

## Foreword and Introductory Remarks

I became involved in these discussions about End-of-Life behaviour and beliefs, because there was an absolute fiasco when my mother died at home just before Christmas 2008: I will not go into details, except to comment that the two things which would have prevented that fiasco were:

- 1) Instead of stressing intra-clinical communication, placing the stress on open and adequate communication between the patient and everyone who is in a position to talk to the patient;
- 2) adopting 'the default should be for everyone to trust and believe everyone else', instead of 'I must rely on a paper trail'

If 2 or 3 times as many EoL patients are to be allowed/facilitated to die at home as currently die at home, then you cannot simply extend what works fairly well inside hospitals (write everything down) to homes: the interactions and discussions inside a person's own home are closer to chaotic and unstructured, than they are to organised.

For home EoL, you need to alter the concept of a professional MDT to a different concept, of encouraging open and adequate discussion between the group of people who regularly talk to the patient ( the patient, GP, live-with and very close relatives {etc}, and regularly visiting DNs), **and then to tell everyone else, including paramedics, to believe what anyone inside that group, including relatives, tells them.**

I have also noticed, that for some reason many people struggle to extract the 'sense' from the Mental Capacity Act. It really isn't difficult, for most EoL decision-making – it often comes down to this or its equivalent (this being specifically for CPR):

**The fundamental concept, is that if a patient has considered the clinical causes and consequences of future CPA & CPR, in the context of his own wider-life circumstances, and the patient has clearly indicated a refusal of CPR for the CPA under consideration, his instruction that CPR should not be attempted should be followed.**

I have also noticed, that clinicians ask different questions from those I myself ask.

This is not invariably because we are concerned, or perceive as important, different issues, although that is a major factor.

Sometimes, **I just cannot fathom how the question is to be used ?**

As an example, I have seen this question, put to relatives about 6 months after the death of their loved one:

‘Was the pain-relief adequate during the final 2 days of life ?’

Now, not only will the memories of precise timelines be a bit vague, 6 months after the death, in all probability, **but how on earth do you use the answer ?**

That question requires hindsight within it – doctors find it almost impossible to say if a person will live for a further 48 hours, as opposed to a further 24 or 72 hours. So even if the answer was ‘the pain relief was very poor during the final 2 days’, **you cannot tell clinicians to ‘make sure that pain relief is good for the final 2 days of life’ !**

How is that question, phrased with the specificity of ‘final 2 days’, useful !!!

**Surely, in any case, dying patients have a right to expect that adequate pain-relief is provided at all times ?!**

CORRECTIONS; I have tried to proof read the following, but there is one minor error I am aware of. When I sent out about 200 Dignity Champion Questions for the ‘opt-in or opt-out’ question, there were about 80 non-delivered e-mails – so I should have said that about 120 people would have received the question (I wrote 180 by mistake).

I hope you find some of the replies to my questions interesting, and I hope you find some of my analyses at the very least thought-provoking,

Yours Mike Stone

Many thanks to everyone who responded to my question about the meaning of that wording in the piece of guidance for laymen, about Advance Decisions.

The collated replies are all given here, along with some context as to why I was so interested in the answers.

I also explain, why only one of the possible answers seems to make any sense to me, when one thinks from the position of a person who might be refusing a future treatment, and in particular who has decided to refuse future CPR.

I have also included, as 'appendages' (but not labelled as such – they are just 'tacked on') some other items:

--- The text of an e-mail I sent out, in which I describe a fundamental way of thinking about what is, and what isn't, properly thought of as a section 4 MCA best interests decision;

--- An explanation of why a discussion of an ADRT replaces the ADRT as the justification for withholding CPR in the future;

--- The replies to a Survey I sent to PCTs, Ambulance Services and Acute NHS Hospitals about a year ago;

--- The replies to a question I sent out to Dignity Champions, investigating a suggestion that it might make sense to make opting-out from CPR a default position (I don't see any sense in that idea, myself);

--- The précised version of an e-mail discussion I had with two of my friends who had both recently lost parents, to see how their answers to certain questions compared with my own: their lay positions, match mine except that some of my answers are modified by my own knowledge of the law.

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## Replies to 'What Do The Words Mean ?'

### PRELIMINARY COMMENT:

The legal principle upon which refusal of treatment is based, is that self-determination overrides any duty to preserve life:

The fundamental principle is the principle of the sanctity of human life ..... But this principle, fundamental though it is, is not absolute ..... it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to

his wishes, even though they do not consider it to be in his best interests to do so .... To this extent, the principle of the sanctity of human life must yield to the principle of self-determination.... Moreover the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it; though in such circumstances especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances.

David, sent me a second e-mail after his first one, after he had looked up some guidance – he ended with this sentence:

**All of which is a long way from the clinicians view that the person 'must specify the circumstances'.**

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THE QUESTION I SENT OUT TO ASSORTED DIGNITY IN CARE CHAMPIONS:

Dear ,

There is a recent piece of guidance for End-of-Life (as in 'about a year to live') or elderly patients/people (Planning for your future care: a guide, published by the National End of Life Care Programme, ISBN: 978 1 908874 01 6, publication date: Feb 2012).

That piece of guidance discusses Advance Decisions to refuse treatment, and on page 7 it uses this wording, which is intended to be guidance for patients:

'Sometimes you may want to refuse a treatment in some circumstances but not others. If so, you must specify all the circumstances in which you want to refuse this particular treatment.'

I HAVE THIS QUESTION:

Does that say, that when refusing a treatment by means of an Advance Decision, you must ALWAYS specify BOTH the treatment being refused, and also the circumstances in which your refusal is to apply ?

Or, does it say you have the 2 OPTIONS of EITHER simply saying 'I refuse treatment X', OR of saying 'I refuse treatment X if ..... is the situation' ?

I have become aware that some people interpret those words one way, and I interpret them a different way.

Please note, I do not primarily want to know what anybody has been taught about Advance Decisions, here - I specifically wish to know, whether if you

simply read those words, you would believe that it were possible to validly write as the instruction on an Advance Decision 'I refuse X.' (where X is the treatment being refused - for example 'any transfusion of blood products of human origin') without including any circumstances ?

Best wishes, Mike Stone

PS If you reply, could you please start by briefly saying what category of person you fall in (is nurse, non-clinician, paramedic or whatever) to make collation of any replies easier.

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Replies to date:

From reading the sentence

'Sometimes you may want to refuse a treatment in some circumstances but not others. If so, you must specify all the circumstances in which you want to refuse this particular treatment.'

I perceive it to mean there are the two options:

of EITHER simply saying 'I refuse treatment X', OR of saying 'I refuse treatment X if ..... is the situation' .

Thanks  
Jo  
Nurse/Healthcare lecturer

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Hi Mike,

I have been a Nurse, Care manager, and am now a full time college lecturer in Health and Social Care.

I interpret the wording as ' you must ALWAYS specify BOTH the treatment being refused, and also the circumstances in which your refusal is to apply'.

Kind regards

Ali

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Hi Mike, I do not have any medical training. I am a police trainer. The question below is how I understand this. I have only a scanty knowledge about 'advance decisions'.

Does that say, that when refusing a treatment by means of an Advance Decision, you must ALWAYS specify BOTH the treatment being refused, and also the circumstances in which your refusal is to apply? **-Yes**

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Hi Mike

I'm a non clinical healthcare trainer, I read the statement as requiring all the circumstances and or reasons being stated if a person refuses all or a specific treatment. It really isn't very clear especially for a layman!

Hope this helps  
Regards  
Cherie XXXXX

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Hi Mike

I work primarily as a Project Manager in an NHS provider service

Interesting point. My view would be that if you write 'I refuse Treatment X' then as the default it should be assumed that you mean in any circumstances, regardless of whether you stay this or not. If you anticipate that there might be exceptions then you should identify those in the Advance Directive. I'm sceptical about others deciding 'on my behalf' when the Directive is in force what the 'exceptional circumstances' are that would warrant my Directive being waived. In relation to end of life care I think as an individual there may well be conditions under which I would regard the quality of life I have as not worth living where others may not take the same view. There was a rather good option piece (Sorry I haven't been able to track down the reference) recently by an American doctor on this around resuscitation issue and invasive life prolonging treatments in terminal care that pointed out that many doctors who might recommend interventions for others at the end of life that are very invasive would not themselves opt for such interventions as the quality of life resulting from such interventions was so poor, particularly in relation to the very short term clinical benefits.

Regards

David XXXX  
Senior Project Manager

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David then sent this follow-up quite rapidly after the above:

Mike

Thanks . I'll be interested to see where this goes. I don't think that most people would necessarily be aware that when making a Advanced Directive that it's conditional on the clinician's opinion as many people may not be told that there are circumstances when there directive will be overruled.. I had a quick look at the Direct.gov summary on this and it says:

A doctor might not follow an advance decision if:

- "•you have done something to contradict the advance decision (for example, changing your faith to a religion that doesn't allow refusal of treatment)
- they think that new circumstances would have affected your decision (for example, a new treatment that could have a big effect on your health condition)
- the advance decision isn't clear about what should happen"

And the summary also says:

"There is no set format for making an advance decision but it is helpful to include the following:

- your full details
- a clear statement of the treatment to be refused and the circumstances in which the decision applies
- the date you wrote or reviewed the document
- your signature or that of the person writing for you (if you aren't able to write)"

So while there is an advisory that the person sets out the circumstances, there is no requirement. There is however the advice (still not a requirement) that the clinician should 'think that new circumstances would have affected your decision' The fact that your condition may be life-threatening is specifically excluded as being of itself sufficient to be considered 'new circumstances'. All of which is a long way from the clinicians view that the person 'must specify the circumstances'.

You ought to set up a Linked-In thread on this!

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I am an Age UK project manager for a DH-funded project re personal budgets. My reading of the guidance is that I would need to specify circumstances, and that this would mean I could not necessarily simply refuse treatment, whatever the circumstances (as I might wish to do, not having the power of prophecy!)

Hope this helps

Dr) Guy XXXXXXXX

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Dear Mike,

As I understand it, If you specify an unqualified rejection of a specific treatment, then that stands in all circumstances, but , if you qualify your refusal, then the clinician may need to consult you to clarify your request. As a person with MS, I certainly hope that this is the case,

Yours ay

Anthony XXXXX

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Dear Mike

I haven't the read the document yet so can only take in the context below.

I think the way its written below is a bit ambiguous. It implies that you could just write a bald statement of refusal. E.g. 'I would not consent to have a leg amputated' or 'I do not consent to have a leg amputated unless this is my only physical injury and the medical opinion is that my mental faculties are intact. Not sure that's a very good example though.

I have a feeling you are supposed to put circumstances in every time

Anne

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Hi Mike,

I am a lecturer in mental health.

The short answer is that any caveat that generates a debate such as this is by its very nature unclear and thus open to the vagaries of individual interpretation and perception.

I would hope that anyone reading this would interpret it as meaning that you are still able to include a generic refusal to all interventions, however as you say the inherent danger is that some will interpret it as meaning something completely different. I am sure some will assume that any treatments not specified in a caveat are OK to continue with.

