dying with dignity/best interest Vs. Balancing serious risk to others(offence-information to share)
• Counter-transference: dealing with feelings –long term relationship, impact on clinical team/for RC (restrict freedom/let dying), impact on other pts
• Specific issues
  -access to patient from family and ability to facilitate this in secure services
  -Treat or not to treat (Advance decision)
  -The will/property and financial affairs
  -After death-NR owns the body/donation of organs to others/research
  -Dementia cases/Paraplegic/ Infectious/cancer cases
Do we need specific guidance for the management of seriously ill/terminally ill forensic patients?
Discussion points

- Which deaths should be investigated
- Coroners and/or Cross Directorate Review
- Criticisms- Doctors anxious about letting people die
- Policy for death and dying in secure unit?
- National Audit (RCP).
- Do we need something similar in MH
- Duty of candour?
- MHA Office understanding of discharge
- Attachments/ Bereavement (staff)