

# A framework for making advance decisions on resuscitation

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**ABSTRACT – Decisions about cardiopulmonary resuscitation (CPR) continue to cause difficulties for healthcare professionals. Current UK guidelines provide information on the underlying principles, but do not include a clear decision framework. The resulting confusion about when and who to ask about CPR can result in an inappropriate burden being placed on patients, partners or families. A simple clinical decision framework is presented, together with the underlying principles. This framework is offered as an aid for clinicians and patients in understanding the current ethical, clinical and legal guidance on decisions about CPR.**

**KEY WORDS: algorithm, cardiopulmonary resuscitation, clinical decisions, hospice care, learning disability, palliative care, terminal care**

Cardiopulmonary resuscitation (CPR) is a life-prolonging treatment, and decisions about CPR should be made according to the same principles and process as other life-prolonging treatments. Two important factors affect decisions about CPR at the time of the cardiorespiratory arrest. The first is that there is little time available for any deliberation since, if CPR is to be successful, it is imperative that it is started immediately. The second is that a collapsed patient lacks the capacity to consent to or refuse CPR. The combination of these two factors has led to the development of policies designed to make the decision about CPR *in advance* of the event. These are often referred to as deciding 'resuscitation status' or making a 'Do Not Attempt to Resuscitate (DNAR)' decision. The idea behind such policies is to make a CPR treatment decision when there is time for deliberation about the benefit, harms and risks of CPR, and to ascertain in advance whether the patient would wish to consent to or refuse CPR. When the patient is involved, the resulting decision is an 'advance decision', sometimes also referred to as an 'advance statement', 'advance directive' or 'living will'.

Unfortunately, the apparently simple idea of making advance decisions regarding CPR has proved extremely difficult to implement in practice. There are several reasons for this difficulty.

- There is a reluctance to appreciate that, as with other life-prolonging treatments, the justification for attempting resuscitation rests on a reasonable balance of benefit to harms and risks.
- There is an obvious difficulty in making a decision about CPR treatment in advance of any knowledge about the clinical circumstances in which the future cardiorespiratory arrest will arise. This leaves professionals unable to ascertain the balance of benefit to harms and risks of CPR when the arrest occurs.
- There is confusion about the role of the patient, partner or relatives in the decision.
- There is a lack of appreciation by both patients and professionals that an advance decision about CPR should be implemented under the same principles, and ethical and legal guidance, as any other advance statement.

## Case examples illustrating confusion in clinical practice

*A 55-year-old woman with a fungating breast carcinoma and widespread metastases was deteriorating day by day because of the cancer. Both the patient and her family had a strong religious faith, and they all realised and accepted that she was dying. The ward doctor took the family aside to ask permission not to resuscitate her when she arrested. The family responded by expressing surprise that resuscitation was possible since they thought she was dying. In view of this option being offered, they asked for her to be resuscitated if she collapsed. The medical team asked for help from the palliative care team who had to explain to the family that her continuing deterioration meant that resuscitation was no longer an option, since it would not succeed. Although initially distressed at being given false hope, they understood and accepted the situation and stayed with her until she died peacefully the next day.*

*A 52-year-old man with dementia related to Down's syndrome had developed the fifth in a repeated series of chest infections, each requiring a longer course of a broad-spectrum antibiotic. On this occasion he was not responding and for several days it had been clear to the clinical team in his nurse-run unit that he was deteri-*

orating rapidly. There had been no decision made about resuscitation, so when he developed Cheyne-Stokes respiration the paramedic ambulance was called and he was admitted urgently to hospital. He died within a few hours of arrival.