If we are to have an advanced decision that includes a specific circumstance then it should be an 'opt in' rather than 'opt out' statement. e.g. I refuse all treatments other than etc. There is still a risk of course for those who say 'other than those designed to ease pain and suffering' as the clinicians perception of their intervention may not match the patients.

The knowledge and experience of both the patient and clinician are very likely to differ so the only person's perception that should count is the patients. If the retail industry are happy to accept that 'the customer is always right' why can't the care sector?

Regards,

Keith.

Admissions Tutor, Mental Health

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I understand this as, it is necessary to state the circumstances in which you will be refusing specific treatment.

Kind regards

Sara XXXXX

Assistant Chief Nurse/Head of School

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Dear Mike

I am a non clinical, practice manager of a GP surgery

I would gently suggest that by only quoting this paragraph, you have taken the meaning somewhat out of context as compared to when you have read the whole document.

My own interpretation would be that I may not want chemo if it was thought I only had days to live, but might want that treatment if it would prolong my life by months, thereby I am specifying under what circumstances I would accept or refuse treatment.

Regards,

Sandra

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Hi Mike,

I am a staff nurse and I work in a national health hospital, I also teach health and social care at the local college.

To me this statement is saying that you need to clarify exactly what it is you want and what the circumstances are that you have based your acceptance or refusal of treatment are.

If it just talks about refusal of treatment on gives no circumstances then it must be taken that the person does not want the treatment whatever the circumstances - but then how do we know that they were fully informed when making that decision if they have not identified any variances.

Linda

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Dear Mike

I am a nurse and a midwife.

My understanding of:

'Sometimes you may want to refuse a treatment in some circumstances but not others. If so, you must specify all the circumstances in which you want to refuse this particular treatment.'

Would be that 'you must ALWAYS specify BOTH the treatment being refused, and also the circumstances in which your refusal is to apply'

Regards

Karen

Senior lecturer midwifery

The University XXXXX

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Hi Mike,

I am a nurse and I would read the statement in that, you may not want to receive a treatment, but you need to state under what circumstances. However if you never want to receive a particular treatment I suppose you could just say that you never want to receive that treatment whatever the circumstances.

Perhaps it is difficult to be very cut and dried over which treatments you want or don't want when your health maybe relatively good - in the beginning.

For example if your disease is very advanced and you have days left to live - you may not want antibiotics, however if the infection had occurred when you were "well" then you may want them.

Regards  
Linda

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Peter XXXXX (Admiral Nurse) In my experience any Advanced Decision needs to be specific to what is actually being refused i.e. I do not want antibiotic treatment if I develop a chest infection. Just by saying 'I do not want treatment' is too vague. There is also the possibility that 'duty of care' issues may be raised suggesting that an 'authority' can override certain decisions in the best interest of the patient.

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Registered Manager EPH,I interpret this to mean either or both.

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Hi,  
I interpret it as 'I refuse treatment x if.....is the situation.  
Kind regards  
Catherine

NB Catherine did not give her role, and the way Dignity Sweeps work means it would take forever to find her details on there: but she has got a '.nhs.uk' address, and I think she is probably a nurse.

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## **MY COMMENTS ON THE REPLIES**

Linda's answer, is very informative in its first two sentences:

I am a nurse and I would read the statement in that, you may not want to receive a treatment, but you need to state under what circumstances. However if you never want to receive a particular treatment I suppose you could just say that you never want to receive that treatment whatever the circumstances.

But Anthony, who suffers from MS, wrote:

As I understand it, If you specify an unqualified rejection of a specific treatment, then that stands in all circumstances, but , if you qualify your refusal, then the clinician may need to consult you to clarify your request. As a person with MS, I certainly hope that this is the case,

David, who gave two lengthy replies, started with:

I work primarily as a Project Manager in an NHS provider service

Interesting point. My view would be that if you write 'I refuse Treatment X' then as the default it should be assumed that you mean in any circumstances, regardless of whether you stay this or not. If you anticipate that there might be exceptions then you should identify those in the Advance Directive. I'm sceptical about others deciding 'on my behalf' when the Directive is in force what the 'exceptional circumstances' are that would warrant my Directive being waived. In relation to end of life care I think as an individual there may well be conditions under which I would regard the quality of life I have as not worth living where others may not take the same view.

And he then looked up some guidance, and concluded with:

So while there is an advisory that the person sets out the circumstances, there is no requirement. There is however the advice (still not a requirement) that the clinician should 'think that new circumstances would have affected your decision' The fact that your condition may be life-threatening is specifically excluded as being of itself sufficient to be considered 'new circumstances'. All of which is a long way from the clinicians view that the person 'must specify the circumstances'.

This is a serious problem – nurses almost all consider you must state the circumstances in which a refusal is to apply, whereas the Mental capacity Act seems to use ‘circumstances’ to qualify an otherwise unrestricted refusal of the stated treatment.

Logically, as it is accepted that a patient who was mentally capable but ‘bleeding out’ COULD just refuse all offered treatment, **without** explaining why he was refusing, then you should be able to just write on an ADRT ‘I refuse CPR’. And technically, that appears to be correct – the Act states that an ADRT is invalid if any stated circumstances are absent: if there are no stated circumstances, none can be absent, hence ‘I refuse CPR’ must be valid.

Sandra, the Practice Manager, thought I had got the context wrong – actually, as I explained in this follow-up e-mail to her, the context is crucial !

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Dear Sandra,

I shall address your point about context – the overall context, involves the type of questions (and more significantly, the variability of the answers given) which you can find in the attachment

You might care to try this one, on your GP(s).

An elderly chap, in his 80s but in good health at the time, visits his GP and says he has been thinking about the future. He explains that he watched his brother die some years after having been left very incapacitated by a severe stroke, and he has seen some of his friends becoming increasingly incapacitated in nursing homes before they died – he isn’t keen on either outcome, for himself.

He has also decided, that the risks of a CPA plus a CPR attempt in the community, mean that the possible outcomes of a CPR attempt which managed to re-start his heart, are, in his opinion, less desirable than being left alone to die in peace, effectively ‘declaring my innings early, if my heart has stopped’. He is willing to give up any potentially good outcomes, because he considers those to be out-weighted by his dislike, or even horror, of those potential outcomes which he considers to be bad.

So, he explains that to his GP, and then continues:

‘So, as you are in charge of my health care, how do I make sure that nobody attempts to re-start my heart if it has stopped pumping blood ? And, if my wife thinks I have stopped breathing or arrested, I want her to be able to call 999 to confirm that my heart isn’t beating – because if I wasn’t about to die, then I would want active treatment to try and prevent my living on but being more clinically damaged than was avoidable – but if paramedics discover I have arrested, then I want them to allow me to die without trying CPR.

I also am not keen on my wife being treated aggressively by the Police – even though she accepts this decision I've made, she would definitely be shocked if I suddenly stopped breathing.

How do we arrange for that to happen ?'

What does the GP do – the issues include:

1) What actual wording on an ADRT works (ie stops paramedics or nurses from attempting CPR) for a refusal of CPR which did not depend on the cause of the CPA ?

2) Can the GP write some sort of DNACPR Order, here ? If the GP did, he would also need to include 'although this chap has refused future attempted CPR, I will not be able to certify his death' – how does that work ?!

I don't think I have taken anything out of context – and I have been discussing these EoL issues with the DH, BMA, GMC, RCGP, WMAS, etc, for a couple of years,

Best wishes, Mike Stone

PS The point of my Champions trawl, is that I was fully aware that almost all nurses, and many other clinicians, think that an ADRT must specify clinical conditions: **but the law says no such thing !** On the other hand, clinical guidance, as currently published, often supports the flawed belief currently held by most nurses – probably because the pre-existing beliefs of many clinicians, mean that they find it almost impossible to properly read the Mental Capacity Act even if they attempt to do that.

I just wanted some more evidence that 'how clinicians read guidance' is a serious problem, in order to pass that on to the Head of EoL at the DH, and to Rebecca Mussell (the BMA's ethics expert who will be involved in the revision of the Joint CPR Guidance) and various other people involved in the writing of the EoL guidance.

What the law says about circumstances on an Advance Decision:

24(1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if—

- (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
- (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

25(4) An advance decision is not applicable to the treatment in question if—

- (a) that treatment is not the treatment specified in the advance decision,
- (b) any circumstances specified in the advance decision are absent, or

(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

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I would also like to point out, that pain is not automatically linked to life-threatening (as anyone who had excruciating pain from a trapped nerve, or a shattered tooth, will understand), and what a person 'feels' is not the name of a medical condition, but the combination of how his medical condition 'feels' to him, and also other life factors.

So, if someone was predicted to die within weeks and was also in excruciating pain or intolerable distress, he might want to create an ADRT based on this idea:

'If my new Will had been finalised, signed and witnessed, then I would already have forbidden future CPR – but, I forbid CPR as soon as my new Will has been signed and witnessed, but if I arrest before then, I would like you to attempt resuscitation'.

The logic, and reasonableness, of that position is obvious – so why on earth, should it be impossible for him to achieve that ? You will note that this is a refusal of CPR which is contingent on a non-clinical circumstance – but, as the GMC Guidance makes clear, patients consider their wider-life circumstances during their decision making.

XX  
XX  
XX

I sent this as an e-mail, to my discussion group, while I was a bit annoyed about something (probably a newspaper piece). It covers a point not properly addressed in the Rules for Death Survey write-up (where I do cover the problems with 'expected death') – this covers a complication concerning how one should think about the section 4 best interests decisions.

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I'm still 'hammering the nail right through the plank' here – it just shows how annoyed part of my mind was by events which are now 3 years old.

Start in the **right** place – so, where is the right place ?

The right place, is either the court case which placed patient autonomy above any right to treat a patient, or the following two sections from the MCA:

- 5(2) D does not incur any liability in relation to the act that he would not have incurred if P—
  - (a) had had capacity to consent in relation to the matter, and

(b) had consented to D's doing the act.

26(1) If P has made an advance decision which is—

(a) valid, and

(b) applicable to a treatment,

the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.

Now, we know that the Act thinks in terms of decisions usually (ie acts and also inaction) from section 1(5) {An act done, or decision made} and section 5(2) is saying that the best interests section exempts a person from liability if CPR is attempted, because it is 'as if the patient had consented to the resuscitation attempt'. Section 26(1) for Advance Decisions is equating an ADRT's refusal of an offered treatment, to a refusal directly from the patient at the time the treatment is offered (obviously impossible, because the Advance Decision deals with anticipation that the patient will not be able to refuse at the time – but the 'concept' is clear, there).

**This is NOT a 'clinical test' – this is very clearly that:**

**'A section 4 best interests DNACPR decision, is justified by the reasonable belief that the patient would have refused attempted resuscitation'**

and

**'An Advance Decision refusing resuscitation, is obeyed because the reader believes the patient would have refused attempted resuscitation'**

**when the resuscitation attempt is being considered (ie during the CPA).**

This is not very difficult – why is it so hard to understand ?

CLINICAL DNACPRs are **different**

Clinical DNACPRs are founded on the principle that doctors **do not need to offer** (and normally should not offer) any treatment which would either be of no benefit, or would harm the patient.

