

**“End of Life Care”
What is it and who needs it?**

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Outline

1. Assisted Dying versus End of Life Care
2. Mental Capacity Act 2005
3. Liverpool Care Pathway
4. Current Situation
5. Conclusion

Assisted Dying versus End-of-Life Care

End of Life Care Definition*

- **End of Life Care** is defined as care that helps those with advanced, progressive, incurable illness to live as well as possible until they die.
- End of life care enables the supportive and palliative care needs of both patient and family to be met throughout the last phase of life and bereavement. It includes the *management of pain and other symptoms*
- **Supportive Care** is defined as *care that helps the patient and their family to cope* with their condition and its treatment from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement.
- **Palliative Care** is the active total care of patients whose disease is *unresponsive to curative treatment*. Control of pain and other symptoms and support to manage psychological, social and other problems. Goal is achievement of the *best quality of life* for patients and families
- **Taken from the NHS/Public Health England's National End of Life Care Intelligence Network (NEoLCIN)**

End of Life Care vs Assisted Dying

- *End-of-life care* is part of traditional palliative care in which medications (e.g. opiates) are given for **evidence-based valid clinical indications** (e.g. severe pain). (Medications may secondarily have negative effects e.g. suppression of respiration - Double effect principle)
- “*Assisted Dying*” legally refers to voluntary assisted suicide and euthanasia which is intentional death.
- If *End of life care* uses opiates, sedatives and fluid limitation particularly in the setting of a pathway they are in effect “*Assisted Dying*”.
This particularly occurs with clinical pathways (like the Liverpool Care Pathway) that do not have a stated pre-specified intent to kill but *predictably* hasten death/shorten life.

Liverpool Care Pathway: Legal Background

Mental Capacity Act 2005

- The Mental Capacity Act was introduced to “empower vulnerable adults to take decisions for themselves and protect the interests of those who cannot do so”
- Most frequent situations: Psychiatric illness, Learning disabled and dementia, impaired consciousness in the elderly.
- The MCA gives guidelines on how to determine if a person is able to take decisions rationally about their treatment. (whether they have “mental capacity” or not)
- In those without mental capacity it establishes a method for determining the person’s “best interest”

MCA 2005: Best Interest

- Best interest decisions are made at a “best interest” meeting. The members can be anyone taking care of the patient. (doctors, nurses, therapists, spouse, close friends or family)
- A “Decision Maker” (DM) for “life-sustaining” decisions is chosen who can be any one of the medical team and does not have to be the patient’s doctor.
- The DM and those present at the “best interest” meeting have to use a special “best interest” checklist.
- The patient or their spouse/family do not have preferential input into the decision and do not have to agree with it.
- Members of the “best interest” group need only to have “reasonable belief” that they are acting in the patient’s “best interest”

MCA: Best Interest Checklist

1. Admonition to ignore patient's age, appearance, condition or behaviour.
2. Consider all "relevant circumstances", (The potential benefits must be weighed against the disadvantages of treatment taking into account the clinical situation and life expectancy) [Includes *Prognosis + Quality of Life Determination*]
3. Encourage the person to take part in the decision and put off the decision if they are improving.
4. Determine which treatments are life-sustaining and balance continuing these against them being futile or burdensome. Admonition not to be motivated by wish to kill patient even from compassion. [Includes *Prognosis + Quality of Life Determination*]
5. Consider past and present wishes and feelings, beliefs and values, written or oral. There is an emphasis on written statements.
6. Consider views of: "People close to the patient" and of an attorney or deputy. Anyone previously named who wants to be consulted, carers, family carers close relatives.

MCA 2005: Problems with “Best Interest” determination.

