

An Open Letter about End-of-Life Behaviour

Some time ago, I wrote the piece 'More Conversation Less Confusion', which was my own personal analysis of contemporary end-of-life beliefs and behaviours in England. My emphasis was on how the behaviour of the various professionals who are involved appears, if one stands in the position of patients and relatives. In particular, how it appears if you are a relative living with an EoL patient who is still at home.

My conclusion, was that it isn't clinical uncertainty which is the main problem, but rather that the complexity of the interactions between the professionals and the laymen is the thing which causes the major problems if situations become complicated, and when relatively unusual events happen. My solution was something I call the Core Care Team, and this smaller document essentially extracts and renumbers the parts of More Conversation Less Confusion that described the Core Care Team, with very few other modifications. So pages 1 – 5 of this piece, were pages 3 – 7 in MCLC, and pages 6 – 10 of this were pages 29 – 34 of MCLC. Between the initial description of the Core Care Team and the directly following elaboration of how the Core Care Team would function in this piece, there were about 18 pages of 'background reasoning' explaining the problems with things such as the terms 'best interests', 'expected and unexpected death', and other issues, in the much longer More Conversation Less Confusion.

The basic issue, is trust: why should the relatives of patients, be 'trusted' any less, than the professionals ?

Mike Stone, March 2014

Should lay and professional carers during EoL, be regarded as in equal possession of non-technical qualities ? So, while things such as clinical expertise should be recognised as varying between lay and professionals, and from clinician to clinician, should qualities such as honesty and the vaguer 'good intentions' be assumed [by guidance and protocols] present in everyone involved, unless there is some [clear] proof of 'wrong doing' ?

And I mean proof of wrong doing – not simply 'confusion'.

The Core Care Team

concept and approach: should this replace the current emphasis on the Multi-Disciplinary Team (MDT) for end-of-life care ?



Isn't the strongest lesson from the Francis and Neuberger reports, that until the clinicians and the laymen start to fully engage with each other, the NHS will continue to leave a trail of very distressed bereaved relatives ?

Question posed by Mike Stone, March 2014.

FOREWORD

After a very unsatisfactory series of events around my mother's death at home just before Christmas 2008, I became involved in a quest to work out why things which appeared insane to me, apparently made perfect sense to various professionals - and vice versa. The issue wasn't the treatment my mother had received, which was fine: the issue was how I was treated by various professionals.

It fairly quickly became clear to me, that this is because although as a patient or relative you regard 'the death and the progression towards the death' as being a **single** process, different professionals **split this** into 'my job, your job' and there simply isn't coherence between the 'behaviour sets' of different professionals. There is also a remarkable amount of lack of clarity, some of which is understandable, and internal contradiction, which isn't acceptable, within the guidance around end-of-life for professionals, as it currently exists. The guidance is improving: but it 'isn't there yet'.

1.77

The professional guidance for clinicians on attempting cardiopulmonary resuscitation (CPR) is not clear. There is a variety of guidelines for the senior clinician (a consultant, GP or a suitable experienced nurse) when considering recommending against attempts at cardiopulmonary resuscitation – the "DNACPR order". This is because there are different obligations attached to plans to start treatment, which requires consent and decisions not to begin a treatment, perhaps because it is futile(50) or too risky.

50 meaning that the treatment will not succeed

From the Independent Review of the Liverpool Care Pathway

INTRODUCTION

I was not at all sure, how to structure this - after about four years of wide-ranging discussions with many people, and after a lot of reading of published guidance and protocols, it is still easier to point at things and comment 'That cannot be right, because ...' than to concisely explain 'the behaviour set which would be balanced and correct'.

After some thought, I have decided to start 'at the end' - by describing the most fundamental part of my 'solution to the problems' - followed by a step-by-step explanation of what is clearly currently either wrong or 'unbalanced in terms of the wider perspective', and ending where I began, with my suggestion for a 'culture shift' (but, by then, with the reader, I hope, having a much deeper understanding of how, and why, adopting this proposal would improve EoL Care).

