JUDGMENT APPROVED FOR PUBLICATION

**IN THE COURT OF PROTECTION** **Case No: COP 12749739**

2015 EWCOP 60

28 September 2015

**Before** :

**THE HONOURABLE MR JUSTICE PETER JACKSON**

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**Between :**

**Wye Valley NHS Trust** **Applicant**

**-and-**

**Mr B (by his litigation friend, the Official Solicitor)** **Respondent**

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**Vikram Sachdeva QC** instructed by Capsticks for the Applicant Trust
**David Lock QC** instructed by the Official Solicitor for Mr B

Hearing dates: 24 and 25 September 2015
Judgment date: 28 September 2015

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# JUDGMENT

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**IMPORTANT NOTICE**

**This judgment was handed down after a hearing in public. It can be reported provided that the terms of a reporting restriction order made on 24 September are complied with. That order prevents the naming of Mr B, the hospital in which he is being treated and the staff who are caring for him. Failure to comply with the order will be a contempt of court.**

**Mr Justice Peter Jackson:**

## Introduction

1. The issue in this case is whether it is lawful for the doctors treating Mr B, a 73-year-old gentleman with a severely infected leg, to amputate his foot against his wishes in order to save his life. Without the operation, the inevitable outcome is that he will shortly die, quite possibly within a few days. If he has the operation, he may live for a few years. Mr B also has a long-standing mental illness that deprives him of the capacity to make the decision for himself. The operation can therefore only be lawfully performed if it is in his best interests.

2. After a hearing on 24 September, at which expert evidence was given, I visited Mr B in hospital the following day. Having received further submissions in support of the operation from both parties, I refused to grant the application. This judgment explains the reasons for that decision.

3. I emphasise that the effect of my decision is not that it would be unlawful to carry out the operation, rather that it would be unlawful to carry it out against Mr B's opposition. Given his views on life and death, it is very unlikely that he will change his mind. But if he does, there is nothing to prevent the operation taking place, unless it is by then too late.

4. Apart from my meeting with Mr B, the hearing took place in public and was attended by Mr Brian Farmer of the Press Association. A reporting restriction order, the terms of which were settled in consultation with Mr Farmer, is in place. While Mr B is alive, the order prevents reports naming him, the hospital treating him and the staff who are caring for him. Anything else can be reported.

## Principles

5. The principles on which the Court of Protection acts in a case of this kind are to be found in the Mental Capacity Act 2005 ('the Act') and in a consistent line of authority built up during the past two decades and culminating in *Aintree University Hospitals NHS Trust v James* [2014] AC 591:

    (1) Every adult capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision. The decision does not have to be justified to anyone. Without consent any invasion of the body, however well-meaning or therapeutic, will be a criminal assault.

    (2) Where there is an issue about capacity:

- A person must be assumed to have capacity unless it is established that he lacks capacity: s.1(2).

- A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain: s.2(1).

- The question of whether a person lacks capacity must be decided on the balance of probabilities: s.2(4).

- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success: s.1(3)

- A person is not to be treated as unable to make a decision merely because he makes an unwise decision: s.1(4).

- A lack of capacity cannot be established merely by reference to—

  (a) a person's age or appearance, or

  (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity: s.2(3).

(3) A person is unable to make a decision for himself if he is unable to understand the information relevant to the decision, to retain, use and weigh that information, and to communicate his decision: s.3(1).

(4) Where a person is unable to make a decision for himself, there is an obligation to act in his best interests: s. 1(5).

(5) Where a decision relates to life-sustaining treatment, the person making the decision must not be motivated by a desire to bring about death: 4(5).

(6) When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and feelings, to the beliefs and values that would be likely to influence his decision if he had capacity, and to the other factors that he would be likely to consider if he were able to do so: s.4(6).

(7) So far as reasonably practicable, the person must be permitted and encouraged to participate as fully as possible in any decision affecting him: s.4(4).