Not attempting CPR, when CPR wouldn't have any chance of working, isn't in any real sense a 'decision' – it definitely isn't a proper section 4 best interests decision because it can be made solely on clinical grounds, while the main section 4 best interests test 'guidance' is 4(6):

- 4(6) He must consider, so far as is reasonably ascertainable—
- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
  - (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
  - (c) the other factors that he would be likely to consider if he were able to do so.

Oh, I'm slowly losing the will to live here – how do bodies such as Central South's CPR policy design group, assemble groups of expert professionals, spend years in development, and manage to come up with such a totally distorted 'description' of some pretty clear law, and very clear legal principles ?

You only need to understand the above, throw in specific 'add ons' such as welfare attorneys are appointed to be the person who considers decisions if the patient cannot, that an ADRT is a decision made by the patient in advance, not 'an expression of wishes', and that coroners control VoD behaviour but VoD is separate from CPR decision-making and VoD is entirely post-mortem, that you cannot observe an event without being present, and you are almost there !

You (clinical groups) don't even get so far as the trickier bits (more than one welfare attorney with joint & several powers, or no welfare attorney but several similarly qualified people who could act as 'proxy minds for the patient', or a patient who made an ADRT a long time before a possible arrest, and who has clearly become 'demented but happy' {which raises the question of is that really a 'different person' to the one who wrote the ADRT ??}).

And nobody has even written down, let alone properly described the 'rules' for, the extension of the principles behind NICE (that health care decisions do have cost considerations) to CPR: that seems to allow a health care system, but not necessarily an individual professional, to decide to not offer CPR to entire groups of people with specific clinical conditions, which would lead to their post-CPR clinical outcomes being 'too expensive for us to justify offering CPR'.

This is a catch-22 – I get so annoyed that unless I write this stuff up and send it off I tend to 'boil over', but writing it up annoys me anyway because it all seems so obvious to me !

Best wishes, Mike

I typed that on Friday to send out today (Saturday) – I've decided to add a bit of a 'tail', to make this one more useful if I further distribute it in the future. As I state above, 'clinical' DNACPRs are different from section 4 best interests decisions – but so are DNACPRs when the patient's refusal is understood so well, that there isn't 'some doubt'.

To use my hierarchy:

### **The DNACPR Justification Hierarchy**

1 A face-to-face discussion with a mentally capable patient, which takes place during the clinical events which lead to his CPA, the outcome of which is that the patient issues a DNACPR Instruction which those who were involved in the discussion can interpret correctly

2 An apparently valid and applicable Advance Decision refusing CPR which has not been discussed with the patient

3 A DNACPR decision made and communicated by either a single welfare Attorney (where only one has been appointed), or agreed and communicated by all Welfare Attorneys

4 A DNACPR decision made and communicated by a Court Deputy

5 A DNACPR decision made by a person who is sufficiently informed of the patient's clinical situation and likely wishes, to enable that person to defensibly consider section 4 of the MCA.

6 A DNACPR action, which is based upon information supporting the reasonable belief that something within categories 1 to 5 makes DNACPR the best available behaviour.

7 If none of the above apply, but it is clear that attempted CPR would be clinically futile, then DNACPR

8 If none of 1 to 7 apply, CPR should be attempted

Only 3 to 5, of those, are 'proper' section 4 best interests decisions: a proper section 4 best interests decision involves someone who isn't the patient, **'trying to work out** what the patient would say, if I could ask him during his incapacity'.

Number 1 involves no 'working out', it is just 'telling the patient everything he needs to know, then directly receiving his instruction'.

Number 2, only leaves (provided the ADRT is expressed clearly), 'did he consider everything which would have affected his decision, and which I am aware of myself?' (section 25(4)(c)).

Number 6, isn't arriving at a section 4 best interests decision yourself, it is 'believing the decision communicated by a better-informed person'.

Number 7, discussed above, does not involve the patient's decision about resuscitation, so isn't anything connected with section 4.

Number 8 is default 'attempt to preserve life' behaviour.

I would also like to add this, as a personal comment, and question.

My dad died from congestive heart failure. His 'dying' was really the 6 weeks he spent in hospital, before he told his consultant he wanted to come home – he came home, and died about 30 minutes later.

My dad was sitting up in bed, and he said 'Oh – I feel funny – hold me' which gave me time to go and hold him, then as I looked at him 'he went'. You do see 'the light go out from someone's eyes'. Interestingly, I think that shows that you can still talk for a few seconds during the start of a CPA – logical, or we would be unconscious between heartbeats.

But, there was clearly no pain – no pain, no 'dramatic fitting': my dad was I think confused that his heart had stopped beating, then unconscious. I can relate to the 'confused' bit, because years ago I used to suffer from sleep apnoea before I had ever heard of the condition: you wake up if you are still not breathing, then you start to breathe, but you only think 'what went on there?'. It was only after many episodes of this, that I once woke up and realised 'I wasn't breathing!'.

So, I am not scared of my heart stopping – but I am scared of pain and disability.

So, as the 'clock for potential brain damage runs from the last beat', if I were at home, I think if I were inside a known EoL situation, or even if I were relatively healthy but very old, **I might be willing to accept a CPR attempt provided someone had seen the arrest happen (provided someone with me, knew that 999 was being called immediately my period in arrest began)**. If I were either very old, or in an EoL situation at home, I have a feeling that I myself would adopt this position – of not being willing to risk 'delayed CPR, and resuscitation with brain damage from the delay).

How, at present, would a GP and 999 facilitate that – how would you cope with 'I refuse CPR unless whoever calls 999, or attempts CPR, was present when I arrested' ?

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South Central came up with this in its Unified Do Not Attempt Cardiopulmonary Resuscitation (adult) policy:

In the 'Situations where there is lack of agreement' section:

10.1. A person with mental capacity may refuse any treatment from a doctor or nurse even if that refusal results in death: and any treatment carried out against their wishes is **technically** an assault. Individuals should be encouraged to make an ADRT. Should the person refuse resuscitation, this should be clearly documented in the medical and nursing notes after a thorough, informed discussion with the individual and possibly their relatives, has taken place. **A verbal request to decline resuscitation is not legally binding**; however it should not be ignored and does need to be taken into account when making a best interest decision. The

verbal request needs to be documented by the person who it is directed to and any decision to take actions contrary to it must be robust, accounted for and documented.

In the 'Definitions' section:

5.5 Advance Decision to Refuse Treatment (ADRT) a decision by an individual to refuse a particular treatment [in certain circumstances](#). [A valid ADRT is legally binding for healthcare staff](#).

Let us investigate those, but before we do, I will pass a comment: the idea that writing down a decision, which exists inside a patient's mind and which he can alter at any time, somehow makes it more permanent or more legally-binding for discussions which take place during known EoL care when the patient retains mental capacity until a CPA occurs, **is prima facie absurd !**

To analyse those, I will use this scenario:

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A person (P) is involved in a car accident, is hospitalised, and while he is in hospital an entirely different degenerative medical condition, which cannot be cured, is discovered. The nature of this previously unknown degenerative medical condition, which will not significantly affect his health until some time in the future after it is anticipated he will have recovered from his injuries and been discharged from hospital, is explained to P by his consultant (C).

A few days after P has been told of this degenerative condition, he summons a nurse (N) and an F2 doctor (D) to his bedside, and he says to them 'I have decided, after much thought, that if I arrest from now on, then whatever caused the arrest you must not attempt to resuscitate me – if I change my mind, I'll let you know'.

Q1 Is this verbal instruction that CPR must not be attempted, an Advance Decision (ADRT) refusing CPR ?

No, it definitely isn't – any ADRT refusing CPR must be written and witnessed.

Now, N and D, according to South Central, can make P's verbal refusal of CPR, which South Central thinks is not 'legally binding', legally binding by persuading P to write an ADRT. P happens to be a welfare attorney under his dad's LPA, he has read the MCA, and he doesn't believe them – but he decides to write an ADRT as advised to by N and D.

So P writes an ADRT refusing CPR, calls over N, and asks her to witness it, which N does.

P then asks N to read the ADRT, and to tell P what N believes the ADRT means. P then says to N 'You have misinterpreted my words on the ADRT – in fact, those words mean .....'. And N replies 'That isn't what they

say'. P retorts 'Section 24(2) of the MCA, explains that on an ADRT 'a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms'' and that he, P, is the layman involved here – and he has just explained to N, what he intended his words to mean, so now N should be able to properly understand his written ADRT.

This unsettles N, and she says 'But that isn't what you wrote !'.

P explains further. 'Section 25(2)(c) of the MCA, explains that an ADRT is no longer valid if the author 'has done anything else clearly inconsistent with the advance decision remaining his fixed decision' and if I agree with you, that the wording on the ADRT does not express my decision about the treatment, then clearly the ADRT isn't valid – **obviously I can't lose an argument, with my own ADRT !**'.

P now gets N to summon D, and then P gives the ADRT to D, and asks D to explain what he believes it means. P can say exactly the same thing as he said to N, to D, if D also misinterprets the words P used on his ADRT.

**THE POINT: N and D have to interpret the meaning of the ADRT by reading its words – but while P is still mentally capable, P can resolve any dispute about the meaning of the wording on the ADRT by explaining, verbally, what he meant when he wrote them.** If he is persuaded by N and D, that his words were so badly chosen that his meaning was not conveyed by them, then clearly he would say 'Okay, scrap that ADRT, I've just retracted it – you know what I am trying to express, tell me what I need to write on the replacement, ADRT, so that any clinician reading it will understand my instruction ?'

**I could continue, but surely I do not need to – the point is, that if you personally have discussed an ADRT with the patient, to confirm that you understand its instruction correctly, then the discussion is what informs your decision to withhold future CPR, not the ADRT.**

Now, that does NOT make a verbal refusal of future CPR an ADRT – it is simply that this type of verbal refusal of a treatment is so clearly understood, that it is the situation in which the clinicians most fully understand the patient's order that the treatment must not be attempted: and that puts the verbal discussion right at the top of the DNACPR Justification Hierarchy.

There is a difference between an ADRT which has been read but not discussed with the patient, and one which has been explained by a patient – Central South's policy creation group, was guilty of some very muddled thinking !

And to get another layperson's view on the fundamental issue, I asked a friend of mine, and his answer was this:

FIRST QUESTION: *If a patient has discussed CPR with his doctor, and the patient then says 'I'm forbidding any future CPR attempts', does the patient expect this order to be followed, or challenged ?*

Paul's answer: If I had a terminal condition and had a poor quality of life (as judged by me) then I would expect the Do Not Resuscitate directive to be followed..... From the doctor's perspective, I would want to be sure that the patient had a full understanding of the probable consequences and associated probabilities and that the patient had made a considered decision.

Paul is, as I am, a person with a chemistry doctorate, and he is annoyingly multi-perspective in his answer (I only asked what the patient would expect) and he hasn't read the MCA – but the important bit in there is '**as judged by me**' !

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What follows next, is the collected answers to a Survey about 'The Rules for Death' which I sent out in spring 2011 to most of England's PCTs, to many of the English and Welsh Ambulance trusts, and to many of England's Acute NHS Hospitals.

I only eventually received 8 replies, and I got various bits of other nonsense about FOI requests (which this one clearly wasn't) and questions about ethical clearance (as a private individual, I don't have an ethical body controlling me, and there was never any ethical issue with this, provided the PCTs etc only passed on my survey, without asking their staff to answer it !)