Because I see highlighting the issues as fundamental (something the Independent Review of the Liverpool Care Pathway also commented on) many of my analyses can be found online: if it seems most appropriate, instead of including such material here, I will point to where it can be found.

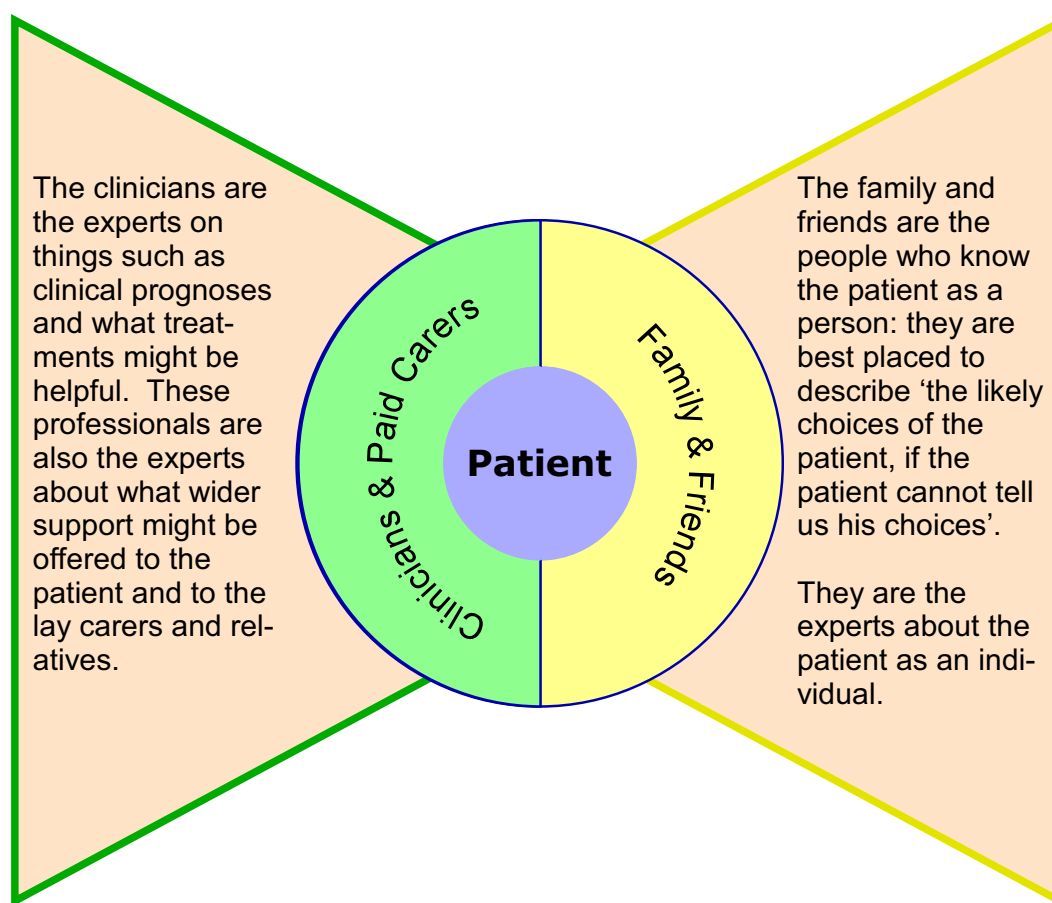
Unless 'the system' - which means individuals clinicians within it - is willing to discuss these issues, end-of-life behaviour will continue to look 'distorted and offensive' to many of the dying and their loved ones. Indeed, it will continue to **be** distorted away from 'a neutral balance' - because while only professionals create their own guidance, they will continue to overly-weight their own perspectives.

Whatever decisions are made about the LCP (our recommendations are listed on page 52), we believe there needs to be a proper National Conversation about dying. Otherwise doctors and nurses are likely to become the whipping-boys for an inadequate understanding of how we face our final days.

