A Submission to the Independent Review of Liverpool Care Pathway to be chaired by Baroness Neuberger

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http://mediacentre.dh.gov.uk/2013/01/15/independent-review-of-liverpool-care-pathway-to-be-chaired-by-baroness-neuberger/

My Background

I am a layman, who became involved in a wide-ranging discussion of End-of-Life behaviour and beliefs, as a consequence of my mother's death at home in late 2008. I tend to examine things from the perspective of live-with relatives and patients, with a concentration on EoL death within the patient's own home.

I am not primarily interested in the LCP, as CPR decision making is more relevant to my issues: however, there are common factors between the non discussion of placing patients on the LCP, and the non discussion that patients have been made 'not for resuscitation'.

My general approach to all end-of-life analyses, is to attempt to promote more balanced (perspective-independent) and coherent behaviour both across different professions, and along timelines as experienced by lay persons when they interact with a series of different professionals. In that vein, my comments regarding the LCP follow.

Some General Comments

The report by the National Confidential Enquiry into Patient Outcome and Death (2012), 'Time to Intervene ? (A review of patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiopulmonary arrest)' included a Foreword by Mr Bertie Leigh, the NCEPOD Chair and also a lawyer. That foreword included this, with my added emphasis in blue:

It is well established that surgeons who operate without the informed consent of their patients are guilty of an assault and will be held to have acted unethically in the eyes of the General Medical Council. There is no basis for asserting that different considerations apply to CPR: certainly there are emergency circumstances in which a doctor is entitled to assume that the patient would wish an attempt at CPR to be made. But that cannot defend the failure over a period of several days to find out what the patient's wishes may be, or where this is not possible, to determine the team's view of the patients' best interests. The surgeon will rightly operate when we arrive in the ED unconconscious after a road traffic cash, but no-one supposes that as a result this entitles them to operate without our consent on another occasion.

It was in the hope of finding out how far that ethical obligation sounds in modern medical practice that I approached this report. Alas, the results are profoundly disappointing and as I read these pages I wondered how many of these interventions would be defensible if charged as assaults before the criminal courts, or as professional misconduct before the GMC. The GMC recognises that CPR should be administered in an emergency, but it is not good medical practice to fail to anticipate the needs of the patient before an emergency arises. If the failure is deliberate or reckless then I suggest that it is arguably criminal.

What Mr Leigh is bothered about – and this bothers me as well – is clearly the failure to obtain consent, for an arrest which could reasonably have been foreseen. There have been many complaints about hospitals making 'clinical' do-not-resuscitate (DNACPR) decisions without telling patients or relatives, and this is one of the major complaints about the LCP – placing patients on the LCP, without telling the patient or relatives. A journalist called Shaun Lintern recently wrote a piece published on Nursing Times website defending the LCP - one of his relatives had died on the LCP – but he also included this comment in his piece (my added bold):

'As a family we were involved in the LCP and DNR decisions, we understood it, we agreed with it and we were willing passengers on my nan's final journey .
That is the crucial difference between my story and the harrowing examples we have seen reported in the mainstream media.

Had I found out my nan had been put on the LCP and a DNR without my or my family's knowledge I would have wanted to tear the hospital down brick by brick with my bare hands. I can totally understand the anger families feel in those situations.

He had previously told us:

'The LCP was a crucial part of ensuring my nan kept her dignity right to end, it meant she did not suffer and allowed her to say her final goodbyes.

She knew she was dying and once treatment to try and save her was stopped she became peaceful and contemplative and I remember spending an hour with her alone where we talked for a final time. Looking back now, it was a conversation that was painful but so comforting to have had.

My nan said things to me that will stay with me for the rest of my life and the peace given to her via the LCP made that conversation possible.'

The reason for this failure, seems to be partly a reluctance to talk about 'the actual death/dying part' (common in both lay and clinical circles) – Professor Hugh Montgomery included in an e-mail to me:

'There are also issues of communicating: raising life-and-death decisions with people who may be terrified can seem cruel. Not to do so can deny a patient the right of self-determination.'