These case studies are based on true situations and illustrate the confusion that exists in the minds of clinical staff when faced with advance decisions about resuscitation. The confusion may stem from the advice in current guidelines and the interpretation of these guidelines by employing authorities. In an attempt to clarify the key issues, an NHS beacon palliative care team working with profoundly learning disabled adults produced a policy for a local NHS trust and a local hospice.<sup>1,2</sup> The principles behind this policy were developed over six years. This paper evolved from this policy and subsequent discussions between the authors, colleagues and participants at a conference on resuscitation policies in palliative care in November 2002.<sup>3</sup>

### Professional guidance and guidelines

Guidelines are available in several key publications.<sup>4-15</sup> The joint guidelines from the British Medical Association, Royal College of Nursing and Resuscitation Council (BMA/RCN/RC) have four underlying principles:<sup>5</sup>

- 1 Timely support for patients and people close to them, and effective communication are essential.
- 2 Decisions must be based on the individual patient's circumstances and reviewed regularly.
- 3 Sensitive discussion in advance should be encouraged, but not forced.
- 4 There needs to be a realistic chance of success in using CPR.

Most guidelines in the UK take account of a number of issues:

- 1 *European Human Rights Act.*<sup>16</sup> This Act is now incorporated into UK law and clinicians must take it into account in decision making.
- 2 *Rights of partner or relatives of an adult patient.* Partners and relatives do not have a legal right to demand, consent to, or refuse treatment on a patient's behalf.<sup>17</sup> The patient's own views, as expressed contemporaneously or in an advance statement, override the wishes of relatives. It is clear from the guidance on consent that a valid and applicable advance refusal is legally binding.<sup>18</sup> The same applies to a patient who does not have the capacity to make a decision about CPR. For a patient who previously had this capacity, it is essential to ask the partner or relatives about the views the patient had about such treatments before s/he lost the capacity to decide.
- 3 *Second opinion.* Part of establishing and maintaining trust between doctors and patients is the need to respect the wish of a patient (or their partner and family if a patient lacks capacity) to have a second opinion.<sup>4</sup>
- 4 *Capacity to consent in adults.* Even in patients with cognitive impairment, the capacity to make a decision can vary greatly and some are able to make valid advance decisions if this is done with someone whom the person knows and trusts.<sup>19,20</sup>

### Key Points

**There is confusion over the interpretation of current UK guidelines on making decisions about CPR**

**A decision about CPR cannot be made if it is impossible to anticipate the particular circumstances in which CPR is proposed**

**When the clinical team is as certain as it can be that CPR can benefit the patient and the particular circumstances in which CPR is proposed can be anticipated, it is usually straightforward to ask a patient with capacity whether they wish to receive CPR**

**When the clinical team is as certain as it can be that CPR cannot benefit the patient, it cannot be offered as a treatment option**

**The need for the clinical team to elicit the concerns of the patient, partner and relatives through clear and continuing communication is fundamental to making sensitive, transparent and realistic decisions on CPR**

An abnormal cognitive test does not exclude the possibility that an individual has the capacity to make a valid decision.<sup>21,22</sup> Capacity therefore depends as much on the complexity of the decision being made as on cognitive function. In Scotland, the Adults with Incapacity (Scotland) Act defines incapacity but not capacity,<sup>23</sup> whereas in the rest of the UK there is no legal definition of incapacity. However, there is a definition of capacity from English and Welsh statute law which is gaining increasing support.<sup>24-27</sup> This states that a person has capacity if s/he can:

- remember and retain the information relevant to the decision in question
  - believe that information
  - weigh that information in the balance to arrive at a choice.
- 5 *Capacity to consent in children and young people.* Most guidelines make it clear that health professionals need to be aware of the law in relation to decision making for children and young people where capacity is not determined by age, but by maturity and the ability to understand.<sup>28,29</sup> Young people aged 16 and 17 years are presumed to have the capacity to give consent for themselves. A child younger than 16 may have capacity and such 'Gillick competent' children can give consent to treatment. A parent cannot override a child with capacity who consents to treatment. Legally, a parent can consent if a child with capacity refuses treatment, although this serious step of overriding a child with capacity will be rare.<sup>5,18</sup> Occasionally, parents have cognitive problems that are similar to the child lacking capacity, and it is important to realise that parents also must have the capacity to make decisions on behalf of their children.
  - 6 *Communication.* Existing guidelines give advice about communication. Several suggest that information about