From the Independent Review of the Liverpool Care Pathway

THE CORE CARE TEAM CONCEPT

My main 'problem or objection', is that the current clinically-authored guidance is offensive to relatives of EoL patients, especially live-with relatives of patients who are in their own homes, because it seems to default to 'we can distrust relatives' as opposed to the more logically correct but less restrictive 'relatives are not usually clinicians'.



The diagram above is centred on the patient, and explains who he is most often 'supported by and in contact with, in an ongoing way'.

Of course, the significance of the yellow and green regions, will vary according to the exact situation: but the expertise of the two groups of 'support providers' will tend towards remaining unchanged.

The 'Family and Friends' are the people who know the patient as a person: they 'have an understanding, gained from life-experiences shared with the patient, of the patient as an individual'. These people, will tend to care ABOUT the patient.

The other category, comprises the people who are 'invited in, to help while the patient dies': almost always paid (but not necessarily), these are the doctors and social carers, etc. They know about their own jobs, and about things like 'average patients' - but they do NOT know about the patient as an individual, in anything beyond a superficial sense (a care worker in a nursing home, with a long term resident patient, might cross over into the other group, and know the patient 'as a person': similarly, if the husband of a cardiologist was dying from heart failure, the wife would, as a cardiologist, presumably know more about the clinical factors, than her husband's GP or district nurses.). These people are invited into the situation, and they care FOR the patient.

I shall now use as shorthand, 'relatives' to mean family and friends, and 'clinicians' to mean the professionals, where this does not cloud the meaning.

If the patient is diagnosed as terminal, but is still healthy, the situation has in a way become 'end-of-life' in a wide sense of the term - but, the patient is only in significant contact with the relatives.

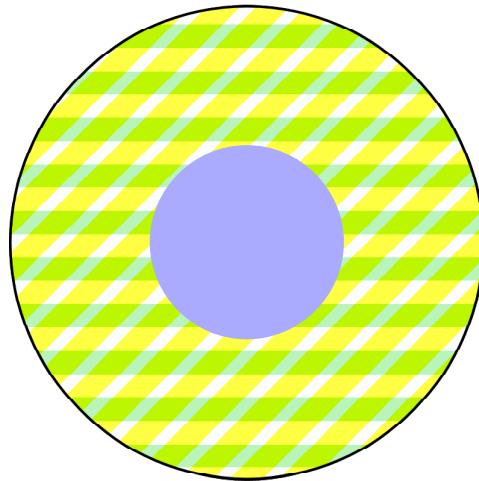
A patient who is very ill but not within 'the dying phase', and who is still in his own home, will have significant ongoing contact with clinicians, but still have much more contact with the relatives.

Any patient who is in a hospice or hospital, will tend to have the most ongoing contact with clinicians and less contact with the relatives - but, it isn't necessarily true that most of the clinicians who 'surround the patient' will be 'deeply involved in an ongoing way' (this lack of deep contact, will probably be truer in hospitals than in hospices, I suspect).

Intervention is by Invitation

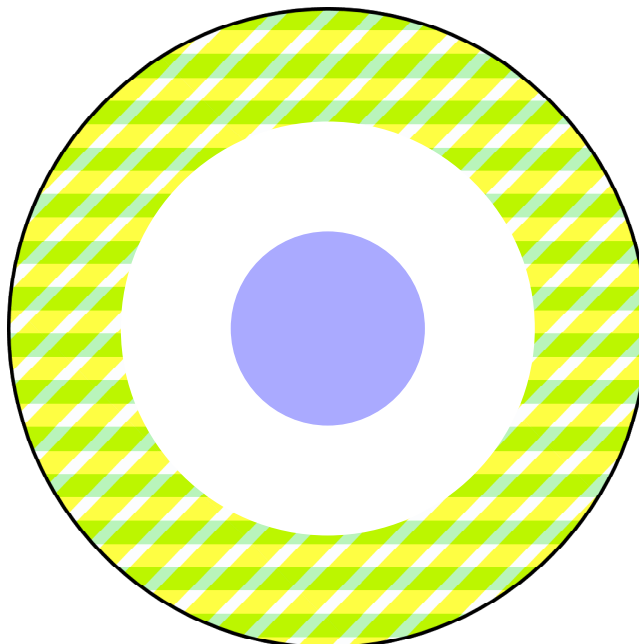
As I have just stated, although there are lots of clinicians around in hospitals, it doesn't follow that they all have a deep 'knowledge about' any particular patient - this is one of the reasons why there is some 'clamour' at present, for a rather stronger linkage between patients and named individual clinicians.

