Please pass this to your AS's lead for End-of-Life involvement.

Dear Sir or Madam,

I am discussing aspects of EoL/CPR/VoD behaviour quite widely, and I have assembled a few sections from my discussion documents, which are most relevant to Ambulance Services.

I am mainly concerned with EoL (final year of life) patients who are in their own homes, and are mentally capable until they arrest.

I would be very interested in the views of your Ambulance Service, especially about:

1) Is the instruction 'I refuse cardiopulmonary resuscitation if my heart has stopped beating, irrespective of what caused the arrest' adequate as the wording on an ADRT ? Or does your region, believe that 'circumstances' (other than 'if I am in CPA') must be present on an ADRT ?

2) I would appreciate any comments about the suggestions I make on page 15 of this PDF (the page with the yellow border) – I am very keen for the statement I label as 1, to be introduced into medical notes.

3) On page 16 (green border) I discuss the difference between the outcomes of attempted CPR for witnessed and unobserved CPAs, and ('Grandfather' is a reference to something discussed in other parts of my writing) the logic is inescapably correct – at home, it must be true that if you are subject to attempted CPR after a CPA the start of which was not witnessed, that you are increasing your risk of being resuscitated 'with brain damage'. And patients are the people who decide which risks to accept, for medical treatments.

How would a person **in your region**, indicate that he was refusing attempted CPR unless the start of the CPA had been witnessed ?

I hope you are willing to contribute to this discussion, by answering those questions,

Best wishes, Mike Stone

PS Please do not pass the questions outside of your AS, for example to regional EoL leads for SHAs – they are already involved in this discussion 'directly', and no paramedic or nurse who is attending a patient in CPA, can contact a regional EoL Lead to ask for an opinion, anyway.

DNACPR Forms: a discussion of their current structure.

Although there are a variety of DNACPR Forms in use at the moment, they all seem to have a similar basic format, and all appear to me to have similar deficiencies and omissions. I am using the/a East Midlands Ambulance Service DNACPR Form here, for no reason in particular.

The objective of DNACPR Forms is clearly to prevent inappropriate attempted resuscitation – beyond that, they are legally complex items, and this complexity is not, in my opinion, properly reflected by the nature of contemporary DNACPR forms. Newcastle (**Newcastle Upon Tyne Hospitals NHS Foundation Trust**) has summed up part of the complexity, when it wrote this:

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders are advisory documents and clinical judgement always takes precedence. Valid and applicable written advanced decisions to refuse treatment (ADRT) are legally binding and an accompanying DNACPR would be similarly binding.

At present all DNACPR orders are Trust-specific and if a patient moves between Trusts the DNACPR order will automatically lapse and must be reviewed and re-instituted if appropriate each time a patient is admitted to the NUTH Trust. This includes the DNACPR policies of the Northumbria Ambulance services. Any existing policy from NUTH will automatically lapse when the patient is discharged from the Trust. ADRT orders remain active regardless of the patient's location and do not need re-signing, but associated DNACPR forms will need to be renewed for each admission.

Now, digging the relevant law out from those – and ignoring for the moment 'clinical judgement always takes precedence', which is disputable to say the least – we see:

written advanced decisions to refuse treatment (ADRT) are legally binding and an accompanying DNACPR would be similarly binding – an Advance Decision is followed on the grounds that it is a decision already-made by the patient, and unless something in sections 24 to 26 of the Mental Capacity Act legitimately allows the ADRT to be ignored, it must be followed if a clinician does not intend to be open to a charge of assault.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders are advisory documents – cannot therefore be true, for any DNACPR Form which is reflecting an ADRT: however, if the DNACPR Form is a record of the signatory's opinion 'that attempted CPR would fail for an existing clinical reason' then that is an opinion being expressed by the signatory. That is 'advisory', in as much as the reader might hold a different opinion about the likely outcome of a resuscitation attempt. And if the expert opinion is correct, any CPR attempt would fail – so, in the most real of senses, 'attempting or withholding CPR is not a meaningful decision'.

Section 2: Reason for DNACPR
(please tick those that apply):

Patient's condition indicates that CPR is unlikely to be successful because ..... ☐

.....