CPR should be displayed for patients and staff, and leaflets should be available for patients and people close to them that explain CPR, how decisions are made and their involvement in these decisions. In particular, they advise that decisions about attempting CPR must be communicated effectively to relevant health professionals. Information must be understandable, especially for a child or a patient with cognitive impairment, and may have to be presented in stages.<sup>30,31</sup> If verbal expression is limited, then any assessment should rely on other forms of expression.<sup>31</sup>

7 *Legal status of an advance statement.* Professionals are not legally bound to provide treatment requested in advance if it conflicts with their judgement about what is clinically necessary or appropriate.<sup>17</sup> An advance statement is legally binding only under the following circumstances:

- it represents the patient's wish to refuse treatment
- the decision was made by an adequately informed patient who had full capacity for that decision
- the patient was under no pressure at the time of the decision
- the statement is clear and applicable in the particular circumstances in which the treatment is proposed.

#### *Interpreting the current BMA/RCN/RC guidelines<sup>5</sup>*

*Whether to ask.* The guidelines make it clear that there is 'no ethical or legal requirement to discuss every possible eventuality with all patients, particularly with those with a low risk of cardiopulmonary arrest'. However, the guidelines also state that 'decisions about whether the likely benefits from successful CPR treatment outweigh the burdens should be discussed with competent patients'. This is often incorrectly interpreted as a requirement that all patients should be asked whether they would or would not want CPR to be attempted. This necessarily implies that the clinician is willing to provide CPR, but in a dying patient CPR is not a treatment that could succeed.

*The dying patient.* The guidelines recognise situations when the clinical team is 'as certain as it can be' that resuscitation would fail and would confer only harms and risks. In this situation, there is no decision to be made about CPR because it could not benefit the patient. This fact needs to be documented and sensitively communicated. Unfortunately, the guidelines also state that in a 'terminal illness, there should be sensitive exploration of their wishes regarding resuscitation'. This directly contradicts the General Medical Council (GMC) guidelines in Para 19: 'Where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation to provide it...'<sup>4</sup> The GMC statement indicates that when a team is as certain as it can be that CPR would fail, it is inappropriate to offer CPR as an option.

*CPR as a default.* When no advance decision has been made, the guidelines state that there should be 'a presumption in favour of resuscitation'. The same guidelines state that it would be unrea-

sonable to resuscitate anyone in whom the 'burdens of treatment clearly outweigh the potential benefits'. There is clearly a contradiction here in cases where the burdens outweigh the benefits such that CPR should not be attempted, yet no advance decision has been made. This 'presumption in favour' of CPR is usually interpreted by UK NHS employing authorities as a default in favour of CPR. The consequence is that DNAR decisions are used to protect such patients from the default of attempting CPR. Such a default position for any treatment is problematic, since it takes no account of the patient's individual circumstances and wishes. No other treatment has a default that results in its automatic application unless the patient opts out of that default. This difficult situation has probably arisen for several reasons:

- lack of time for deliberation when cardiorespiratory arrest occurs
- inevitable lack of capacity of the patient at the time of the event
- knowledge that unless there is a successful CPR attempt the outcome of the cardiorespiratory arrest will be death.

*DNAR as a default.* Some clinicians caring for dying patients believe that most of their patients are in the situation where the 'burdens of treatment clearly outweigh the potential benefits'. This 'presumption against' CPR has been interpreted by two hospices in the UK as a default of not resuscitating. The consequence is that patients in these units have to 'opt-in' to receiving CPR.

*Circumstances in which CPR is proposed.* An advance refusal made without regard to the circumstances in which CPR is proposed is problematic since a clinical team cannot be sure if the current cause of the arrest was anticipated by the patient. While it is always possible to imagine circumstances where CPR might be beneficial, a long list of imagined scenarios is of no use to the attending resuscitation team. Clarity about the particular circumstances in which treatment is proposed is essential in any advance statement.<sup>17,32,33</sup> GMC guidance<sup>4</sup> describes in Para 86 a 'foreseeable risk of cardiopulmonary arrest' as a component in an advance decision. It is surprising therefore that the BMA/RCN/RC guidelines fail to include this as an essential step in making a decision about CPR.