6. Whether or not a person has the capacity to make decisions for himself, he is entitled to the protection of the European Convention on Human Rights. In the present context, the relevant rights are found in:

   Article 2: *Everyone's right to life shall be protected by law*
   Article 3: *No one shall be subject to ... inhuman or degrading treatment ...*
   Article 9: *Everyone has the right to freedom of thought, conscience and religion*

7. The starting point is a strong presumption that it is in a person's best interests to stay alive. But this is not an absolute, and there are cases where it will not be in the patient's interests to receive life-sustaining treatment: *Aintree v James* at [35].

8. At [23], Baroness Hale noted that the Act gives limited guidance about best interests. Every case is different [36]. At [39], she said this:

   *"The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."*

9. As Baroness Hale put it at [44-45], the purpose of the best interests test is to consider matters from the patient's point of view. Where a patient is suffering from an incurable disability, the question is whether he would regard his future life as worthwhile. As was made clear in *Re J* [1991] Fam 33, it is not for others to say that a life which a patient would regard as worthwhile is not worth living.

**Discussion**

10. Where a patient lacks capacity it is accordingly of great importance to give proper weight to his wishes and feelings and to his beliefs and values. On behalf of the Trust in this case, Mr Sachdeva QC submitted that the views expressed by a person lacking capacity were in principle entitled to less weight than those of a person with capacity. This is in my view true only to the limited extent that the views of a capacitous person are by definition decisive in relation to any treatment that is being offered to him so that the question of best interests does not arise. However, once incapacity is established so that a best interests decision must be made, there is no theoretical limit to the weight or lack of weight that should be given to the person’s wishes and feelings, beliefs and values. In some cases, the conclusion will be that little weight or no weight can be given; in others, very significant weight will be due.

11. This is not an academic issue, but a necessary protection for the rights of people with disabilities. As the Act and the European Convention make clear, a conclusion that a person lacks decision-making capacity is not an *"off-switch"* for his rights and freedoms. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would therefore be wrong in principle to apply any automatic discount to their point of view.

12. In this case, the Trust and the Official Solicitor consider that a person with full capacity could quite reasonably decide not to undergo the amputation that is being recommended to Mr B, having understood and given full thought to the risks and benefits involved. However, the effect of their submissions is that because Mr B himself cannot balance up these matters in a rational way, his wishes and feelings are outweighed by the presumption in favour of life. It is, I think, important to ensure that people with a disability are not – by the very fact of their disability – deprived of the range of reasonable outcomes that are available to others. For people with disabilities, the removal of such freedom of action as they have to control their own lives may be experienced as an even greater affront that it would be to others who are more fortunate.

13. In some cases, of which this is an example, the wishes and feelings, beliefs and values of a person with a mental illness can be of such long standing that they are an inextricable part of the person that he is. In this situation, I do not find it helpful to see the person as if he were a person in good health who has been afflicted by illness. It is more real and more respectful to recognise him for who he is: a person with his own intrinsic beliefs and values. It is no more meaningful to think of Mr B without his illnesses and idiosyncratic beliefs than it is to speak of an unmusical Mozart.

14. Further, people with Mr B's mental illness not uncommonly have what are described by others as *"religious delusions"*. As appears below, he describes hearing angelic voices that tell him whether or not to take his medication. Delusions arising from mental illness may rightly lead to a person's wishes and feelings being given less weight where that is appropriate. However, this cannot be the automatic consequence of the wishes and feelings having a religious component. Mr B's religious sentiments are extremely important to him, even though he does not follow an established religion. Although the point does not arise for determination in this case, I approach matters on the basis that his Article 9 right to freedom of thought and religion is no less engaged than it would be for any other devout person.

15. This is another manifestation of the principle that the beliefs and values of a person lacking capacity should not be routinely undervalued. Religious belief has been described as a belief that there is more to be understood about mankind's nature and relationship to the universe than can be gained from the senses or from science: *R (Hodkin and another) v Registrar General of Births, Deaths and Marriages* [2014] AC 610 at [57]. Religious beliefs are based on faith, not reason, and some can strongly influence the

believer's attitude to health and medical treatment without in any way suggesting a lack of mental capacity. Examples include belief in miraculous healing or objections to blood transfusions. There may be a clear conceptual difference between a capable 20-year-old who refuses a blood transfusion and an incapable elderly man with schizophrenia who opposes an amputation, but while the religiously-based wishes and feelings of the former must always prevail, it cannot be right that the religiously-based wishes and feelings of the latter must always be overruled. That would not be a proper application of the best interests principle.

