

Neutral Citation Number: [2021] EWCOP 11

Case No: 13703893

COURT OF PROTECTION

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 27/01/2021

Before:

THE HONOURABLE MRS JUSTICE LIEVEN

Between:

THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

- and -

Robert Bourn (by his litigation friend, Sharon Bourn)

Respondent

Applicant

Miss Emma Sutton (instructed by DAC Beachcroft LLP) for the Applicant Mr Parishil Patel QC (instructed by Irwin Mitchell LLP) for the Respondent

Hearing dates: 27 January 2021

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MRS JUSTICE LIEVEN

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the hospital concerned and the treating doctors and the entire medical team must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mrs Justice Lieven:

- 1. This is an application brought by the Newcastle upon Tyne Hospitals NHS Foundation Trust in respect of a young man, Robert Bourn. Robert is aged 30 and is under the care of the Trust in respect of his oncology care. Robert proceeds by way of his Litigation Friend, Sharon Bourn, who is his mother. The Trust is represented before me by Miss Sutton and Mrs Bourn is represented by Mr Patel QC. I am very grateful to both of them for all of their assistance.
- 2. The issue before me in this case is whether the form of cancer care set out by the Trust is in Robert's best interests and whether I should make a declaration to that effect under the Mental Capacity Act 2005. Happily, in the course of the hearing, having heard evidence from three medical clinicians Mrs Bourn has accepted that the treatment plan is in Robert's best interests and that in fact the matter is now agreed. However, both parties agree that it would be sensible for me to continue to give a short judgment.
- 3. The background is that Robert has a diagnosis of Fragile X Syndrome, a genetic condition causing learning disabilities which affects something like 1 in 4000 boys and men. He also has atypical severe autism, dysphagia and has limited verbal communication. He lives at home with Mrs Bourn and his father and brother and has a package of care.
- 4. On 27 September 2020, Robert was diagnosed with testicular cancer and on 8 October that year underwent surgical removal of his left testicle, a procedure called an orchidectomy. Sadly, following a CT scan on 10 December 2020, it became apparent that the cancer had spread into Robert's lymph nodes and that his presentation was consistent with metastatic germ cell cancer. In general terms, this is a highly curative type of cancer using chemotherapy. It is proposed by the Trust that chemotherapy will start tomorrow. It is agreed by all sides that without treatment Robert will be likely to die within a year and therefore the "do-nothing option" is not an option on the facts of this case.
- 5. It is important to record that despite the various problems that Robert has, he is described by his treating Oncologist as being a "fit lad with no physical difficulties". This is important because for a number of aspects of the chemotherapy, as other than the difficulties I have set out, Robert is a 30 year old man with no other physical problems.
- 6. This application was made by the Trust on 14 January 2021 under the Mental Capacity Act 2005 for personal welfare orders relating to serious medical treatment. I have heard evidence from three clinicians, two of them treating clinicians, the first being Dr X, Consultant Oncologist at the Trust Hospital and secondly, Dr Y, a Critical Care Consultant at the Hospital. Thirdly, I heard evidence from Professor Z, who is a Professor of Oncology practicing at The Royal Marsden in London and Surrey and who was asked to provide a second opinion in this case.
- 7. The legal issues I can deal with extremely briefly. As I said, this is an application under the Mental Capacity Act 2005. There is no issue that Robert does not have capacity to make decisions regarding his treatment. Dr X explains in his evidence that he sought to explain the situation to Robert, but that Robert did not and could not respond. Without any contest, I find that Robert does not have capacity.

- 8. The issues then becomes one of what is in Robert's best interests and I am asked to make a declaration under section 16 of the Mental Capacity Act 2005 that the treatment being proposed by the Trust is in his best interests.
- 9. The first line treatment for someone with Robert's condition (metastatic germ cell cancer) and aged under 40 is for chemotherapy consisting of Bleomycin, Etoposide and Cisplatin "BEP" chemotherapy. It is recorded in the evidence base that this regime has a potential cure rate of 95-98%. However, in Robert's case, because of his learning disability and inability to tolerate clinical interventions, there have to be variations from the first line treatment. In particular, to provide Robert with BEP would require long periods of general anaesthetic, some 70 hours for each of the three cycles proposed, to allow the IV infusion that would be necessary. Both of the treating clinicians and Professor Z freely accept that such prolonged general anaesthetic would not be acceptable. Therefore, it is agreed that one change to the first line treatment plan is that Cisplatin has to be replaced with a different chemical called Carboplatin, because that can be given in a much shorter time.
- 10. There were in evidence three outstanding issues as to the form of treatment Robert should receive. Professor Z, who was brought in to give a second opinion, was of the view that every effort should be made to provide Robert with treatment that is as close to the standard procedure as possible. This was to maximise the prospects of the treatment being successful. He proposed three changes to the treatment plan the first being that rather than four cycles of chemotherapy, Robert should start with an operation on his lymph nodes, called retroperitoneal lymph node dissection surgery, with the acronym of "RPLND". Secondly, there was an issue around whether the Etoposide should be given orally or by IV infusion under general anaesthetic. The third issue was whether Robert should be given Bleomycin.
- 11. I will deal quite briefly with each of these issues in turn. As far as the operation is concerned, Professor Z was concerned that because Cisplatin has to be replaced by Carboplatin, which is somewhat less efficacious, it was important in order to maximise the prospects of Robert's cure that he should start by having an operation and then have two cycles of chemotherapy. The evidence was that if Robert was to have the operation in Newcastle, it would have to be an open operation, which has a prolonged recovery period. Dr X and Dr Y both suggested something in the order of seven days in hospital and that this would be extremely difficult for Robert to tolerate and could arguably be rejected on that ground alone.
- 12. However, at The Royal Marsden, these operations can be carried out robotically with quicker recovery time and in a less invasive way. Professor Z investigated with his colleagues if this would be possible and confirmed that it was certainly surgically possible on Robert's condition. However, the view of those surgical colleagues was that such surgery would need to be carried out before chemotherapy because the surgery would be less likely to be successful after the chemotherapy.
- 13. There is a real issue, or would have been, if Mrs Bourn's position had remained that surgery ought to be considered, of whether or not The Royal Marsden would be able to take Robert at the present time, or how quickly if at all. There is also the issue around Robert having to travel to the South East with or without his mother and stay there for at least some little time. So it was by no means clear that the operation at The Marsden would have been a realistic prospect, within the requisite time period.