- The determination of what is in the patient’s “best interest” depends on the combined assessment of a group of people of varying medical expertise, varying knowledge of the patient, varying degrees of medical experience and varying medical vocation. The patient’s doctor may not be the main decision maker.
- The husband/wife and family have limited input into the decision. The MCA was the legal basis for blocking patient’s families from taking their relatives off the Liverpool Care Pathway in several reported instances in the press.
- “Best Interest” has been described as “Legal Fiction”. Holm et al, Health Care Analysis, 2008

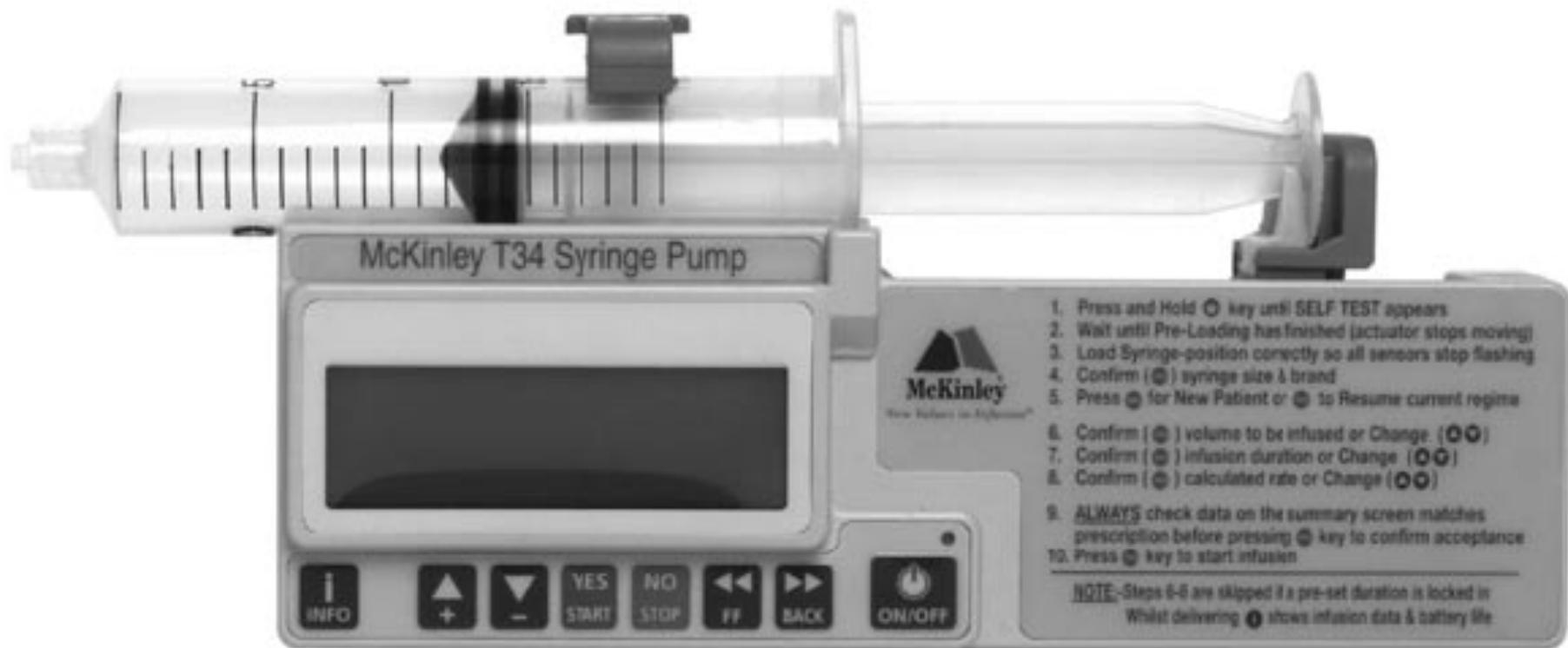
Liverpool Care Pathway

Liverpool Care Pathway

- Developed in the 1990s by John Ellershaw, Professor of Palliative Medicine at Liverpool University in the Marie Curie Palliative Care Institute.
- Described as an integrated care pathway to “drive up sustained quality of the dying.”
- Goal was “to transfer the best quality for care of the dying from the hospice movement into other clinical areas”