CPR is not in accord with a valid Advance Decision to Refuse Treatment ☐

Patient does not consent to CPR ☐

The above section is from the EMAS Form, and interestingly it has three reasons, none of which is 'Attempted CPR would not be in the patient's best interests'. Some DNACPR forms, probably the majority, present three slightly different reasons – this one is a WMAS Form:

Cardio Pulmonary Resuscitation (CPR) is not to be undertaken on this patient because:
(Please tick all relevant boxes)

Attempting CPR is unlikely to restart the patient's heart and breathing.		❑
The expected benefit of the treatment is outweighed by the burdens.		❑
Attempting resuscitation is against the competent patients expressed wishes.		❑
Discussion has taken place with:	The patient	❑
	The patients relative/significant other	❑

(Name _____)

The first reason, is a clinical opinion about the success of attempted CPR: interestingly, both use 'unlikely to be successful' as opposed to 'would fail to succeed'.

While 'CPR would fail' is conceptually clear, 'CPR would probably fail' appears to be all that can usually be said in all honesty – but the ethics and legality of using 'would probably fail' as a reason for withholding CPR, are much more challenging. Challenging to the point of 'extreme awkwardness as a legitimate justification'.

The third reason, 'the patient does not consent/has refused', is legally and conceptually much simpler, and wholly in line with normal legal and ethical principles:

Ms B v An NHS Hospital Trust.

Following an illness, Ms B became tetraplegic and reliant on an artificial ventilator. She asked that the ventilator that was keeping her alive be

switched off, and claimed that the continued provision of artificial ventilation against her wishes was an unlawful trespass.
The court was asked to decide whether Ms B had the capacity to make the decision about whether the ventilator should be removed. The Court held that Ms B did have capacity to refuse treatment and had therefore been treated unlawfully.
Where a patient has the capacity to make decisions about treatment, they have the right to refuse treatment – even when the consequences of such decisions could lead to their death. If a doctor feels unable to carry out the wishes of the patient, their duty is to find another doctor who will do so.

But this introduces the complication for CPR, that any patient who is in arrest will be unable to directly refuse CPR at the time paramedics or other clinicians arrive – and there is enormous muddle, about exactly how a patient exercises that right to refuse future CPR. There is a very serious confusion, about what is necessary for an ADRT refusing CPR to be valid: in particular, although it appears that 'I refuse CPR' should be perfectly adequate on an ADRT, many clinicians believe that you must specify 'circumstances' or else an ADRT isn't valid. That does not seem to be true, if you actually read the Mental Capacity Act itself.

I sent this question to a lot of Dignity in care Champions, and the answers are not consistent:

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.

For example, answers from apparently similarly-qualified senior nurses included these:

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

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

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 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

There is also a belief, presumably because of section 25(6)(a) of the MCA, that a verbal refusal of future CPR is less 'legally binding' than a written ADRT refusing CPR.

This cannot be true, partly on simple logical grounds, but also because of sections 24(2), 24(3) and 24(4) of the MCA:

(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.
(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.
(4) A withdrawal (including a partial withdrawal) need not be in writing.

When you think about those three sections, then it is easy to construct this thought experiment, which proves that what matters is your understanding of the patient's refusal of CPR, not whether it has been written down:

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 who is still mentally capable, and able to talk to you, after he created his ADRT.

I will show the EMAS Form on the next two pages, because I wish to move on to a discussion of the potential involvement of Welfare Attorneys (or, to be precise, of a single welfare attorney – there are potential complications if several welfare attorneys are involved, and they are so intricate I will not be discussing them here).

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)

NHS

This document applies to CPR decisions exclusively and must be used in accordance with local resuscitation policy
The person must be appropriately assessed to ensure they receive all other appropriate care.
Form developed by the NHS in the East Midlands.

Section 1: DNACPR Category. Delete A or B to identify which applies

A. For a person at the end of life. DNACPR applies across all care settings. No review necessary.

OR

B. DNACPR decision for periodic review during admission/change in place of care or on discharge. State the first review date in section 5. (Should option A then become applicable a new form must be completed)

ORIGINATED BY (Optional):
e.g. Doctor in training (PRINT) ..... Signature .....
GMC No ..... Date .....

