BJA

British Journal of Anaesthesia, 119 (S1): i90–i98 (2017)

doi: 10.1093/bja/aex359
Critical Care

Demands and requests for ‘inappropriate’ or ‘inadvisable’ treatments at the end of life: what do you do at 2 o’clock in the morning when . . .?

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Abstract

In an era when healthcare has become increasingly complex and patient expectations are higher than ever before, we can find the decision-making process for patients, potentially at the end of their lives, increasingly difficult. In the shift from paternalism to patient choice, we can struggle to know what to do when faced with a patient, their family, or both requesting or demanding inadvisable, inappropriate, or futile treatments. It can feel as if we are being asked to subject patients to intrusions and interventions that ‘just feel wrong’. In this article, we aim to look at how ethical frameworks, legal statute, case law, and professional guidance, as they apply in the UK, interact when we make these decisions, and we discuss some of the conflicts and challenges that such guidance pose.

Key words: demands, inappropriate; end of life

What do you do at 2 o’clock in the morning when a patient, their family, or both request a treatment that you feel is inadvisable, inappropriate, not in their best interests, or futile? This question demonstrates the dilemma often faced when making potential end-of-life care decisions. The question, although relating to an acute, urgent situation, could equally be applied to any end-of-life decision where fundamental differences exist between what the clinician and the patient (or their family, or both) feel is appropriate. Should we err on the side of the patient’s autonomous wishes or should we do what we feel, in our professional ‘medical’ opinion, is right for the patient, despite the worry that, should this difference of opinion escalate, we may end up in court?

A lack of understanding on our part may contribute to this dilemma. We may feel comfortable from a clinical perspective in our decision-making, but are we altogether at ease with the legal and ethical perspectives? It can, at times, feel as though we are making decisions driven by fear of litigation, rather than in our patients’ best interests. With an increasing legal and ethical emphasis on patient autonomy,[1 2] are we now in the position of simply asking patients, ‘What do you want us to do?’. With that comes the worry for many that we may be moving away from being professionals, with a lifetime of experience in making these difficult decisions, to becoming simply physiological technicians, acquiescing to potentially unrealistic expectations. As trained professionals, we have a moral imperative to use our training, experience, and knowledge to benefit our patients.

The authors appreciate that there are numerous, often complex reasons why patients and their families make such requests and demands. All are personal and important to them and should be considered sensitively and thoughtfully. Exploring these reasons and recognizing when potential conflicts in opinion are arising is fundamental in preventing escalation of such situations.

In this article, we explore the professional guidance, legal statute, case law, and ethical frameworks that help to steer us when such challenging situations arise. As we will see, however, the guidance can only ever be just that. Putting it into practice is often much easier said than done.

Clinical and professional guidance

Extensive guidance exists to aid decision-making at the end of a patient's life. Both the General Medical Council (GMC)[3] and the British Medical Association (BMA) guidance[4] in this regard are fundamental reading for any doctor. The former is certainly the benchmark by which any doctor is judged should they unfortunately face a 'Fitness to Practice Panel' over any of their clinical decisions taken in this area. It is not the intention of this article to provide a summary of or to repeat this guidance, and the authors cannot stress enough the importance for those who are involved in end-of-life decision-making to familiarize themselves with this guidance.

These end-of-life situations highlight repeated themes of conflicting interests of patients, clinicians, and society. Patients have an interest in receiving care that is consistent with their values and preferences; clinicians in not being compelled to act against their professional judgement; and society in protecting individual rights, fostering professionalism in its clinicians, and ensuring fair allocation of resources.[5]

In essence, the GMC guidance sounds obvious: use 'specialist knowledge and experience and clinical judgement' and the 'patient's views and understanding of their condition' to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient.[3]

Decision-making for patients with capacity

For competent patients, this is relatively straightforward; patients weigh up their various options and any non-clinical issues that are relevant to them and decide whether to accept or refuse any or all of the options (which, of course, competent patients are ethically and legally entitled to do no matter how irrational we may deem their decisions to be).[3]

