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THE TRICKY MATTER OF ASSESSING CAPACITY AND THE WOMAN WHO LOST HER SPARKLE

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Patients who have capacity are able to make medical treatment decisions for themselves. The by-product of this is that a competent patient can refuse treatment, even where that treatment is life-saving and even where others might consider that refusal irrational or foolish. [1]

The legal test for assessing capacity to consent to or refuse treatment is set out in this article - 'The substitute decision-maker: a guide for health care providers'. The basics are that the patient should be able to understand and agree with what is being proposed.

If capacity is in dispute, it is important to have a psychiatric evaluation of the patient. A second opinion can be offered. If the patient appears to be lacking in capacity simply because they are unable to communicate their decision, consideration can be given to obtaining input from a speech and language therapist who may be able to assist.

When the hardest decisions of all, those around life and death, are hanging in the balance, the treatment provider needs to ensure that those decisions are validly made.[2] *No treatment provider wants to be before the coroner or their regulating body explaining why treatment wasn't rendered to a patient who may have been lacking in capacity when they refused it. In very rare cases, approaching the courts may be the only way to ensure that all parties' rights are properly safeguarded.*

A life that sparkles

The author represented a hospital in the UK in 2015 in a capacity and best interests treatment decision involving a woman who became known in the media as 'the woman who lost her sparkle'.

The patient was 50 years old when she attempted an overdose on the beach with some tablets and a bottle of champagne. Her attempt was unsuccessful and she was taken to an acute liver unit for treatment. She had also suffered kidney damage and required dialysis for a prolonged period. Her prognosis was for an eventual full recovery.

For the first couple of months the patient complied with dialysis treatment, however she then began to complain that she did not want further invasive treatment and should be left to die. Her reasoning for this was erratic, but seemed to focus on what she perceived as the loss of her quality of life. She did not want to become 'old and ugly'.

The hospital's psychiatric team was called to assess the patient and she was seen by an highly

experienced and leading psychiatrist. Her reasoning was thought to be flawed, as it was based on some denial on her part of the good prognosis she had been given. She was also very eccentric and assessed as likely having a narcissistic personality disorder that might impinge on her ability to make treatment decisions. She was thought to place undue emphasis on superficial considerations, whilst not considering her potential for recovery and the feelings of her family and friends. A second opinion was obtained, which was supportive of the initial one.

The hospital's dilemma

This may have been a situation that could have been worked through had it not been for the following:

1. Very unusually, the patient's own daughters came forward to say that they believed their mother had capacity and, although it was an awful decision for them, she should be allowed to refuse life-saving treatment. They said that their mother had always been capricious and that her decision to die was in keeping with her personality. So there was a very real dispute about capacity.
2. Forcing someone to have dialysis against their will, particularly for a prolonged course of treatment, is highly invasive and difficult for the treating clinicians to countenance. It would involve chemical and perhaps physical restraint. In light of this, and the patient's adamancy that she would not accept dialysis, what was in the patient's best interests was also not clear.

The hospital now had a problem that could no longer be talked through amongst the parties, and it was felt that the only way to obtain a proper determination that protected the patient, her family, and the hospital was to ask the Court of Protection sitting in the High Court to make a determination on capacity and, in the event it was lacking, best interests.

A difficult and controversial decision

The hearing was held over several days. The testimony of one of the patient's daughters was extremely persuasive - she told the court that her mother's life had 'to all appearances' been fairly glamorous, and that her mother did not want to be 'poor, ugly or old'. Her mother 'has said the most important thing for her is her sparkly lifestyle'. The daughter said that her mother 'kept saying she doesn't want to live without her sparkle and she thinks she has lost her sparkle.'

In a controversial finding, the court preferred the evidence of the patient's daughters over that of two psychiatrists who had assessed a lack of capacity (a psychiatrist instructed by the Official Solicitor who was acting independently on the patient's behalf had his evidence discredited as he had interviewed the patient after she had received opiate medication). So effectively the court went against all of the medical evidence on capacity before it and found that the patient was competent to refuse dialysis.[3] The court held:

'C is a person to whom the epithet 'conventional' will never be applied... C has led a life characterised by impulsive and self-centred decision-making without guilt or regret. [She] has had four marriages and a number of affairs and has, it is said, spent the money of her husbands and lovers recklessly before moving on when things got difficult or the money ran out. She has, by their account, been an entirely reluctant and at times completely indifferent mother to her three caring daughters. Her consumption of alcohol has been excessive and, at times, out of control... In particular, it is clear that during her life C has placed a significant premium on youth and beauty and on living a life that, in C's words, 'sparkles'.'

Active treatment was withdrawn and the patient was transferred to a hospice. She died a few

weeks after the final hearing.[4]

It was certainly the author's view, and also that of all of the treating team (including the medical team providing dialysis) that it was imperative that the court was able to adjudicate on these issues. The psychiatric evidence was too complex, and the stakes too high, to just have kept fingers crossed and hope the correct outcome was reached.

The full decision can be read here:

[1] *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84

[2] In an interesting case reported by the Medical Journal of Australia in 2014, a woman's sons consented for thyroid surgery on her behalf when she refused it on the basis that in her native Sicily, scarring to the neck indicated mafia throat –slitting. She was found to lack capacity to refuse the life-saving operation: https://www.mja.com.au/journal/2014/201/8/consent-capacity-and-right-say-no

[3] http://www.bbc.com/news/uk-34985442

[4] https://www.theguardian.com/law/2015/dec/02/woman-refused-treatment-losing-sparkle-dies

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