

I am going to make some comments on a 'high-level' piece about the principles of Advance Care Planning (ACP) which has just been published:

'The Universal Principles for Advance Care Planning has been jointly published by a coalition of the partners listed above, in response to the Care Quality Commission report 'Protect, Connect, Respect – decisions about living and dying well' (2021).'

It is Gateway ref: B0845 and we are informed that the most-recent version will be at:

www.england.nhs.uk/eolc/resources/

There is a lot to like about this publication, but I also have some significant issues with it – one of my issues, being that a concern about DNACPR decision-making has, in this piece, become rather 'submerged' within wider Advance Care Planning. There are issues with cardiopulmonary resuscitation (CPR) which definitely need to be addressed separately from ACP more generally.

I will start by commenting on a form of wording – here on page 4 – which has always annoyed me:

'All discussion with the person should convey a sense of ownership of the process.'

As a patient, what am I being told? **Are you telling me that the patient does own the ACP process** – or are you telling me that the patient does NOT own the ACP process, but should be misled into believing that he/she does own the process? Because if the second – well, being led to believe that you 'own something', if it subsequently it turns out that you do not own it, is unacceptable 'duplicity' of the worst kind in the healthcare context.

My first point which is about the 'overall coherence of' the guidance, is that we are told that ACP involves a patient who can at the time make his or her own decisions (a capacitous patient) – on page 6:

'ACP is a **voluntary process** of person-centred discussion between an individual and their care providers about their preferences and priorities for their **future care**, **while they have the mental capacity** for meaningful conversation about these.'

This leaves an enormous hole: what about 'planning ahead' which does not take place until the patient has lost mental capacity? Wales has tackled this problem, by introducing and using the concept of FUTURE CARE PLANNING (FCP) which covers planning whether or not the patient is capacitous – a paper by Taubert and Bounds explains FCP:

<https://spcare.bmj.com/content/bmjspcare/early/2022/01/31/bmjspcare-2021-003498.full.pdf>

I BELIEVE THAT ENGLAND SHOULD PROMPTLY MOVE TO FUTURE CARE PLANNING INSTEAD OF ADVANCE CARE PLANNING.

The guidance is clear about what it considers to be an ACP discussion – we are told on page 6:

‘Advance Care Planning discussions can occur over time, between people and those important to them, such as family, friends, people in their communities as well as with health and care professionals.’

So, it seems that a relevant conversation between a person/patient and a relative or friend is definitely part of ACP – which must presumably be true even if no clinicians are involved. It must be true even if no professionals are aware of the discussion – therefore the ‘discussions within the family’ mentioned by a patient’s wife in a Journal of Medical Ethics paper I contributed to, do count as ‘ACP’. A link to the JME paper can be found in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

I am less happy with this, on page 9:

‘The person agrees the outcomes of their advance care planning conversation through a shared decision making process in partnership with relevant professionals.’

The ‘outcome of’ a conversation – an ACP conversation in this instance – is ideally mutually-improved understanding: information and ‘views’ will have been exchanged. Unfortunately, it is possible – and definitely does happen during ‘healthcare conversations’ – that misunderstanding will occur: each of the parties involved, believes that the conversation ‘meant a different thing’.

I note that suddenly, we have had this ‘outcome of’ term introduced, and the family, friends, etc have disappeared: this ‘outcome of ACP conversations’ seems to only involve the patient and ‘relevant professionals’. WHY? And, it is worth digging-into the phrase ‘shared decision making process’ in that sentence above as well: almost none of the documentation which the professionals create, contains ‘decisions’.

From now onwards, I hope it will become clear, why I wrote earlier that CPR involves issues which mean it needs to be specifically-addressed, separately from FCP/ACP more generally.

