Resuscitation Decisions in the Nursing Home.

These notes are not intended as an algorithm to lead one to the correct conclusion. There are no correct conclusions in an infinitely variable number of circumstances. They are I hope a fairly succinct statement of the issues which may prompt appropriate decision making. The opinions and indeed precedents are not necessarily definitive, merely indicative.

Discussion about resuscitation decisions is a fairly narrow field and refers to action following a sudden collapse. It should not be conflated with the deterioration at the natural end of life - Allow Natural Death (AND). Existing protocols almost invariably talk in terms of an anticipated collapse which can be discussed with the patient, with clinicians, with next of kin or significant others. This is not sufficient guidance for the care home environment.

1 Protocols for Treatment

There are many different protocols for initiating or withholding resuscitation, but they all seem to stop short of what would be appropriate in a care home. The holy grail would seem to be a system to which all parties can turn for guidance, which is robust enough to withstand a panicky locum or paramedic team at 3.00 am, which can distinguish ethically between a chest infection and end stage pulmonary disease, which is sensitive enough to discuss with patients and responsive to their changing wishes and also their changing health, which gives value to the feelings of family without overruling those of the patient - especially tricky, again, in cases of mental impairment.

The decision whether or not to resuscitate is at root an ethical one, not a medical one. Ethical issues do not have right answers, only right questions. Do Not Resuscitate or DNR decisions should rightly be described as DNAR - Do Not Attempt Resuscitation. There is no guarantee of the success implicit in the former acronym. Sixty per cent of all resuscitations are successful, and up to half of those will be well enough to return home. The discharge rate reduces to 1% in non-witnessed arrests. Whither then the quality of life of the resuscitee?

Guidance from the joint statement by the BMA, RCN and Resuscitation Council notes that the way decisions are made in A&E departments is not the same as in nursing homes for older people. The ethical difference is not defined. What of the older person admitted from a nursing home to A&E in response to a panic call in the small hours? On which side do the criteria lie?

Without the protective framework of the hospital or other medical supervision, it becomes difficult for the autonomous nurse, being often the sole clinician on duty, to reach a decision on intervention. Most nursing home policies - if you can call them that - of flying by the seat of the pants and ringing 999 if in doubt, are unsatisfactory for patients, families and indeed staff and do not address anybody's needs or wishes.

Resuscitation decisions are not entirely coterminous with decisions to treat; to
withhold or withdraw treatment. Although ethically the decision to treat a chest infection and decision to undertake full blown CPR may be on the same continuum, a distinction can be drawn. Somewhere across that continuum a line must be drawn saying "thus far and no further". Treatment beyond this point is not appropriate. How though to decide where to draw that line?

Regnard & Hockley (2004) list what is and what is not resuscitation; most interventions are comfort measures and only cardiac massage and CPR are truly resuscitation measures. They do make a point that "an advanced decision can only be made if the circumstances of the arrest can be anticipated". This point may affect or be affected by the provisions of the Mental Capacity Act (see below), in ways yet to be tested. The Act gives more robust validity to advance directives which have been carried out in the prescribed manner. They could still be overruled by a subsequent appointment of Lasting Power of Attorney. Importantly, they may also not apply if it can be considered that the circumstances may not have been foreseen by the patient.

2 Anticipatory or Advanced Decisions and Directives

Resuscitation policies generally focus around the issue of anticipation. If the cardiac arrest or its probability can be anticipated and discussed with the patient, then advance decisions may well be valid. This judgement reduces the cohort of patients who should not be resuscitated, by their own decision, to those with known and unstable heart disease. It follows that all other patients, who collapse in whatever circumstances, should receive the benefit of attempted resuscitation, although Regnard & Hockley (op cit) point out that at the end of irreversible terminal disease CPR treatment will not succeed and is not an option. It is unrealistic and potentially cruel to suggest it as such. They also make the very telling observation that CPR is generally offered "by default", i.e. if no alternate directive exists, and that this is very suspect ethically as no other treatments are offered on this basis.

This at least gives some guidance for the nurse. It is not unreasonable to include all the disease processes of older age in this categorisation although caution must be used. It can be argued (as I have myself) that no 90 year old of my experience has ever recovered from being 90. This is not a sustainable argument for resuscitation however, as old age and frailty are not terminal diseases as such. Whether or not therefore to resuscitate is based on other factors. Could it be based on a subjective assessment of the patient's "quality of life"? Should it?

3 The Surprise Question

In continually focussing on whether or not a catastrophic event can be anticipated, protocols thereby imply an exclusivity. The counter argument would be what has come to be known as the Surprise Question. Although expressed as guidance for clinicians it could be turned around to be guidance for the patient:

"Quality of life improvement teams in the United States have found that comprehensive end of life services are best triggered by the recognition that the patient is 'sick enough that dying this year would not be a surprise'. If programmes for end of life care targeted those who 'reasonably might die', instead of focussing on
a prognosis of less than six months, many more patients and their carers would benefit from proactive care." (Murray et al 2002)

This statement has been rewritten as the question "would it be a surprise if this person were to die in the next 12 months?" In other words, if it would not be a surprise that this person were to die within the next 12 months (through illness or process which is not susceptible to curative treatment), it is reasonable to deliver the same kind of service as to one who is certain to die within that time frame.

In reversing the emphasis, one can easily see that a patient might reasonably expect or anticipate "not to be here this time next year" and plan accordingly, with our help, for what happens in a crisis. A formal system such as the Gold Standard Framework includes a specific question about resuscitation wishes. Patients almost invariably welcome questions on the subject.

