Note: under ‘feedback’, paramedic no 1 wrote ‘I DO NOT WISH TO RECEIVE FEEDBACK, AND I HOPE AN AMBULANCE IS NEVER CALLED FOR ME OR MY FAMILY.’

FEEDBACK FOR YOU

If people are kind enough to complete the survey, then I will provide feedback of the results collected to any PCT which has arranged for at least one clinician to respond, or to any individual clinician who has responded, if you indicate that you wish this.

I would also be happy to receive any comments about this area from either PCTs or individuals, and anything along the lines of ‘those are good questions – but you could also have asked ‘X’, which has been troubling me/us’ in particular would be of interest to me.

Please indicate if you wish to receive feedback.

If you wish to receive feedback, do you just want the discussions groups’ ‘overall conclusions about the feedback’, or do you also want to receive the completed surveys themselves (**please note to anyone who is filling in the survey – this is NOT a ‘confidential’ survey, and responses will be distributed –** that does not mean ‘individuals’ names’, but it **does** mean ‘a paramedic from Durham said’ or whatever, and if you wish to retain anonymity, do not include any personal details which would identify you on the survey form) ?

Please supply the e-mail address you wish the feedback to be sent to:

If any individual is sufficiently interested in this area, or bothered by it, to wish to further discuss the existing ‘belief and behaviour sets’ with me, then feel free to e-mail me at:

mhsatstokelib@yahoo.co.uk

Please note that I e-mail from a public library, and my online time is quite limited – however, **I believe very strongly that this ‘area’ needs a lot of cleaning up**, so I will respond to any comments or points raised, even if not necessarily immediately.

The ‘What do the Words Mean ?’ Survey – must an Advance Decision include ‘circumstances’ ?

I asked by means of trawling Champions on the Dignity in Care website, what the wording in some recent guidance about Advance Decisions actually means – the guidance was for patients, and the issue was did it say that you must include circumstances on an ADRT ?

The latest guidance being published, does not actually challenge the idea that you can refuse an offered treatment ‘full stop’ – but it still isn’t clear enough, and it is obvious that at the moment, the majority of nurses think you must specify circumstances.

This should be much easier to explain – after all, the principle for an Advance Decision is pretty clearly that for those circumstances you have considered when you wrote the ADRT, you can refuse the treatment in all of the considered circumstances, or you can use one or more of those circumstances to qualify your refusal.

The above 'concept' stems from section 25(4)(b), although the way the Act is written it is linguistically challenging to use a circumstance to allow the treatment (it appears that linguistically, 'I refuse CPR unless my CPA appeared to be caused by anaphylaxis' can't be written – I think some 'pragmatism' must be applied to the Act).

The circumstances in section 25(4)(c) are those the patient might not have been aware of, when he wrote his refusal – obviously, they cannot include any circumstances relevant to section 25(4)(b).

The easy way to clear this up, would be to explain in guidance how to word a refusal which has no contingency on the prevailing circumstances, and to publish this along with 'clinicians will understand that your refusal did not depend on any qualifying circumstances, if you use this wording'.

Or, to publish in guidance that simply writing 'I refuse 'specified treatment'.' indicates that the circumstances are irrelevant – for example, that 'I refuse cardiopulmonary resuscitation.' means that section 25(4)(b) does not apply to the refusal.

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'.

THE QUESTION I SENT OUT TO ASSORTED DIGNITY IN CARE CHAMPIONS (this was the e-mail I used):

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.

Further Preliminary Comment: actually, those words are not entirely unambiguous, until you realise that they are inside a section about Advance Decisions – so any reader, presumably is making a refusal of treatment.

When you add that ‘on’, you would get this, which is much less ambiguous:

‘When you are refusing the specified treatment, sometimes you may want to refuse the treatment in some circumstances but not others. If so, you must specify all the circumstances in which you want to refuse this particular treatment.'

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

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

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***

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

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

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 your 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 circumtances'. 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!

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 XXXXXXX

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

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

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

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

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

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 identifed any variences.

Linda

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

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

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.

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

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.

Dear Mike,
I work as a qualified Nurse in the community setting, providing education and support to the generic workforce in order to help them provide better care to people approaching the end of their lives.
As a team, we also promote the use of the three National End of Life Tools, one of which is the Preferred Priorities for Care Document (PPC), which is an example of an advance care plan. This document is intended to be used to record a statement of wishes, rather than a legally binding advance directive, or refusal of a particular treatment, although these issues often arise as a result of

conversations around the PPC.