ORIGINATED BY AND/OR ENDORSED BY (Obligatory):
Responsible clinician/nurse (PRINT) ..... Signature .....
Designation ..... Date ..... Organisation .....
If applicable GMC No .....

Addressograph Label

Patient name:

Address:

Date of birth:

NHS No:

Telephone No:

Location of patient when DNACPR form completed

Section 2: Reason for DNACPR (please tick those that apply):

Patient's condition indicates that CPR is unlikely to be successful because ..... ☐
.....

CPR is not in accord with a valid Advance Decision to Refuse Treatment ☐

Patient does not consent to CPR ☐

Section 3: Communication with patient and carer/relevant others (Tick all that apply):

It is good practice to explain why CPR will not be attempted, *unless doing so would cause unnecessary distress.*

This **has** been discussed with the patient ☐
This **has** been discussed with ..... *(name)* on ☐
date..... Relationship to patient .....
contact details .....
This **has not** been discussed with the patient because it would cause unnecessary distress or they lack capacity (delete as applicable) ☐
This **has not** been discussed with any relevant other e.g. family/carer because ..... ☐

Fully record details of all CPR discussions in the patient's notes

Section 4: Complete section below only for patients who lack capacity

Does the patient have a legally appointed and registered welfare attorney?	**Yes** ☐	**No** ☐
Have they been consulted and discussion documented? (if yes to question above)	**Yes** ☐	**No** ☐
If no attorney or others to contribute to Best Interests decision, has an IMCA been contacted?	**Yes** ☐	**No** ☐
Confirm that decision made following the best interest process of Mental Capacity Act	**Yes** ☐	**No** ☐

Fully record details in the patient's notes

Section 5: DNACPR review. Please complete if indicated by B in section 1 on the date stated below

Date of review	Reviewer's name (capitals)	Reviewer's signature	Next review due	Designation & contact details	Location of patient

Section 6: IF DNACPR CANCELLED – CLEARLY CROSS THROUGH DOCUMENT WITH 2 LINES NAME, DATE AND SIGN with a reason for cancellation

Section 7: Organisational communication

The clinical team must ensure the DNACPR paperwork accompanies the patient on transfers and that professional colleagues receiving the patient are aware of the decision

Patient's GP ..... Telephone No .....
Address .....

Professional contact out of hours Name .....
Telephone No ..... Address .....

Has person in charge of patient's daily care (e.g. GP, Community Nurse or Care Home) been informed Yes No

A copy should be kept in the notes exclusively for audit purposes and marked as COPY.

When at home or place of care/residence ensure the original form is accessible to visiting health or social care professionals. E.g. place the form at front of community notes or message in a bottle. Ensure it is ready should an emergency/urgent call be made

Does the patient have a preferred place of care at the end of life? Yes No

If yes, where? Tick Box - Home ☐ Hospital ☐ Care Home ☐ Hospice ☐ Other (please state) .....

MAKING A DO NOT ATTEMPT CARDIO-PULMONARY RESUCITATION (DNACPR) DECISION FRAMEWORK

NHS

Healthcare Professional Completing This DNACPR Form

This will vary according to circumstances and local arrangements. In general this should be the most senior healthcare professional immediately available. Whether in the acute hospitals or the community setting, this will be a senior experienced, doctor or nurse, who has undertaken appropriate training and education in communication and resuscitation decision making, according to the requirements of their employer. This decision should be shared with the Multi-disciplinary Team at the next opportunity.

Is cardiac or respiratory arrest a clear possibility in the circumstances of the patient?

NO

It may not be possible to make an advance CPR decision if you cannot anticipate what you would write on the death certificate if the patient arrested. If you cannot anticipate an arrest you cannot consent for or obtain refusal of CPR since any arrest will be unexpected.

Consequences:

- The patient should be given opportunities to receive information or an explanation about any aspect of their treatment. If the individual wishes, this may include information about CPR treatment and its likely success in different circumstances.
- Continue to communicate progress to the patient (and to the partner/family if the patient agrees). Continue to elicit the concerns of the patient, partner or family.
- Review regularly to check if circumstances have changed.

