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Albion Chambers COURT OF PROTECTION

Advance Decisions and the court's approach

The ability of a person with capacity who has reached the age of 18 to make Advance Decisions in respect of a refusal of treatment is contained within the Mental Capacity Act 2005, Sections 24-26. On the face of it, s.25 which covers the validity and applicability of Advance Decisions, makes it very plain when a decision is not valid.

25(2): An advance decision is not valid if P:

- has withdrawn the decision at a time when he had capacity to do so
- has, under a Lasting Power of Attorney created after the Advance Decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the Advance Decision relates
- has done anything else clearly inconsistent with the Advance Decision remaining his fixed decision.

Equally, it is plain that the treatment which is proposed and which may be objected to, must be specifically referred to in the Advance Decision, as is set out in subsection 4:

An Advance Decision is not applicable to the treatment in question if:

- that treatment is not the treatment specified in the Advance Decision
- any circumstances specified in the Advance Decision are absent
- there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the Advance Decision and which would have affected his decision had he anticipated them.

This applies equally to life-sustaining treatment as set out in s.5:

An Advance Decision is not applicable to life-sustaining treatment unless:

- the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk
- the decision and statement comply with subsection (6).

Subsection 6 provides:

A decision or statement complies with this subsection only if:

- it is in writing
- it is signed by P or by another person in P's presence and by P's direction
- the signature is made or acknowledged by P in the presence of a witness
- the witness signs it, or acknowledges his signature, in P's presence.

How have the courts approached this difficult area in practice?

Two extremely challenging, both intellectually and no doubt emotionally, decisions have been made in 2012 by Mr Justice Peter Jackson sitting in the Court of Protection. The first decision was that of *Re: D [2012] EWHC 885 (COP); [2012] COPLR 493*, in which an Advance Decision was made by a man in his early 50s who had developed a swelling in his thyroid gland which was thought might be malignant. He gave a signed letter to his sister-in-law when he was facing imminent surgery which read: *"To whom it may concern: I authorise [and then his sister-in-law's name and address] to act my behalf in the event of me being unable to make decisions for whatever reason. In particular, I authorise the above to liaise with the medical profession in making decisions regarding any further treatment. More specifically, I refuse any medical treatment of an invasive nature (including but not restricted to placing a feeding tube in my stomach) if said procedure is only for the purpose of extending a reduced quality of life. By reduced quality of life I mean one where my life would be one of a significantly reduced quality, with little or no hope of any meaningful recovery, where I would be in a nursing home/care home with little or no independence. Similarly, I would not want to be resuscitated if only to lead to a significantly reduced quality of life."*

Sadly, during an operation, he suffered a cardiac arrest as a result of which he suffered severe and irreparable brain damage and was being treated by the clinical team which included artificial nutrition and hydration and, for a period of time, artificial ventilation. It was considered by the clinicians that he was in a permanent vegetative state. An application was made by the NHS Trust to withdraw treatment and to allow for carefully planned palliative care, which would lead to his death. The application was supported by all medical staff who had clinical responsibility for him, his family and friends, expert witnesses and the Official Solicitor representing the person.

In relation to the Advance Decision as set out in the letter, the court found that this did not comply with s.25(5) and s.25(6). It is clear from the terms of the letter written that there was no reference to artificial nutrition and hydration being provided as treatment to sustain his life.

The judgment does not go on to consider whether, if the letter had referred to either him being in a minimally conscious state (MCS) or a permanent vegetative state (PVS) this would have sufficed to be considered a valid Advance Decision. No issue was taken as to whether the person did or did not have capacity at the time he wrote the letter or in fact that his sister-in-law had witnessed his signature on the letter. However, in a profoundly humane judgment, Mr Justice Jackson at paragraph 18 summarised in six short points the reasons why the declaration sought was granted.