4 Parameters to Bear in Mind

The main issues confronting the nurse would seem to be:

i capacity of the patient to make decisions

i consent of the patient

ii the expectation and rights of the patient (to receive the "best" care)

iii existing quality of life of the patient

iv duty of the nurse

v capability of the nurse

vi likely success of the treatment (and resultant quality of life)

I do not suggest that the likelihood of success or quality of life should be deciding factors, being the most subjective of the criteria. They can and will colour the decision, rightly or wrongly. In making the decision the nurse will have to consider the weighting of all these issues.

Opinions differ as to what the clinical responsibility is. Positively withdrawing life-support - an act to end life - is normally unlawful, but initiating procedures to save life is a different matter. The NMC code of professional conduct states that as a nurse "you are personally accountable for your practice ... [and]...answerable for your actions and omissions regardless of advice or directions from another professional" (my italics). The point is also made in the rubric that you should obtain consent to treat patients, which is not possible following collapse. The nurse is therefore in a position where (s)he alone can decide what is in the patient's best interest.

Charles Foster, a barrister, argues (2003) that a doctor can choose not to treat. That "... might get him into trouble with his employers or the GMC; it would not get him into trouble with the law of tort". There is nothing intrinsically illegal about deciding not to initiate resuscitation. Whether a nurse would feel comfortable with that decision is another matter. There is an instance of a nurse who made exactly that decision being reported for abuse, but the worth of a nurse does not lie merely in avoiding litigation.
Consent to Treatment

The best defence for giving or withholding treatment of any kind is the patient's known and documented wishes. Where a patient has been asked beforehand what their preferences are, and it is documented that they do not wish to be resuscitated, it is reasonable to withhold treatment. Any other course of action could be construed as assault. Consent to treatment cannot be merely compliant and non-dissenting, it must be voluntary and consenting. Is it then reasonable to initiate the "default treatment" without having checked first?

I would argue that the circumstances of the arrest or collapse do not dictate the response. The patients themselves in their lucid moments dictate the response. Though there is no direct judicial authority for an advance directive, it "may be binding on the practitioner when it expresses a refusal of treatment that the patient has anticipated". The nurse should not initiate treatment to which (s)he knows the patient would have objected had they had the opportunity.

Cognitive Impairment and the Mental Capacity Act 2005

The Mental Capacity Act lays out a set of principles to follow:

- The individual is presumed to have capacity.
- The individual is not by default unable to make a decision.
- The individual is not incapable just because their decision appears unsound.
- Those acting on behalf of the individual must act in their best interest.

The Act does protect clinicians making decisions in the patient's best interest if they have taken reasonable steps to establish capacity or lack of it, and to decide what the best interest of the patient would be. It also establishes a Lasting Power of Attorney (replacing the Enduring Power of Attorney) who can make decisions not only on financial but healthcare matters as well. In theory the Lasting Power of Attorney can refuse life sustaining treatment for the patient. It has of course yet to be tested against the nurse's duty to act "regardless of advice or directions from another professional" (supra).

The questions that the Act requires us to ask include whether or not the person will regain mental capacity, what their past wishes may have been, and the views of any appropriate person (e.g. close family).

Best Interest, Benefit & Quality of Life

I conclude that best interest is the heart of the matter but defining it is an extremely subjective task; there is no objective test. It includes emotional and welfare issues in addition to medical ones, and all factors in a person's welfare must be considered as part of the decision. The joint statement by the BMA, RCN and Resuscitation Council mentioned above refers repeatedly to "best interest" but does not define it. This guidance also makes the point that "no benefit is gained if only a very brief extension of life can be achieved" and that the burdens of the treatment may outweigh the benefits.
How brief is brief, and what is the benefit of that short extension to the patient and the family?

An apparently comfortable and symptom free life may be purgatory for someone who has lost all that makes life meaningful for them. Conversely, a life which might seem intolerable to an observer might be actually quite comfortable for the individual.

This is a particular problem when the patient is cognitively impaired. Relatives might suggest that Mum is so far gone in dementia that she is no longer herself and would be horrified if she knew the state which she had reached, "so don't give her antibiotics if she gets a chest infection". Actually Mum is very happy in her confusion, is still mostly continent and does not mind if she isn't. She likes to talk to the other residents even if the conversation does not make sense. She enjoys the activities and appreciates affection. Is it in her best interest to pull the stops out .... or is it in the family's best interest not to?

To take the opposite problem, will the family insist on every effort being made to revive someone whose quality of life is, in the view of the clinician, quite dreadful? Could an advance directive compel clinicians to act against their judgement? Mr Justice Munby (2004). has indicated in the Court of Appeal that intolerability (i.e. poor quality of life) is too narrow a test on which to make decisions, but stops there (from our point of view) by indicating that decision making should be a consensus process. As we can see, views can differ markedly as to what is the patient's best interest.

Genuine grief on the part of families who cannot bear to see Mum like that may also play a part in forming their attitudes.

8 The Interim Position

Until the Mental Capacity Act has been tested and examined (and probably even then), the nursing home nurse making a resuscitation decision is in limbo. Default positions - ringing 999 if in doubt - are not sufficient although legally probably quite safe. It is still uncertain as to whether a nurse attempting resuscitation with the best of intentions in defiance (or ignorance) of an advanced directive to the contrary would be entirely culpable. On the one hand assault, on the other best interest. The concepts of best interest and benefit seem to be the core of the decision making process. When that decision falls to the nurse, there is little but opinion to guide. It will be impossible to prove that we got it right.

Asking the individual, and witnessing and recording the decision in writing, is an important first step. Involving all "stakeholders" - attending physician, next-of-kin, close family and friends, is an important second step although autonomy of (and confidentiality for) the individual must still be the guiding principles.

The overarching principle would be that such decisions are not taken "on the hoof" but thought out and thoroughly explored beforehand. The nursing home nurse is in a unique position in relation to the patient. Time (usually) to build the relationship of trust and openness with both patient and family on which these decisions are based.
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