Clinicians are also influenced by their own experiences, and a nurse posted the following during a discussion on the Nursing Times website:

'If only it were that simple. The 'public' do not consist of 'like-minded' people who all want the same things from clinicians. Probably difficult for you to understand, but there are often reasons why people don't ask questions. People often know instinctively and don't need someone spelling it out to them. Some people genuinely don't want to know. I saw a doctor receive a punch in the face after imparting the reality of a patient's condition. His crime? According to the patient, it was because the doctor had taken away his hope. It isn't about clinicians not admitting that people are dying. It is nowhere near as simple as that.'

Even if doctors do discuss 'the death part', they do not always do so wholeheartedly: as a social worker who works primarily with the elderly/terminally ill wrote to me (the e-mail is included within a lengthy file which can be downloaded from http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?forumID=45&obj=viewThread&threadID=667) {my added blue):

'In my experience some patients do welcome the choice to decide following discussion with a doctor for a DNAR , they view their general quality of life as so poor its is a realtively easy choice for them . However I have generally found that it is very difficult for Doctors to have this discussion and they tend to obscure the information with medical jargon, talk around the subject ,and often in such a short timescale that it often leaves the patient wondering exactly what the purpose of the discussion actually was , It is only after, perhaps with the support of another professional , trusted nurse etc that they actually come to terms with the questions / discussion / prognosis etc. Just because it is difficult for doctors to summarize a persons prognosis / condition and effect of the conditions on their daily life and ask a persons opinion on DNAR doesn't mean that it should be changed.'

However, it is clear from the principle of Informed Consent (or patient self-determination, or patient autonomy, etc) that patients alone decide whether to accept an offered treatment (otherwise, it is legally assault) – 'Treatment and care towards the end of life: good practice in decision making' published by the GMC includes a description of the interaction between a doctor and a mentally-capable patient:

14 If a patient has capacity to make a decision for themselves, this is the decision-making model that applies:

(a) The doctor and patient make an assessment of the patient's condition, taking into account the patient's medical history, views, experience and knowledge.

(b) The doctor uses specialist knowledge and experience and clinical judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.

(c) The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

(d) If the patient asks for a treatment that the doctor considers would not be clinically appropriate for them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment. They should explain their reasons to the patient and explain any other options that are available, including the option to seek a second opinion or access legal representation.

That blue section, interests me here: both DNACPR (clinical as opposed to refusals) and the LCP involve 'medical non-interventions' – **how, if the patient is not informed of an intention to not intervene, does the patient seek an independent second opinion about the potential clinical effectiveness of the intervention ?** It is, I think, reasonable for a patient to assume that unless he has been told otherwise, CPR would be attempted and that clinicians would be actively attempting to keep him alive – surely it makes sense to assume that patients would have requested those things, unless clinicians are certain of the opposite ?

There is an interesting NHS CHOICES page at:

http://www.nhs.uk/Conditions/Consent-to-treatment/Pages/Problems.aspx

It covers decision-making during mental incapacity, and it states:

There are rules governing when life-prolonging treatment can be withheld or withdrawn when the patient's consent is not available.

The relatives and friends of the person receiving the treatment, along with the healthcare professionals responsible for the person's care, should decide whether treatment should be continued. They should consider whether:

- *the treatment is in the best interests of the person (in terms of quality of life and how long they will live)*
- *how much the treatment is improving their condition*

It is important to recognise, that this does **not** state who is actually 'making the decision' – that page, is in fact the logical consequence of sections 4(6) and 4(7) of the Mental Capacity Act.

In common with cardiopulmonary resuscitation (CPR), LCP patients will often lack mental capacity – and despite the 'apparent assertions' of the MCA's Code of Practice (actually, upon a full reading of the Code, some of its'assertions' turn out to be not really present), unless there is a Welfare Attorney (an attorney appointed under the LPA with powers over clinical interventions), the MCA does not define who can be a section 4 decision maker.

Before moving on to the stated objectives of the review of the LCP, I wish to point out a more general point about the nature of any 'end-of-life pathway'.

The Administration of Morphine

Consider morphine, being used for pain-relief. The pain could be during active treatment of another condition, or during palliative care. But there is nothing in the principle of Patient Consent, to suggest that the requirement to obtain consent to guard against a charge for assault, differs according to whether or not the patient is expected to live or die.