What happened in the LCP

- 1. Diagnosis that someone is in the “last hours or days of life” is made by a multi disciplinary team of doctors, nurses, and other medical support staff.
- 2. Syringe driver for subcutaneous infusion of: Morphine (pain killer), Midazolam (sedative) and Glycopyrrolate (secretions) “*Anticipatory*” prescribing.
- 3. “Unnecessary” interventions/observations stopped. May include nutrition and hydration.
- 4. Four hourly observations but decision *rarely* reversed.
- 5. Patients die in a mean time of 29 hours. (UK NCDHAH audit data)



Personal case of patient taken off LCP

- 71 year old man with history of a brain haemorrhage and epileptic seizures. He had mild dementia. His wife and daughter were very supportive. (Patient of Italian origin and spoke English poorly)
- He was admitted under my care with epileptic seizures. He was confused, agitated, hallucinating and aggressive at times. He developed pneumonia and was needing one-on-one nursing.
- I found him deeply unresponsive on a Monday morning and was told he had been put on the LCP over the weekend after a consultation between the doctor covering and the ward sister. He was on morphine via a syringe driver.
- The relatives were distressed and told me they had not agreed. I removed the patient from the LCP despite significant resistance. His seizures came under control and four weeks later patient was discharged home to family.
- 14 months later he was admitted to a different hospital with pneumonia. A “best interest meeting” between doctors, nurse and a physiotherapist decided to put him on the LCP and patient died 5 hours later.

Major flaws of the LCP

- The diagnosis that someone is dying is an educated guess and is frequently wrong.
- Stopping fluids and nutrition. Although “not part of LCP”, became almost routine.
- Sedation of elderly (opiates, midazolam) increases confusion, leads to drowsiness, reduces oral intake and *removes mental capacity*. Combination of dehydration and sedation is rapidly fatal. (The LCP was an abandonment of evidence-based medicine.)*

*Pullicino P (2012) The dangers of abandonment of evidence-based medicine in the use of the Liverpool Care Pathway. Catholic Medical Quarterly, 62; 28-31.

Can't Doctors tell when someone is going to die?

- A prediction that a person with terminal cancer has 6 months to live is only 80% accurate.
- Less than 50% accurate for 6 month survival in medical conditions like heart failure, pulmonary disease, HIV, liver disease, renal disease.
- Prognosis of imminent death (within days) is very inaccurate and becomes a self-fulfilling prophecy. *(If you diagnose someone as “dying” you stop trying!)*
- Prognosis for cognitive outcome is a major factor in attempting to determine quality of life. It has to be made separately but is even more difficult than predicting death outcome.

Spread of LCP

- In 2004 8.5% of all deaths in NHS were on LCP. By 2012 this reached 29% or estimated 130,000 patients.
- Reasons for rapid spread:
 1. Financial rewards for NHS Trusts to reach targets. The same CQUIN system used as for smoking cessation targets. (£30m in 4 years)
 2. Major hospital savings on length of stay costs for elderly.
 3. LCP was an answer to the elderly “bed-blocker” problem.
- Palliative care nurse-driven teams that were independent of consultant in charge of patient were set up and empowered by MCA 2005.

Neuberger Report

- By 2012 multiple inappropriate deaths were being reported in the press: Patients being diagnosed “dying” and then all fluids stopped. Relatives prevented from giving fluids.
- Government set up a committee headed by Baroness Neuberger.
- Report came out in mid-2013
 - LCP to be stopped by June 2014.
 - Greatest concern was the withholding/prohibition of fluids.
 - Did not recognize LCP was flawed but said it had been used “inappropriately” (this reflected ambiguity of committee some of whom were palliative care physicians)
 - Stressed that specialized “end of life care” not needed just good compassionate care.
 - Senior responsible clinician essential for every patient.

**Situation
Since LCP**

2015: *NICE Guidelines for Care of dying adults “in last days of life”.

Guidelines incorporated flaws of LCP: Diagnosis of “dying, Dehydration and Anticipatory prescribing of opiates. MCA-supported “best interest” decisions. Exclusion of spouse in decision-making.

1. Recognize when patient is in the “last days of life”

(symptoms: fatigue, loss of appetite, social withdrawal, mottled skin, Cheyne-Stokes respiration).

