Consent to treatment—autonomy of disabled persons (B v D (by his litigation friend, the Official Solicitor) and another)

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Private Client analysis: How did the Court of Protection (CoP) decide on the best interests of a man who suffered brain injuries in relation to receiving stem cell treatment? Sophia Roper, barrister at Serjeants' Inn Chambers considers the case of B v D (by his litigation friend, the Official Solicitor), and says while it makes no new law, it may well pave the way for more cases of this kind in the future if followed.

Original news

B v D (by his litigation friend, the Official Solicitor) and another [2017] EWCOP 15

Provisional consent was given by the CoP for D, a member of the British Army who had sustained a serious brain injury while serving abroad, to travel to Belgrade to receive stem cell treatment following an assessment of the advantages and disadvantages of giving and refusing consent. Ultimately, it was held that there was a strong argument that D's safety, in not giving consent for the treatment, might be brought at too high a price in terms of his happiness and emotional welfare.

What is the significance of this case?

In a case that had all the makings of 'an adult Charlie Gard', a mother (B) was applying to take her brain injured son (D) abroad where he would pay for an experimental or pioneering (the terminology depends on one's viewpoint) procedure in the hope that his serious brain injury would be cured. His treating doctors in England were opposed to the treatment, which had not reached the stage of clinical trials in the US or Western Europe, and there was little if any research evidence in the international literature which showed that this procedure might work for D's particular condition.

The Official Solicitor (who was substituted for the mother as litigation friend once proceedings were commenced) was of the view that the treatment was not in the patient's best interests and so resisted the application.

Yet the similarities end there. D was 27, an adult, who had sustained a traumatic brain injury in an assault some four years previously. Despite his 'very significant disabilities, including extensive physical disabilities, and global cognitive impairments...reduced attention, concentration, information-processing capacity, memory, executive functioning', he appears to have been cognitively relatively high functioning.

Most importantly, D could express his own wishes and feelings forcefully. D told the judge that he wanted to undergo the procedure because he believed it would 'make him normal'—he had the money to pay for it (from his personal injury award), and he desperately wanted to go.

Mr Justice Baker held that, subject to certain conditions being met, the procedure would be in D's best interests, and so his travel abroad for the procedure could be further pursued. In doing so, he placed D's wishes and feelings at the very heart of the case, giving them preference to the views of the professionals involved in the case both as treating clinicians and as experts.

The judgment will stand with *Wye Valley NHS Trust v B* [2015] EWCOP 60, [2015] All ER (D) 04 (Oct), for its humanity and as an example of judicial respect for the autonomy of a disabled person rendered unable to make his own decisions. It may, however, have some unfortunate unintended consequences if it leads (or misleads) other vulnerable people into believing that there is some kind of miracle cure out there for their brain injury that their English doctors have been keeping from them.

How helpful is this judgment in clarifying the law in this area?

Although the judgment makes no new law, cases expressly considering the assessment of capacity in detail are relatively rare, and it is interesting that the judge specifically recorded D's treating neuropsychologist's reasons for considering that he lacked capacity to make decisions about his medical treatment (although these do not form part of his judgment, capacity not being in issue).

The neuropsychologist said that D was 'not able to follow the description or the rationale of how [the proposed stem cell treatment] might work'. It could reasonably be said that this sets the bar too high for capacity to make decisions about medical treatment—many capacitated people cannot follow precisely how the treatment which their doctors propose for them will work, nor do they need to do so to decide whether or not to have it. However, D's treating neuropsychologist also said that his 'rigid thinking patterns made it impossible for him to think flexibly about the pros and cons of the

treatment', which is within the direct scope of section 3(4) of the Mental Capacity Act 2005 (MCA 2005), and therefore sufficient to found a conclusion of lack of capacity in this case.

The importance of ascertaining and giving proper weight to D's own wishes and feelings under MCA 2005, s 4(7), is emphasised. This is not new, but fits with the general direction of travel we have seen in the CoP since the Supreme Court's determinations in *Aintree University Hospitals NHS Foundation Trust v James and others* [2013] UKSC 67 and more recently in *Briggs v Briggs (by his litigation friend, the Official Solicitor) and others* [2016] EWCOP 53, [2017] All ER (D) 02 (Jan). This is however a very good example of how the *Aintree* effect leads to D's decision for himself (albeit an incapable one) being upheld and supported by the CoP properly recognising that autonomy should not end with a finding of lack of capacity.

It is also interesting to note that D was found to be suggestible, and that as his mother had told him the treatment would make him 'normal', he said he would do it. In the instant case, the judge found that the views expressed by D were 'genuinely his own', but this is likely to be a source of debate in future cases if greater weight is routinely placed on an applicant's wishes.

