THE MEDICAL ETHICS ALLIANCE

RESPONSE TO THE NICE DRAFT GUIDELINES ON END OF LIFE CARE FOR ADULTS

Introduction:

The Medical Ethics Alliance (MEA) is a coalition of six faith and non faith based medical and nursing bodies. Our objective is to initiate discussion on ethics within healthcare professions and participate in public debate.

The MEA welcomes the opportunity to take part in this consultation on what is to replace the Liverpool Care Pathway. We do so in the understanding that the final guidelines will in all probability, influence the end of life care for most people . Following our conference in 2013 at the R S M entitled, "Natural Death is a Pathway Needed?", we were contacted by many families who had had very distressing experiences of the LCP.

In "More Care less Pathway", the Baroness Neuberger report, she says that good standard care is better than poor palliative care. We therefore recommend that good standard care be recognised more in the draft guidelines. A wider and ongoing consultation with authorities like the Royal Colleges should be encouraged. One of the problems with the LCP was that it had developed mainly from the experience of deaths from cancer. The manner of death from say, renal failure, stroke disease. COPD etc... varies so much that it is not possible to draw too heavily on the clinical experience of mainly cancer deaths.

Anticipating the end of life; (para 1.1)

This was one of the major problems with the LCP with some patients being deemed imminently dying when they were not. Most doctors have had experience of this error (myself included) but if it leads to a drug regime which is incompatible with survival, it will lead to the same problems as the LCP. Nothing but constant review and a willingness to recognise improvement will suffice. This is another reason why there needs to be a doctor in daily change who has an intimate knowledge of the patient.

Family members and people with Enduring Powers of Attorney may well wish to ask certain questions such as;

"Are you sure that death is imminent?"

"Can you be sure that the person will not experience thirst?"

"Will the drugs you give take away consciousness?"

"How will drugs interact?"

"Will life be shortened?"

"If the persons condition changes for the better, what changes will you make?

The importance of consciousness; (para 1.2)

Nowhere in the guidelines is there an adequate mention of the supreme importance of consciousness. It has been said "The last week of life may be the most important week of life", and this is true not only for emotional support and family communication, but also spiritual support.

To rob a person of their consciousness is a grave matter which is **not mentioned in the draft guidelines.**

There is a welcome mention about communication with the patient and family as one of the main problems with the LCP was that patients were being put on it secretly. Relatives began to suspect this and sometimes would not leave the loved one for fear that a syringe driver would be set up, and they would lose consciousness. If this happens again with the new guidelines they will be discredited.

There is a problem with **advance directives** however, a they only **become applicable if the foreseen condition actually arises.** Thus they can only have a limited usefulness though as a measure of communication they are important. This may include a preference to die at home but the person may still need admission to relieve distressing symptoms.

Who is responsible for the day to day management?; (para 1.3)

Central to our view is that **care of the dying is at least as important as care of the acutely ill** and that there must be a senior doctor, be it consultant or general practitioner, with clear responsibility. This is also called for in *"More Care less Pathway"*. That doctor should also be responsible for the individual care plan as stated in the Nueberger report.

We are not sure this is clear in the draft guidelines. There is a place for multi discipline teams but these cannot take the place of the doctor with overall responsibility and an **individual care plan**. This doctor should also make the day to day decisions including symptom relief and prescription in the same way as they would if managing acutely ill patients. **We return to our view that terminal care is as important as acute care. This may be implicit in the draft guidelines but should be clearly stated.**

Nutrition and hydration; (para 1.4)

Many of the most distressing cases in the evidence to Baroness Neuberger were of horrifying situations that can only be described as patients **dying of thirst. This is totally unacceptable!** If the draft guidelines do not eliminate this danger, then they will also be discredited. As a doctor who has seen death from thirst twice, I can say it is something not easily forgotten . Dr Gillian Craig of the MEA is submitting her own evidence on this. Moistening the mouth does not relieve thirst. There is evidence for this in animal experimentation (Dogs with an oesophageal fistula were not relieved of thirst by drinking).

We recognise that there has been progress in the draft guidelines on hydration and this is welcome but **adequate hydration, howsoever given, is a necessity for all.** We do not accept that dehydration can be diagnosed from the signs in the draft guidelines. **That is far too late.** Fluids should be routinely given by mouth, tube or stoma if possible, or by the intravenous or subcutaneous route if necessary. We simply **do not accept the view that the**

dying do not experience thirst. Nor do we accept that mouth hygiene relieves thirst. The draft guidelines says nothing about nutrition. Why is this? We have learnt of deaths that are caused by both dehydration and patients who have been starved over weeks.If such deaths are to be avoided , and they are all to obvious to relatives, the guidelines needs to be much more robust. **Nutrition and oral hydration should be patient driven** but there is a **basic need for fluids.**

Anticipatory prescribing; (para 1.5)

Anticipatory prescribing versus reactive prescribing was one of the major problems with the LCP. There is an urgent need to address this. The elderly may be particularly vulnerable. The draft guidelines **actually mentions "4 or 5" drugs without mentioning what they are.** This is unclear and potentially dangerous and likely to lead to over sedation and drug interaction. There is also the likely hood that the drug regimes would become protocols, one of the main problems with the LCP. If necessary the doctor with overall responsibility can be contacted , in the same way they would have been with a patient with acute illness. **Drug regimes must be based on patient need not prognosis. A lethal regime must not be allowed to build up as happened in some cases with the LCP.**

Evidence base of drug regimes;

The draft guidelines with commendable truthfulness states in a number of places that the **evidence base is "low" or "very low".** Interestingly, although in the section on recommended research there is a welcome recommendation for random controlled trials, but there are no recommendations on research to close these gaps. Why not? It is well know that Diazepams and Opiates poteniate each other but their metabolism will also depend on hydration and liver or renal function and the elderly are very susceptible to sedatives.

Conclusions;

(ii) The imminence of death cannot be certain, and no management should take place which could cause or hasten death.

(ii) The risk of thirst must be avoided and patient driven nutrition should be included.

(iii) A named senior doctor must be overall charge with responsibility for the individual care plan.

(iii) Consciousness should be preserved wherever possible.

(vi) There should be daily reactive prescribing.

(vii) There needs to be much more research to build up a proper evidence base, especially of medication at the end of life.

(viii) We welcome greater openness in discussion with the patient and relatives. There needs to be a two way dialogue. Advance directives have a limited application.

(ix) There should be daily re assessment of the person by the responsible senior doctor so that medication or the course of management can be changed.

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