2. Hydration:

Discuss the risks and benefits of clinically assisted hydration with *the dying person* and those important to them. Advise them that, for someone *who is in the last days of life*:

Clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, *but may cause other problems*.

It is uncertain if giving clinically assisted hydration will prolong life or extend the dying process

It is uncertain if not giving clinically assisted hydration will hasten death.

3. Allows for anticipatory prescribing with: morphine, midazolam, glycopyrrolate.

*National Institute for Clinical Excellence.

Errors about Hydration in the Elderly

1. **The body needs less fluids when it is “shutting down”**
This is based on symptom based research not on fluid balance physiological research. It also presupposes you can diagnose imminent death.
2. **The risk of parenteral hydration balances its benefits.**
No proportionality between lethal and non-lethal side effects. Stopping hydration will kill. Overhydration is easily recognisable and treated.
2. **Giving hydration may prolong the “dying process”.**
This sets up a non-evidence based concept of a “dying process” that proceeds inevitably once it starts. It opens up fears that the patient may die a lingering death. Also time of death cannot be predicted. Diagnosis of a patient being in “dying process” is a self-fulfilling prophecy.
2. **Uncertain if not giving hydration will hasten death.**
This again is based on the concept of a predictable “dying process”. Clearly not giving fluids causes death by dehydration. This is basically lying to patients as most pathway deaths are due to dehydration.