#### *Interpreting the current GMC guidance*

The GMC guidelines<sup>4</sup> provide useful advice on withholding and withdrawing life-prolonging treatment, including CPR. In particular, they make it clear in Para 93 that CPR decisions are advance decisions that need regular review. However, the guidelines give contradictory advice on whether or not to ask the patient. Para 87 recognises circumstances when CPR is unlikely to help but then states that, 'failing to give patients or, where appropriate, those close to the patient, the opportunity to be involved in reaching a decision can cause more distress at a later stage'. This has been interpreted as meaning that all terminally ill

patients should be asked, despite the clear indication earlier in the guidelines (Para 19) that when a team is as certain as it can be that CPR would fail it is inappropriate to offer it as an option.

### Proposed clinical decision framework for advance decisions on resuscitation

Table 1 summarises the aims of the proposed framework, and Fig 1 shows the framework for the CPR decision. This framework is based on ten principles:

- 1 *Circumstances of CPR.* When the particular circumstances in which CPR is proposed cannot be anticipated, it is not possible to make an advance decision that would be of any help to the clinical team attending the arrest since the balance of benefit to harms and risks cannot be quantified in advance. Since any circumstance can be imagined, a helpful check is to consider only those anticipated circumstances about which the patient needs to be informed as part of informed consent.
- 2 *When CPR could help the patient.* When the particular circumstances in which CPR treatment is proposed can be anticipated and the patient is not dying, then an advance decision is possible since it is possible to estimate the balance of success against harms and risks. If such patients want to discuss CPR, the conversation is straightforward and not usually distressing to patients.<sup>34</sup>
- 3 *When CPR cannot help the patient.* In the situation where a death is expected as an inevitable consequence of an underlying disease and the clinical team is as certain as it can be that resuscitation would fail, it is an unnecessary burden to offer the patient this option or to ask partners and families of patients who lack capacity whether CPR treatment would be the patient's wish.<sup>4</sup> When a patient is