When a patient has thought about 'ACP' and is talking to 'relevant professionals' (usually doctors and nurses in the context of healthcare) the patient will want to know which treatments would be offered. Then the patient might express a view on those interventions – would she want them, would she refuse them, is she uncertain and therefore doesn't want to 'plan ahead' beyond saying 'I would want to decide at the time'. Many of these 'future options' which would be available to a capacitous patient (or would be considered during best-interests decision making) are delivered ONLY BY doctors and nurses: surgery, skilled nursing-care, etc. That is NOT TRUE for CPR – CPR is taught as first-aid, so many friends, relatives and family-carers can attempt CPR. A person could have discussed the future with his family, and indicated that he would always want CPR to be attempted: a relative could agree to always attempt CPR, and/or to always phone 999 and try to get paramedics to attempt CPR. So, a 'patient' and a family-carer capable of performing CPR, could 'agree the outcomes of their advance care planning conversation through a shared decision making process' WITHOUT ANY PROFESSIONALS BEING INVOLVED. It is worth pointing out, that DNACPR is not 'a treatment' – DNACPR is the withholding of a treatment: as such, a relative who could not perform CPR, could 'agree an outcome' with the person (who I often describe as 'the loved-one') of 'trying to prevent CPR from being attempted' if the person made it clear 'I would NEVER want CPR if my heart had stopped beating'.

Page 6 of the guidance, tells us the following:

'The outputs of these discussions may include one or more of the following:

- An **advance statement** – of wishes, preferences and priorities, and may include nomination of a named spokesperson
- An **Advance Decision to Refuse Treatment (ADRT)**
- Nomination of a **Lasting Power of Attorney (LPA)** for health and welfare who is legally empowered to make decisions up to, or including, life sustaining treatment on behalf of the person if they do not have mental capacity at the time, depending on the level of authority granted by the person.
- **Context-specific treatment recommendations** such as emergency care and treatment plans, treatment escalation plans, cardiopulmonary resuscitation decisions, etc.'

Of that list, a patient can entirely independently of any other person, do the first (create 'an advance statement'). The second is something which a person can do independently of any other person, except for the involvement of a witness to the person's signature on a written document (obviously a verbal ADRT, does require a listener!). The third involves the person and his/her chosen Attorneys. Only the fourth, necessarily involves doctors, nurses, etc. And if 'planning ahead' is made when an end-of-life patient is at home, and other people are sharing that home, then the crucial first-step of any planning is between the patient and the people living with him [who in that situation will often be 'family-carers'].

Things such as the ReSPECT form, 'DNACPR forms' (by which I mean forms signed only by clinicians – so I am not including ADRTs refusing CPR) and other documents which are referred to in the fourth item on that list, typically provide information. Sometimes the information is presented as 'a recommendation' but it is almost never 'a decision': the document would be 'an instruction' if its purpose were to convey 'a decision'. An ADRT refusing CPR can reasonably be described as an instruction, and it is defined as being a decision.

It turns out – and this causes endless issues with how various documents are described in guidance, etc – that it isn't really possible [except for a written ADRT] to record a DNACPR decision in advance of a cardiopulmonary arrest, unless a court ruling is involved.

On page 12 of the guidance, there is a list under the title 'Therefore we should see that.....' and three of the things in the list are:

'The **outcomes are based on the person's preferences and priorities** about their future care, **informed by the relevant professionals' knowledge and experience** of the condition(s) and its likely future course.

Health and care workers involved in the conversation recognise that **the person with mental capacity has a right to make decisions to refuse treatment** that health and care workers do not agree with or may think unwise. In the same way, if a decision thought 'unwise' by others is the basis of a valid and applicable ADRT made while the person had capacity and which they have not withdrawn, this is legally binding.

Everybody involved in ACP understands that **clinicians are not legally bound to offer treatments which they judge would not be of benefit**, including cardiopulmonary resuscitation, chemotherapy, oxygen, intravenous antibiotics, etc. but they must discuss and explain this to the person or, if the person lacks capacity, with those important to them. In the infrequent instances where this isn't discussed, the reason needs to be clearly documented. These must be individualised judgements, and not blanket decisions based on age, disability, care setting or background. A second opinion should be offered in the event of a disagreement.'