One PCT contacted me about a month ago, having mislaid my survey request for about 6 months: it has subsequently been kind enough to supply a response by a GP and a nurse.

So in total I have got replies from 2 Paramedics, a GP, a Consultant in Palliative Care and 4 nurses: two of the nurses work in the same PCT, and both paramedics worked in the same PCT (a different PCT from the nurses). Although small, this sample is large enough, and diverse enough (both in role and answers supplied) to be 'informative'.

I have collected all 8 replies, and added my explanations of why I asked those particular questions, below. I have also left the survey in its entirety as it was sent out, to give some 'background' for any readers who did not receive the survey when it was sent out originally.

## Survey about 'The Rules for Death'

### Background Information

The questions in this 'survey' were written by me (Mike Stone) and they are not intended to be a statistically-tested survey – instead, they are intended to be questions which will help to establish how 'uniform' the current 'belief set' around 'death' is across different parts of the country, and between different professional groups within any given PCT's region.

The questions, if answered, will also help to establish what different people believe, in some of the least clear areas.

The survey's answers would be fed into a discussion of End-of-Life Care, which is long-running and ongoing within an ad-hoc e-mail discussion group which includes the relevant person at the Department of Health, a Senior Paramedic, a Senior Lecturer who organises Verification of Death courses, the Lead on a CPR/VoD Policy Design Group for a PCT, and myself (I am the 'amateur' on this group – I come at this from the perspective of a family carer or relative, or potential patient).

Any replies will be forwarded to everyone in the group in their 'raw' form (I am assuming there will not be a huge response – if there is, it would make more sense for the replies to be sent to me, and for me to forward them on in bunches: however, I have no idea of the response level in advance). The e-mail address for me, is:

[mhsatstokelib@yahoo.co.uk](mailto:mhsatstokelib@yahoo.co.uk)

and the e-mail addresses for the entire group are;

**NOTE: The e-mail addresses were in the Survey as sent out, but I have redacted them here.**

### Purpose of the Specific questions

It has become very clear to the group, that the 'correct' behaviour 'around death' is influenced by issues of law, ethics, morality, role, personal experience and personal 'beliefs' and – **crucially** – 'perspective'.

Many of these issues are complex and so unclear as to require much 'clarification': I myself, am very concerned that there is currently inadequate information about 'how a person's perspective influences their beliefs and behaviour', and until that is better understood, I do not see how 'compromises which appear sensible from **all** perspectives' can be achieved. In particular, I am unhappy that the perspectives of patients and relatives, are not currently given an adequate 'weighting'.

If sufficient people will reply to this survey, I hope their answers will shed some illumination on the above issues.

## THE SURVEY ITSELF:

This is intended to be completed by the addition of answers to 'Q1', 'Q2' etc, and to then be saved as a file (please use either .doc or, preferably, to make sure there are no 'version issues', .rtf) and then e-mailed back.

There is no question of 'marking' going on here – this area is so complicated, that almost no two people agree about all of the answers – but I do want answers from **individuals**: I wish to know how operational professionals are **interpreting** 'the rules and guidance'.

Therefore, it would help if whoever is completing the form could include the following information:

- I1 Which PCT covers your working area?
- I2 What is your role (District Nurse, GP, Paramedic etc)?
- I3 How much experience do you have in your role?
- I4 Have you undertaken any specialist training which is influencing your answers?
- I5 Does your local PCT allow suitably trained nurses to verify 'expected' deaths?

The questions, which are intended to shed some light on beliefs, follow, numbered Q1 to Q9.

Some of these are 'very open questions' which invite a complex response; others can be answered simply 'yes' or 'no'.

I would appreciate it, if respondents would insert their answers directly after the point at which the question appears – for example:

**Q7** Does the term 'expected death' mean the same thing, in Newcastle and Bristol ?

**Yes, of course it does ! An 'expected death' is the same thing as a death with a DNACPR order in place !**

I am not giving that as a 'sample answer', but merely to illustrate that I would like answers directly after my questions, and that I need to know what people **individually believe**.

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GP: NHS Rotherham, GP, 24 years. 14 = yes, and 15 = yes.

Consultant Doctor: NHS Medway, Consultant in Palliative Medicine, 27 years. 14 = yes, 15 = Yes – after training and if expected death.

Paramedic no 1: Wirral, Paramedic, lots. 14 = no, 15 = no. (please see note below).

Paramedic no 2: Wirral, Paramedic, 19 years. 14 = no, 15 = no.

Nurse no 1: NHS Gloucestershire, EoLC Facilitator, 26 years of nursing (4 years Community Nursing (DN), 11 years Specialist Palliative Care, 5 years GSF/EoLC project work. 14 = Yes – palliative care degree, DN qualification, Masters module in health and social care, 15 = Yes as part of an EoLC Study Day.

Nurse no 2: NHS Gloucestershire, End of Life Care Education Facilitator, Medical nursing background, more recently in last 2 years specifically in end of life care education – care homes and community. 14 = diploma in palliative care, 15 = yes.

Nurse no 3: University Hospitals of Leicester. Palliative Care, Liverpool Care Pathway Facilitator/Macmillan Sister, 5 years. 14 = Completed the OU Death and Dying course, 15 = Not that I am aware of.

Nurse no 4: NHS Rotherham, Commissioning Manager (Registered Nurse), 28 years in NHS. 14 = yes, and 15 = yes.

NOTE: someone on the Wirral, appears to have modified my form before passing it on to the area's paramedics. For 14 and 15 above, and questions 6 and 9, they inserted 'yes/no' boxes, and said 'circle correct answer' – I don't think, that is possible in Word. I have assumed that the option these paramedics made **red**, or added an asterisk to, was the chosen answer.

### Scenario : 'Father and Son'

A father is living at home, with only one family carer, who is his son. This is supposed to be an EoLC situation, so the father is expected to die within at most a year (determined, I assume, by divination). The father has been seeing his GP and is, therefore, 'sort of aware' of treatment options and outcomes.

The father has not refused CPR, and is not considered to be sufficiently 'near death' for his death to be considered 'expected', or for a 'clinical' (i.e. for CPR to be predicted to fail) DNAR order to be in place: so there cannot be a DNAR 'Instruction' in place. The expectations for a CPA could range from 'unlikely' to 'almost sufficiently likely, for the situation to be an 'expected death''. The father is in some sort of discomfort, which he considers to be severe. Either pain, or something else, such as struggling to breathe. This could be either continuous or episodic in nature.

One evening, the father initiates a conversation with 'Son, I'm really struggling here. I really can't put up with this. Would it upset you, if I'm just allowed to die, if you think I have stopped breathing?'. It could end with 'We'll sort this out with the GP tomorrow, but if I die before then, don't phone 999'.

**Q1** What 'should' the son do, if he thinks his dad has stopped breathing, before anyone else has been told of the conversation?

**Q2** As Q1, but with 'should' replaced with 'would' (in other words, Q1 is asking for your opinion of the 'theoretically and morally correct' behavior – by contrast, Q2 is asking you for an opinion, as to how you think 'sons' would actually behave in that situation).

**COMMENT:** this scenario leaves open the question of whether, if the son lets his dad die in peace and then afterwards calls out the GP, the GP would certify the death: but I can see no reason why patients and their relatives should be aware of post-mortem procedures.

### Why I asked Question 1

This question must start with the law – it is actually 'what law governs the son's actions, and what might he be charged with?'.

English law, is very clear in that a patient has an 'absolute' right to refuse any offered treatment, and that right takes precedence over the 'general duty to preserve life'. The supremacy of patient self-

determination (also called autonomy, considered refusal, etc) is the foundation of our law, for situations in which a patient has considered and refused an offered treatment.

So, as the father has told the son 'if I stop breathing, I myself would not call for any medical intervention', it would be very perverse to argue that the son 'should' call someone.

Legally, this hinges on whether the son can 'make a best interests decision' under the MCA. Now, he does need to either phone someone, or leave his dad to die (the question of being sure he has stopped breathing, is relevant, but a side-issue), so it seems he must make a decision:

MCA 1.5 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 the basis of best interests decision-making, is section 4.6:

He must consider, so far as is reasonably ascertainable—

- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.

Then, the test for correctness of the son's behaviour is section 4.9:

In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

It is very difficult to argue that the son would **not** 'reasonably believe' that letting his dad die peacefully, wasn't acting in his dad's best interests, when his dad had clearly explained that was his wish !

Carol and I, become very 'vexed' when we read suggestions that an ADRT must be regularly resigned, in order that any clinicians who read it are 'reassured it is up-to-date'. **Because that 'mindset' is backwards.** The responsibility to ensure that your ADRT is up-to-date, and accurately expressive, rests with its author – the reader, must assume that the ADRT is indeed up-to-date, unless there is evidence that it is not. This 'you must keep re-signing an ADRT' is a distortion of the correct emphasis: patients are responsible for their decisions, and clinicians who follow such decisions, are 'absolved'.

Now, it should be clear to the reader of Father and Son, that I am describing the time when the father has reached the 'I would be happier, if I did not wake up tomorrow' point. Naturally, he will probably want to discuss this, and explain it, to the people he cares for, first: it is those people, who he knows will perhaps be upset, and will need to understand it. Although his son will have seen his 'suffering' – the son will probably immediately understand, his dad's decision.

And the father, is not an expert in NHS protocol – but it his decision, and when he adds to 'we will sort this out with the GP tomorrow' the further instruction 'but if you think I have stopped breathing before then, don't call 999 and let me die' **that is also the father's decision, and he bears responsibility if it is followed.**

Nurse no 4's comments, are fundamentally wrong. As I said this was an EoLC situation, **it should be reasonable to assume** that the GP is keeping the father informed of the clinical factors – so the father should adequately understand his prognosis. So 'he might live out a peaceful life, if he were resuscitated' could be true – although, it seems unlikely in this case. I said 'he is in discomfort, which he considers to be severe' and I mentioned 'such as struggling to breathe'.

My dad died from congestive heart failure, and there is not any treatment which removes 'struggling to breathe' for that condition, as a patient nears death. And, if the father understood the current 'mess'

which exists for ADRT, he would **not** assume that writing an ADRT would give him control over his decision to refuse CPR – he would realise, that only by not calling anyone to his CPR, and by telling everyone who might be present when he had a CPA that he wanted no treatment for it, could he be reasonably certain that **his decision** would be followed.

## Answers to Q1

GP: He should do what his father asked him to do.

Consultant Doctor: Wait and call GP later to certify the death

Paramedic no 1: Preferably make a quick note in care package AND/OR do not call 999.

Paramedic no 2: Respect father's wishes, in the event and contact and discuss with GP ASAP, call 999.

Nurse no 1: If an Advance Decision to Refuse Treatment (ADRT) has not been made and the father has not verbalized his wishes to a professional involved in his care then the son would have to call 999 as his conversation with his father has not been witnessed and not evidenced as "in his best interests"

Nurse no 2: respect his fathers wishes and not phone 999

Nurse no 3: Either ask his father to document his wishes in some form, or if possible contact the out of hours GP, and see if that would be an appropriate course of action

Nurse no 4: He should dial 999 as there is nothing formal that acknowledges his dads wishes. If he does nothing he will be in trouble as it will be classed as neglect also dad may have been having a bad day and if resuscitated may go on to live the rest of his life pain free, with dignity and in control by completing an advanced directive.

