End of life – where are we now?

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Introduction

1. Since the multitude of reflections provoked by the case of *W v M and others* [2011] EWHC 2443 (CoP) at the end of last year, there have been yet more difficult end of life decisions for the Courts this year. The tension between concepts of autonomy and dignity on the one hand, and respect for the sanctity of life and the duty to take steps to preserve it on the other, remain real and not easily resolved.

E, an anorexic woman – an "intuitive" judicial response to a unique case

2. The case of *A Local Authority v E and others* [2012] EWHC 1639 (CoP), [2012] 2 FCR 523 concerned an anorexic woman, for whom death was imminent. Peter Jackson J identified at the outset the unique character of the case:

   > *E's case has raised for the first time in my experience the real possibility of life-sustaining treatment not being in the best interests of a person who, while lacking capacity, is fully aware of her situation ... Her situation requires a balance to be struck between the weight objectively to be given to life on one hand and to personal independence on the other.*
   >
   > *A further element of the situation is that in 2011 E twice attempted to make advance decisions refusing the treatment that is now proposed.*

3. The Court was asked to choose between two options:

   - remaining in the community hospital for palliative care until E died from starvation
   - transfer to an ICU, where she would be fed with a PEG or nasogastric tube, involving restraint or sedation if necessary, and thence to a specialist facility for the treatment of eating disorders, where she would be offered therapy.

4. As to E's capacity to make decisions about these treatments, the Court found:

> *... there is strong evidence that E's obsessive fear of weight gain makes her incapable of weighing the advantages and disadvantages in any meaningful way ...*
>
> *... she is now subject to strong sedative medication and is in a severely weakened condition ... E lacks capacity in her current situation ... (paras 49 – 51)*

5. As to advance decisions generally, the Court held:

> *I consider that for an advance decision relating to life-sustaining treatment to be valid and applicable, there should be clear evidence establishing on the balance of probability that the maker had capacity at the relevant time. Where the evidence of capacity is doubtful or equivocal it is not appropriate to uphold the decision (para 55)*

6. The Court went on to find that E lacked capacity to make the advance decisions upon which reliance was placed in her case because of doubt about the quality of the evidence as to her capacity at the material time. In the context of her mental state at the time, the absence of a "full, reasoned and contemporaneous assessment evidencing mental capacity to make such a momentous decision" left the advance decision insupportable (para 66).

7. There was "guarded" evidence as to whether E might, upon refeeding, return to a quality of life that she would regard as worthwhile and whether she might then regain capacity (para 72). At the hearing, E described her life as "pure torment" (para 76). The Court found itself in the circumstances unable to elucidate her beliefs and values and said this:

> *It depends upon an assessment of her true identity. Has she been so ill for so long that her illness would remain part of who she is, even if she had capacity? Or is she still the person she was before anorexia took her in its grip? Looking ahead, will E always see herself as a victim, or can she come to see herself as a survivor? (para 78)*

8. The evidence of the court-appointed expert was that, if E was force-fed to restore her BMI to 17, then she had a 20 – 30% chance of recovery (para 90). He considered the risks associated with refeeding to be better than death (para 97).

9. The Court distinguished E's case from others thus:

> *In contrast to the case of W v M (above), where the patient was in a stable, minimally conscious state, E is in an inexorably deteriorating, highly conscious state. In contrast to the cases of Re W (A Minor)(Medical Treatment: Court's Jurisdiction) CA [1993] Fam 64 and Re C (Detention: Medical Treatment) [1997] 2 FLR 180, E is not a teenager but an adult with an entrenched history of acute difficulties. In further contrast to many medical treatment cases, the psychological impact of the proposed treatment upon E is of a different order to many other cases. The treatment would not consist of a single operation or procedure, but a wholesale overwhelming of her autonomy for a long period whose exact length could only be measured in hindsight once it was known whether treatment had succeeded or failed. Further, because of the complexity of her condition, the success of treatment is particularly uncertain. Perhaps finally, in distinction to more recognised situations, there is the fact that E and her family and her medical team had already firmly embarked on the course of palliative care and had psychologically adjusted to the prospect of imminent death (para 117).*

10. The Court recognised both the importance of the presumption that all steps will be taken to preserve life, and those circumstances in which it might have to yield (paras 119 – 120). It acknowledged the importance of individual autonomy and that force-feeding amounted to an assault and a potential breach of Article 3 ECHR (para 126), as well as the weight to be attached to the wishes and feelings of a person who, while lacking capacity, is fully engaged in decision-making (para 127).