16. Having commented on the process of evaluating wishes and feelings, I refer to the Law Commission's current consultation paper No. 222: *Mental Capacity and Deprivation of Liberty*. It proposes [Proposal 12.2] that s.4 of the Act might be amended so that an incapacitated person's wishes and feelings should be assumed to be determinative of his best interests unless there is good reason do depart from the assumption. It is said [12.42] that there is insufficient certainty about the weight to be given to a person's wishes and feelings and that prioritising them would reflect to some degree the approach of the United Nations Convention on the Rights of Persons with Disabilities.

17. In the above discussion, I have identified some of the circumstances in which the wishes and feelings of incapacitated individuals might be unjustifiably undervalued. However, my respectful view is that the Law Commission proposal would not lead to greater certainty, but to a debate about whether there was or was not *"good reason"* for a departure from the assumption. To elevate one important factor at the expense of others would certainly not have helped the parties, nor the court, in the present case. All that is needed to protect the rights of the individual is to properly apply the Act as it stands.

18. Lastly, I refer to the principle at s. 4(4) that so far as is reasonably practicable, the person must be permitted and encouraged to participate as fully as possible in any decision affecting him. In this case, given the momentous consequences of the decision either way, I did not feel able to reach a conclusion without meeting Mr B myself. There were two excellent recent reports of discussions with him, but there is no substitute for a face-to-face meeting where the patient would like it to happen. The advantages can be considerable, and proved so in this case. In the first place, I obtained a deeper understanding of Mr B's personality and view of the world, supplementing and illuminating the earlier reports. Secondly, Mr B seemed glad to have the opportunity to get his point of view across. To whatever small degree, the meeting may have helped him to understand something of the process and to make sense of whatever decision was then made. Thirdly, the nurses were pleased that Mr B was going to have the fullest opportunity to get his point across. A case like this is difficult for the nursing staff in particular and I hope that the fact that Mr B has been as fully involved as possible will make it easier for them to care for him at what will undoubtedly be a difficult time.

**The facts**

19. Mr B was an only child whose parents died when he was in his 20s. He had a number of relationships with women that did not last and he describes occasions when he fell foul of the law as a young man. In his mid-20s, he developed paranoid schizophrenia. He has been treated with antipsychotic medication, generally with sufficient success to allow him to live in the community, though his medical notes running back to 1994 describe over 10 compulsory admissions for treatment since then. He has only been fit to work briefly. He has for many years experienced persistent auditory hallucinations in which he hears voices of angels and of the Virgin Mary. He told me that they had stopped him from thieving. He told me that he did not consider himself to belong to any particular religion, saying *"I'm not fussy"*, but he explained that Mary wants him to be a Catholic. He had a 20 year relationship with a woman also suffering from mental illness, who died in 2000.

20. For some years, Mr B has suffered from Type II Diabetes. His compliance with medication is at best patchy and the diabetes is not well controlled.

21. Until his admission to hospital in 2014, Mr B lived alone in an upstairs flat which he described as *"not ideal"*. He had difficulty in looking after himself and the conditions were somewhat squalid. His care coordinator describes him as being *"fiercely independent".* Mr B told me that he would sleep very little, spend his mornings shopping for food or browsing local charity shops before returning at lunchtime and remaining at home for the rest of the day. He has a long-standing interest in collecting interesting books and paintings, also clocks and radios. The picture is of an isolated but not unsociable person with an interest in the outside world whose mental illness did not cause him undue distress.

22. Unfortunately, about 12 to 18 months ago Mr B developed a chronic foot ulcer that has not healed despite various interventions. In July 2014, he was admitted to hospital. Amputation was discussed but in the event the ulcer was debrided and insulin treatment was restarted. In August 2014, he was transferred to another hospital for convalescence and rehabilitation. In December 2014, he went to another hospital for further rehabilitation. In January 2015, he transferred as an informal patient to a psychiatric hospital because his psychotic illness had relapsed. This led to a further transfer in March 2015 for continued psychiatric treatment.