Traditionally, the third of those has usually turned into what amounts to 'if clinicians believe that CPR would be futile then CPR should not be attempted'. The meaning of 'futile' has always been 'a bit 'slippery'' but I think by now – 2022 – we should be writing 'if CPR could not restart the heart and breathing' instead of 'if CPR would be futile'. Alex Ruck-Keene, a barrister involved with the MCA, wrote in our JME paper:

'If there is a situation in which CPR would simply not work to restart the heart or breathing, then the paramedics would be under no duty to attempt it, as there is no duty to seek to carry out a futile procedure.'

Ben Troke, a solicitor with expertise in the MCA, writes in his recent book 'A Practical Guide to the Law of Medical Treatment Decisions' (on page 133):

'I tend to think of 'futile' as meaning there's ***no benefit*** ...'

If we accept my position that in 2022 we should be using 'if CPR definitely could not restart the heart and breathing then not offering CPR would be justifiable', then it turns out that IN ADVANCE OF a cardiopulmonary arrest most honest doctors would admit they cannot meet that test. Almost always, a doctor can only say 'I believe that a future attempt at CPR would be ALMOST CERTAIN to not restart this patient's heart'. AT THE TIME OF an arrest, it would sometimes be possible to decide with certainty that CPR couldn't work: decapitation or a massive chest injury come to mind.

It might be possible, rarely, to say with great confidence that future CPR could not work – I suppose if it were certain that a patient had extremely-fragile ribs, it could be asserted that chest-compressions would not work [but perhaps electrical methods might work].

It isn't obvious, how the patient's 'wishes and preferences' can be at the heart of the decision about CPR, if the clinicians refuse to offer CPR 'because we think it would fail'. And – if it would fail as the clinicians predicted, then whether or not CPR were attempted, the patient would be dead.

We can also have a peculiar situation, when the patient is at home. It is perfectly possible to conceive of a situation when a GP might be convinced that CPR couldn't

be successful, but the patient was still mobile. In that situation the GP might 'make the patient DNACPR' even if the patient wanted CPR to be attempted. If the patient arrested at home, 999 paramedics would probably not attempt CPR. But, if this patient collapsed and arrested in the street, walking to a local shop, it is very likely that any attending paramedics would attempt CPR.

I believe the time has come, for the NHS to change its position to 'CPR should be attempted, if while capacitous [and informed of the likely outcomes of CPR] the patient had asked for CPR to be attempted'. And I sincerely hope, that people who are in arrest, do not feel CPR while it is being attempted.

I outlined why I believe the change is necessary a few years ago:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-I-believe-that-CPR-should-be-attempted-if-a-mentally-capable-patient-had-asked-for-CPR-to-be-attempted/1051/>

If we do change, then it must be for everyone: on grounds of 'fairness and consistency' if CPR is to be offered when the clinicians predict it would not work, then that offer must be made to all capacitous patients.

As I wrote in the Journal of Medical Ethics paper, decent end-of-life care requires everyone supporting the patient to be working together:

'When my mother died about 10 years ago, I might have found myself as a relative trying to prevent a 999 paramedic from attempting CPR, but in the event, I found myself being 'confronted by' 999 personnel who seemed unable to understand why when my mum died at the end of a peaceful 4-day terminal coma, I had NOT felt the need 'to phone someone immediately'. This prompted me to embark on an investigation into end-of-life (EoL) guidance, protocols, mindsets and laws, which revealed to me a situation I can, at best, describe as urgently requiring improvement, especially but not exclusively for EoL-at-home, and which, in complex and confusing situations, protects professionals at the expense of damaging relatives and, sometimes, even patients.

From my family carer perspective, this situation has to change. And, the direction of change must be one which improves the support given to patients, by promoting integration between everyone, lay and professional, involved in supporting patients. This 'model' requires 'us and us' as opposed to 'us and them': it emphasises

teamwork between family carers and the clinicians who are in regular and ongoing contact with the patient, and it replaces 'multidisciplinary team thinking', with genuine professional-lay integration.

Anyone can listen to a patient—provided you are present to listen: if only a relative is present, only the relative can listen. Often it will require a clinician, such as a 999 paramedic, to confirm that a patient is in cardiopulmonary arrest, but the family carer who called 999, is the person most likely to know if the patient would have wanted CPR. Put simply, the clinicians are the experts in the clinical aspects, and the family and friends are the experts in 'the patient as an individual'.