11. The Court described the balancing exercise as "intuitive" (para 129).

12. The Court concluded thus:

> *I would not overrule her wishes if further treatment was futile, but it is not ... The competing factors are, in my judgment, almost exactly in equilibrium, but*

> *having considered them as carefully as I am able, I find that the balance tips slowly but unmistakably in the direction of life-preserving treatment (para 140).*

Perhaps the most interesting question arising from this case is whether the Court would have concluded differently if it had been the case that there was no untried treatment available to E, or how it might decide her future should such treatment be tried and fail.

13. The genuine availability of treatment features frequently in such cases. For example, in *AVS v An NHS Foundation Trust* [2011] EWCA Civ 7, the Court of Appeal upheld the decision of The President, Sir Nicholas Wall, to strike out a claim for a declaration that a particular course of, life-prolonging, treatment was in AVS's best interests where there was no clinician willing and able to provide that treatment. It seems that this case might have provided an answer to an issue raised, at least rhetorically, in the as yet unreported case of *L*, which was decided over the Summer.

Mr Nicklinson – no change in the law of assisted suicide and euthanasia until Parliament acts

14. Earlier this year the Courts were asked to revisit the law of assisted suicide in the case of *R (Nicklinson) v Ministry of Justice and others* [2012] EWHC 304 (QB), [2012] EWHC 2381 (Admin), [2012] 124 BMLR 191. Mr Nicklinson, who was massively disabled by a stroke, but completely capable, sought declarations that it would not be unlawful for his GP or another doctor to terminate or assist in the termination of his life, alternatively that the law of murder and/or assisted suicide is incompatible with his right to respect for private life or that the domestic law fails adequately to regulate the practice of euthanasia.

15. At the earliest stage the Court was asked to grant an interim declaration that Mr Nicklinson's solicitors may lawfully take steps in respect of the application without exposing themselves, or expert witnesses, to the risk of prosecution under the Suicide Act 1971. Charles J was persuaded to make a broad declaration that the solicitors may obtain information from third parties and experts for the purposes of placing

material before the Court and third parties may co-operate in so doing without the people involved acting in any way unlawfully (para 25).

16. Months later, Charles J considered whether the substantive application for declarations had any prospect of success or whether there was some other compelling reason for the matter to be tried. His Lordship viewed the case as an exemplar of the conflict between the sanctity of life and the individual's right to self-determination (para 16). He decided that *Re A*, the conjoined twins case, provided support to the argument that the law of necessity, as a defence to a charge of murder or assisted suicide, was not clear. He was further persuaded that the fact that Parliament, although it had had the opportunity to do so, had not changed, the law, was not a complete obstacle to the Court developing the common law (para 32).

17. Charles J also found that Mr Nicklinson had an arguable case in relation to Article 8 (para 45), but not in relation to Article 2 (para 51).

18. An application for permission was after a further few months considered by a Divisional Court comprising Toulson LJ, Royce J and Macur J, together with that of another Claimant, and after the Attorney-General intervened. Mr Nicklinson sought a declaration requiring the DPP to clarify his policy so that those who do provide assistance to those seeking euthanasia know their position under domestic criminal law, and, by the time of this hearing, a declaration that Article 8 requires that voluntary active euthanasia is a defence to murder by reason of necessity.

19. The Court noted that the Law Commission had recommended in 2006 a consultation on "mercy killing" (para 52) but that there had not yet been one.

20. The Court considered whether the case of *Re A* offered support for the Claimants' contentions and found, contrary to Charles J's initial optimism, that it did not.

> *Those highly unusual features, which were critical in the case of Re A, are absent from the present case. If in this case a doctor were to administer a lethal drug to Tony, there could be no defence to a charge of murder based on lack of causation, lack of intent or quasi-self-defence (para 72).*

21. The Court was not persuaded, also cf Charles J, that the Court was entitled to interfere, as it was being asked to, with the common law (paras 79 - 84).

22. The Court accepted that it would be impossible to legalise any form of euthanasia without a surrounding framework of safeguards and it would be impossible for the court to introduce or monitor such a regime (paras 85 – 86). Interestingly, Macur J made this distinction from the work of the Court of Protection:

> *Judges of the Family Division sitting in the Court of Protection adjudicate upon applications for declarations in relation to the [withdrawal of life-sustaining treatment] and have become well accustomed to the "balance sheet of best interests" which informs the decision of the Court. However, Mr Bowen QC does not succeed in persuading me that this process may reassure society that the development of common law for which he contends is merited by separate consideration of individual circumstances by individual tribunals of whatever stature and experience (para 152).*

23. The Claimants sought to develop the principle of dignity, established before the ECHR in *Pretty v UK* [2001] UKHL 61, [2002] 1 AC 800 at para 65, and frequently meditated upon by Judges in the Court of Protection.