It is equally important to note that two special studies had been carried out to analyse observations on a continuous basis, namely the WHIM assessment (the Wessex Head Injury Matrix) and the SMART system (Sensory Modality Assessment and Rehabilitation Technique) – both of which confirmed the patient's PVS status, with expert evidence provided that the prospect of recovery was really, really low and even this occurred, it would be at an absolutely minimal level involving no more than a minute or so every month or so of awareness of the most basic kind.

So it can be seen from the above case, that whilst the Advance Decision was not upheld as it fell foul of the provisions of s.25 of the MCA 2005, it appears to have been considered as part of the overall evidence in the case in informing the Judge and leading to his conclusion. It must be stressed, though, that in this particular case the medical evidence appeared to be overwhelmingly in support of the declaration being made.

By way of contrast, Mr Justice Jackson also provided the court with guidance later in 2012 in the case of *A Local Authority v E and Others [2012] EWHC 1639 (COP); [2012] COPLR 441.*

The facts of this particular case were very different to that of the earlier case involving the facing of surgery. It highlights, in my view the "kid-gloves" approach adopted by the courts to mental health issues within COP.

The case of E involved a woman who suffered from anorexia nervosa and other chronic health conditions in the most severe form. In July 2011, she signed a document saying she did not want to be resuscitated or to be given any medical intervention to prolong her life. A further Advance Decision was made by her in October 2011 stating that if she was close to death she did not want tube feeding or life support, but would accept pain relief and palliative care. On the day she signed it she was also admitted to hospital pursuant to section 3 (the provision of treatment) MHA1983. In March 2012, she was further detained under the Mental Health Act pursuant to s.3 and was initially tube fed, but when she opposed this the tube feeding was stopped. On 20 April she was admitted to hospital for palliative care and placed on an "end of life" care pathway with high doses of opiate medication to which she was physically addicted.

Proceedings were instituted on 18 May 2012 when the local authority made the application to the Court of Protection. At this stage, E was not subject to the provisions of the Mental Health Act. The options available for the court was either that there should be no intervention other than palliative care until she died from starvation, or a transfer to an intensive care facility in a specialist unit for the treatment of advanced eating disorders, where she would be stabilised and fed through a naso-gastric tube or PEG inserted through the stomach wall.

Mr Justice Jackson whilst considering the presumption that E has capacity (on the balance of probabilities considering s.1(2) and 2(4)), considered that E lacked the capacity in her current situation. In terms of E's Advance Decisions, the judge concluded that E had lacked capacity to make the Advance Decision in July 2011 and that whilst the formalities required in s.25 were complied with in relation to the formal Advance Decision witnessed by her mother and a mental health professional in October 2011, the learned judge decided that at the time the decision was signed, on the balance of probabilities E did not have capacity.

The judge in his judgment refers to the fact that on the day the Advance Decision was signed in October 2011, E was again placed under the Mental Health Act and received into the care of a mental health professional for assessment. The receiving physician did not deal specifically with the question of capacity, but the learned judge said: *"but his general approach can be deduced from the fact that he recommended treatment, despite recording E's opposition very fully"*. It seems to me that this is stretching to the limits the issue of capacity. Equally there is no mention in the judgement of a T2 via a SOAD in respect of treatment. Very few patients detained under the Mental Health Act lack capacity, and of course under the Mental Capacity Act 2005, whether a person lacks capacity or not is issue and time specific. The court does appear to have considered the functional approach on the issue of capacity as set out in s.2 and s.3. However, the court, in determining that E lacked capacity, was then able to reach the conclusion that E lacked capacity to accept or refuse treatment in relation to any interventions that are necessary in conjunction with forcible feeding.

The judge went on to consider the best interests factors and conducted a balance-sheet approach, and it does appear that the preservation of life was at the forefront of his mind. Indeed, at paragraph 119 he refers to the EHCR and states: *"It is the most fundamental of the Convention rights"*. He balances this out with considerations of the reported case of Airedale NHS Trust v Bland [1993] AC 789, and also reflects the MCA code of practice, paragraph 5.31, in which it is stated "All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery".