In the event of an unexpected arrest: carry out CPR treatment if there is a reasonable possibility of success (if in doubt, start CPR and call for help).

YES

Is there a realistic chance that CPR could be successful?

NO

It is likely that the patient is going to die naturally because of an irreversible condition. Where a decision not to attempt CPR is made on these clear medical grounds, it is not appropriate to ask the patient's wishes about CPR (or those close to the patient where the patient lacks capacity), but careful consideration should be given to whether to inform the patient of the decision.

Consequences:

- Document the fact that CPR treatment will not benefit the patient, e.g. *The clinical team is as certain as it can be that CPR treatment cannot benefit the patient in the event of a cardiac or respiratory arrest due to advanced cancer, so DNACPR (Do Not Attempt CPR).*
- Continue to communicate progress to the patient (and to the partner/family if the patient agrees or if the patient lacks capacity). This explanation may include information as to why CPR treatment is not an option (as described above) and might include; *Unfortunately CPR will not work in your circumstances and we need to ensure all others know about this decision to ensure your comfort at the end of your life, if that is OK?*
- Continue to elicit the concerns of the patient, partner and family.
- Review regularly to check if circumstances have changed.
- To ensure a comfortable and natural death effective supportive care should be in place, with access if necessary to specialist palliative care, and with support for the family and partner.
- If a second opinion is requested, this request should be respected, whenever possible.

In the event of expected death, AND (Allow Natural Dying) with effective supportive and palliative care.

YES

Does the patient lack capacity?

YES

In adults: is there is an Advance Decision to Refuse Treatment (ADRT) refusing CPR, or signed valid Welfare Attorney (LPA) order (with accompanying 3rd party certificate) with the authority to decide on serious medical conditions - the most recent order takes precedence. Otherwise make a decision in the patient's best interests, following the processes stipulated by law, e.g. the Mental Capacity Act.

NO

Are the potential risks and burdens of CPR considered greater than the likely benefits of CPR?

YES

When there is only a very small chance of success and there are questions whether the burdens outweigh the benefits of attempting CPR: the involvement of the patient (or, if the patient lacks capacity, an ADRT, Lasting Power or Attorney as above or those contributing to Best Interests) in making the decision is crucial. When patients have mental capacity their own view should be the primary guide to decision-making. In cases of doubt or disagreement, a second opinion should be requested.

NO

CPR should be attempted

v49 Adapted from: 2007 BMA/RC/RCN Joint Statement on CPR; Regnard C & Randall F. Clinical Medicine, 2005; 5: 354-60; and A Guide to Symptom Relief in Palliative Care, 6th ed Radcliffe medical Press, 2010.

Agreed by the NHS in the East Midlands

Section 4 of the EMAS Form, on page 9 of this PDF, has a tick-box for 'confirm that this decision follows the MCA's best interests test', to be completed if the patient lacks capacity.

It is far from clear – in fact, the opposite is pretty clear – that you can necessarily perform a section 4 best interests test other than when you are at the point of applying the treatment: I can see how 'the system' **would like** it to be possible to arrive at a best interests decision in advance, but that is a huge simplification of the test. If it were possible to be certain that future CPR would fail for a pre-existing clinical reason, then that can be determined and recorded in advance of the subsequent CPA – **but that isn't, actually, a section 4 best interests decision**. Because section 4(6) is irrelevant, if CPR would definitely fail. And it is far from clear, that 'CPR would definitely fail' can be stated in any but the most extreme cases: it apparently cannot be predicted, merely because a patient is on an end-of-life pathway.

The recent NCEPOD 'Time to Intervene ?', investigated attempted CPR in hospitals, and it noted that the outcomes of attempted resuscitation were much worse if the start of the arrest was unobserved. The GMC's guidance for EoL, is very clear that while mentally capable, a patient is informed of the clinical outcomes of offered treatments, and of no treatment, and then the patient decides whether to accept or refuse, also considering his/her wider-life factors. And creating an ADRT, or verbally refusing future CPR, can only be done while the patient is mentally capable, and not during an arrest.