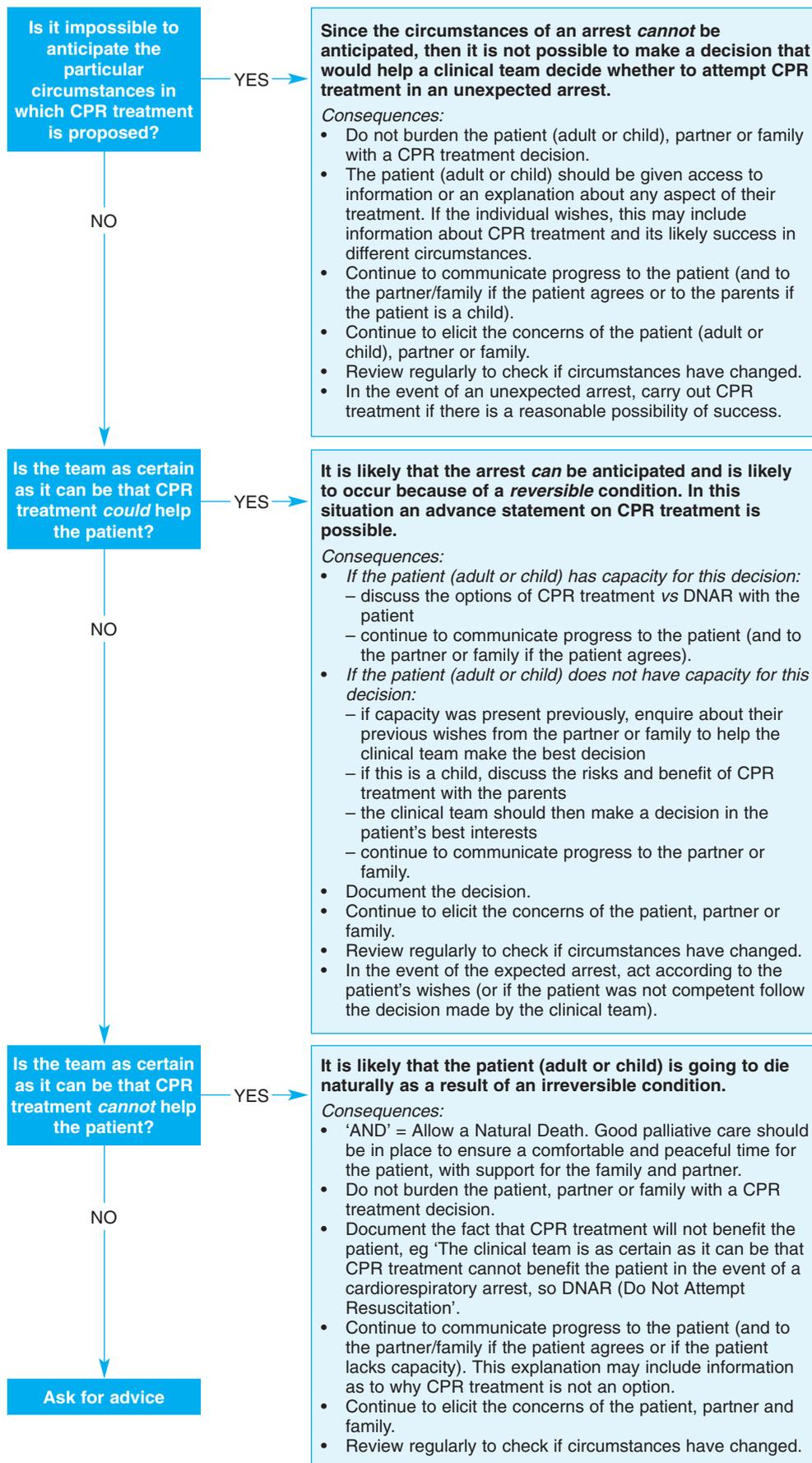
dying, good palliative care should be in place (such as the Care of the Dying Pathway<sup>35</sup>) to ensure a comfortable and peaceful time for the patient, with support for the relatives and partner. If necessary, this should include support from a specialist palliative care team.

- 4 *Communication.* Being unable to anticipate the circumstances in which CPR is proposed, or being in a situation where CPR is not an option, should never prevent patients being given as much information as they wish about their situation.<sup>4</sup> Throughout a patient's care, partners and families can be told about his/her condition if the patient consents to this disclosure. Where decisions regarding CPR arise and the patient lacks capacity, then the clinical team must make the decision based on a judgement of benefit balanced against harms and risks, together with what can be determined from the partner and family about what the patient would have wanted based on previously expressed wishes. Continuing dialogue with patients with capacity, and with the partners and families of patients who lack capacity, is fundamental to this process and eliciting a person's concerns is a key clinical skill.<sup>36–40</sup>
- 5 *Quality of life.* Medical decisions regarding which treatment to offer to patients with capacity, or which treatments to provide to patients lacking capacity, should be based on the patient's best interests, and not on a professional's opinion of the patient's quality of life. This is challenging to many doctors and nurses who feel that including estimates of quality of life in their treatment decisions is both sensible and caring. In reality such estimates are very subjective and often at variance with the view of the patient.<sup>41</sup> Even the clinician's perception of a patient's preferences for resuscitation is often at variance with the patient's actual wishes.<sup>42</sup> Problems such as depression can affect a patient's choice,<sup>43</sup> and depression needs to be identified and treated before a patient makes a decision about CPR. A court case in the UK in 2004 questioned the reliance on quality of life in the GMC guidelines, and the Disability Rights Commission in the UK has gone further by asking for quality-of-life factors to be removed from the GMC guidelines.<sup>44</sup> The Disability Rights Commission suggests instead that doctors should use the 'intolerability test', whereby a treatment should be withheld or withdrawn if the consequence is that the patient would view their life as intolerable.<sup>44</sup> The key to this test is that the intolerability must be viewed from the patient's perspective, not the doctor's.
- 6 *Default positions.* This framework purposefully excludes any default position on CPR treatment.
- 7 *Need for a bedside assessment.* A common driving force for an advance resuscitation decision is the understandable attempt to avoid a rushed bedside assessment at the time of cardiopulmonary arrest. However, advance decisions about CPR never avoid the need for such an assessment in the following situations. For example:
  - If no decision is in place and a patient unexpectedly arrests, then a decision on CPR has to be made by the