> *The very essence of the Convention is respect for human dignity and human freedom. Without in any way negating the principle of the sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.*

24. However, the Claimants failed for the same reasons articulated by the ECtHR in that case at paras 76 and 77:

> *The Court does not consider therefore that the blanket nature of the ban on assisted suicide is disproportionate. The Government has stated that flexibility is provided for in individual cases by the fact that consent is needed*

from the DPP to bring a prosecution and by the fact that a maximum sentence is provided, allowing less penalties to be imposed as appropriate ... It does not appear to be arbitrary to the Court for the law to reflect the importance of the right to life, by prohibiting assisted suicide while providing for a system of enforcement and adjudication which allows due regard to be given in each particular case to the public interest in bringing a prosecution, as well as to the fair and proper requirements of retribution and deterrence.

Nor in the circumstances is there anything disproportionate in the refusal of the DPP to give an advance undertaking that no prosecution would be brought against the applicant's husband. Strong arguments based on the rule of law could be raised against any claim by the executive to exempt individuals or classes of individuals from the operation of the law.

25. The Court concluded thus:

There is no Strasbourg authority which supports the proposition that a blanket ban on voluntary euthanasia is incompatible with Article 8 (para 118).

Where a matter is within the margin of appreciation left to individual states, it is also up to the state to determine which organ of the state should decide what legal regime to adopt (para 119).

...

I conclude that it would be wrong for this court to hold that Article 8 requires voluntary euthanasia to afford a possible defence to murder. To do so would be to go far beyond anything which the Strasbourg court has said, would be inconsistent with the judgments of the House of Lords and the Strasbourg court in Pretty, and would be to usurp the proper role of Parliament (para 122).

26. As to the DPP's policy, the Court said:

From the DPP's policy statement, I believe that it would be clear to a person who, in the course of his profession, agreed to provide assistance to another

with the intention of encouraging or assisting that person to commit suicide, that such conduct would carry with it a real risk of prosecution (para 139).

...

The DPP has published details of two cases in which he concluded that there was sufficient evidence to prosecute a doctor for an offence under section 2, but he decided on the particular facts that it would not be in the public interest to do so. In one case the assistance provided was minimal, consisting of the giving of some advice, and there was no evidence that the advice contributed significantly to the outcome. In the other case, involving a doctor aged 79 who had been struck off the register, the DPP concluded that "on the very particular facts of this case, the likely penalty would be a conditional discharge" (para 144).

Ending the lives of young children – Baby X and KH, aged 3

27. At about the same time as the decision in *Nicklinson*, Hedley J considered a case concerning a Muslim family whose baby, X, had suffered a massive brain injury, and where the responsible clinicians considered that it was in X's best interests to be transferred from a ventilator to a palliative care pathway – *NHS Trust v Baby X and others* [2012] EWHC 2188 (Fam).

28. Hedley J adhered to the "intellectual milestones" for such a decision that had been identified in *Wyatt v Portsmouth NHS Trust* [2005] EWCA Civ 1181, [2006] 1 FLR 554 by the Court of Appeal:

    i) the Judge must decide what is in the best interests of the child

    ii) in doing so, the child's welfare is a paramount consideration

    iii) the Judge must look at it from the assumed point of view of the patient

    iv) there is a strong presumption in favour of the course of action that would prolong life but that presumption is not irrebuttable

> v) *the term "best interests" encompasses medical, emotional and all other welfare issues*
>
> vi) *the court must conduct a balancing exercise in which all relevant factors are weighed.*

29. As to the evaluation of X's best interests, Hedley J encapsulated the position of his parents thus:

> *... the essential case being advanced on behalf of the parents was that as X has no consciousness or awareness of self or surroundings and as he has no apparent perception of pain, there were few if any burdens on X in the continuing of life however slight the benefits might also be (para 12).*

This was a novel approach to the balance sheet exercise, which ultimately did not attract the Court.

30. By contrast, the position of the hospital, accepted by Hedley J, was as follows:

> *I think the overwhelming probability ... is that X will not progress from his present position, in any way that is meaningful, in terms of improved life experience ... if treatment be continued, then he will remain ventilated. In the longer term he will require tracheostomy; the naso-gastric tube will have to be replaced by a PEG. He will remain at risk of potentially fatal respiratory infections and the more generalised problems associated with cerebral palsy and increasing spasticity (paras 13 and 14)*

31. It was suggested on behalf of the parents that their views, in support of the continuance of life-sustaining treatment, should be part of the assessment of best interests. Hedley J, following the decision of Holman J in *An NHS Trust v MB* [2006] EWHC 507, rejected this argument (para 21).