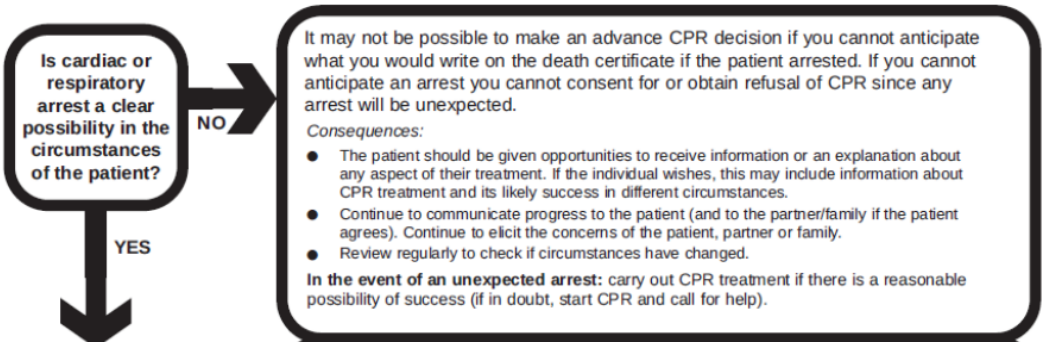
So, presumably a patient is perfectly entitled to consider the difference in likely outcomes, of attempted CPR for observed and unobserved CPAs – this must be true, on purely logical grounds, because the patient must be allowed to consider everything he himself considers relevant. And the difference in outcome, is possibly even more marked for a patient who is at home, when he presumably has a greater chance of being found in arrest, as opposed to being observed arresting. So whether by means of an ADRT's conditionality, or by communicating this to a GP/relative/nurse, a patient could say:

'I refuse CPR, unless someone believes he or she observed the start of my CPA'

Although section 4 of the EMAS form requires the combination of mental incapacity prior to the CPA and also that instruction, such a combination is in principle possible: and it makes it impossible to confirm before the CPA, that DNACPR would be in the patients best interests, unless you ignore what he has said.

But written as the conditionality for an ADRT, when in principle it would need to be written as 'I refuse CPR if the onset of my CPA was unobserved' (section 25(4)(b) is a 'pain to work with' !), then it does mean that logically a paramedic would need to ask 'Did you call us because you think you saw your dad arresting, or because you found him apparently not breathing ?' and the paramedic would be forced to believe the answer: that ADRT requires an

observer for the onset of the CPA, in order for it to be invalid, and clearly a paramedic called to a patient already in arrest, could not have observed the onset of the CPA.



This, from the second page of the EMAS DNACPR Form, simply isn't true. To start with, for my 'problem' of elderly patients who are within EoL Care, a CPA is always a 'clear possibility' because even apparently healthy elderly people, 'suddenly die' much more often than younger adults.

And a patient is at liberty to refuse any treatment which he has considered might potentially be offered: he can also decide for himself, whether or not the events which lead to the treatment being 'offered' are relevant. The significant factor, is that the patient has himself considered possible future events (see section 25(c) of the MCA for example) – how probable an event is, and what factors are relevant, are things the patient would take into account.

For example, some people simply refuse blood transfusions – it doesn't matter, to some people, why the transfusion is considered necessary if life is to saved, these people have an absolute 'no blood transfusion' stance.

Similarly, if a patient is suffering intolerable distress, he might refuse future CPR whatever caused a future CPA: and, if a person is both rational and very concerned about 'successful resuscitation but with a brain damaged by oxygen starvation', the person could make the previously-discussed 'I refuse CPR unless the CPA was observed' decision about CPR.

It is perfectly possible, to refuse CPR for an unexpected CPA: this is very inconvenient for post-mortem protocol design, when patients are at home, especially if one does not intend to ignore the human rights of live-with relatives. But inconvenient, is not the test: compliant with the law, and logically absurd, are the right tests.