People making big decisions often talk to their friends and family in the hope that this will help them decide, and may be entirely convinced by the strength of argument or feeling of someone they love or respect. Incapacitated people who can hold such conversations will no doubt do likewise. To what extent, if any, therefore, should the weight given to a person's views be reduced because he is influenced by the views of other people to whom he is close?

What are the practical implications of the judgment?

Practitioners engaged in proceedings concerning novel forms of treatment should not assume that the court will necessarily follow the recommendations of the expert with the biggest reputation. It is a long time since anyone thought that the CoP would always prioritise medical best interests over the more holistic best interests which are contemplated by MCA 2005, s 4(6).

But this decision reminds us that, just as a capacitated person can make an unwise decision, so can the MCA 2005 and the CoP endorse what objectively may be an unwise decision, simply because it is the decision which an applicant wants to be allowed to make.

Those acting for such applicants will be encouraged by the decision—it gives hope to those whose clients want things which may not be terribly good for them, and which may entail taking risks. The spirit of the decision goes well beyond the (extremely narrow) scope of experimental treatment, and can be applied to other and more common problems faced by the CoP, eg:

- an applicant who wishes to live at home despite a mass of professionals saying this is not safe
- an applicant who wants to dispense with at least some of the care which professionals think is needed, and
- an applicant who wants to live or have contact with someone who professionals say is no good for them

Do you have any predictions for future developments in this area?

Despite there being no new law nor fresh application of legal principle here, the practical implications of the judgment are potentially far-reaching for cases involving unproven treatments.

The procedure in question was 'autologous stem-cell therapy'. Stem cell treatments are routinely used and have proven efficacy for certain types of condition, but traumatic brain injury is not one of them. There was no scientific evidence that the procedure being proposed would have any effect on someone like D who had suffered a traumatic brain injury.

The particular treatment proposed was unlicensed and unavailable in Western Europe or the US, but was provided at private clinics in Moscow and Serbia. The 'chief doctor' of the clinic had carried out many successful stem cell transplantations, but fewer on people with D's problems. He told the judge that of these, about 20% had significant improvements to their physical and cognitive disabilities and quality of life, and 60% had some improvement in cognitive function.

Neither the doctor nor the clinic had yet published any research papers, nor did they provide the court with documented outcome data regarding this treatment to support this impressive success rate. The doctor cited two research papers in his written reports, but one related to a different type of stem cell treatment and the other suggested that there was 'minimal pre-clinical evidence of benefit when stem cells were delivered more than one week after traumatic brain injury' (D's injury had occurred four years previously).

The doctor accepted in oral evidence that there were risks associated with the treatment, but said these were small, and agreed that his clinic did not follow the European guidelines regarding stem cell treatment, although he said the differences in procedure were insignificant. He himself had not met or assessed D, nor read his medical records, nor spoken to any of his clinical team, but based his advice that D was suitable for stem cell treatment on a questionnaire completed by his mother and a single medical report.

The court also heard from a professor of experimental biology at the University in Milan, a widely recognised expert in the use of stem cell therapy as a treatment for multiple sclerosis and other disorders of the central nervous system. He had been working on brains with stem cells since 1995 and was currently involved in a clinical trial involving brain stem cells. The professor was severely critical of the proposed procedure, saying that there was no pre-clinical and clinical scientific evidence that it could benefit D's permanent neurological damage, and that there was insufficient evidence to rule out short- or long-term side effects, including tumour formation. He contrasted the areas where stem cell treatment was routine as being ones where 'real and reliable' research data was available, saying that there was no published research to support the clinic's arguments.

Both the Ministry of Defence (the other party opposing the application) and the Official Solicitor preferred the evidence of the independent expert, and therefore opposed the application of D's mother. A judge is of course entitled to prefer the evidence of one expert over another. Both experts gave evidence by phone via an interpreter, but he had the advantage of hearing them and so evaluating their credibility.

It is surprising, however, that the judge went beyond what was necessary to find that it was in D's best interests to have the treatment, and accepted the evidence of the clinic doctor that 80% of those treated showed some improvement. A High Court judge's finding of such an extremely high success rate in treating brain injury is a significant endorsement that may have ramifications beyond this case.

'Stem-cell tourism' is already a recognised phenomenon, with clinics in Eastern Europe selling therapy to desperate people for a sweeping catalogue of diseases. This finding may lead to many more such cases being brought in the future.

Interviewed by Alex Heshmaty.

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