



Preferred Place of Care – Ethical Issues in End of Life Care

Les Storey
University of Central
Lancashire, UK



THE ACCUSATION

'GPs SEND THE TERMINALLY ILL TO DIE IN A&E'

FOR THE PROSECUTION: AN A&E CONSULTANT IN BRISTOL

The A&E department is busy this afternoon. Not many drunks yet, but the usual chest pains, accidents, collapses, minor injuries, chesty kids and sociopaths. Noisy as always. There's a bed shortage, one ward is closed (MRSA), and we're perilously close to missing the 98% four-hour target. Morale is low. A typical day.

Margaret arrives by ambulance, with blue

flashing lights. She has come from a nursing home, where she has spent the last four years. She is 88 and was widowed ten years ago. She has a son but he rarely visits. She has dementia and is on an array of medications, none of which is reversing the ageing process.

Margaret is clearly moribund. What do we do? Nothing? Tempting, but unrealistic in the

circumstances. So we put up a drip, take some bloods, do an ECG and order a chest X-ray. The results are irrelevant.

She is dying; is virtually dead already. She arrests. Resuscitation is mercifully unsuccessful.

Documentation is completed and Margaret is taken to the mortuary. Rest in peace, Margaret.

Why must it be like this? Why must her last hours

be spent in drama and noise and pain? Why can't she die in peace at the nursing home? Why couldn't the GP have kept her comfortable? Is this the death you would want for yourself or your partner?

This is a new phenomenon – why has it developed? Shipman? Fear of litigation? Fear of taking decisions? Laziness? I don't know. But I know it is wrong.

GPs and the Government have accepted this 'out-of-hours' arrangement. Referrals such as these are therefore inevitable. The hospital with greater expertise should have taken greater responsibility and exercised better judgement with this presentation.

There should be records of Margaret's condition available to an out-of-hours doctor, who should give appropriate care, even if that means disturbing the next of kin or GP at home. Sending her to A&E is an abrogation of responsibility that occurs too many times.

Cases like this are not uncommon, but the patient's own GP is rarely the instigator. Key factors include pressure from relatives, staff unwilling to take responsibility and fear of litigation. The main problem rests with out-of-hours cover, and the real fault is the health climate we have created.



Ethical Considerations in Palliative Care

Withdrawing or withholding treatment

Feeding and fluids

Sedation

Resuscitation

Choice in Place of Care

Capacity to make decisions



Futile Treatment

BMA has said

“Health professionals are not obliged to provide any treatment which cannot produce the desired benefit. Treatment is usually considered unable to produce the desired benefit either because it cannot achieve its physiological aim or because the burdens of the treatment are considered to outweigh the benefits for the particular individual. (This is sometimes called ‘futile’ treatment.)”



Tell dying patients the truth to give them back their life

- Although death is a difficult subject, patients and their families benefit from knowing the truth
- Some patients may even live longer than expected because they are able to concentrate on new ways of enjoying life that benefit their health
- By diagnosing death you are giving back life to the patient, they are able to make end-of-life decisions

Mel McEvoy Nurse Consultant,
Nursing Standard March 15th 2006



Mental Capacity Act

Advance Directives are advance refusals of treatment.

Advance Statements are statements of wishes

Mental Capacity Bill (2007)



Advance Decisions

Advance Directives are advance refusals of treatment.

'UK doctors are legally compelled to abide, unless they can demonstrate good medical reason for going against patient wishes'

Dr Albert Day – Medical Professional Society



Advantages of Advanced Decisions

- Respect the patients human rights
- Encourages full discussion about end of life decisions
- Doctors are more likely to give appropriate treatment
- Help difficult decision-making
- Family/friends do not have to take difficult decisions



Disadvantages of Advanced Decisions

- Difficulty in initiating discussion
- Anticipating the future and how an individual responds to such circumstances is complex
- Frequently updating any advanced decisions
- Ensuring the advanced decisions are known to care providers