23. For whatever reason, the treatment given to Mr B for his mental illness during 2015 was not a success and in May he was made the subject of compulsory detention under s.3 of the Mental Health Act. Nevertheless, he continued to resist medication for his diabetes and antibiotics for his foot, with the consequence that by the time his mental health had begun to recover in August, his physical health had markedly deteriorated. He was becoming tired and lethargic and the infection was becoming systemic. His foot was not only infected but putrefying and the bone itself had become infected (osteomyelitis). He was refusing all treatment, but allowed his dressings to be changed.

24. Eventually, it became impossible to manage his physical health in a psychiatric unit and he was transferred to a general hospital ward on 12 September.

25. Meanwhile, a best interests meeting on 8 September, concluded that an application should be made to the Court of Protection. This was done on 15 September and the Official Solicitor arranged for his agent Ms Chapman to meet Mr B for a detailed discussion on 17 September. The matter first came before the court on 18 September, when the present hearing was fixed. I gave directions for expert reports from Mr John Scurr, consultant surgeon, and Dr Tyrone Glover, consultant psychiatrist. Mr Scurr was able to report on the basis of reading the medical records, while Dr Glover examined the records and met Mr B on 20 September. Both doctors produced written reports and gave evidence by telephone on 24 September.

26. On 25 September I met Mr B in his hospital room. We had a discussion lasting over an hour in the presence of my clerk, who took a note, and a nurse, Mr F, who was invaluable in making sure that I understood everything that Mr B wanted to say.

**Medical status**

27. Mr B has peripheral neuropathy, a complication of diabetes resulting in reduced sensation in the feet. This can lead to the patient being unaware that they have damaged their foot, leading to ulceration and subsequent infection. With normal sensation, the injuries would be extremely painful, but because of the neuropathy, Mr B has been able to tolerate marked deterioration beyond that which a normal patient could endure. In such circumstances, the first approach is to clean the wound, debride it surgically and administer antibiotics. However, treating such infections with antibiotics has a very low success rate, and once the bone is infected, surgery is inevitable. High doses of antibiotics may hold the infection but are unlikely to cure it. In a non-compliant patient there is a serious risk of infection spreading up the leg and the presence of diabetes facilitates ongoing infection. Similarly, infection makes it more difficult to control diabetes. Once putrefaction has occurred, healing will never take place.

28. Mr Scurr advises that matters have reached the point where debridement is no longer possible and amputation is the only clinical option. It is not possible to say whether a below-knee amputation would be sufficient or whether the surgeon would find that the infection had spread so far that an above-knee amputation was required. The longer the delay, the more likely the latter option, which is a much more disabling outcome.

29. Mr Scurr explained that within a matter of days he would expect Mr B to succumb to overwhelming infection. He did not expect the current position to continue for more than a week or two at the outside. There will come a point where the buildup of infection will cause Mr B to *"fall off a cliff"* medically and it will not then be possible to save him.

30. Mr Scurr has significant experience of successful amputations on patients with similar medical profiles to Mr B. He also had experience of patients who had died of septicaemia where there had been no intervention. He told me that where successful operations could be carried out, these patients had in due course come to terms with the loss of a limb. Sometimes, the patient's pre-operative confusion arose from the extent of the toxic infection and once the leg has healed they came to accept their condition. He acknowledged that amputation is a distressing condition, but considered that Mr B could rehabilitate with an artificial limb if amputation was accompanied by intravenous antibiotics and improved diabetic control.

31. I also accept the evidence of Dr R, the Trust's consultant orthopaedic surgeon, that the risks of undergoing surgery include the possibility of wound infection, knee stiffness, phantom pain, and anaesthetic and cardiopulmonary risks associated with the procedure. He also refers to the risk of surgery causing deterioration in Mr B's mental health.