And these forms ignore the possibility that the person who calls a paramedic, might be a Welfare Attorney empowered to make decisions about life-sustaining treatment. Even if the patient was mentally capable until the arrest occurred, once the patient is in arrest, the MCA is pretty clear that the Welfare Attorney can refuse CPR on behalf of the incapable patient: in fact, calling a

paramedic, to check that the patient is in arrest and will die if untreated, and then telling the paramedic to let the patient die having established that the patient is in arrest, is entirely in line with correct MCA best interests decision making, if you are a Welfare Attorney and you have been told by the patient to forbid CPR 'whatever caused me to arrest'.

Attempting CPR after a Welfare Attorney has said 'I do not consider attempted CPR to be in his best interests' is in my opinion legally dangerous, because the Act seems to require that a challenge to the authority of a Welfare Attorney must be made in advance of the treatment being performed – the wording used in the relevant section of the MCA is:

> '*while a decision as respects any relevant issue is sought from the court*'.

It isn't entirely clear, that attempting CPR and afterwards applying to the court is consistent with 'while' – and, logically, the Welfare Attorney was given the power to make those decisions by the patient, **so paramedics or other clinicians should not be going against a Welfare Attorney without very good reason.**

But This Much is Clear

1) Calling 999, or not calling 999, **is** a decision.

2) Thinking about a section 4 best interests decision, involves a mental analysis of a lot of information, unless there isn't really a best interests decision being made (i.e. unless you are simply not attempting CPR, because the patient has forbidden CPR and he has directly explained this to you personally). That is too much information, for a 999 paramedic to deal with and analyse, during a call to an arrest: **whatever a 999 paramedic can do, he or she cannot 'make a section 4 best interests decision, and justifiably use section 4(9) as a legal defence'.**

3) **But at the same time, patients must have some sort of legal expectation, that if they have the legal right to refuse offered treatments, including CPR, somehow 'the system' must facilitate this.**

4) The main problem to sorting all of this out, in terms of something that would 'work logically', is that currently 'the system' is resistant to properly accepting that except for lack of clinical expertise, live-with relatives must be treated as full members of the patient's Care Team. **And clinicians are totally hung-up, on 'patient confidentiality', even when the patient isn't bothered by 'confidentiality' but is bothered that his instructions are being ignored.** Nobody would expect hospital care to work properly without the clinicians who are going of-duty, passing on relevant new information to the clinicians who are coming on-duty – at home, the relatives who live-with a patient, tend to be the closest to a 24/7 presence there is. Logically, if you

keep live-with relatives up-to-date, they can up-date anybody else – and, also logically, a patient would often be able to tell a live-with relative something, before he could tell anyone else, so often a live-with relative will necessarily be more up-to-date than dropping-in clinicians.

If you make it ‘as mandatory as possible’ that GP, live-with relatives and district nurses all talk to each other as openly as possible, then you will with luck have a situation where **all of that small group of people** ‘are up to speed with what the patient wants’ – **then tell everyone else, to be guided by anyone within that group**.

As I have asked the RCGP: what is the difference between a patient saying to his GP ‘I’ve had enough of this – if I arrest from now on, I forbid CPR’ and the patient saying to a relative who he is living with ‘I’ve had enough of this – if you think I have stopped breathing, then don’t call anyone and let me die in peace’ ?

Where exactly, unless you bring in the rather obnoxious and very offensive ‘we don’t trust relatives’ line, is the difference, ethically and morally ?

Suggestions to Improve End-of-Life Care and Verification of Death behaviour for Patients in Their Own Homes

Instead of only dealing with 'expected death', and consequently allowing the 999 services to behave too 'aggressively' for 'somewhat earlier EoL deaths' if the GP cannot attend, introduce an earlier statement within medical notes from the GP, where the GP 'would **not** be **surprised** by a death'. The 'new' statement, is number 1, below.

1) 'Any future natural death of this patient must not be regarded as sudden or unexpected, but I would need to examine the body post-mortem before deciding whether or not I would certify the death'

2) 'If this patient subsequently has a death which does not appear to have been unnatural, in the opinion of a suitably-trained clinician, then I will certify that death even if circumstances prevent me from attending the death in person'

At home, often the only person the patient is physically able to talk to, is a relative - and communication chains can be almost totally unstructured, and chaotic. So it isn't reasonable to believe that you can properly explain to people who have not been directly involved with the patient the overall situation, by things such as EPaCCS: and it isn't reasonable, to behave as if patients and relatives do not talk to each other, when nobody else is present.

