



Article of the Month

December 2019

This November, after nine months work on revision and updating of the 2015 document, the new guidance was launched at the RCP in a stimulating conference with a good representation from palliative medicine. It will be published finally in January 2020. I had the privilege once again to represent both the RCP and APM on the working group and contributing particularly to sections 4 and 5 covering the ethics and law around decision-making and the practical aspects of starting or continuing life sustaining treatments. I would like also to thank two APM members, Amy Gadoud and Julie Raj, for their help and support in the final drafting.

In the five years since the initial guidance, there have been both significant developments and clarifications in the law governing care and decision-making, and accumulated experience of care and symptom management, when continuing life sustaining treatments can no longer be justified. Sections 4 and 5 cover these and alongside the [Joint RCP/BMA guidance on Clinically Assisted Nutrition and Hydration](#) offer definitive advice and approaches in an increasingly important area of our work.

With the changing demographic of our patients, more and more of whom lack mental capacity. The principles and guidance in these two documents are applicable across our whole practice and are now required reading for the specialty. Ahead of the guidance's official publication, there are two critical areas I'd like to highlight to open discussion.

First, there is a most helpful realignment of reasoning on decisions around the giving and discontinuation of treatments that follows the Supreme Court judgment in [Aintree v James](#). It is now clear in law at the beginning of section 4 in the guidance that

- 1. Neither a patient nor their family, nor indeed the Court of Protection, can require a doctor to give a particular treatment. However, any treatment that doctors do decide to offer must only be given on the basis that it is in the patient's best interests, taking into account their likely wishes, insofar as these can be known.*
- 2. It is the giving, not the withdrawing of treatment that needs to be justified. Clinicians may not simply give treatment by default to avoid holding difficult conversations.*
- 3. The critical question to consider of a patient in PDOC is no longer whether they may emerge from VS or MCS, but whether they will recover a quality of life that they themselves would value.*

This phrasing in point 2 is what matters for it upends the usual way that doctors address treatments and in particular consigns the scary and unhelpful terms 'withholding and withdrawing' to the bin. The newspeak is start and discontinue. Doctors' default to this point that 'if I can treat, then I must treat unless I can justify withholding it' must be replaced with 'It is the giving, not the withdrawing of treatment that needs to be justified.'

This is of course precisely right, and we have known it, in that the reason why one should stop a treatment – even if it may be life-sustaining – is in order to stop inevitable harms when the benefits are no longer realisable: we are duty-bound no longer to subject someone to something that is pointless.

We are allowed also to see *'pointless'* as failure to restore a quality of life that the person would have valued. Whilst this of course brings other challenges to the table, discontinuing treatments through this lens has nothing to do with bringing about death; instead it has everything to do with sparing a patient further harm, resonates exactly with our current duty of care and puts flight to the disingenuous notion of passive euthanasia. So, when it comes now to considering treatment being started, we can help our colleagues with the question:

'Is this treatment going to be of any benefit in helping this patient realise what matters to them?'

At each clinical review, instead of contorting over withdrawal, we should ask

'Is continuing this treatment still of any benefit in helping this patient realise what matters to them?'

If either answer is *'No'*, our duty is to remove the treatment as an option on offer. This of course is why statement 1 is so clear: It is a matter of professional duty and expectation.

The second point comes from Section 5. Here, based on the accumulated experience of the 5 years since the first guidance, we have broken down people with PDOC into 3 categories.

Category 1: Patients for whom death is imminent as a result of other causes such as infection, complications of the brain injury (e.g. acute hydrocephalus, raised intracranial pressures, bleeding etc.) or other inter-current conditions that may be unrelated to the brain injury.

Category 2: Those with other co-morbidities or frailty that will inevitably result in death, not necessarily imminently but most probably in less than one year

Categories 3-5: Those with a stable or upward trajectory who may live for a number of years (or even decades), but for whom a decision has been made that continued life-sustaining treatment (including CANH) is not in their best interests.

It is important to distinguish them because they are likely to die differently when life-sustaining treatments are stopped. Categories 1 and 2 includes those familiar already to palliative care and geriatrics and present no real challenges to us. On the other hand, categories 3-5 may: they are patients in whom one may need to escalate drugs rapidly and use high doses of anticonvulsant and sedation in order to secure what we have called *'calm coma'* as the person dies. As in the original guidance, we explain the biology behind this in that section followed by protocols to guide prescribing.

Overall the key message for us in palliative medicine is that we are both needed and welcomed by rehabilitation physicians in teamworking. The guidance is clear that palliative care should be a core part of the extended teams needed to provide adequate care for all these groups.

As co-signatories and endorsers of the guidance, the APM is here to support you should you be asked to be involved in patients with PDOC or parallel clinical challenges. Contact the Office and we will direct you to the colleagues in the speciality with the right expertise.

We will send out the link to the final document when it becomes available early in 2020.

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