## Why I asked Question 2

I think that almost all relatives, would in reality call someone – and whoever they try to call, I think they would almost always end up with a 999 paramedic. I think the relatives less likely to call someone immediately, would be: people who work in health care; people who are Asperger's or autistic; anyone whose experience of that situation, was 'a second time'.

So, the situation will be that a paramedic is attending a CPA, with no written/recorded DNACPR Order, and a son (probably very 'unsettled') who says 'My dad told me last night not to call anyone, if he stopped breathing – he was going to sort this out with our GP later today – but I called, to check what I'm supposed to do, etc'.

Those paramedics who have thought about this, do not like it ! And I don't like the suggestion, that in such a situation a paramedic should attempt to assess the honesty of a relative.

So, either paramedics must be told to assume by default that relatives are honest, which leads to 'If he told you that, we are supposed to let him die in peace' (and no CPR, if he is in CPA), **or** paramedics must be told to behave as if the relative is lying, and to attempt CPR. I prefer the assumption that relatives are usually honest, so I go for the former option !

**I intensely dislike 'we can assume that relatives are lying, with no proof either way' !**

It has been commented on, that GPs and other doctors often do not properly discuss 'the actual dying part of EoLC' with patients and their relatives. However, if a GP did discuss EoLC and death properly, would the GP end the discussion with 'Oh – by the way – health care professionals will assume, **if there is no evidence one way or the other**, that your spouse/children/siblings are being dishonest and lying to us'. **Do 'you' think you could get away with that ?!**

## Answers to Q2

GP: I think some would and others wouldn't.

Consultant Doctor: As for 1.

Paramedic no 1: Most people will call GP/District Nurse/Macmillan Nurse for advice, and invariably be told to call 999.

Paramedic no 2: Respect his wishes, not call 999 but still contact GP for advice.

Nurse no 1: From my experience most would call 999 because of the moral and ethically duty not to let someone they loved die with an attempt to save their life. The son has to live the rest of their lives with the knowledge that if they didn't act "what if" and can severely affect their grief process unless they felt the action produced more good than harm (their father would be at peace rather than suffering).

Nurse no 2: As above.

Nurse no 3: He will probably ring 999, having recently done some teaching about end of life with the local ambulance service, this is a situation which arises on a regular basis

Nurse no 4: I think the son would dial 999 as he would want his dad to have every chance at life, also he may panic at seeing his dad die. This nurse also wrote the following, after my 'comment': 'You cannot assume that dad dies in peace, also there could be guilt at the "what if" as dad may be successfully resuscitated and have time to put his affairs in order and see family before he dies.'

## Scenario: 'Grandfather'

An elderly chap, perhaps in his 80s, has decided that if he has a CPA, he does not want to be resuscitated. Perhaps he has a horror of 'waking up in hospital after a nasty stroke', or perhaps he has seen friends 'slowly rotting away' and has decided he would prefer to 'declare his innings earlier, and before he becomes that incapacitated, should he have a CPA'.

He isn't suffering from 'any one thing in particular, which is expected to kill him anytime soon', so he may not even be seeing his GP regularly. So, if he has a CPA, his GP would be unable to certify his death as natural.

Nevertheless, if he has a CPA for any reason, he is quite firmly decided that he simply wants to be allowed to die, he has explained this to his family and they understand it.

So, the 'huge problem' is how does he make sure he is left to die in peace if he has a CPA, and how do we make sure his family are not 'beaten up' if they do let him die in peace ?

**Q3** How does grandfather make certain he is not resuscitated if he enters CPA?

**Q4** How do we make sure that if grandfather's wife were to allow him to die in peace, she is not 'beaten up' by the system (ie the Police) afterwards?

**COMMENT:** this scenario is effectively 'how does a guy who wishes to refuse CPR for a sudden death, enforce his wish?

### **Why I asked Question 3**

This problem is crucial, if two or three times as many people are to be allowed to die at home as currently do that, as surveys suggest might be the case. The fundamental principle of the law, is that people have the right to refuse CPR irrespective of how ill they are, and irrespective of the cause of any CPA. Because the concept, is that only a person himself, can be the judge of his own quality of life (present or anticipated). This is most easily seen if you read sections 24 – 26 of the MCA, which set the rules for Advance Decisions.

But many clinicians, do not seem to understand that: many clinicians, think that people are allowed to forbid CPR because of the cause of a CPA, when logically if you reject a CPR attempt, you are rejecting the 'the way your life would be after CPR, if it re-started your heart'. If your existing and anticipated future lives are both 'intolerable', then the combination of a CPA+CPR will not improve that life. For example, CPR will not repair a broken neck, or prevent the progress of a degenerative illness.

**The guidance needs to specify sample wording, which all clinicians will accept means 'I am rejecting CPR, and the cause of the CPA is not relevant to my rejection of CPR'.**

### **Answers to Q3**

GP: He can never be certain. His best chance is to make his wishes known to family and physician. He could write and advance directive.

Consultant Doctor: Advance decision to refuse treatment and ensure a DNAR is completed

Paramedic no 1: He does not, family panic call 999 and ambo man starts futile resus which CANNOT be done properly in a moving ambulance; HAVE WRITTEN DOCUMENT CLEARLY STATING DO NOT RESUS; signed and dated.

Paramedic no 2: Living will, involving family members and medical staff.

Nurse no 1: To discuss with the professionals in his care about Advance Care planning, most importantly an ADRT

Nurse no 2: Use of an advance directive

Nurse no 3: ADRT and DNA-CPR to be logged with GP and ambulance service, the family have already been informed, of his wishes. Copy in a prominent place within the home. If any hospital admission occurs, ensure that this information is transferred.

Nurse no 4: Completes an advanced directive.

### **Why I asked Question 4**

At the moment, it isn't clear how Grandfather avoids CPR for a 'sudden' death, using an ADRT. So, logically grandmother is forced to not call anyone, if she is composed enough.

This leaves both grandfather, and grandmother, in an unacceptably invidious situation – that wording, discussed when I explained the reason for question 3, is necessary.

### **Answers to Q4**

GP: Again I don't know that we can 'make sure' but I think a witnessed advance directive would suffice.

Consultant Doctor: DNAR in place and ADRT in place. If he completes the ADRT his wish must be respected. If DNAR completed CPR should not occur.

Paramedic no 1: WRITTEN DOCUMENT STATING DO NOT RESUS SIGNED AND DATED; OR if no time to put into place, pray you get a mature and experienced ambo crew that have not been beaten by the system themselves.

Paramedic no 2: Communicate involve and inform at all stages.

Nurse no 1: By following the Mental Capacity Act and the Advance Decision guidance (Advance Decisions – A guide for Health and Social care Staff) and clearly documenting in the Clinical Records and G.P Practices, OOH's and everyone involved in the patient's journey of the ADRT (communicating, coordinating and evidencing is paramount)

Nurse no 2: As above plus joint discussions with her husband and GP, use of ACP, LPA

Nurse no 3: If the above is in place, hopefully this would help

Nurse no 4: advanced directive is a legally binding document.

**Q5 Do you believe that a suitably-empowered Welfare Attorney 'speaks as if he were the patient', or do you believe that a suitably-empowered Welfare Attorney 'issues instructions after consulting with clinicians and other people', when the patient is mentally incapable ?**

### **Why I asked Question 5**

I will not run through the MCA to prove this, but a Welfare Attorney is appointed by the patient, **to be the person who considers** the MCA's best interests test. Not 'as a joint decision with doctors' – the Welfare attorney asks questions of other people, if he needs to, and then the Welfare Attorney's decision is the one which has legal force.

If you wish to simplify that, then it comes out as 'the Welfare Attorney makes the best interests decision'.

Patients do not 'make best interests decisions' – patients 'just issue an order'. As it happens, since the MCA, in a 'real' sense, clinicians do not make 'best interests' decisions either, but that analysis is for another place !

### **Answers to Q5**

GP: A think a suitably empowered Welfare Attorney would be best placed to make a decision after consulting with clinicians and other people.

Consultant Doctor: LPA allows decisions to be made by the attorney – if patient has lost capacity then wishes of attorney should be respected – he should be heard in exactly the same way as the patient would be if he had not lost capacity

Paramedic no 1: Subjective and irrelevant, we all make decisions within the moment that cannot be catered for before hand. Unless it is written down anyone calling 999 is at the mercy of the lottery that is the ambulance service (you could get anything from a great crew to your worst nightmare turning up= INCONSISTENT).

Paramedic no 2: Issues instructions after consultation.

Nurse no 1: No it speaks as a process not in the first person

Nurse no 2: Depends on the character of the person.....

Nurse no 3: I think the answer is actually a combination of the two, it must be very difficult not to be influenced by the clinician and associated others, who may well know the patient better.

Nurse no 4: no, the advocate needs to liaise with everyone who knows the person to ensure as far as possible their wishes are upheld.

## **Q6 Do you believe that both of these combinations are possible?**

See my answer to 6(2), below.

### **1 A DNACPR decision and a death which is not 'expected'**

GP: yes

Consultant Doctor: Yes – patients may not wish CPR at any time, and express this and ask for DNAR

Paramedic no 1: No.

Paramedic no 2: No.

Nurse no 1: Yes.

Nurse no 2: Yes.

Nurse no 3: Yes.

Nurse no 4: yes if CPR is a futile treatment option, Also correct documentation must be completed and shared with all key people.

### **2 An expected death and an 'attempt CPR' instruction.**

GP: no- CPR is a treatment, and as such must be given as the result of a clinical decision, not an order from a patient, nor anyone else.

Consultant Doctor: In theory – but DNAR is medical decision and if the doctor does not feel CPR is appropriate the patient cannot insist on this

Paramedic no 1: No.

Paramedic no 2: No.

Nurse no 1: Yes.

Nurse no 2: Yes.

Nurse no 3: Yes.

Nurse no 4: This depends who wants the attempt, if CPR is a futile treatment option then it should not be attempted even if the family wants it. If a patient wants it then a medic (doctor) needs to explain the implications and outcome if they are of the medical opinion it would be futile.

## **Why I asked Question 6**

There seems to be an enormous amount of confusion, and some deliberate obfuscation, surrounding 'expected death'. There is also some conflation between CPR decision-making and Verification of Death behaviour.

Briefly. CPR decision-making is governed by the law, and the concepts of expected and sudden death are nothing to do with CPR decision-making. Verification of Death behaviour, is defined locally by Coroners, and the concept of 'expected death' is relevant to such protocols (and, in fact, defined within those local protocols). Certification of death, does have some law, but is something only a doctor who has been involved with the patient can do – unlike verification.

This was **not** the question 'can the nearness of a patient's death be accurately predicted?'

It was about 'expected death' in its only **meaningful** sense – the fact that nurses are allowed to verify 'expected' deaths, without the intervention of other professionals.

And the reason nurses are allowed to do that, is to:

- 1) show consideration for bereaved relatives, by allowing for faster removal of bodies, and
- 2) simplify, by 'relaxing', post-mortem 'cause of death' examinations,

where the death of a patient is expected to inevitably happen very shortly, because of a known illness.