There are also risks with morphine, which will tend to increase as dosage increases: at very low doses, there is little risk but also less effectiveness in relieving pain, at massive doses death would be almost certain – but there is a window between the two, where a dose of morphine sufficient to adequately relieve the patient's pain, might carry a risk of causing the patient's death.

This is not unique, within medical practice: general anaesthesia always carries a small risk of death, but even so some 'cosmetic' surgery is performed under GA.

Going back to section 14 of the GMC guidance (reproduced earlier) it is explained that the role of doctors is to describe prognoses and risks of offered treatments (and of no treatment): **it is the patient who considers whether the risk is acceptable**.

Obviously, a person who is in the final stages of life, and in great pain, might very well wish to titrate his morphine dose against his experienced pain, with much less consideration of the 'but at that dosage, it **might** actually kill me' factor: a person who is receiving morphine for pain relief because of, for example, a badly broken but predicted-to-heal leg, would presumably be much more reluctant to accept any risk of the morphine dose being fatal. See, in this context, section 4(5) of the MCA (shown below): if the motivation

is to relieve pain, and death in fact occurs, unless one were reasonably certain that death would occur, the death does not necessarily appear to be 'illegal'.

A friend of mine, died from cancer in 2008, and he was very clearly aware **only** of pain, during his final week or so of life – he was 'screaming in agony' but unaware of anything else in his life, apparently, for that final week.

In this context, I am not sure why the following are 'accusations':

The LCP sedates people into unconsciousness;

The LCP hastens death because the average length of time on it is 29 hours.

Provided the sedation, or the 'hastening' (and there will often be uncertainty about 'hastening' in any event), **is at the patient's request**, why are they 'accusations' – or more specifically, and most simply, why is requested sedation, if sedation is the only adequate palliation available, not acceptable when the point of an EoL pathway is 'palliation' ?

Without consent from the patient, or the rather more complex (horribly more complex, actually, for these things) MCA Section 4 justification, sedation appears to de facto be an illegal assault (non-interventions, seem to be legally more complex: although for mentally incapable patients, section 1(5) of the Mental Capacity Act states 'An act done, **or decision made**, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.', and section 4(5) states 'Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.').

This argument is rather 'technical-legal', but clarity is required because clinicians are very 'nervous' even about relatively clear areas of law (and wrong about some areas !). The avoidance of obtained consent, when there was a clear opportunity to discuss a predictable future event and that opportunity was not taken by clinicians, does look very legally dubious indeed (see Mr Leigh's comment, above).

This probably cannot be changed – but why use the term 'LCP' ?

The LCP is clear about the importance of communication. It is designed to support professionals, who may not be palliative care specialists, to provide personalised, hospice style-care. It encourages staff to anticipate the treatment an individual may need, and to be ready to provide it swiftly, but it does not dictate the treatment anyone should receive. The issue is therefore not about the merits of the LCP itself, but about how it is being used.

I think calling 'the overall care' 'being on the Liverpool Care Pathway' is conceptually confusing – all people are doing, are changing behaviour when the patient's situation changes (from being cured, to dying, in essence). There are clinically-proven methods of providing palliation, but these need not only be involved in the care of the terminally ill: likewise, a patient is entitled to refuse some active interventions but accept others (it is reasonable in some situations, to accept all types of active intervention except for a blanket refusal of attempted CPR). The widespread confusion/conflation between clinical effectiveness, and a patient's right to refuse interventions (a right which is ongoing and applies to **each individual** intervention), is probably one reason why the communication your webpage stresses as being so important, does not always occur – if every aspect of 'the LCP' were thought of as being a separate 'intervention', and it were understood that these individual interventions required patient consent, then surely clinicians would be more-or-less forced to talk to patients (or for mentally-incapable patients, 'relatives') ?

Hospital or Home

If 'the LCP' is the gold-standard for EoL care, then it should presumably be used both at hospital, and also at home (even if some things would not be possible, or would need modification, at home).

