

Added Note: this survey was performed in 2012 and the results can also be downloaded from

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/What-do-these-words-mean-/648/>

as an RTF file.

I was reminded of my survey, by a tweet from a doctor:

<https://twitter.com/DrDavidWarriner/status/1095050450926297089>

What follows, is the survey as I posted it back in 2012, but here as a PDF.

I have been discussing certain End-of-Life issues with various people and NHS bodies for a couple of years, with a particular emphasis on patients who are within their own homes, and how relatives who live with those patients fit in to the system.

In response to an e-mail I sent to the Royal College of GPs, late last year I received a reply from its President about the issues(s) I had raised in my e-mail, and she included the text of a recent paper she had published which discussed opting-in to resuscitation as an alternative to the current opting-out situation.

I sent the e-mail shown next, to about 200 Dignity Champions, and all of the replies which I received are shown below – the general reaction of people who read such collations is ‘interesting’, and Dignity in Care is one of the few ways to obtain opinions from a diverse categories of people, who often do not come together and directly discuss clinical, and related, issues.

I have placed this on the Dignity site, partly because I am sending out another set of questions, and I hope that by including a reference to this collation, it will encourage a greater response rate to my new questions – unless it is possible to find out what different groups of people believe is correct (GPs, district nurses, patients, relatives, paramedics, etc), it isn’t at all clear how the behaviour of professionals can be aligned and made consistent, **so that from the position of a relative who is living with an EoL patient the professionals seem to all be trying to do the same thing:** which from the position of a relative, will normally be ‘doing what the patient would have wanted’,

Best wishes, Mike Stone

PS

There is an interesting and predictable difference of perspective, in these replies.

The people who would need to actually ask a patient if he would wish to refuse CPR, are sensitive to the awkward reactions or even confrontations which asking the question sometimes causes – but the people who deal with relatives after deaths, or who see the

confusion which can arise if the wishes of patients about resuscitation were not discovered in advance of an arrest, are much more likely to stress that patients must be asked the question.

My own position, is that the great advantage of asking the question, is that simply following a patient's own order that CPR must no longer be attempted, hugely relieves the 'burden' from everyone else, relatives and clinicians alike – it is **very** difficult and complicated if resuscitation might be clinically possible when a patient arrests, but the patient's own position is unknown !

THIS IS THE EMAIL I SENT OUT TO DIGNITY CHAMPIONS:

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 pre-existing illnesses. Their conclusion is that a vague notion of patient autonomy is being allowed to trump the duty to provide the information necessary to support valid decision-making.'

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

Regards, Mike Stone

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

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

@xxxxxxcarehome.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
xxxxxxx 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 relatively easy choice for them . However I have generally found that it is very difficult for Doctors to have this discussion and they tend to obscure the information with medical jargon, talk around the subject ,and often in such a short timescale that it often leaves the patient wondering exactly what the purpose of the discussion actually was , It is only after, perhaps with the support of another professional , trusted nurse etc that they actually come to terms with the questions / discussion / prognosis etc. Just because it is difficult for doctors to summarize a persons prognosis / condition and effect of the conditions on their daily life and ask a persons opinion on DNAR doesn't mean that it should be changed.

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

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

that I have worked with have not promoted this or even been aware of this

Regards alan

Alan L

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

St John Ambulance.

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

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

INTERESTING FOLLOW UP EMAILS (the replies above were initial responses to my original e-mail, but the 2 below were e-mails which arrived after a little further discussion of the issue):

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