Advance Care Planning

- Preferred Place of Care (PPC)

helping to initiate and develop the sensitive conversation around preferred place of care and death between patient, carer and health care professionals to achieve a greater likely-hood of fulfilling the patients wishes

www.cancerlancashire.org.uk/ppc

www.eolc.nhs.uk



Key components

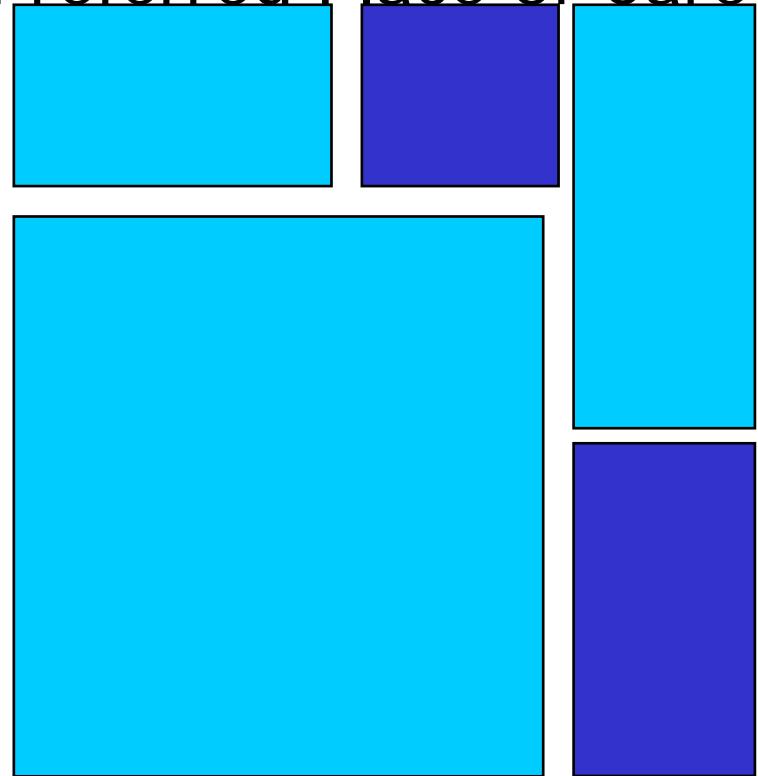
- Identification of palliative patients
- assessment of both patient and carers needs
 - include current and anticipatory
- developing an advanced care plan
- ongoing assessment and review
- communication
- education

Birth Plan

Death Plan



Preferred Place of Care





PPC- principles

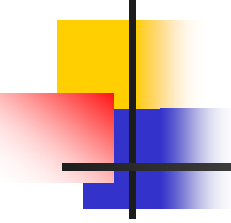
- The individual is asked about their wishes and preferences
- Wishes and preferences are recorded
- Wishes and preferences can be acted on in a variety of settings (when you are not there)



The PPC Document

- Guidance notes
- Demographic Data
- Family Profile
- Carers Needs

Identifying and Recording Preferences

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- The explicit recording of patients/carers wishes can form the basis of care planning in multi-disciplinary teams and other services, minimizing inappropriate admissions and interventions.
 - In relation to your illness what has been happening to you?
 - Have you had any particular thoughts about your care? What would you like or not like to happen?
 - Place of Care – Choices



Feedback from organisations using PPC

- Potentially the most important development in services for people with MND
- Nurses have increased their levels of confidence in their communication with dying patients and relatives
- As a result of this project, difficult, complex discussions are managed at an earlier stage of the patients' illness
- Collaboration between primary healthcare teams has improved
- Patients have confirmed their wish to remain involved and to be included in any discussion around the planning of care at the end of their lives

Table 6 Choice over, and actual place of death, for 1st 100 PPC patients

location	where wanted to die	where actually died (no. and %)				
	no. and %	Home	Hospice	Hospital	Community Hospital	on way home
Home	72	67	3	1		1
Home or Hospice	13	8	2	3		
Hospice	9	1	8			
Community Hospital	2				2	
Hospital	1	1				
Home or Community Hospital	1				1	
Home or at families or Hospice	1	1				
Home or Hospital or Hospice	1			1		
total	100	78	13	5	3	1

bold (choice not met for 10%)



Was patient choice met? If not, why not?

“Admitted to hospital but wanted to come home asap. Died in ambulance on reaching home”

“Husband unable to cope. Patient requested admission to hospice for respite”

“No bed available at Hospice and family unable to cope at home”

“Family situation changed, unable to cope. Discussed with family and patient”

“Admission to hospice. Sent home, deteriorated, family decision to keep home”

“Admitted to hospital, fell and broke hip. Partial hip replacement,

“Delay in delivery of hospital bed meant wife unable to cope lifting”



Robert

- Robert, aged 19 had osteo-sarcoma,
- Knew he was dying, he wanted to be at home
- The Friday night crisis.
- OOH service contacted
- GP contacted Paramedics
- Robert's mum, Julie confronted them and forced them to read what Robert had written on the PPC.
- Robert settled after this he was lucid and calm, with no complaints other than the dyspnoea .

- Robert died at home, as he wished, with all his family and friends in the room, his dog under the bed, and his beloved mobile phone still in his hand.