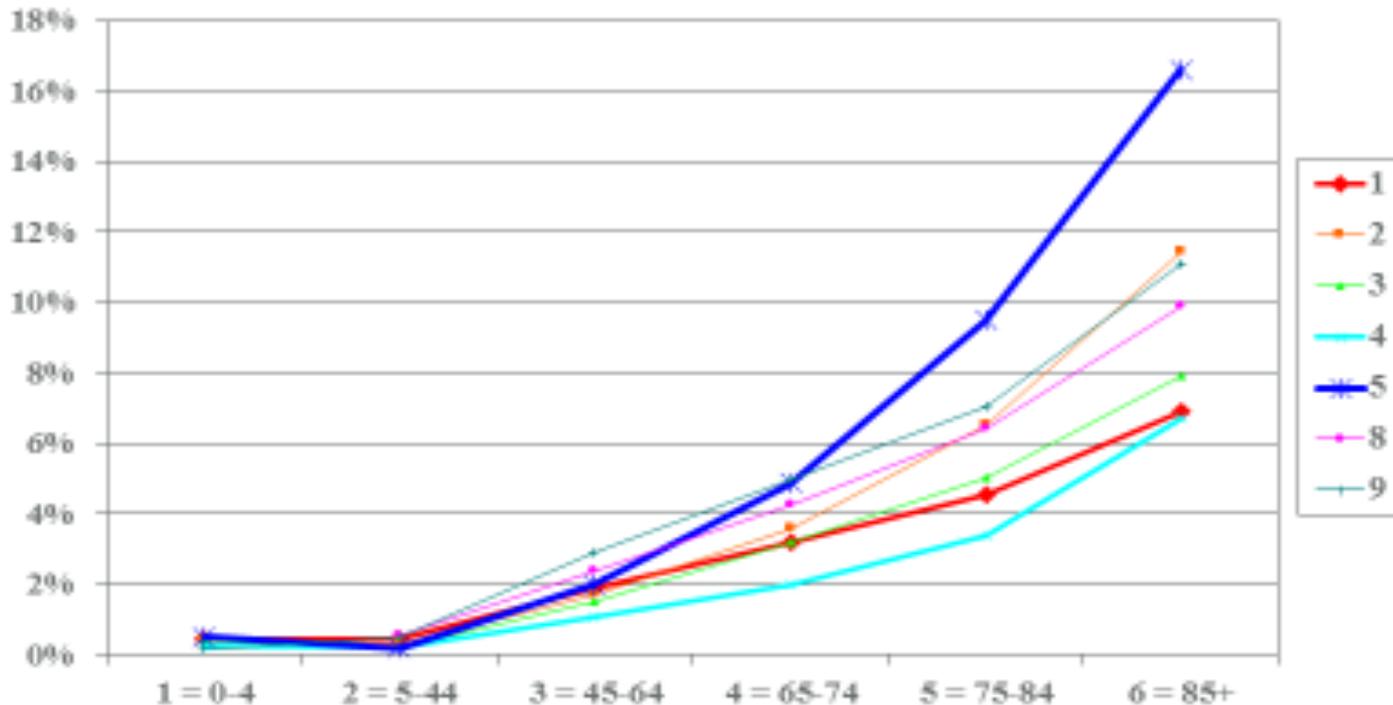
Current Situation

- Neuberger Report stopped the LCP by name, but errors of the LCP were incorporated into end of life care pathways throughout NHS.
- Statistics of patients dying from end of life care are no longer available.
- Recent BMA guidelines encourage doctors not to report dehydration on death certificate
- Occasional cases still reported in the press, but without legal proof of wrongdoing press are hesitant to get involved.
- Very worrying UK mortality and life expectancy statistics.

Cases reported to me

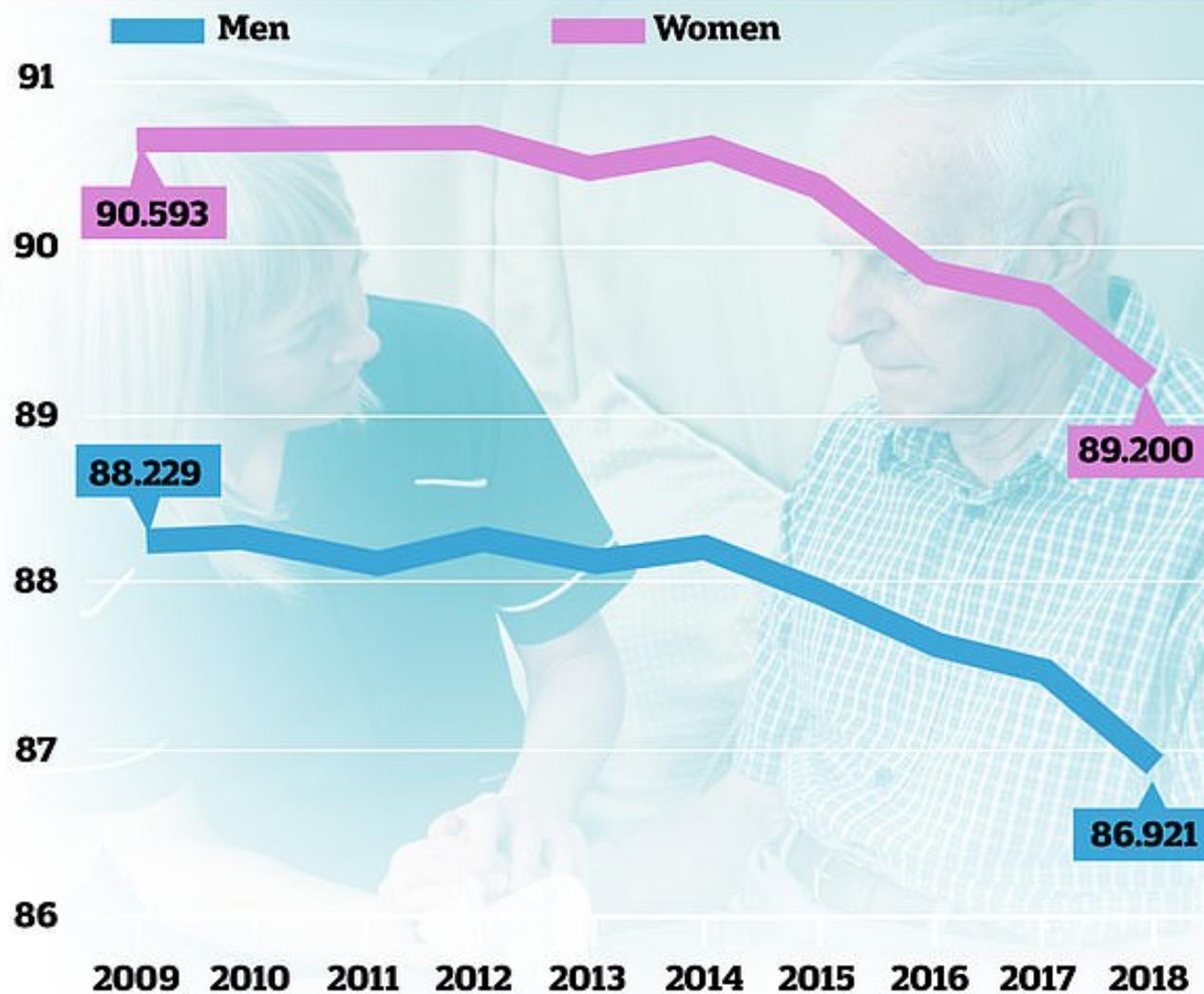
- Because of my interest in LCP I have had about four people a year contact me personally to ask help in getting justice for their loved ones who appear to have been dehydrated and sedated but were not obviously dying.
- Recent case sent to me
 - 84 yr-old woman admitted after collapse with anaemia.
 - Prior hip replacements, osteoporosis, diarrhoea.
 - 10 days after admission fracture of femur discovered.
 - During surgical repair lost 3 units of blood, but given only one.
 - Transferred from recovery to medical ward. Patient alert.
 - Put on end of life care. IV canula removed. Fluids denied despite family repeated requests. Died following day.