But it doesn't matter if an 'opportunistic infection' piggy-backs and actually causes the death, and all nurses are doing is verifying that the patient has died, and that the death appeared to be natural. Without 'looking too hard' or intruding on the grief of the bereaved, and without 'trying to connect the death to the known illness'. Those nurses, and there are many, who think 'a death is expected because it is caused by the final illness' are missing the point : the death is expected, because the known illness would inevitably and imminently, cause a death, even if in the event something else (still natural) actually causes the death (this is subtle but influences 'thinking' – basically, if cancer makes you so ill that you catch a chest infection, and that chest infection kills you, the chest infection is irrelevant. You would not have caught it, if you had been healthy, so the public health aspect does focus on the 'deeper' illness.)

In essence, a death becomes 'expected' at the point when a GP effectively promises to certify any subsequent natural death: with that promise to hand, Coroners can then relax post-mortem protocols, so that trained nurses can attend the death if the GP is unavailable, verify the patient is dead, and arrange for the body to be removed, safe in the knowledge that the GP will subsequently certify.

Which is fine: except, 'somewhat earlier EoLC deaths' are often certified if the GP attends the death, but only after the GP has examined the body, etc. These 'earlier but entirely natural' deaths, cannot be described as 'expected', and are currently usually called sudden, and worse still, **thought of as sudden**. WHICH IS VERY WRONG! The point at which a patient's EoLC deterioration has reached the point when a GP formally describes the future death as 'expected' depends on the knowledge and experience of the GP, and precisely when the GP visits the patient. There is great uncertainty about whether a situation which becomes described as 'expected death' on Monday 17<sup>th</sup>, could not equally well have been so classified on Sunday 16<sup>th</sup> or Tuesday 18<sup>th</sup>.

This sharp disjoint is **WRONG**. There are basically 3 'categories of EoLC deaths', which are best described in these terms. Imagine that the GP receives a call after the patient has died, **then when driving to the house**, the GP will basically have one of 3 thoughts:

- 1) He has died as I expected (expected death)
- 2) He probably died from his illness, and this death is perhaps a bit 'early' but it doesn't surprise me (in other words 'there is a good chance I will certify this one')
- 3) I am surprised he has died, and I probably will not certify this death at the scene.

2, which is much more akin to 1 than it is to 3, is usually called 'sudden' at the moment, but only 3 should be called (or thought of as) sudden. **VERY ANNOYING and VERY UNHELPFUL FOR RELATIVES !!!!**

## **Q7 Does the term 'expected death' mean the same thing, in Newcastle and Bristol?**

### **Why I asked Question 7**

See above: the only meaningful use of 'expected death' is in connection with VoD behaviour, and in that sense the behaviour which a local Coroner allows, defines expected death (before 2006, the NMC had a definition of expected death – but then they changed their guidance, and now the NMC simply tells nurses to verify death in accordance with local protocols).

So, it is very unlikely, that expected death will mean exactly the same thing, in Newcastle and Bristol.

### **Answers to Q7**

GP: I - don't have the experience to answer this question.

Consultant Doctor: See above

Paramedic no 1: I do not know

Paramedic no 2: Probably not

Nurse no 1: Should be!

Nurse no 2: I would hope so but I expect it does not!

Nurse no 3: I would have hoped so

Nurse no 4: Predicting death is not a scientific process, it is very difficult for clinician to say with accuracy when someone will die. The clinician uses their experience and clinical judgement to assess the clinical facts and form an opinion regarding the outcome.

**Q8 What actual wording on an Advance Decision is adequate to indicate that a patient is forbidding future CPR attempts whatever causes any future CPA? Does writing on an ADRT 'I refuse CPR if I am in CPA' {with or without the use of the abbreviations} indicate that an attending clinician should not attempt resuscitation? And if that wording does not prevent resuscitation attempts, what precise wording would prevent CPR from being attempted?**

### **Why I asked Question 8**

Also see above.

Basically, a person has a legal right to refuse future CPR while he is quite healthy and he does not know what might stop his heart. The outcome of continued life into old-age, or of a CPA+CPR combination, is so uncertain that Grandfather is entitled to 'declare my innings early, if my heart stops for any reason'.

But he cannot exercise that right, unless he is confident that **every** clinician who attends his CPA, will understand whatever wording he uses to indicate 'I'm refusing CPR, and this refusal does not depend on why my heart stopped beating'.

Appropriate wording (and training !) needs to be published – preferably, in the Joint CPR Guidance !

### **Answers to Q8**

GP: I think that wording is adequate.

Consultant Doctor: What is being talked of ? Advance statement is not binding, as not specific , but should be taken into account in best interests decision. ADRT is binding if specific and states that realises that life is at risk and could lead to death.

Paramedic no 1: No words, people react in any given situation in any given way, the greater the decision to be made the narrow the field of what if's are available. i.e one paramedic will not resus, another will. SERVICES MUST ENSURE THAT DO NOT RESUSCITATE MEANS THAT REGARDLESS OF SITUATION.

Paramedic no 2: That would be fine for me, however it should be current and witnessed by relevant clinicians etc.

Nurse no 1: The wording should be specific regardless if its CPR or another refusal of treatment and has to be related to the condition not just generic

Nurse no 2: Not answered.

Nurse no 3: I think if it documented that a refusal for CPR in the event of a CPA would be suitable, equally if a patient does want resuscitation that too should be clearly identified and duly verbalised across all care providers involved

Nurse no 4: Wording that is clear not ambiguous the professional assisting the completion of the ADRT can assist with wording.

**Q9 Have any of your answers to the above questions, been influenced by any materials you have read, which originated from either the LCP or GSF Teams?**

### **Why I asked Question 9**

I was prompted to send the survey out, by annoying 'non-answers' from both of those teams. The GSF claims it has not really issued guidance for home deaths, and I don't think either the GSF or LCP teams properly understand the law for 'death/dying': the clinical factors, yes, but the law, no.

### **Answers to Q9**

GP: Yes.

Consultant Doctor: Not answered.

Paramedic no 1: No.

Paramedic no 2: Yes.

Nurse no 1: Yes definitely as we have all three tools in this PCT and because of my own experience

Nurse no 2: no, these are from the heart whether right or wrong, though life's experiences must have some influence

Nurse no 3: Not consciously, it has been answered from a purely professional and personal perspective.

Nurse no 4: yes.



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XX  
XX  
XX  
XX

I sent out the following letter to about 200 Dignity In Care Champions, and probably about 180 received the question (the e-mails go indirectly, and although you get 'undeliverable' returns from some addresses, not until a Champion replies do you discover his/her e-mail address).

I show the replies, to the suggestion that the default position for CPR should be altered from opt-out to opt-in, after the letter I sent (the text quoted inside the letter, is from a paper by Iona Heath, President of the RCGP – she sent it me in some e-mail correspondence).

My position is that opt-in makes no sense, and a person has the legal right to opt-out – but that doctors must actually try to discuss clinically possible CPR with patients, if it seems at all possible that an informed patient would refuse such attempted resuscitation.

The responses are interesting: those clinicians and others, who need to initiate discussions about CPR see the problems the discussion might cause – by contrast, those people who see the distress (often after the death) that inadequate 'preparation for the death' causes to the bereaved, or to patients, see the adverse consequences which result when doctors have avoided early discussions with patients about their wishes for resuscitation.

Dear ,

During the current discussions of End-of-Life Care, some doctors have proposed that the frail elderly should 'opt-in' to attempted cardiopulmonary resuscitation, as opposed to 'opting-out'. Their argument is as follows:

“The default position for most medical interventions is that patients have to opt in by giving informed consent for the procedure. Why should this not be the position for CPR? Those in previously good health and who therefore have the best chance of survival after CPR would be likely to opt in without hesitation but those already in poor health would have to be offered a realistic assessment of their prospects if they needed resuscitation. Dementia, dependent status, metastatic cancer and a serum creatinine raised above 133umol/L all predict failure to survive until hospital discharge. Doctors are well used to seeking informed consent and outlining possible adverse effects, whereas the processes of discussing opting out through DNAR orders appear much more difficult for patients, doctors and relatives alike. In a recent article, Mallery and colleagues (J Palliat Care 2011; 27: 12-19) report a qualitative study of how hospital physicians approach resuscitation planning with families when older patients already have limited life expectancy and a considerable burden of existing

illness. They found that while the physicians were good at exploring the relatives' goals and values, they did much less well at providing explicit information about the expected outcomes either of CPR or indeed of the preexisting illnesses. Their conclusion is that a vague notion of patient autonomy is being allowed to trump the duty to provide the information necessary to support valid decision-making.'

I wish to gather some opinions about this 'opt-in' idea for CPR, so I am e-mailing some Dignity Champions who are listed under a variety of occupations, and if people will express their views about this idea, I intend to forward those opinions to a person who supports this 'opt-in to CPR' idea,

Regards, Mike Stone

PS To make comparing any replies easier, if you are kind enough to reply, will you please start your e-mail with a description of your role within healthcare.

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## **REPLIES RECEIVED:**

Subject: RE: Dignity Champions - A Message from mike stone-Reply from Hospital Chaplain

Dear Mike

My feeling would be that you could die from not opting in, and without it being discussed with relatives. Opting out means you have to discuss it with the relatives or with the patient, failing to do this will increase litigation and relationship problems with families. Doctors need to take time out to discuss their relatives condition at end of life.

It is fundamentally different from "The default position for most medical interventions is that patients have to opt in by giving informed consent for the procedure." The different being certain death if CPR is not applied when necessary. Families need to be ready and prepared to accept that the point has come not to resuscitate, and therefore the practice should remain that is up to the families to opt out.

Kind Regards

Revd Barry B

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Dear Mike

In my opinion I could not support the 'opt-in' option. I believe that getting treatment is a fundamental human right and therefore should not be something that one has to 'opt-in' to obtain.

Furthermore it will treat the elderly to a different set of principles and therefore discriminating against the elderly.

Regards  
Avi

@xxxxxxcarehome.net

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Good Afternoon Mike,

Firstly may I say that I am a Social Care Manager not working in Healthcare.  
We provide Community Care for mostly elderly people. However, I do think that having an 'opt-in' policy is a very good idea. It would help not only the person involved with the communication of the situation but also help relieve the relatives/friends of making a very difficult decision. I myself have been in this situation with my own family and also within my job role.

Best Regards

Alicia W  
Branch Manager  
xxxxxxxx Homecare Ltd

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Hello

I am a national training manager for a domiciliary care company and although to some degree I agree with opting in I find myself worried for those who may lack capacity. It is more prudent of the care profession to work as a team in developing stringent end of life strategies that would enable individuals to plan their care. A definite opt in would/ could result in individuals with some degree of quality of life being given no choice if they have not given any written/verbal instructions.

Regards

Mandy

Amanda F  
National Training & Development Manager

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Hi Mike

My role is as a Social worker working primarily with the elderly/terminally ill

Shouldn't the default position be to retain human life and only make the decision not to do CPR after informed discussions with the person /and their relatives or Health and Welfare Lasting power of Attorneys if applicable . 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 relatively 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.