Currently, most clinicians are coming round to the view that DNACPR Forms must stay 'with the patient' – usually, right at the top of the medical notes. This has resulted in the odd situation, that most hospitals have guidance which does **not** state that patients **must** be informed of 'clinical' DNACPR decisions – but for patients who are home, if the DNACPR Form is also at home and sitting on top of their medical notes, it is effectively impossible to not 'tell the patient/relatives' of the DNACPR decision.

Presumably, this will also be true, if the LCP is employed in a home setting.

It seems to make little sense, to have an objective to allow more patients to die at home, and for the 'discussion/disclosure' to be effectively unavoidable for patients who are at home, if hospitals are to have a policy of only optional discussion/disclosure !

The LCP does not hasten or delay death

That assertion was made in the recent '**Consensus Statement: Liverpool Care Pathway for the Dying Patient (LCP)'** and it has an interesting consequence, for patients who are mentally incapable.

The complication of decision making for incapable patients in the absence of a Welfare attorney is highlighted by that NHS Choices webpage I have already referred to: basically, there is no 'ranking decision-maker' in this situation (the Code of Practice allows for the creation of a sort of pseudo-ranking within professionals – but not between professionals and typical relatives), and legally **everyone individually** has a **legal duty** to act in the patient's best interests.

But if there is a Welfare Attorney, then this person is given **legal power** over best interests decisions by section 6(6) of the MCA. It is not the case that Welfare Attorneys are appointed to be 'consulted' by clinicians – Welfare Attorneys are appointed to make the decision.

And although Welfare Attorneys must specifically be appointed to have authority over decisions relating to life-sustaining treatment, if the LCP 'neither hastens death, nor extends life' then **all Welfare Attorneys are empowered to forbid all interventions that are 'part of the LCP'**. I am not sure that this is correctly understood within clinical circles. My guess would be 'it is not'.

Uncertainty

Very few people are very good at handling uncertainty, and clinicians are always trying to improve the accuracy of clinical prognoses. there are also wider-life uncertainties, involved in decisions which are in anticipation of the future.

But, it is important to place these uncertainties correctly: they form part of the things the decision-maker considers, in reaching his or her decision. So, returning to section 14 of that GMC guidance, clinical uncertainties are to be described as such, within the information about clinical outcomes (14(b)) that mentally-capable patients use in deciding which, if any, treatments to accept (14(c)). It is important to note, that this is **not** 'shared decision making': the patient makes the decision, the clinicians provide clinical information:

(b) The doctor uses specialist knowledge and experience and clinical judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.

(c) The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

Chronology

One complication, for ‘potentially upsetting discussions’, is that if a doctor explains ‘You are going to die, within months’, then potentially an upset patient will react immediately. However, if this conversation is avoided, and the patient and the relatives are unaware that the death is almost inevitable until it is upon them, the post-mortem complaints from angered relatives along the lines of ‘We were unprepared for the death – why did not tell us in good time ?!’ happen when the clinicians who caused the problem, are often long-gone from the scene. It will, by then, perhaps be difficult to even identify ‘who contributed what to this situation’, when relatives are trying to work out who they feel behaved wrongly !

Next-of-Kin and Patient Confidentiality

When a patient is mentally incapable, and decisions are being made in accordance with the requirements of section 4 of the MCA, the Act itself (sections 4(6) and 4(7)) very clearly starts from the concept of:

‘If we could somehow ask this incapable person, what would he say to us ?’

That is essentially, as a starting point, the same process as for a mentally-capable patient, but substituting ‘persons who know the patient well enough, to reasonably believe that they would have a valid opinion about what the patient would have said’ as ‘proxy minds in lieu of the patient’.

The NHS Choices page, translates that requirement into plain language:

The relatives and friends of the person receiving the treatment, along with the healthcare professionals responsible for the person’s care, should decide whether treatment should be continued.

The information it is necessary to supply to the proxy minds, is the clinical information that would be subject to patient confidentiality while the patient was making his own decisions: and the proxy minds, are the people who could validly consider the question, a different concept from next-of-kin.

There are serious issues, around both Patient Confidentiality and Next-of-Kin, once patients are no longer mentally capable – these issues need to be addressed.