It is important, in the context of what I have just written, to understand that I drew my diagram like this:



There is a deep and continuing level of CONTACT between the patient and his surrounding support team: the patient is 'at the core' and the team 'envelops the patient'.

There are other professionals, such as paramedics or others who might have temporary and not ongoing contact with the patient, who are at times involved, but who are **not** part of 'The Core Care Team'. These 'less involved professionals', might be temporary members of an MDT - but they are not, **and can never be**, members of the Core Care Team.



What is the difference between a patient saying to his GP "I'm refusing attempted CPR from now on, if I arrest for any reason" and the patient saying to a relative who is living with him "If you think I've stopped breathing, do not call anyone until after I'm dead - so if you think 'I'm dying' I want to be left alone to die, and from now on, I don't want anyone to try and 'bring me back'" ?

My Suggestions for Alterations to EoL Behaviour

I believe that the MDT 'concept' leads to an unhelpful 'mental attitude' on the part of professionals, and that it needs to be replaced by the new concept of the Core Care Team (CCT). The Core Care Team comprises the GP, the relatives/others who are living with the patient (live-with relatives, as shorthand, which I shall abbreviate to LWRs) and the regularly-attending District Nurses (DNs).

This is the problem, for dying patients who have retained mental capacity, and who therefore have the legal right to refuse offered treatments both at the time of offering, or in anticipation of a potential offer: the basic issue, is **how can a patient elucidate a decision** (the fundamental one, is 'I'm now refusing any cardiopulmonary resuscitation (CPR) attempt') **to someone who isn't there** ? Why should clinicians, for reasons of 'neat record keeping', expect that a patient who had decided he had 'now had enough, and has thinks he would be better off dead', and who therefore had decided to refuse future attempted cardiopulmonary resuscitation (CPR), would not decide to explain this to his 'nearest and dearest' first ?

If you were the dying, or suffering, patient, and you had decided to forbid future CPR, wouldn't you wish to first discuss this with the people who might be upset by your decision - the LWRs ? **And then afterwards**, *after your loved ones understood why you had taken the decision*, communicate it to the clinical team ? But nobody who has decided to refuse future CPR - a really serious decision - should be expected to say 'I'm going to refuse CPR from tomorrow': once the patient has explained his

refusal to his LWRs, they and he are aware that he does not want attempted CPR from that moment onwards. Not 'once it has then been discussed with a clinician' - from the time the patient explains his refusal, to his relatives (**I have had that conversation, and 'once you have been told, you have been told': full stop, this is not negotiable simply for the convenience of clinicians or the police !**).

Why would a dying man accept that the word (unsupported) of his wife, or of his adult child, should not be believed as the default position of professionals ? **If the NHS considers that the unsupported word of live-with relatives can be assumed to be questionable, in the absence of any evidence to support an accusation, or implied accusation, of dishonesty, then GPs must be told to inform patients and relatives of this assumption** (which is currently implicit within much guidance and attitude) **at the start of EoL Care**: see where that gets you !

This is part of a deep problem with EoL at home, even aside from a general reluctance on the part of everyone to actually discuss 'the dying bit': the communication chain is horribly complicated. Patient, relatives, GP and DNs can talk to each other at different times, and in different locations, in every possible combination, discussions are more likely to be unplanned than planned, and everyone involved has got 'a background'.