**Table 1. Aims of an effective framework for a CPR decision.**

- To ensure that decisions regarding CPR are made according to whether CPR could succeed, the medical circumstances of the patient, the patient's wishes and best interests, current ethical principles, and current legal positions, including the Human Rights Act.
- To make advance CPR decisions transparent and open to examination.
- To clarify the situations when advance CPR decisions are needed.
- To ensure patients, families and staff have information on making decisions about resuscitation and that they understand the process.
- To avoid burdening patients, partners and relatives with a CPR decision when CPR cannot benefit the patient, or the particular circumstances in which CPR is proposed cannot be anticipated.
- To ensure that a continuous dialogue is promoted between clinicians, patients, partners and families.
- To avoid resuscitation attempts that have no realistic prospect of success and which therefore would only result in the harms and indignities of the procedure.

Fig 1. Framework for a CPR decision.



team at the bedside. If the attending team considers that CPR has a reasonable chance of success, then it should proceed, eg in a post-myocardial infarction arrhythmia. However, if the team considers that CPR could not benefit the patient, then it should not proceed, eg in a massive haemorrhage from a carotid rupture due to malignancy.

- If a DNAR order is in place, then it is still necessary to check that the anticipated circumstances of the DNAR order are being met.

All arrest teams should follow the 'ABCD' process of airway, breathing, circulation and then decision. Unfortunately, few teams are trained in the processes needed to make the decision to continue or stop CPR.<sup>45</sup>

8 *Reviewing the CPR decision.* Since the clinical condition of a patient can change, it is essential to document the next anticipated review of the CPR decision. While this does not mean burdening the patient and family with a CPR decision each time, it does require staff to monitor clinical change and to be sensitive in picking up any change of views during the continuing dialogue with the patient. The frequency of review will depend on the clinical situation, eg a month-by-month deterioration could prompt a monthly review, whereas week-by-week deterioration could prompt a weekly review. Any change in the decision on CPR needs a new documentation sheet.

9 *Documentation.* Clear documentation enables a check to be made that the decision was sensitive to the patient's needs, and was transparent, realistic, and ethically and legally justifiable. Recording the process is the key to auditing practice to assess what percentage of decisions meet these standards. It is not sufficient to write 'not for resuscitation' in the notes. As a minimum, the following should be recorded:

- the patient's capacity for this decision
- whether the team is as certain as it can be that the patient is dying
- whether the circumstances of the arrest can be anticipated
- a summary of the decision of the patient or the clinical team
- the anticipated circumstances in which the decision is to be enacted
- a list of key people who witnessed the decision
- the next review date or clinical change necessitating review.

Since the decision may need to be accessed rapidly, it should be in a prominent position in the notes. It is also helpful to have documentation available for informing patients, partners and relatives.

10 *When consensus is difficult to achieve.* Although the senior doctor responsible for the patient has the authority to make the final decision,<sup>4</sup> it is wise to reach a consensus with the patient, staff and relatives. On occasion, a clear decision is difficult simply because the benefits equally balance the

disadvantages; in such cases waiting for an agreed period of time may help. When one or two members of the team hold a minority view, the rest of the team should respect their views and be prepared to review the situation after a time period agreed by the whole team. Advice from outside the clinical team can be invaluable, especially from the primary healthcare team, palliative care team, chaplain, and social worker. Ethical advice can be helpful, eg from a local clinical ethics committee. Staff or family with continuing concerns initially should be advised to approach the consultant and senior nurse for discussion. Staff who still have concerns should approach their line manager. Staff and family who still feel dissatisfied should contact the person who has responsibility for clinical governance within the organisation. The courts may have to be approached for the final say. This is usually a last resort, although courts can be helpful in deciding complex cases.

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