So:

THROW AWAY the concept that the 'primary unit' is the professional multi-disciplinary team, and

REPLACE IT WITH the idea that unless it is known that this is not the case, it should be assumed that in an **overall sense** the GP, anyone who shares a home with the patient, and those district nurses who are regularly attending, are ALL 'inside the loop and informed about the situation' - the 'Primary Team' becomes 'GP, Live-with relatives and regular DNs'.

Table 4.3 shows that one percent of the patients in this study (7/578), who underwent CPR, were on an end of life care pathway. It is not clear if the care pathways did not include DNACPR direction or if this was due to lack of documentation or handover of information. However it is difficult to conceive a situation where attempted CPR in the setting of an end of life care pathway can be clinically appropriate or in the best interests of the patient.

Six out of the seven patients had return of circulation and survived the cardiac arrest. However all seven patients died before hospital discharge.

From 'Time to Intervene ?'

Table 5.3 shows the responsible clinicians' reasons for making a DNACPR decision.
The answers to this question could be multiple. However, in all but four cases the absence of medical benefit (unlikely to survive) was the given as a reason. There were also concerns by these clinicians about quality of life but it appeared that these were secondary concerns compared to likelihood of survival.

From 'Time to Intervene ?'

Table 6.7 Arrest was witnessed assessed against patient outcome

Witnessed	Patient survived to discharge		
	Yes	No	Subtotal
Yes	69	261	330
No	11	165	176
Subtotal	**80**	**426**	**506**
Not answered	5	41	46
Total	**85**	**467**	**552**

From 'Time to Intervene ?'

It was either the former chairman or the former president of the RC(UK) who told me during a phone call, that 'doctors can tell if CPR would definitely fail'. Well, if 6 out of 7 patients who were on an end-of-life care pathway were 'successfully' resuscitated, that is reasonably clear evidence that he is wrong - only 'in extremis' is an 'unsuccessful outcome' for attempted CPR '100% certain'.

Table 6.7 from 'Time to Intervene ?' makes it clear that within hospitals, a successful outcome of attempted CPR is much less likely if the CPA is not witnessed. This must logically be true for patients who are at home as well, and it must therefore be a legitimate factor in the decision-making of someone such as 'Grandfather'. So logically Grandfather **must** be able to issue an instruction (whether or not by means of an ADRT) to the effect that:

'I am only willing to allow attempted resuscitation, if the start of my CPA was witnessed'

At home, this would require that the 999 Services accepted the word of live-with relatives, as to whether the relative believed he had witnessed the actual arrest - this is nothing to do with 'who the decision-maker is' (it is clearly Grandfather, here) and everything to do with 'ARE RELATIVES FULL MEMBERS OF THE CARE TEAM ?'.

‘Blending’ and the MCA Best Interests Test

What I mean by blending, is the logical re-interpretation of the section 4 best interests test as the situation moves across this transition:

A mentally-capable patient who can consider his own treatments and issue refusals ... to ... a mentally-incapable patient with no rational method of ‘establishing his ‘likely position” about an offered treatment.

When considering CPR, section 4(5) of the MCA tells us that a DNACPR decision must not involve ‘motivation to bring about the person’s death’ and the Code says that ‘DNACPR out of compassion’ is not allowable. That is very restrictive, and very awkward, for any situation when a DNACPR decision would be meaningful (i.e. for any DNACPR when CPR might be successful).

But we do know that patients have the right to refuse any offered treatment, including CPR, so at the left-hand end of the arrow/transition path shown below, the justification for DNACPR can legally be ‘the patient had considered and refused CPR in advance of the CPA’.

If that had not happened, but everyone who ‘knew the patient well enough to act as a ‘proxy mind’ {thinking ‘for’ the incapable patient} agreed that the patient would have refused CPR, then it looks as if ‘there was an informed consensus opinion that the patient would have refused CPR’ is also okay - because the justification is still reverting, but by ‘indirect discovery’, ‘this particular patient would have refused’.