It seems that the Doctors actually spend more time having the discussions with family /next of Kin representatives etc and I have always held the view that this was because they were more fearful of complaints / litigation etc arising later than actually getting an informed opinion from the person at the centre of the decision.

When a decision is made or if a patient themselves wants a DNAR there should be more publicity/ information provided to individuals so that they are aware they can inform their area ambulance service of the DNAR being in place . I am not aware of how it is dealt with nationally , but I have always found that most of the professionals that I have worked with have not promoted this or even been aware of this

Regards alan

Alan L

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Hello

Having worked on a care of the elderly ward as a ward sister for a few years. We had an excellent consultant and he would discuss the option of CPR on every admission with the pt- if the patient was found not to have mental capacity or able to make the decision he would ensure an mdt with involvement of the relatives was always done. This always worked on our ward- ( except a few occasions where there were different circumstances with relatives-)

I feel the decision should still be an patient + mdt decision and wherever possible to involve the relatives ( at the pt agreement).

I feel that sometimes in particular in a larger acute hospital the decisions are often made not to attempt cpr without a full explanation of the potential outcome/ prognosis post cpr.

Hope this makes sense,

Eleri

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Mike

Our Trust I feel is good around DNAR decisions with patients and families and I feel an OPT in excludes those who may at theta moment in time be in pain etc but have a curative treatment and therefore change their mind, therefore an opt in could change from day to day.

DNAR decisions can be reversed but I think an opt in that could change day to day would be difficult to communicate across the whole team therefore poses a risk

Elaine G  
Patient Safety & Risk Co-ordinator  
Medical Services Directorate  
XXXXXXX Hospital

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My role is a practice educator for acute and community services, clinical role is district nursing.

I do not believe that an opt-in approach is the best way forward, particularly for a group of patients who are already at risk of being sidelined because of their age and frail nature.

DNAR orders should be individually discussed with each patient and decided according to their individual needs. To suggest that they should not be resuscitated automatically because of their diagnosis is verging on inhumane.

Resuscitation status may be similar to other medical interventions to which patients give informed consent, so in the same way they should be communicated with in relation to the appropriateness of the intervention and a decision reached on what is the best choice for them, this clearly indicated on their patient notes.

We are entering dangerous ground if we take the stance that patients are not to be resuscitated unless it indicates on their notes. Unfortunately we are not in an arena where communication is successful in all situations and until we are automatic opt-in/opt-out is not really a reliable method of advance care planning.

Kind regards,

Jayne

Jayne M  
Practice Education Facilitator  
Professional Development Unit  
XXX Healthcare NHS Trust

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My view would be not to have an opt in but have a clear advance care planning discussion instead as patients reach the ceiling of the treatment stage of their illness or before. We do this well in cancer care but not so well in other chronic disease and complex cases

It's not the position of all medical conditions either as in an emergency the patients best interests are acted upon by the clinician without consent

Lesley

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Hi

I honestly don't think it will make much difference as you still need the GP to have the conversation to see if they want to opt in, I don't think you can just assume people do not want to be resuscitated just because their medical condition would make it difficult / impossible.

I think it is just a different term for the DNR conversation and I don't think it will make any difference what you call it, I would prefer a not for active treatment, treatment escalation plan so people can choose what level of treatment they have ie they may want antibiotics for a chest infection but not be resuscitated, this gives a much clearer picture on how to treat people and they then have a better understanding of all the options

Best wishes

Janet

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Hello Mike, I am an RGN with over 33 years experience behind me. The last 5 years have been spent working in a mental health capacity for younger adults, so the DNR issue rarely occurs. However, I do think the opting in idea is a good one, as so many older people live healthier and more fulfilled lives. The problem is that cardiac

arrest for the elderly rarely just happens, and if they survive the ordeal, they may be left with permanent damage which reduces their quality of life. The whole idea of giving people more choice, information and autonomy over their right to survive, has to be a good one. We have all been to so many cardiac arrests, when the wishes of the person suffering are the last thing to be considered. I find this debate very interesting.

Regards, Alison.

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My present health care experience is within the giving advice information and training to family and other informal carers. These people care 24 hours a day for a variety of conditions. Ages of the delegates range from 30 - 89 years. The St John Ambulance Carers Support Programme deals with carers caring for all conditions.

I can only give a personal opinion of CPR and the older adult. My Mother had Dementia and during the last few days of her life needed nursing/hospital care. As I am a health care practitioner I requested that she NOT be resuscitated.

A) Because she had reached the end of her life and

B) she had Dementia and under the strategy she would not be considered and for us rightly so.

The problem is if the protocol states with ..... they should be or with something else they should not be it becomes very difficult to manage. It needs to be very clear which ever way is decided.

Perhaps one issue for consideration is that it should follow the donor method if we opt in or out the CPR guidelines would echo this.

More of a problem is the collapse in the street and a first aider

that then "has a go" and creates a problem for acute hospital staff.

The whole issue is then surrounded with the issue of timely death, the per-longing of life with treatments and procedures and the wish of the person affected and the thorny issue of euthanasia.

The UK needs to be very much more open about death as many of the population will not have had to deal with this issue until they are mature and this creates difficult and excessive grief symptoms

Regards  
Judith

Judith G MSc RGN

CSP Manager

St John Ambulance.

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Dear Mike

I work as a consultant in eldercare in a district general hospital.

I believe that an opt in option for attempting resuscitation may be appropriate depending on the setting. The vast majority of the patients on my ward are frail, with multiple comorbidities, and often have cognitive impairment. It is rarely appropriate to attempt CPR, and the onus is on the medical team to make patients 'not for resuscitation'. Sometimes we have confrontational discussions with relatives who feel that we are being ageist / giving up on treating their relative etc. These discussions can be very burdensome to the family, who may feel that they are required to make a life or death decision about their loved one, even when it is explained to them that it is ultimately a medical decision about an intervention that will be both traumatic, undignified and almost certainly unsuccessful. These discussions can detract from the actual care and treatment that we are giving, placing undue emphasis on a 'formality' that we have to comply with.

As a dignity champion I would not want my nearest and dearest undergoing CPR if they were nearing the end of their life, especially if it was because the medical team had not had the opportunity/time/forethought to fill in the paperwork to prevent such an intervention.

However, if you are talking about a cardiology or a medical admissions unit, the situation is quite different and I think an opt out option remains appropriate.

I believe it is impossible to generalise, and that both options should be explored according to the population of patients in a given setting.

Regards

Madeleine P

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Practice Development Facilitator.

I think that the opt in for CPR would be a good thing if the information given is of a high enough quality. At present I feel that patients and relatives are not always given clear but compassionate info on potential outcomes.

Sandie

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## INTERESTING FOLLOW UP EMAILS

Hi Mike

Thanks for these. I think my final comment of the population not being open and able to talk about EoLC/CRP is the underlying issue.

We as a group have lost the plot – death will occur for us all. However is the process of death and what we would like to occur during and following death that needs to be discussed. The End of Life strategy encourages HCP's to complete an end of life care plan but in fact Nurses are often guilty and feel unable to complete them and so not do them.

They quote that they feel unprepared to do these that they have difficulty in identifying the stages associated with the end of life and they themselves struggle with the whole issue of talking about death.

As I say to friends the Victorians talked all the time about death and mourned very outwardly but they did not talk about sex. Today we talk insistently about sex and nothing about death, people will cross the road syndrome occurs and the medical professions have for many years told people they can cure them. It's not really surprising that people demand treatment, surgery, expensive medicine and then CPR.

When you think it's only about 40 years ago that CPR became a common place procedure, we have to accept that it only works and restores normal life in a very small % of cases. There needs to be open discussion about the cases that would not benefit like in terminal cancer, dementia, large CVA, and others and that CPR would NOT be an option. Who would lead this? I'm not sure and again it rules out emergency or home care.

Open discussion is the key

Regards  
Judith

Judith G MSc RGN CSP Manager  
St John Ambulance

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Hi Mike,

Firstly I would agree about lack of knowledge of the MCA, it is something I am quite passionate about (the need to increase practitioners knowledge).



## E-Mail correspondence with my friends Paul and Pam

Two married friends of mine, who I've known since university (they moved to Canada ca 1980), have both comparatively recently lost parents (in England). I am frustrated by the lack of information about relatives' and patients' 'views' for EoLC: the people with the ongoing experiences are medics, but medics are - because of both their training and their greater, and different, experience - likely to have a different perspective from that of patients and relatives.

I am using my friends to try and get some further 'relatives' perspectives' (I have sought similar feedback from various bodies, with no luck so far). I have tried to not 'lead' too much, but I did need to make my questions very clear. Paul knows me better than Pam, as we were on the same course at university, and were in the same tutorials and football team, etc – so Paul is fully aware that my currently weird mental state, is only even weirder than it originally was. Paul is also of the same sex as me; I am unsure if there is a sex difference of some sort, which sometimes inserts itself into discussions which involve death. The e-mails did branch off into an unexpected side-shoot, in itself interesting and relevant.

Because Paul and I exchange e-mails a few times a week, I had made Paul aware of certain aspects of my e-mail exchanges with various parts of the 'system', so when I asked these questions by e-mail, he was already aware of how complicated the discussions surrounding 'the CPR decision' get, and how entrenched and varied opinions are – but he had not read up on the background, or followed the discussion in great detail (Paul is now starting to show signs of 'getting hooked': analytically, many of the issues are fascinating – but operationally, being on the wrong end of a very poorly thought out, and inconsistent, 'belief set' is no fun at all! Pam, who thinks I have 'closure issues' is definitely right in respect of my experience causing me long-term mental damage: both the immediate behaviour of 999, then the ongoing subsequent behaviour {both in terms of its actions and its non-actions} of my local PCT. Pam is not aware of the depth of my subsequent 'investigations', or of the ease with which logical paradoxes can be discovered in the existing clinical literature {something which really bothers me - **logical contradictions within a single document** should simply not be present}, or of how stubbornly and persistently 'stupid and inappropriate' the behaviour of 999 appeared to be, from my position at the time).

Paul confirmed to me that he had not, in fact, 'done any background reading' and that his answers were 'as a man in the street' (admittedly, one with a D.Phil in chemistry, who 'thinks like a scientist'):

**I asked Paul, at the end of the e-mail exchange, 'Is it fair for me to describe all of those answers as being 'your answers based on your own 'common-sense view' and NOT influenced by having done any serious 'reading up' on the subject ?' and Paul replied 'My views are based upon my experience of the world and no reading on the topic'.**

There are several e-mail exchanges, which deal with different questions. The e-mails are shown in order, for any particular issue, but with comments inserted either between e-mails, or at the end of the particular set of e-mails.

Pam has italicized quotes from my e-mails in one of her replies, so I have used plain black for Pam's e-mails to me (similarly Paul's e-mails are in black), and italicized blue for my e-mails to her. The e-mails are verbatim (unless a typing error would otherwise have caused confusion). I have grouped the e-mails by the question(s) they are addressing. I have added my comments, either during or after a particular set of e-mails, in green.

The 'full e-mail discussion' occupies most of this document, but I have here included an edited version, revealing the 'highlights'. For these I have corrected typing mistakes, unlike in the 'full' version.