However, the judge weighed the competing factors, concluding in paragraph 140: "The competing factors are, in my judgement, almost exactly in equilibrium, but having considered them as carefully as I am able, I found the balance tips slowly but unmistakably in the direction of life-preserving treatment. In the end, the presumption in favour of the preservation of life is not displaced".

It can therefore be seen that even where on the face of it there is a valid Advance Decision, the courts can, in effect, look at the circumstances which pertain at the time that decision is applicable and reach a different conclusion. In effect, the court utilises the power in s.25(4)(c) even where the issue relates to life sustaining treatment.

PVS and MCS – how the law differentiates between the two

Mr Justice Baker's decision, reported in *W (by her litigation friend B) v (1) M (by her litigation friend, the Official Solicitor), (2) S and (3) An NHS Primary Care Trust [2011] EWHC 2443 (Fam); [2012] COPLR 222*, looked carefully at the position where a person is in a state of PVS and where they are in a state of MCS.

The court determined the application by deciding whether the withholding/withdrawal of life sustaining treatment, including ANH, was in the patient's best interest by reference to s.4 of the MCA 2005 and the authorities deriving from *Airedale NHS Trust v Bland [1993] AC 789, HL*. Mr Justice Baker decided that there was no rationale for extending the approach adopted by the House of Lords in Bland to non-PVS cases. Indeed, Lord Gough in Bland had specifically distinguished between cases in which, having regard to all the circumstances, it may not be in the patient's best interests to continue treatment and cases in which a patient was permanently insensate and thus unable to benefit from all the treatment. Lord Gough had observed: *"in both classes of case, the decision whether or not to withhold treatment must be made in the best interests of the patient. In the first class, however, the decision has to be made by weighing the relevant considerations. There is no justification for introducing a requirement of clinical instability before embarking on a balance sheet approach in MCS cases. To do so would introduce an impermissible gloss on the best interest test, and undermine the clear requirement laid down in s.4 of the MCA to consider all the relevant circumstances when determining best interests. It would also lead to a lengthy satellite argument as to the meaning of "clinical instability" and the diversion of legal and medical resources into determining that issue"*. Mr Justice Baker went on to consider that if in fact a patient is demonstrating what may be seen as the components of clinical instability, that is unquestionably an important factor to be taken into account in the balance sheet analysis itself, and the learned judge gave the example of a patient not experiencing undue pain or discomfort and not suffering from any acute illnesses and seems psychologically settled, and thus the longer the patient demonstrated those kinds of symptoms, the greater period of clinical stability and the more weight to be attached to those factors in the balancing exercise.

This was, however, the first case where an application was made to withhold or withdraw ANH from a patient diagnosed as being in a MCS. As a result, Mr Justice Baker made a number of observations which were approved by the President of the Court of Protection which were designed to assist in future applications for the withdrawal of ANH:

- Such a case must be referred to the court – COP Practice Direction 9E, paragraph 5. Applications must be made to a High Court Judge and must be, as a matter of good practice, allocated at the earliest opportunity to one judge who will be responsible for case management and ultimately conduct the final hearing.

■ It is crucial that the proper assessment tools are utilised, those of SMART and WHIM. Cases may be misdiagnosed if those tools are not used (in W, the patient was in fact first diagnosed as being in VS and some time after the application was made, the SMART test administered and disclosed in fact the patient was in MCS). Thus, every step should be taken to diagnose the patient's true condition before any application is made to the court, and as such there should be formal testing in the form of SMART diagnosis test, coupled with WHIM tests carried out over a period of time. Accordingly, no order for the authorisation of withdrawal of ANH from a patient in VS or MCS should be made unless (i) a SMART assessment (or similarly validated equivalent) has been carried out to provide a diagnose the patient's disorder of consciousness; and (ii) in the case of a patient thereby diagnosed as being in MCS, a series of WHIM assessments have been carried out over time with a view to tracking the patient's progress and recovery (if any) through MCS.