But at the red end of that arrow, when nobody can ‘individualise’ the patient, how can CPR be legitimately withheld ? Prima facie, it would appear that unless it is known that the vast majority of patients in similar clinical situations would refuse CPR, it looks very tricky: even then, it isn’t obvious how ‘patients make decisions by considering clinical outcomes within their own wider-life situations and beliefs’ can be made to fit.

It seems to me, that it is legally necessary to keep to the green end of that arrow - by getting DNACPR decisions direct from the patient if at all possible, or by getting a consensus ‘family decision’ failing that: otherwise, DNACPR Instructions when CPR might be possible, look very dubious, legally.

> From ‘Time to Intervene ?’ by NCEPOD, page 63:
>
> In some circumstances DNACPR decisions may involve quality of life considerations. There are circumstances where CPR may work and the patient may survive but concerns exist about the burden of disease and quality of life after CPR. In these circumstances it is very important to enter into sensitive discussions with patients and/or next of kin, to understand their views and to allow an agreed course of action to be followed.

The patient is mentally capable and can consider possible future treatments	The patient is mentally-incapable but there are people who can act as ‘proxies’ in providing the patient’s likely views	There is no logical way of establishing the likely views of this patient if he is regarded as an individual

So the situation to be considered, is as shown below.

Before a CPA occurs	During a CPA	If CPR has been attempted 'successfully'
The patient has a clinical condition, knowledge of which is used in treating him. He also 'feels the consequences' of that condition - you don't 'feel heart-failure': you feel difficulty in breathing, etc. And he **is influenced by those 'clinical feelings',** when he '**forms his opinion about his wider existence**' - other, non-clinical factors, affect the patient's **quality of life.**	This is the period after the patient has entered CPA, but while resuscitation could perhaps still be successful.	If CPR had been attempted, and the heart and breathing restored, the patient is now in this, new, clinical situation. At best, this will 'feel' as it was before his CPA: at worst, it will 'feel' a lot less good, to the patient. **The justification for a DNACPR, is that the patient would prefer to be dead, rather than 'feeling, or experiencing, his potential life from this time onwards'**.

The important considerations here, are mainly:

1 There is a difference between a patient's clinical condition, and how he experiences that condition. If a patient visits his GP and says 'I've got severe back pain - can you get rid of it, please ?' the GP needs to work out what is causing the pain: is it pulled muscles, a damaged spine, a knee injury causing bad posture, etc. But the patient **feels, or experiences,** the pain - he does not 'feel' the clinical condition.

This distinction is important for CPR, because the patient's decision is based on **quality of life considerations - 'what he feels'**.

2 The question is 'would the patient accept or reject the way he would 'feel' about his remaining life, after resuscitation, if CPR were successfully attempted ?'.

It is **definitely not** 'do I know what caused the CPA ?' (unless, weirdly, **the patient has issued an instruction that he should only be 'left to die' if a particular clinical cause of a CPA is observable**: why anyone would do that, baffles me).

3 A patient might, and this is much more likely, think to himself 'if resuscitation returned me to a relatively undamaged condition, I would like it to be tried - but not if after CPR, I would feel worse than I do now'. So the patient might **specify a clinical restriction** in his CPR decision: for example, and I assume he would ask his doctor, what is possible here, a patient might say 'could you try CPR if my peanut allergy causes a CPA, but **not** if it looks as if I had a stroke, and that caused the CPA' (if he had both a peanut allergy, and a medical condition known to generate blood clots).

4 So the CPR decision is related to the patient's potential experience of life **after** the CPA.

5 But, curiously, the concept of 'expected and sudden death' is related to the Coroner's specifications for Verification and Certification of Death - so the concepts of expected and sudden death, are related to the patient's clinical condition **before his CPA, but this is only to be considered AFTER the patient's death**.

By contrast, **any DNACPR decision, is related to the patient's PREDICTED clinical condition AFTER the CPA on the assumption that CPR is attempted during the CPA, but this is considered BEFORE** (and possibly, but not necessarily, during) **his CPA**.

A DNACPR Decision, is NOT the same thing as 'an Expected Death'

Author Mike Stone E-mail: mhsatstokelib@yahoo.co.uk