You asked for my personal understanding of the following statement:

'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.'

My understanding of this would be that you could decide to make an advance decision to refuse a specific treatment under any circumstances, in which case you would need to be very specific about which treatment you were refusing, but would not need to list all the circumstances in which this decision would apply, because you want it to apply in all circumstances.

On the other hand, you may decide to refuse a treatment, but only under certain circumstances, in which case you would need to list all the circumstances in which this decision would apply. Obviously there are particular rules relating to Advance Decisions to refuse a life sustaining treatment.

I hope that answers your question and good luck with your survey.

Warm regards

Helen

Dear Mike

Your email about End of Life guidance interested me as I am a live-in carer and my client of 20 months has just passed away.

I would interpret the Advanced Decision query as I refuse treatment X if .... is the situation.

This was a situation that my client, his family and myself were just involved with.

Very interesting and difficult topic and I am keen to read the publication.

Regards
Barbara

Hi Mike

My current role is Local Authority Commissioner, but I was formerly the MCA Coordinator.

If I was reading this as a lay person I would assume that I only needed to specify the circumstances if I wished to distinguish between different sets of circumstances. If I simply wished to refuse the treatment regardless of the circumstances, I would assume that I wouldn't need to specify them.

In other words my interpretation would be 'you have the 2 OPTIONS of EITHER simply saying 'I refuse treatment X', OR of saying 'I refuse treatment X if ..... is the situation'

However this may not be helpful to professionals who need to determine whether an ADRT is applicable, and it would certainly make the ADRT inapplicable if the person had not specified that they wished to refuse treatment, even if life at risk. It is therefore a badly worded piece of guidance!

Regards

Cate

Dear Mike,

I expect you can use either option you have proposed. Option 1 would be more imformative and not leave the final clarification to health professionals but the general public may not be aware of all the facts to make an informed decision when completing an this detail when completing an advanced directive.

Kind regard

Pauline

Registered Nurse

Critical Care Unit.

Dear Mike

I am an operating dept practitioner Registered with the HPC It reads to me that you would need to list all circumstances in which you want to refuse treatment.

Bob

Principal O.D.P. Main Theatre

Emergency Theatre coordinator

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yes, you must ALWAYS specify BOTH the treatment being refused, and also the circumstances in which your refusal is to apply – that is how I read it.

I am a commissioner of social care

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

This is a serious problem – the 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 ! Having explained the point, so far I have received no further reply from Sandra, or from her GP(s).

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-weighed 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 thought 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, <u>think</u> 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.

CLOSING COMMENTS

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/experiences' is not the name of a medical condition, but the combination of how his medical condition is experienced by him (in terms of pain and disabilities), 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.

The Survey about Consent for CPR

The suggestion that opting-in to CPR might make sense, was from a paper passed on to me by Iona, and Iona is President of the RCGP.

I have probably had all of the replies I will receive on this, and all are below along with some 'highlights & summary': my position is still that you can legally opt-out, but clinicians should have the discussions so that patients can exercise that right !

And although there are problems centred on the fact that it makes 'very little overall sense' to try and resuscitate very frail/ill end-of-life patients, whereas paramedics are by necessity forced to 'assume consent' for things such as traffic accidents, etc, the opt-in/opt-out thing is flawed as a suggestion in my view: all it does is 'move the problem' (it becomes 'how are the frail/dying defined ?').

There are many references to 'the discussions with patients and relatives about CPR' below, and as usual things split into 2 distinct camps:

1) Those people who see the problems non-discussion causes for patients and relatives, something which I consider to be extremely relevant for patients who are at home, and
2) Those clinicians who need to instigate CPR discussions with patients and relatives, who see the reactions (potentially distress or arguments) and are influenced by those reactions.

(This compilation was originally e-mailed to Iona and some others, so this was the 'covering letter' in the e-mail)

Iona ,

I have sent an e-mail to about 200 or so 'listed' email addresses for Dignity in Care Champions. About 70ish are 'non-deliverable', and so far these replies have come in, which I have copied below.

I also show, after the e-mail I sent out, the e-mail I then send to some of those people who are against 'opt-in'.