We need to all work together. We need more stress on involvement, and less stress on who is a professional and who is a relative or family-carer. We need more stress on the understanding within the group of people who are in ongoing-contact-with the patient, and less stress on documents which attempt to impart SOME OF that understanding to 'external' clinicians.

Written by Mike Stone, March 2022

Twitter @MikeStone2_EoL

ADDED EXTRAS IN THIS PDF VERSION

I will start, by mentioning that a current DNACPR Policy for Wales, looks as if it has adopted my position on CPR which has been predicted as almost certain to fail. In a section headed 'A clear request for CPR – when CPR is not clinically in the patient's best-interest' and which starts with

'A patient might insist that CPR is provided - even when (for clear clinical reasons) the clinical team feel it to be an intervention which cannot provide clinical benefit. When a patient requests CPR following a discussion that clearly outlines very significant risks and burdens, the senior clinician must record fully the patient's expressed wishes alongside their own clinical views.'

we can read an 'Audit point' which includes:

‘It should be considered an “exceptional clinical event” to pursue a DNACPR position that is contrary to the expressed wishes of the patient.’

However, it would be fair to say that the Policy is not entirely internally-consistent on this – sections of the policy seem to imply that if CPR is predicted to fail then it need not be offered. And these two sentences from the Policy, describe two different situations ‘in MCA terms’:

‘A patient might insist that CPR is provided - even when (for clear clinical reasons) the clinical team feel it to be an intervention which cannot provide clinical benefit. When a patient requests CPR following a discussion that clearly outlines very significant risks and burdens, the senior clinician must record fully the patient’s expressed wishes alongside their own clinical views.’

If an intervention ‘cannot provide clinical benefit’ - the first sentence – then it would not normally be on offer as a treatment (however, as I have already argued, I think for CPR an exception should be made to that rule/principle). But the second sentence, which describes a situation when the attempting of CPR involves ‘very significant risks and burdens’, is different. **If we start by assuming that CPR is being offered**, then whether it is attempted should be a decision made by a capacitous patient, or if the patient isn’t capacitous a proper best-interests process should be followed. If we don’t start by assuming CPR is being offered, then we need to be clear about why not: it isn’t legitimate for the doctors to say ‘CPR wouldn’t be in the patient’s [MCA] best interests’ because, among other things, best-interests determinations are made for interventions which **are being offered**. For many interventions, the NHS does not offer them because the cost of the intervention is considered too great to justify it being offered – perfectly legitimate, provided the position is applied consistently and individual patients are not discriminated against. But, as I have pointed out, the default position is very-much that CPR is almost always ‘on offer’. So, in general, ‘the NHS’ [rather than individual doctors] applies ‘clinical views’ as to the likely outcome of certain interventions, and if the outcome would be less than a certain ‘cost-benefit cut-off point’ then the intervention will not be offered to anyone. That second sentence, is ‘muddling’ whether CPR is being offered or not, and who would be deciding whether CPR would be attempted – and the ‘muddle’ is removed, if you analyse the situation correctly.

If anyone wants to read my thinking about the Mental Capacity Act, as it would apply to CPR, and also some pieces about CPR/DNACPR, then I suggest these pieces on Dignity in Care:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-we-need-a-different-way-of-explaining-and-teaching-the-Mental-Capacity-Act-MCA/1114/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/435/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/DNACPR-at-Home-and-a-Twitter-thread-what-is-the-legal-situation-for-relatives/1110/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/>

I wrote a BMJ rapid response a few years ago, which called for 'shared documentation' instead of clinically-generated documents [such as the ReSPECT form] which exclude the signatures of non-clinicians:

<http://www.bmj.com/content/352/bmj.i26/rr-5>

In this series of responses, Jay Ilangaratne has provided links to the Tracey and Winspear rulings, and Richard Venn has commented that 'Ongoing dialogue around 'Emergency Care and Treatment Plan' is a start in the right direction'.