■ The court was alarmed that public funding was not available to members of the family to assist them in making the application (in Re: W, the advocates acted pro bono). The court requested that consideration should be given to extending the rights to non-means tested public funding to family members seeking to bring this type of application, and also to applications for the withdrawal of artificial nutrition and hydration.

■ Such applications should be heard in open court, but subject to a reporting restriction order that prevents identification of the patient's family members, care home and its staff. The court considered it was imperative that the press should be as free as possible to report cases of this sort, as the issues are of fundamental importance to all of us, collectively and individually, so that society as a whole could consider this debate.

How does this leave practitioners?

As it was once famously said: *"there are two things in life which are certain – death and taxes"*. Here, looking at the former, there does need to be an open public debate as to how and in what manner people receive end of life care. On the face of the act, drawing up an Advance Decision is quite a simple matter. However, as can be seen from the authorities, the implementation of such decisions is not always a straightforward matter. It appears that the courts will go to great lengths to preserve life. This has been graphically exemplified in the battle held by Tony Nicklinson who suffered from "locked in syndrome".

Arguably, is there merit in making an Advance Decision if the court considers the provisions of s.25(4)(a) and (c) are considered in such a way, and in particular the "changed circumstances" applicable in (c), that such a decision is voidable? Are people simply left to place an application before the court arguing best interests and having to rely upon the "balance-sheet" approach? Should the courts authorise a pro forma form in which there is a list of treatments which can be ticked yes or no by the individual making the Advance Decision so as to prevent the families of people who come within the Court of Protection seeking a remedy where they believe that their loved one has, in fact, made an Advance Decision, only to be told that it does not comply with the criteria in s.25. Clearly there needs to be a public debate about these issues so as to provide a level of certainty for those who wish to have control and self determination of the end of their lives to as opposed to being controlled by others, through the auspices of the court.

Claire Wills-Goldingham

Statutory Wills - principles

The power to make statutory will derives from the Mental Capacity Act section 18(1)(i). Schedule 2 paragraphs 1-4 provides guidance on what can be achieved by an application for a Statutory Will.

Although the Court has the power to make a Will for a person under the Act, it is only exercised within the legislative framework. The powers of the Court are subject to a number of conditions:

■ the powers are only exercised where P lacks capacity to make a decision to a particular matter (section 16 (1))

■ the decision or order of the Court must be made on P's behalf (section 16 (2)(a))

■ the powers of the Court are always subject to section 1 (principles) and 4 (best interests) of the Act (section 16 (3)).

These conditions lead to a number of consequences which help to explain the nature of a Statutory Will, the form it takes, and how the Court exercises its jurisdiction.

Lack of Capacity

It is a fundamental principle of the Act that a person's capacity to make a decision is specific to the decision itself. The Court cannot proceed until it has medical evidence on P's capacity. Whilst the test for mental capacity under Section 3 of the Act can be viewed as a modern restatement of the test propounded in *Banks v Goodfellow* [1870] 5QB 549, Banks is still regarded as the test for testamentary capacity: see *Scammel v Farmer* [2008] EWHC 1100 (Ch)). The underlying principle of establishing testamentary capacity is that, the testator's mind must go with his testamentary act. If the deceased did not have testamentary capacity he could not have known and approved the contents of his will. In Banks Cockburn C.J stated at p.576:

'It is essential…that a testator shall understand the nature of his act and its effects; shall understand the extent of the property of which he is disposing; shall be able to comprehend and appreciate the claims to which he ought to give effect, and, with a view to the latter object, that no disorder of the mind shall poison his affections, pervert his sense of right, or prevent the exercise of his natural faculties, that no insane delusion shall influence his will in disposing of his property and bring about a disposal of it which, if his mind had been sound, would not have been made'.