Recording and disseminating discussions, although necessary to an extent, is not adequate. For example, when my own mother was 'terminally comatose' at home, and with the GP and lead DN present, I asked the GP 'What would you like me to do, if my mother dies ?'. I knew that 'if' was when, and so did the GP - but people say 'if' not 'when', sometimes. If you recorded that conversation, would you record what I had said (apparently leaving some uncertainty, if read for example by the 999 services subsequently), or would you distort the historical record by replacing the 'if' by 'when' ?

I would claim, that the nature of the discussions when EoL patients are at home, is so complex, chaotic and often 'implicit', that a process-based approach to record-keeping is so doomed to either incompleteness, or to ambiguity and therefore the potential to mislead, that instead the primary reliance must be the distinction between 'the people who are involved with the patient in an ongoing way' and those who are not.

Basically - 'you needed to be there, to properly understand it'.

The MDT concept, does not do that: the MDT concept introduces a primary division, between professionals and laymen.

The CCT concept, by contrast, introduces a primary division, between those people, lay or professional, who have been able to talk to the patient and to each other on an ongoing basis, and everyone who is outside of the CCT group.

Which fits better, for EoL at home ?

The Mechanistic Implications of CCT versus MDT

The way the MDT 'concept' works, is fairly well understood by clinicians in theory, even if in practice implementation is variable. So I will concentrate on the 'mechanism' implied by the CCT concept. It basically only involves a few 'directives', with the members of the CCT being told to follow these principles, and to create for each patient and LWR(s), on an ad hoc basis, 'whatever works best for you as a group' (this does not exclude things such as EPaCCS - it merely relegates the significance of such formalised records):

1) Everyone in the CCT, and the patient, must attempt to keep talking to each other, sufficiently that nobody is deprived of any information that person would 'reasonably need to know' - so the stress is on 'keep talking to each other, as openly as possible, because if you don't talk, then confusion and false assumptions can easily be the result'.

2) This does not preclude record-keeping, but it downgrades written records to a status secondary to an explanation of a record, given by anyone within the CCT who says 'that actually means'. So, the second implication is that everyone outside of the CCT, must be instructed to believe what anyone within the CCT is saying, as the default position: paramedics must be told to believe what LWRs are telling them, even if the information is not supported by records (because a patient-relative conversation, can have taken place but not yet been recorded: there is also an issue, in that currently the NHS seems determined to only allow specified professionals to up-date records, and you cannot write something down in real-time, if you are not present !).

3) The professionals must, if they think a relative has done, or said, something 'strange, confusing or wrong', ask the relative why it was

done or said. And the professionals must tell the LWRs 'to ask us to explain why we are doing things, that seem wrong or inappropriate to you' (see Note 1).

COMMENT: A downside of process-based behaviour, the approach currently taken by the NHS to cover this area, is that it inherently promotes confusion - because there is no way that patients and relatives can be familiar with 'the process'. The CCT concept, forces everyone to talk to each other, and to develop within the CCT a 'process' which will work for the group as a whole, on a case-by-case basis - inherently, that makes everyone discuss and understand 'the process'.

SECOND COMMENT: The MDT approach, separates clinicians and (for VoD {Verification of Death protocol} design) other professionals, from patients and relatives, and consequently things such as EoL guidance and CPR/VoD policies are written by groups of, usually, only professionals. Also, hospital-based clinicians, perhaps because hospitals are inherently more 'structured' than primary healthcare, seem to be writing guidance which then 'bleeds out into primary settings': so hospital-based nurses and doctors, are formulating the behaviour sets for EoL patients who are in their own homes. Within a hospital, doctors and nurses are always present, and should be able to successfully implement 'a known process' - but EoL at home, should have a belief and behaviour set which is being designed by the people involved: by GPs, patients, LWRs, DNs and paramedics. The CCT concept, if adopted, would promote that change to the way guidance is created.

THIRD COMMENT: If the patient has lost mental capacity, and a decision is being made without a previously-elaborated clear instruction from the patient, the framework of the Mental Capacity Act does not say who can make the decision (unless there is a suitably-empowered attorney under the Lasting Powers of Attorney act - a person I usually describe as a Welfare Attorney). The Mental Capacity Act is complex if there is not a Welfare Attorney, and clinicians often believe the decision-making devolves to them: it doesn't, and I would direct the reader to an NHS Choices page (reference 1).