- 14. If I had thought that there were real benefits, I would have considered adjourning for further investigations to be undertaken with The Royal Marsden. However, in my view, the evidence (even before Mrs Bourn's acceptance) pointed towards the conclusion that there would be little benefit to Robert in going down the operation route and having two cycles, rather than remaining in Newcastle providing the four cycles of chemotherapy. There is necessarily an element of the unknown regarding whether Robert will be able to tolerate four cycles of gruelling chemotherapy treatment. However, Robert is physically in no different condition to any other fit and healthy 30 year old man and therefore there is a high level of optimism that he will be able to tolerate it. In those circumstances, there is no basis in my view to pursue the surgical route rather than stay with the Trust's treatment plan of four cycles of chemotherapy.
- 15. Turning to the two issues that relate to chemotherapy, both of which are now agreed by Mrs Bourn. In terms of the Etoposide, the issue is whether this should be given intravenously under general anaesthetic or orally. Because Robert will not tolerate clinical interventions, the giving of Etoposide intravenously necessarily involves general anaesthetic. Professor Z raised two issues and concerns first of all, it was his experience that giving Etoposide IV was the standard route for this treatment and he was concerned firstly, that if the drug was given orally, it might be difficult to ensure Robert was taking the full dose and secondly, whether the absorption rates remained the same.
- 16. Dr X gave evidence first, that in relation to the absorption rates, if the dosage was slightly tweaked then sufficient absorption rates could be achieved, even if the drug was given orally. He also confirmed that it was now standard in Newcastle to give Etoposide orally and in the main this appeared to work well. He confirmed he could place the medication in sufficiently small capsules meaning Robert would take four or five a day and this in all likelihood would make it acceptable for Robert to take. He also said that if taking them did not work, then a liquid form of the drug was an option (which is used for children) and could be made available, which he thought also could work. Both Dr X and Dr Y agreed that if Robert could not tolerate the Etoposide given in either of these ways then they would consider giving it intravenously under general anaesthetic. I am confident however that as far as that is concerned it is right to proceed at this stage with giving Etoposide orally.
- 17. The final issue is that of Bleomycin. As I have said already, that is part of the normal chemotherapy regime for this form of cancer. However, Bleomycin has some very serious risks and side effects related to it. In particular, it creates a risk of pulmonary toxicity in a proportion of cases which causes acute inflammation of the lungs and make it easier for the lung lining to be breached. This in turn can lead to acute respiratory distress syndrome or "ARDS", which in 10% of cases can lead to death. I note that Robert does not have any of the risk factors which put people at particular risk when Bleomycin is given. However, once Robert has had the Bleomycin and the first round of general anaesthetic, the risks to him of any subsequent doses does go up I think, quite significantly.
- 18. In those circumstances, and combined with the circumstances of the current Covid pandemic which means that if some patients had contracted Covid the risks relating to Bleomycin go up very considerably, the position of the hospital for all patients with Robert's condition and underlying lack of risk factors, is that they are not giving Bleomycin at the current time to those in his position. Professor Z was concerned that

if Bleomycin was not given in Robert's case, this could lead to a material 10% reduction in the likelihood of chemotherapy achieving a cure. Dr X did not accept that statistic. He suggested the 10% fall related to the more generalised population of those with metastatic germ cell cancer, and not to the people with the relatively low risk disease in Robert's category.

- 19. In any event, given that Bleomycin is not currently being given to patients with Robert's characteristics, and given the very considerable side effects and risks that go with them; and given Dr X and Dr Y had clearly thought extremely carefully about the risks and benefits of this situation, in my view, there is no ground not to accept their evidence that it is not in Robert's best interests to have Bleomycin.
- 20. So, for all of those reasons, I consider that the Trust's proposed treatment plan is in Robert's best interests. I am extremely glad that Mrs Bourn came to the same conclusion, as the success of the treatment plan will turn as much on her commitment and involvement as it will to the chemicals involved. I am very glad that she is now fully supportive of the plan.