**FIRST QUESTION:** *If a patient has discussed CPR with his doctor, and the patient then says 'I'm forbidding any future CPR attempts', does the patient expect this order to be followed, or challenged ?*

Paul's answer: If I had a terminal condition and had a poor quality of life (as judged by me) then I would expect the Do Not Resuscitate directive to be followed..... From the doctor's perspective, I would want to be sure that the patient had a full understanding of the probable consequences and associated probabilities and that the patient had made a considered decision.

Some clinicians, and some guidance, dispute the above, claiming that an Advance Decision is legally binding, but a properly-discussed verbal refusal is not: those people have not read the MCA, the current Joint CPR Guidelines or thought properly about the question, so far as I can see !

SECOND QUESTION: *Pam's dad died in hospital last year, and he was going to die - the question was how much intervention would he receive. He was mentally capable, and in theory the process of Informed Consent/Considered Refusal should have taken place. IN THEORY the doctor should have explained the clinical outcomes which would follow the choice (which was the removal of a catheter).*

*So I asked Pam, when the doctor asked her dad, did the doctor explain the clinical factors to him ?*

Pam's answer: She did not tell my Father what the consequences of his response would be - this was a case of her manner indicating to him what she was asking.

ALL of the clinical guidance, explains that Informed Consent requires the INFORMATION TO BE PROVIDED !

As it happens, although Pam's dad was mentally capable, before asking her dad, the doctor asked Pam and her brother 'What do you think he would want ?'. But Pam's two aunts, who lived next-door to her dad (their brother) were not asked - I assume this is because Pam and her brother were the legal next-of-kin, BUT THE MCA DOES NOT SAY 'ask the next of kin', IT SAYS 'ASK THOSE WHO MIGHT KNOW THE ANSWER' !

THIRD QUESTION: *If a father is the patient, and is living at home with one family carer, his son, and the father raises the question of CPR one evening while the two are alone, and explains that he would no longer wish for it to be attempted (and why), and then says 'We'll sort this out when the GP visits tomorrow - but if I die before then, don't call 999, just let me die in peace', what should the son do, if his dad arrests before the conversation has been disseminated ?*

Paul's answer: Firstly, the son needs to be sure in his own mind that the father's decision is final and not just the result of going through a bad patch and therefore has a definite probability that it may change..... If the son decides that this is the father's final decision and the CPA happened before the meeting with the doctor, then I think if the son wants to follow the father's wishes then he adopts the "John Powell approach". (John Powell was a maintenance supervisor in his 70's who has a dicky heart. He has told his wife that if she ever comes home and finds him collapsed on the floor she is to immediately get back in the car and come back in two hours).

John Powell is quite correct - the only way a patient can be certain his wish to not be resuscitated is followed, is to tell his son to NOT CALL ANYONE. There is an issue here of the son must act on what he knows, not what the system knows (but the son must also consider what will happen, if he calls someone who does not know of the conversation): I am seriously 'at odds' with 'the system' over what should happen here, and what is reasonable behaviour for the Police in this scenario.

FOURTH QUESTION: *This was 'If your spouse were comatose, but potentially clinically recoverable, and the only way his/her likely wishes about CPR could be established was if the GP asked you 'Do you know what he/she would say', how should that 'work' ?*

Paul's answer: In my response to your "final" question I am assuming that the doctor in the scenario has had no direct contact with Pam (pre-coma) on CPR or any related beliefs.

I must admit that I am having some difficulty with the either/or nature of the question as the situation has two parties (the doctor and myself) with separate and distinct packages of information:

Only I (based on the aforementioned assumption) has knowledge of Pam's beliefs, views and opinions

The doctor has the knowledge of the potential scenarios and their related probabilities both for the CPR and for the larger "coma" issues

This is what sections 4(6) and 4(7) of the MCA seem to say – work out what the incapable patient would have said, by describing the clinical outcomes to 'those who are close to the patient' and asking them to supply the answer: again, what happens next, is where I disagree with 'the system' (although at the moment, it seems GPs simply do not ask the question).

Pam's answer: I've read the question. I don't like answering it without discussing with Paul - but I might do - we'll see what Paul says. First instincts might be relevant here since it will be spur of the moment things that would happen if a circumstance like this ever arose and my first instinct is that medical people would tell me everything there is to know and let me ask as many questions as I wanted to ask, then any decisions that were made would be made jointly through further conversations between medical staff, me and our children. Whew - it gets morbid very quickly.....and your mental state might be much improved if you'd move on from this morbid topic to brighter things.

Pam does not like this question, but she is wrong to say the question quickly gets morbid: it starts morbid, and the answer quickly gets complicated. There are lots of points which flow from that scenario, too lengthy to discuss in this summary. But Pam's instinct, was to discuss this 'among her family' – which is what the MCA logically suggests should be done. But, going back to my second question, when Pam's dad was dying in hospital, a doctor canvassed the views of Pam and her brother, but NOT those of her father's two sisters. Pam's views on that, are interesting:

My aunts were not involved in the decision. The doctor explained the options to John and I (leave the catheter in and he would live for longer - maybe weeks, maybe months she couldn't say; or remove the catheter and he would die sooner but still she couldn't say when - maybe after a few days maybe a few weeks - as it turned out it was only a little over a week). I was more confident in giving the doctor my opinion than John - that I felt he wouldn't want to spend whatever time was left hooked up to tubes. The doctor said that she now had to explain the situation to my father and find out what he wanted. She was very good and very sensitive and we all three walked back to my father's bed; she bent down low so she wasn't towering over him and just asked if he'd like his tubes removed. He said yes; she looked at John and me and said that was a pretty clear response.

*Secondly, and ignoring any considerations of 'sensibilities', who do you think was most likely to 'understand your dad's feelings' – your brother and you, or his sisters ?*

I'm biased - but I think I had the best understanding (even better than my brother although we were in agreement anyway). His sisters would have given a different response - but my feeling is that their response would have asked for what was best for them, rather than my father - i.e. keep him alive as long as possible to postpone their grief. And my father would have wanted not to hurt anyone's feelings, so if John and I hadn't been around to give our opinion then he would have gone along with his sister's wishes.

*Thanks Pam,*

*This is helpful - an aspect I'm very bothered about, along with people not actually being willing to talk about death, is that people have a (nasty and unhelpful) tendency to 'assume things about other people'.*

*You may be right about your sisters, and whether they would 'answer the wrong question'. But you had told me that your dad and his sisters were very close, and lived in the two attached halves of a semi-detached house: you have lived in Canada for 30 years, and unless your dad and John talked a lot, then why would it be a reasonable assumption that you and John (next of kin) would be more aware of your dad's opinion about 'dying' than his sisters would be ? And surely, won't it be true that 80 and 90 year olds have a much closer perspective on dying, than 40 and 50 year olds - because of its proximity ?*

Here are some more factors that come into play where my family is concerned:

1. My father and his sisters were / are non-practising but privately believers in God – so my feeling is that they didn't / don't want to make decisions for themselves or anyone else about death – they wanted / want to leave it in God's hands.
2. My opinion about how my aunts might feel is coloured by watching their behaviour when my mother died (only about 9 months prior to my father); they didn't hold my mother in much high regard and didn't really care whether she lived or died but they could see it was upsetting my father so they kept telling him that she was looking better and said "where there's life there's hope". He decided to listen to them which made my job of preparing him for the end pretty much hopeless.

The intention of the MCA is quite clearly to get the incapable patient's 'answer', and if her Dad was indeed religious, surely Pam's aunt's could equally well say 'Our brother and we are religious, and we all believe you are supposed to try and stay alive for as long as possible – Pam and her brother are not religious, and they are saying that because they don't like seeing their dad suffer'. I object to doctors being told they are 'judges' for this type of HONEST disagreement between relatives, in this type of situation - clinicians should stick to **purely clinical things** (the prediction of prognoses) and should **keep out of non-clinical areas**, such as making subjective judgements of the morality, and honesty, of relatives.

**FIFTH QUESTION:** *Clinicians have quite correctly noticed that if they believe that CPR could not work, telling a patient this might distress the patient. This is true, but whether it is sufficient grounds to not tell the patient, is much more complicated.*

*But my question was, whether or not the patient is told that CPR would not work, does a relative who is caring for that*

*patient, need to be told this ?*

Paul's answer: As a close relative actively involved with the patient (particularly if living with the patient) then the relative should be informed of the situation.

There are lots of reasons, why a relative needs to know that CPR would fail, if it has been decided it would fail: it is not sensible, psychologically, to leave a relative with the belief that a CPA 'might not definitely be the end' if it is known that CPR would not work (again, the precise reasons are too lengthy for this summary).

The full e-mail exchanges are now detailed, along with my analysis of why they are relevant to a discussion of clinical behaviour, as it happens at present, and to the law.

This exchange of e-mails with Pam, concerning the death of her father in hospital (England) during the summer of 2010, was designed to draw out 'what the doctor said, to whom'.

*Dear Paul and Pam,*

*I asked about this, very briefly, when you were over this side of the pond - I didn't really understand the answer, and I got the impression that was because you were unsure of the answer.*

*I would like an answer to this one, because there is increasing evidence of serious confusion (and contradictory behaviour) all over the place: I want to try and separate intellectual laxity, from moral difference.*

*As I understand it, Pam's dad, who was at the time speaking for himself, was receiving some type(s) of medical intervention, the withdrawal of which would inevitably lead to his death, and this treatment was withdrawn. I assume that Pam's brother, and Pam's dad's sisters, were also involved in conversations in the hospital.*

*Please tell me the answer to these questions - the answers are not 'what anyone else thought was going on', but specifically what you understood was going on:*

*Treating 'the withdrawal of the medical intervention (defined above)' as the decision which was made, was it your impression that this decision was made by the doctors, Pam's dad, or Pam's relatives ? Or by a combination ? Or were you left unclear about who was making the decision ?*

*If a combination, please explain which combination, and if it wasn't made clear to you, how the decision was made, please make that clear in your answer.*

*I feel it would be overly intrusive to ask Pam's aunts this question, but I would be interested to know what Pam's brother's answer would be (I am not asking you to ask him, that is up to you),*

*All the best, Yours Mike*

I am really clear on how the decision to remove my father's catheter (which lead to death because the poisons from his kidneys were no longer being drained) was made. My aunts were not involved in the decision. The doctor explained the options to John and I (leave the catheter in and he would live for longer - maybe weeks, maybe months she couldn't say; or remove the catheter and he would die sooner but still she couldn't say when - maybe after a few days maybe a few weeks - as it turned out it was only a little over a week). I was more confident in giving the doctor my opinion than John - that I felt he wouldn't want to spend whatever time was left hooked up to tubes. The doctor said that she now had to explain the situation to my father and find out what he wanted. She was very good and very sensitive and we all three walked back to my father's bed; she bent down low so she wasn't towering over him and just asked if he'd like his tubes removed. He said yes; she looked at John and me and said that was a pretty clear response. So I would say that she technically asked the patient - but found out from the next of kin how she should phrase the question she would ask the patient.

This is a complicated area with so many factors affecting how the decision is made and although the end for neither of my parents was "perfect" - the end is the end and there's no point in over-analysing how it happened.

Hope this helps,

Pam.

*Thanks Pam,*

*I'm still not entirely clear on this. I thought, your dad had originally told the doctors, he wanted the tubes removing ?*