32. Taking account of the possible risks and physical disadvantages of surgery, I nevertheless accept the evidence of Mr Scurr and of Dr R, that the preferred medical treatment for Mr B is an immediate amputation, without which he will shortly die.

33. Mr B's life expectancy following an operation is limited. Given his current condition and his co-morbidities, any estimate is bound to be extremely tentative. The only information I have is from a locum consultant endocrinologist, whose *"very approximate guess"* is that Mr B might live for about three years.

**Capacity**

34. Based on the following evidence, I am satisfied that Mr B does not have the capacity to make treatment decisions about his foot:

    (1) He suffers from persistent and treatment-resistant Schizoaffective Disorder, otherwise known as Bipolar Affective Disorder with Psychotic Symptoms.

    (2) In consequence, he experiences auditory hallucinations that tell him whether or not to take his medication: *"If the Lord says it's no, it's no."* Although he did not make a similar connection when speaking about amputation to Dr Glover or to me, he told Ms Chapman that because the Lord doesn't want him to have his leg taken off he is not doing it.

    (3) He does not understand the reality of his injury. Asked how things would go if he did not have the operation, he told me that his leg would get better with proper care and if he was allowed to use it.

    (4) He also mistrusts the doctors to the extent that he expressed the fear that if they put him to sleep for the operation, they could do anything. He did not seem

reassured by my telling him that they would not go beyond treatment that the court permitted.

(5) Whenever anyone speaks to Mr B about treatment for his leg, he becomes agitated and will shut down the conversation so that the pros and cons of the various options cannot be further discussed.

35. I find that there are limitations in Mr B's ability to understand the information about his damaged foot and a clear inability to weigh the relevant medical evidence as part of the process of reaching his decision. In reaching this conclusion, I rely as much upon Mr B's statement that he should be allowed to use his leg as part of the process of recovery as upon his auditory hallucinations. Accordingly, in agreement with the opinions of his treating psychiatrist and Dr Glover and with the submissions of the parties, I find that the presumption of capacity is rebutted.

**Best interests**

36. The following considerations favour the conclusion that an operation to amputate Mr B's leg would be in his best interests:

(1) Making all the allowances for the fact that some patients confound confident medical predictions, Mr B will shortly die without surgery.

(2) His death is avoidable. It would deprive him of a continued existence that may be measured in years.

(3) There is no indication that Mr B's quality of life before he came into hospital in July 2014 was unacceptable to him. He clearly faced many difficulties, but he maintained a stable way of life that contained at least some pleasures.

(4) It is possible that after an operation he would adapt and recover some quality of life.

37. The following considerations speak against the operation being performed:

(1) Mr B opposes it in the strongest possible terms. He has consistently said this over the entire period that amputation has been under discussion, which is now about a year. During my meeting with him, he made these various statements in answer to my questions:

*I don't want an operation.*

*I'm not afraid of dying, I know where I'm going. The angels have told me I am going to heaven. I have no regrets. It would be a better life than this.*

*I don't want to go into a nursing home, [my partner] died there.*

*I don't want my leg tampered with. I know the seriousness, I just want them to continue what they're doing.*

*I don't want it. I'm not afraid of death. I don't want interference. Even if I'm going to die, I don't want the operation.*

All this was said with great seriousness, and in saying it Mr B did not appear to be showing florid psychiatric symptoms or to be unduly affected by toxic infection.

(2) If the operation is to be carried out successfully, Mr B will have to be sedated to overcome his resistance and will have to remain sedated for some time afterwards to help him with his inevitable feelings of outrage and distress. His cooperation with rehabilitation will then be required, including a willingness to take his antipsychotic medication and antibiotics, together with whatever other medication is required by a recent amputee.

(3) While the operation would probably be a surgical success, there are always risks associated with surgery in a person of Mr B's age and characteristics.

(4) There is in my view a significant chance that Mr B's mental health and well-being will be further compromised following an operation. Even if he does not suffer some of the risks of amputation (phantom pain etc.), the loss of his foot will be a continual reminder that his wishes were not respected. Further to that, his religious sentiments will undoubtedly continue and he will believe that the amputation was carried out against the Lord's wishes.