32. Hedley J concluded:

> *It is important that "quality of life" judgements are not made through other eyes for "quality of life" may weigh very differently with different people depending on their individual views and aspirations. A life from which others may recoil can yet be precious.*

> *At the same time preservation of life, however important, cannot be everything. No understanding of life is complete unless it has in it a place for death with comes to each and every human with unfailing inevitability. There is unsurprisingly deep in the human psyche a yearning that, when the end comes, it does so as a "good death". It is often easier to say what that is not rather than what it is but in this case the contrast is between death in the arms and presence of parents and a death wired up to machinery and so isolated from all human contact in the course of futile treatment (paras 24 – 25).*

33. In the case of *An NHS Trust v Mr H, Mrs H, A Borough Council, CB and KH* [2012] EWHC B18 (Fam), Peter Jackson J was asked to make declarations in relation to an advanced care plan in which it was proposed to withhold life-sustaining treatment from KH in the event of a deterioration in his condition.

34. Interestingly, both Judges had regard to *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice* to which doctors often refer, although it is not a statement of law but rather a tool for ethical decision-making (para 11).

35. Peter Jackson J was inclined to use the Mental Capacity Act 2005 approach to assessment of best interests, than to adhere solely to the approach under the Children Act 1989 (paras 10 and 14).

36. Peter Jackson J dealt with robustly with the suggestion that the views of KH's parents, who both lacked capacity, would have little weight:

> *I readily accept that an involved and capacitous parent may be better placed to express views that assist in assessing best interests than one who is less involved or capacitous, but that is a matter of evidence and not one of principle. Parents who lack capacity may still make telling points about welfare and it would be wrong to discount the weight to be attached to their views simply because of incapacity. It is the validity of the views that matter, not the capacity of the person that holds them (para 16).*

37. Although Peter Jackson J approved the advanced care plan put before him, he was unwilling to make declarations in relation to circumstances which had not crystallised (paras 41 – 44).

Ms Rabone – another perspective, but a similar balance?

38. Looking at the issue of the end of life from a different perspective, similar themes emerge, but perhaps with a different emphasis in the decisions in *Rabone v Pennine Care NHS Foundation Trust* [2012] UKSC 2, [2012] 2 AC 72. Lord Dyson held that Article 2 involves:

> *... a general duty on the state "to put in place a legislative and administrative framework designed to provide effective deterrence against threats to the right to life" ... [and] the "operational duty" ... to take "preventative operational measures" to protect an individual whose life is at risk ...*
>
> *... there will be a breach of the positive obligation where: "the authorities knew or ought to have known at the time of the existence of a real and immediate risk to the life of an identified individual or individuals from the criminal acts of a third party and that they failed to take measures within the scope of their powers which, judged reasonably, might have been expected to avoid that risk (para 12)*

39. It is worth noting the key role that vulnerability plays a key role in a finding that such a duty arises under Article 2:

> *When finding that the Article 2 operational duty has been breached, the ECtHR has repeatedly emphasised the vulnerability of the victim as a relevant consideration. In circumstances of sufficient vulnerability, the ECtHR has been prepared to find a breach of the operational duty even where there has been no assumption of control by the state, such as where a local authority fails to exercise its powers to protect a child who to its knowledge is at risk of abuse as in Z v UK ... (para 23)*

This seems to fit with the caution that Judges demonstrate in finding that an individual has capacity to make a decision to end his life, or that it is in his best interests for it to be allowed to end. It is consistent with the approach taking to the law of assisted suicide and euthanasia, which tends often to focus on the risks that a change in the law would pose to the vulnerable.

40. On the other hand, Lady Hale, empahsised the contest between autonomy and the obligation to take steps to preserve life, even in this context:

> *People suffering from mental disorders have the same human rights as everyone else and are entitled to enjoy those rights without discrimination on account of their mental status. So we must start from the proposition that they are entitled to the same freedom and autonomy as everyone else, unless there is some justification within the scheme of the Convention for interfering in this (para 95).*
>
> ...
>
> *Autonomous individuals have a right to take their own lives if that is what they truly want (para 100).*

It remains to be seen whether arguments based on such concepts of autonomy or dignity will lead to any changes in approach in the near future.

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