Death rate by agegroup for each country

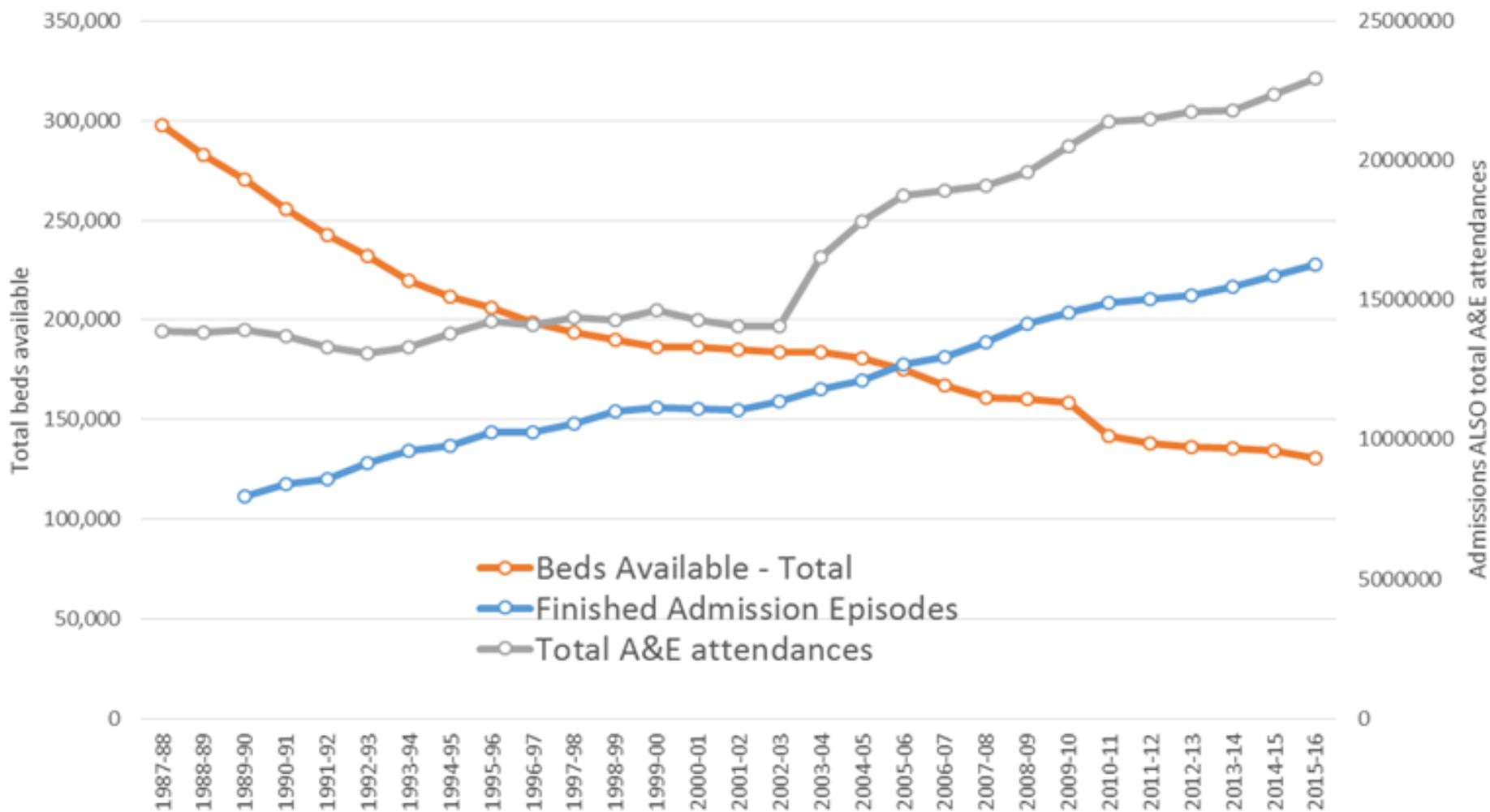


1: USA, 5: UK, 2,3,4,8,9: Sweden, Netherlands, Hong Kong, Singapore, Australia (NSW) (data courtesy of Sir Brian Jarman)

LIFE EXPECTANCY IN THE UK



England annual Total beds available, Admissions and Total A&E attendances



The Way Forward: Challenging the MCA sidelining of relatives.

- In a recent court case (NHS Aintree vs James) Baroness Hale ruled that the decision makers “must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be”.
- We are currently working with Lord Alton, Catholic Peer to develop a bill to replace spouse/family centrally as decision makers in end of life issues.

Conclusion

End of Life Care What is it?

- Dame Cicely Saunders: symptom control, especially pain. Reduction of physical and mental distress. Never do anything to shorten life.
- Modern Palliative Care has however accepted that dehydration and sedation are part of end of life care. This can hardly be called “care” however and is effectively euthanasia.

End of Life Care

Who needs it?

- Most acute hospital patients can be treated by their own consultant and team, including end-of-life care.
- Traditional Palliative care is valuable in particular groups of patients: terminal cancer in particular where patients request admission to hospice.
- Looking after sick patients and controlling their symptoms is done on all medical wards and traditionally all doctors do this. Decisions on reducing level of care can be taken by the individual consultant together with the patients close relatives, and use of second opinions as necessary.
- The labelling of a subgroup of patients as “dying” and treating them according to separate “end of life care” protocols is to be avoided as it leads to euthanasia.

PATIENT END-OF-LIFE-CARE BILL OF RIGHTS.

- **1. Sufficient fluids will be given to me by mouth, by tube to the stomach or by drip into a vein or under the skin, to relieve thirst and keep me hydrated, unless I decide against this.**
- **2. My bodily nutrition will be maintained by any reasonable means unless I decide against this.**
- **3. Unless I decline it, I will be given pain control to keep me as pain-free as possible, without the use of sedation.**
- **4 . I will not be sedated unless indicated by a specific diagnosis. If this need arises either I or my relatives will be informed and given this specific reason.**
- **5. If I am thought to be dying, I will have the right to ask for a second opinion on my diagnosis and the likely outcome.**
- **6. I have the right to ask to see the pastor of my choice.**
- **7. I will be involved in all medical and nursing decisions that are potentially life-altering and no medication will be given to me by syringe driver without my agreement or that of a spouse or close relative.**
- **8. Do not resuscitate orders will not be written up without my consent or that of my relatives.**
- **9. Any decision to reduce the level of active care, such as stopping antibiotics, or reducing the oxygen supply or withdrawing medication will not be made without my consent or that of my relatives.**
- **10. Should I lose the mental capacity to participate in my care, for example in situations such as those considered above, my spouse or the relative who is acting for me should be consulted, or if I have no living relatives, an Independent Mental Capacity Advocate should be appointed to take these decisions.**