‘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’.

If I get more replies, I will collate them and send them to you. I am also now including a brief ‘what people said’ section, next.

I cannot see how ‘opt-in’ can possibly work – the point is, if CPR might be refused by patients, there must be an obligation to raise the issue with the patient (or, for mentally incapable patients, with ‘the nearest and dearest/proxy minds’).

Best wishes, Mike

WHAT PEOPLE SAID – summary

Against Opt-In (5): Revd Barry B, Avi, Alan L, Elaine G, Jayne M (also stressed the need for the discussion).

For Opt-In (3): Alicia W, Alison (but she wants patients to have more choice), Lesley M.

Supportive of ‘having the discussion’ as opposed to either opt-out or opt-in (4): Amanda F, Eleri, Lesley, Janet.

Judith G gave a much more complex answer, which was in essence that people are not talking enough about ‘dying’.

Madeleine P gave a much more complex answer, which also mentioned that the actual discussions are problematic from her position (consultant in eldercare in a district general hospital): compare that with Alan L who said ‘However I have generally found that it is very difficult for Doctors to have this discussion and they tend to obscure the information with medical jargon, talk around the subject ,and often in such a short timescale that it often leaves the patient wondering exactly what the purpose of the discussion actually was.’

Jane A gave a more complex answer which began with ‘I have very strong views on the need to discuss resus status with patients as part of their admission. I have been witness to so many problems stemming from lack of clarity over resuscitation status over the years.’

Eleri also started with 'Having worked on a care of the elderly ward as a ward sister for a few years. We had an excellent consultant and he would discuss the
option of CPR on every admission with the pt'

Judith G's follow up e-mail also included :

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

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

THE E-MAIL I SENT OUT TO PEOPLE:

Dear ,

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

‘The default position for most medical interventions is that patients have to opt in by giving informed consent for the procedure. Why should this not be the position for CPR? Those in previously good health and who therefore have the best chance of survival after CPR would be likely to opt in without hesitation but those already in poor health would have to be offered a realistic assessment of their prospects if they needed resuscitation. Dementia, dependent status, metastatic cancer and a serum creatinine raised above 133umol/L all predict failure to survive until hospital discharge. Doctors are well used to seeking informed consent and outlining possible adverse effects, whereas the processes of discussing opting out through DNAR orders appear much more difficult for patients, doctors and relatives alike. In a recent article, Mallery and colleagues (J Palliat Care 2011; 27: 12-19) report a qualitative study of how hospital physicians approach resuscitation planning with families when older patients already have limited life expectancy and a considerable burden of existing illness. They found that while the physicians were good at exploring the relatives' goals and values, they did much less well at providing explicit information about the expected outcomes either of CPR or indeed of the preexisting illnesses. Their conclusion is that a vague notion of patient autonomy is being allowed to trump the duty to provide the information necessary to support valid decison-making.’

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

Regards, Mike Stone

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

AN E-MAIL I SENT TO SOME OF THE PEOPLE WHO RESPONDED

Thank you ,

That is exactly my own position - the imperative is to discuss CPR whenever a CPA is likely, or a refusal of future CPR would seem possible (for example a paralysed ex-rugby player).

I cannot see how 'opting in' to CPR could work, for the same reasons as you. And if you had opt-in, then with no proof of anything else, paramedics would have to leave accident victims to die if they arrested – which looks very unreasonable, and psychologically impossible, to me.

The problem, is that clinicians do not like discussing 'dying', because of the problems of doing that,

Best wishes, Mike Stone

PS   Do you want to see the answers from other people, as I will be collating the responses ?

REPLIES RECEIVED:

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

Dear Mike

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

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

Kind Regards

Revd Barry B

Dear Mike

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

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

Regards
Avi

@xxxxxxxcarehome.net

Good Afternoon Mike,

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

Best Regards

Alicia W
Branch Manager
xxxxxxxx Homecare Ltd

Hello

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

Regards

Mandy

Amanda F
National Training & Development Manager

Hi Mike

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

Shouldn't the default position be to retain human life and only make the decision not to do CPR after informed discussions with the person /and their relatives or Health and Welfare Lasting power of Attorneys if applicable . In my experience some patients do welcome the choice to decide following discussion with a doctor for a DNAR , they view their general quality of life as so poor its is a realtively easy choice for them . However I have generally found that it is very difficult for Doctors to have this discussion and they tend to obscure the information with medical jargon, talk around the subject ,and often in such a short timescale that it often leaves the patient wondering exactly what the purpose of the discussion actually was , It is only after, perhaps with the support of another professional , trusted nurse etc that they actually come to terms with the questions / discussion / prognosis etc. Just because it is difficult for doctors to summarize a persons prognosis / condition and effect of the conditions on their daily life and ask a persons opinion on DNAR doesn't mean that it should be changed.