(5) There is a possibility, which may not be known until surgery begins, that a below-knee amputation would be inadequate and that Mr B would lose his leg altogether.

(6) Mr B's current quality of life is in his own estimation very poor. When I asked him how things are, he replied *"rough"*. His foot gives him shocking pain when he is turned. He said that he was *"suffocating"* in hospital. He would have no regrets about missing his next birthday, which is imminent, or Christmas. In contrast, he became emotional about distant personal events that continue to give him sadness.

(7) If surgery is successful, there is no possibility that Mr B can return to the sort of life he led before July 2014. He will never live in his own accommodation again. He has now been in hospital for 15 months and, given his multiple physical and mental difficulties, a discharge date cannot be predicted. The best that can be hoped for is that he might be discharged to a care home or, more likely, a nursing home, which he does not want.

(8) On the evidence, the process of recovery and rehabilitation would occupy a considerable part in Mr B's remaining lifespan. If things went as well as they could, he might be rehabilitated only to die.

(9) If Mr B does not have the operation, he will receive palliative care to ensure that his last days are as comfortable as possible for him.

38. Dr Glover concluded in his report that on balance, and by a very fine margin, it would be in Mr B's best interests to have a below-knee operation. He fairly observed that while a body of his peers would almost certainly agree with his view of capacity, they would probably splinter widely in their views on best interests. Giving evidence, he said that frankly he did not know where the welfare balance should fall. In those circumstances, he felt more comfortable morally in opting to support the continuation of life and being challenged on that conclusion.

39. On behalf of the Trust, Mr Sachdeva submits that very little weight should be given to Mr B's wishes and feelings and religious beliefs because they were intimately connected with the cause of his lack of capacity. The preservation of life is a very weighty factor in this case and should prevail.

40. On behalf of the Official Solicitor, Mr Lock QC does not accept that no significant weight should be given to Mr B's wishes and feelings. He also disagrees that slight value should be given to his religious beliefs, which are sufficiently long-standing to be integral to him. Religious beliefs are a matter for the individual and do not need to be mediated through organised religion.

41. Mr Lock submits that there is a question over the enforced continuation of a life of limited independence in circumstances where Mr B is adamantly against a course that he understands would prolong his life. Yet there is a possibility that with optimal care, Mr B would rise above the difficulties. The Official Solicitor essentially adopts the position of Dr Glover. He submits that Mr B has a life worth living and that this, together with the inherent importance of the continuance of life, has led the Official Solicitor to the conclusion that on a very fine balance the benefits of treatment outweigh the detriments and to support the application. However, given my meeting with Mr B, he submits that I am better able to reach a conclusion.

**Conclusion**

42. Having considered all of the evidence and the parties' submissions, I have reached the clear conclusion that an enforced amputation would not be in Mr B's best interests.

43. Mr B has had a hard life. Through no fault of his own, he has suffered in his mental health for half a century. He is a sociable man who has experienced repeated losses so that he has become isolated. He has no next of kin. No one has ever visited him in hospital and

no one ever will. Yet he is a proud man who sees no reason to prefer the views of others to his own. His religious beliefs are deeply meaningful to him and do not deserve to be described as delusions: they are his faith and they are an intrinsic part of who he is. I would not define Mr B by reference to his mental illness or his religious beliefs. Rather, his core quality is his *"fierce independence"*, and it is this that is now, as he sees it, under attack.

44. Mr B is on any view in the later stages of his life. His fortitude in the face of death, however he has come by it, would be the envy of many people in better mental health. He has gained the respect of those who are currently nursing him.

45. I am quite sure that it would not be in Mr B's best interests to take away his little remaining independence and dignity in order to replace it with a future for which he understandably has no appetite and which could only be achieved after a traumatic and uncertain struggle that he and no one else would have to endure. There is a difference between fighting on someone's behalf and just fighting them. Enforcing treatment in this case would surely be the latter.

46. The application, which was rightly brought, is accordingly dismissed.

47. I conclude by thanking the parties and witnesses for the quality of their contributions and by paying tribute to the high standard of care and treatment that Mr B is now receiving.

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