Decision made on P's behalf

It is important to understand that where the Court authorises a Will on behalf of someone who lacks capacity, it is an actual Will that is being made. The law relating to the form and the execution of the Will applies to a Statutory Will as it does to any other Will, except that the Statutory Will is being made on behalf of P (see: Section 9 of the Wills Act 1837).

As long as the Statutory Will is properly executed by someone authorised by the Court, the Statutory Will has the same effect for all purposes as if P had capacity to make a valid Will (see: Schedule 2, paragraph 4 (3)).

Is it in P's best interests?

The Act has introduced a new approach to making decisions and in particular whether or not a decision is in P's best interest. Section 4 requires the person making the determination to consider a number of factors and all the relevant circumstances.

In *Re P* [2009] EWHC 163 (COP), Lewison J at paragraphs 37 to 44 held that the statutory test of best interest must be applied in Statutory Will applications. Previous to the Act, the Court had to do what P himself might be expected to do if he had not been mentally disordered - this was known as the 'substituted judgement approach'. The Act does not contain this statutory instruction. The Court is not now looking for a result based on a hypothetical degree of capacity; it is, instead, taking P as it finds him at the present moment, and then acting in his best interest, in the same way as any other decision made on behalf of a person without capacity.

In *Re P* at paragraph 44, Lewison J stated as follows:

"...In deciding what provisions should be made in a Will to be executed on P's behalf and which, ex hypothesi, will only have effect after he is dead, what are P's best interests? Mr Boyle stressed the principle of adult autonomy; and said that P's best interests would be served simply by giving effect to his wishes. That is, I think, part of the overall picture, and an important one at that. But what will live on after P's death is his memory; and for many people it is in their best interests that they be remembered with affection by their family and as having done "the right thing" by their Will. n my judgement, the decision maker is entitled to take into account, in assessing what is in P's best interests, how he will be remembered after his death."

In addition to the principles set out in Section 4 of the Act, the Court must now also take into account, when assessing P's best interests, how he will be remembered after his death.

The authorities were further considered by Morgan J in *Re G(TJ) [2010] EWHC 3005 (COP)*. This case concerned maintenance payments by P to her daughter. The focus of the decision was to what extent the court should have regard to its own view of the decision that P would have made had she had the capacity.

At paragraphs 34 to 38 Morgan J provides an insightful opinion on what is the meaning of 'best interest'. In particular at paragraph 37 he states:

"The court is not obliged to give effect to the decision which P, acting reasonably, would have made (the test of 'substituted judgement') but section 4(6) appears to require the court to consider what P would have decided (or, at least, the balance sheet of factors which P would be likely to have considered). My provisional view is that, in an appropriate case, a court could conclude that it is in the best interest of P for the court to give effect to the wishes which P would have formed on the relevant point, if he had capacity."

At paragraph 55 and 56 he summarised the authorities and his understanding of what is the 'best interests' test:

"55. ...it is absolutely clear that the ultimate test for the court is the test of best interests and not the test of substituted judgment. Nonetheless, the substituted judgment can be relevant and is not excluded from consideration. As Hoffmann LJ said in the Bland case, the substituted judgment can be subsumed within the concept of best interest...

56. Further, the word "interest" in the best interests test does not confine the court to considering the self interest of P. The actual wishes of P, which are altruistic and not in any way, directly or indirectly self-interested, can be a relevant factor. Further, the wishes which P would have formed, if P had capacity, which may be altruistic wishes, can be a relevant factor. It is not necessary to establish that P would have been aware of the fact that P's wishes were carried into effect. Respect for P's wishes, actual or putative, can be a relevant factor even where P has no awareness of, and no reaction to, the fact that such wishes are being respected."

Therefore 'best interests' decisions can be based on an element of 'substituted judgement' as they are 'subsumed into the consideration of best interest.' (see: paragraph 65.).

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