The Resuscitation Council UK is currently hosting a consultation about a proposed 'universal' ECTP (ref 1). I dislike many features of the 'prototype' ECTP, for example that a patient can only be either 'FOR CPR' or 'NOT FOR CPR': it is very clear, from considerations of consent law or from the Mental Capacity Act's description of Advance Decisions, that a patient's refusal or acceptance of CPR [or a CPR best-interests decision] could be conditional - it can be 'CPR should not be attempted unless 'specified conditionality' (although it is 'technically' very difficult to write an ADRT refusing CPR with that structure - you can apparently {see MCA 25(4)(b)} only write 'I refuse CPR if 'specified conditionality''). It is equally clear that if there is a suitably-empowered welfare attorney, best-interests CPR decision-making falls to the attorney [and not to anybody else {MCA 6(6) and 6(7), and MCA Code of

Practice 7.29]] if CPR might be clinically successful (and I do not consider 'we will not offer CPR, because in our expert opinion CPR could not be successful in restarting the heart' as being a 'best-interests decision': it doesn't seem to be a decision at all, if the prediction is correct, because the outcome is death with or without CPR). The ECTP prototype also mentions shared decision making, which I greatly dislike as a phrase (ref 2).

The recent ruling by Mr Justice MacDonald (see ref 3) has made it clear that mentally-capable patients make their own decisions, which are not then to be questioned by others, and I have pointed out above that sometimes it is legally clear that a welfare attorney [or, but never for CPR, a court deputy] is the decision maker. The Winspear ruling starts its point 4 with 'Although the precise terms of that conversation are a matter of dispute,' and exactly who said what during Tracey, is very uncertain indeed. The ECTP prototype does mention conversations between clinicians, patients and relatives - but it does not suggest that such records of conversations, should be 'signed off' by 'all sides': the ECTP wants only clinicians to sign. Similarly, the ECTP does not seem to want attorneys and deputies to sign to confirm their decisions - again, it wants the clinicians to do the 'signing off'.

This is both legally dubious - people should sign for whatever they are responsible for, so a clinician signs for a clinical prediction, a welfare attorney signs to 'authenticate' his/her own best interests decision, etc - and anachronistic. This type of 'clinical control' of 'patient records' reinforces inappropriate distinctions between clinicians and involved laymen, it potentially introduces 'bias', and it definitely does not promote the necessary cooperation and integration between the clinicians, family, friends, and if they are present attorneys and deputies, which decent 'joined-up' care requires.

Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients.

The complexity of best-interests decision-making, and my mother's death (see ref 4), convince me that we should be pushing for patient-expressed decisions made in advance: so it is Advance Decisions which need to be promoted. But there seems to be an agenda to encourage patients to create 'written advance statements', which - unlike a written advance decision - cannot 'just be followed in an emergency'. In contrast to this push to promote the essentially 'very challenging in application' 'written advance statement', nobody seems to be trying to address the problem I mentioned in reference 5 of a patient at home expressing a decision to only a family carer.

I am not reluctant to state, and the perceptive reader might have discerned this, that I am very annoyed by this situation.

Ref 1 <https://www.resus.org.uk/consultations/emergency-care-and-treatment-plan/>

Ref 2 <http://www.bmj.com/content/349/bmj.g4855/rr/761712>

Ref 3 <http://www.bmj.com/content/351/bmj.h6575/rr-0>

Ref 4 http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=814&forumID=45

Ref 5 <http://www.bmj.com/content/350/bmj.h2877/rr>

I will stress, that it isn't the usefulness of 'planning ahead' which I object to – my objections are to 'clinical control of the documentation of that planning ahead'. As I wrote in that BMJ rapid response:

Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients.

I will also point out, that I am very suspicious [based on my own limited experience in 2008] about the understanding of EoL-at-Home within the police. I am not persuaded that the average police officer understands the complexity of the situation when patients are dying at home, with the extremely complex issues around both communication and 'who can legitimately make which decisions'. By excluding the signatures of family-carers [and patients] from 'NHS documentation' that gives the impression 'that the doctor [or sometimes the nurse] makes the decisions' - it simply isn't true, and family-carers **are not** 'mere passive observers'.