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

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

Regards alan

Alan L

Hello
Having worked on a care of the elderly ward as a ward sister for a few years. We had an excellent consultant and he would discuss the option of CPR on every admission with the pt- if the patient was found not to have mental capacity or able to make the decision he would ensure an mdt with involvement of the relatives was always done. This always worked on our ward- (except a few occasions where there were different circumstances with relatives-)
I feel the decision should still be an patient + mdt decision and wherever possible to involve the relatives (at the pt agreement).
I feel that sometimes in particular in a larger acute hospital the decisions are often made not to attempt cpr without a full explanation of the potential outcome/ prognosis post cpr.
Hope this makes sense,
Eleri

Mike

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

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

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

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

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

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

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

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

Kind regards,

Jayne

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

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

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

Lesley

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

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

Best wishes
Janet

____-

Hello Mike, I am an RGN with over 33 years experience behind me. The last 5 years have been spent working in a mental health capacity for younger adults, so the DNR issue rarely occurs. However, I do think the opting in idea is a good one, as so many older people live healthier and more fulfilled lives. The problem is that cardiac arrest for the elderly rarely just happens, and if they survive the ordeal, they may be left with permanent damage which reduces their quality of life. The whole idea of giving people more choice, information and autonomy over their right to survive, has to be a good one. We have all been to so many cardiac arrests, when the wishes of the person suffering are the last thing to be considered. I find this debate very interesting.
Regards, Alison.

____

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

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

A) Because she had reached then end of her life and
B) she had Dementia and under the strategy she would not be considered and for us rightly so.

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

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

More of a problem is the collapse in the street and a first aider that then "has a go" and creates a problem for acute hospital staff.

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

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

Regards
Judith

Judith G MSc RGN

CSP Manager

Dear Mike

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

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

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

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

Regards

Madeleine P

Jane A
Patient Advice & Liaison Manager
Bereavement Manager
Prior to this worked as RN on CCU and A/E

I have very strong views on the need to discuss resus status with patients as part of their admission.
I have been witness to so many problems stemming from lack of clarity over resuscitation status over the years.

On the surface Opt in sounds great. As a nurse I got so upset and frustrated at the amount of patients being inappropriately

resuscitated; prolonging a painful death and what I thought lacked
dignity in death.
I would always try and coordinate Drs to speak with families and
patients (if able) about the resus status. Some Doctors are better
than others at communication over this issue. A decision can often
depend on the way people are guided and counselled over this matter.
Some families think CPR will work a miracle and always bring their
loved ones back to a healthy life- which sadly is not the case. It
is a difficult subject to speak about.

PROS
1. It would raise awareness over all and help in many circumstances
to allow patients to die with dignity and families to be more
informed.
2. It would aid better communication overall between patients,
families and team (encourage discussion of a plan.)
3. Would help stop some patients being inappropriately resuscitated.

CONS
1. Deciding what stage to do this at? Situations often too complex/
not always appropriate on admission as status not yet determined;
may lead to increase legal issues.
2. An opt in system would definitely add to the work load of staff -
generating more discussions with patients and families where
otherwise would not have the issue raised (this can be a pro as well)
3. It would be challenging too if a 'healthy'/younger patient (where
previously assumed to have been resuscitated) has opted out and then
staff are in a situation in which they have to leave someone
possibly to die without intervention.
4. patients not understanding the difference between CPR and
resuscitation; down to Drs to communicate (can be a pro?) i.e.
giving them every chance but stopping at CPR if its not appropriate.

I think there is a good argument for trying this out and seeing
where it leads and evaluating how it works.

Kind Regards,

Jane

Jane A
Patient Advice & Liaison Manager
Bereavement Manager
XXXX Area Health Trust

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

Sandie P

Hi

I support this - job title and details below

L

Lesley M
Assistant Director of Nursing

XXXXXXXXXX University Hospitals NHS Trust
Trust Headquarters_____

INTERESTING FOLLOW UP EMAILS

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

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

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

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

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

Open discussion is the key
Regards
Judith

Judith G MSc RGN CSP Manager
St John Ambulance

Hi Mike,

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

I may have responded to the issue prematurely from a personal viewpoint but even after considering more objectively I am still concerned about the implications.

Basically I think we have relied on the virtues of practitioners involved in the past, where patients who are clearly dying have not been actively resuscitated as their death is expected and it would be unkind and fruitless to attempt CPR. Communication between the patient, relatives and professionals involved has supported planning and eased decisions for patients to die without unnecessary interventions. We as an organisation didn't have a DNAR policy so have relied on MDT decisions (involving the patient/relatives) regarding resuscitation.

The thought of patients automatically being not for active resuscitation unless they specifically indicate the desire to be resuscitated is concerning as it appears to be withholding treatment rather than making an individual patient decision on whether it is the best option or not. What is needed is something better than we have now – i.e. better communication, better documentation, better planning, rather than a 'cover-all' plan to not resuscitate unless you ask us to do so.

I have come across a number of elderly patients who have diagnoses where in the event of a cardiac arrest they would probably not be successfully resuscitated. However they are relatively active and involved in family life so unless they deteriorated to the point where death seemed to be predicted I think to choose not to resuscitate them would be unkind (for want of a better word). Patients should be the ones who make the decision in all eventualities and using advance care planning, which is becoming more available gives them the opportunity to do this.

When patients have lost capacity I accept that an opt-in scenario may be appropriate but when do we judge someone as being 'frail elderly' and would you allow your relative to be admitted to a nursing home whose philosophy is 'we do not actively resuscitate any of our residents unless they specifically indicate that is what they want to happen'? I'm not sure I would – I guess it would depend on how 'sick' my relative was and whether I was expecting them to die soon or not.

The legality of DNAR orders is a difficult one; our organisation is undertaking the difficult task of initiating a policy at the moment – long overdue I might add. However, I would rather go down this route than an opt-in, opt-out approach.

I hope I have expanded enough, I am confusing the personal and professional I know but I find it's difficult to separate the two when it comes to end of life decisions.

Kind regards,

Jayne

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