Difficulty can arise, however, if patients ask for treatments we consider clinically inappropriate. The GMC guidance (based upon the case of *Burke v GMC*)[6] states that doctors 'do not have to provide the treatment'.[3] In reality, the guidance and good practice dictate that we should do the following: explain why we consider the treatment inappropriate; discuss other options available to them, including advice from a more experienced colleague; and offer a second opinion or offer advice from the local ethics committee or mediation service (if available). If, despite these measures, significant disagreement persists, the advice is that we should seek counsel from our legal colleagues. Navigating through difficult and contentious ethical decisions is, after all, what courts do, and where significant conflict exists, it is the court that is the ultimate arbiter in deciding where a patient's best interests lie.[3] However, this is not without its own problems. Whilst a court can rule upon what is lawful or not, it is rightly reluctant to dictate to doctors that they must provide (or withdraw) treatments that the doctors themselves consider clinically and ethically inappropriate or inadvisable. For example, in the case of *Miss B v An NHS Trust*, this necessitated transfer of the patient to another unit, where the treatment in question (namely her ongoing artificial ventilation) was subsequently withdrawn.[7]

Decision-making in the incapacitated patient

The above is all very well for competent patients. However, the difficulty for intensive care patients is that by the time 'end-of-life' decisions are being made, patients are often, by virtue of their illness, lacking in capacity. In these circumstances, under statutory law in England and Wales (courtesy of the Mental Capacity Act 2005)[8] and Scotland (Adults with Incapacity Act 2000),[9] whether and what treatment is provided is determined by what would be of benefit to and in the best interests of the patient. As we shall subsequently discuss, establishing benefit and best interests in practice is exceptionally complicated. Who gets the final say in this can be just as problematic. If the patient has a Lasting Power of Attorney (LPA) in place for their welfare, things are relatively straightforward. Where one exists, the LPA effectively steps into the shoes of the patient in terms of being able to provide consent to receive treatment on behalf of the patient. In the absence of this, however, it is a common myth to assume that loved ones, a named next of kin, or both can consent on the patient's behalf. They cannot. What they can do (courtesy of the statutory law) is give an indication as to what the former competent patient may have considered to be in their own interests, and it is this information that helps to determine where the patient's ultimate best interests lie. As the GMC guidance states,[3] it is important to be clear about this, as at times relatives may be left feeling that they are being asked to make the difficult decision as to whether or not to treat. If conflict arises between the healthcare team and the loved ones or next of kin (or indeed between members of a healthcare team) as to what is in the best interests of the incompetent patient, then the path for resolution of that conflict is no different from that described above for the competent patient.

At 2 o'clock in the morning, with an urgent decision needing to be made, the number of these 'conflict resolution' options available may be few, leaving the on-call physician at a loss as to how best to proceed.

Where the doctor feels that further treatment is inappropriate, the BMA reiterates the GMC guidance; if the treatment would not 'achieve any clinical benefit to the patient, for example because it is unable to achieve its physiological aim, the healthcare team should not offer it'.[4] A patient's wishes should always be discussed with them (assuming, of course, that they have capacity), but the fact that a patient has requested a particular treatment 'does not mean that it must always be provided'.[4] We should make efforts to comply with 'reasonable requests ... about the provision of life-prolonging treatment'. However, the decision regarding what treatment to offer rests with the clinician.

But the same guidance also suggests that there may, in fact, be arguments for complying with requests from patients for treatment to be continued or at least provided for a 'limited period'. For patients holding views that there is 'intrinsic value in being alive', provision of life-prolonging treatment would, 'in virtually all cases, provide a net benefit'.[4] 'Virtually all' in this context seems to imply that withholding treatment because it is not in their best interests would be a rare event.[10]

Thus, it appears that there is a degree of contradiction in the professional guidance. The GMC guidance states that we may offer patients treatments that we feel are 'clinically appropriate' and of 'greatest benefit', which the patient can accept or decline, but for requests we feel are inappropriate, we 'do not have to provide the treatment'.[3] On the contrary, from BMA guidance, if the patient feels there is benefit to receiving those treatments, despite us deeming them inappropriate, inadvisable, or futile,