I asked NHS CHOICES who wrote that page - the answer was 'we worked with a consultant with a special interest in consent law to ensure the information was still current and accurate'.

Note 1: I am not going to discuss in great detail my own experience of my mother's death, because it is horribly complex - but I will give a personal conclusion, which arose from my own analysis of that experience. I was caused a significant amount of subsequent 'distress and confusion', because of something that resulted in 'crossed wires' between the district nurses and myself, without either party realising this: this would have been resolved within seconds, if the nurses had simply asked me 'Why did you say that?', instead of deciding that a 'neutral' comment I had made, was a complaint (I then assumed that the next thing the nurses said, some time later, was a request for information, and they thought they were asking me for permission to do something {as there was no reason to ask me for permission - they should have been asking my mother that question - I did not even realise this particular piece of confusion had happened, until days later when at 3am I came across a note I objected to}): making judgements based on unsupported assumptions, leads to a spiral of confusion. Very unhelpful ! Explaining that episode properly takes an age - but 'ask do not assume' is definitely the lesson !

Now, I am of course not suggesting that there are not some 'nefarious relatives': I am simply stating, that without adequately open communication good EoL behaviour tends to become impossible to consistently achieve, because communication and confusion are inversely correlated. Everyone should be 'keeping an eye on everyone else', but it is a bit rich for the professions which produced Shipman, Mid Staffs, Winterbourne View, and Hillsborough, to try and claim the moral high ground for themselves !

There is no reason at all, to believe that if a husband of 50 years becomes end-of-life, and he and his wife have involved professionals to help them as he dies, that this in any way implies that the husband 'intended to hand all of the decision making over to the professionals, if he loses capacity'. Most laymen, I'm fairly sure, would say

We invited the doctors and
nurses to help us - we didn't
invite them to tangle us up in
weird protocols, or to make
things worse !!!

It should be easy to see in all of this, that my basic contention is that for end-of-life at home, especially if the patient is mentally capable, the thing that can cause the most problems for relatives, is 'communication'. Events can happen very quickly during EoL, frequently there are no clinicians in the home, and there is a conflict between the fact that mentally-capable patients can express their own decisions, but 'the system' seems to want the GP to somehow 'authorise and record everything'.

Almost always, everyone around the patient - the GP, relatives and nurses - is trying to 'do their best for the patient': so live-with relatives should be regarded as 'full members' of the 'patient's support team'. The relatives might be lacking in clinical expertise, but they should be regarded as in equal possession of things such as 'honesty and good intentions'.

Currently, the people sharing a home with the patient seem to have a strange status which varies from 'involved somehow' to 'potential suspect' (see reference 2). That is, to say the least, 'biased logic' - unless one starts by assuming that relatives 'are not to be trusted', their 'more present than any of the professionals' position, should place the live-with relatives as central to 'co-ordinating the overall behaviour'.

This was in essence extracted from a longer piece of mine called 'More Conversation Less Confusion' in which I also covered the meaning of the terms 'best interests' and 'expected death', and also investigated the Mental Capacity Act - if anyone wants it, I'll e-mail it on request (my contact is mhsatstokelib@yahoo.co.uk).

Author Mike Stone

Ref 1 <http://www.nhs.uk/Conditions/Consent-to-treatment/Pages/Problems.aspx>

I would also recommend a series of what the BMJ describes as 'rapid responses' (comments about its articles) to anyone who wishes to understand some of the current problems with end-of-life - I posted two comments in a series of eight comments, and the eight comments come from several perspectives and cover an awful lot of the issues:

<http://www.bmj.com/content/347/bmj.f4085?tab=responses>

Ref 2 is one of those rapid responses, and the direct link is

<http://www.bmj.com/content/347/bmj.f4085/rr/654490>