Adults who refuse blood transfusion in emergency, urgent and elective circumstances

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ABSTRACT
Surgeons dealing with an adult refusing a blood transfusion find themselves in an unenviable position, torn between wishing to preserve the patient’s life while also respecting his or her wishes. This article looks at the legal framework for such circumstances as set out in the Mental Capacity Act 2005.

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Jehovah’s Witness – Blood transfusion – Capacity – Autonomy

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Adults in England and Wales can refuse any treatment that a clinician proposes. While they have capacity, they can do so by a simple verbal refusal. Providing an adult patient retains his or her capacity for this decision and refuses steadfastly to have blood during or following surgery, even if this decision may lead to death, this decision must be respected. Plainly, alternatives to blood transfusion can be employed but the patient’s decision is determinative.

If time permits, the surgeon or anaesthetist may decline to operate in these circumstances but must then take reasonable steps to find a colleague who is willing to participate on the patient’s terms. When surgery is necessary as an emergency that is so pressing that such a referral is impractical, a surgeon is advised to operate and respect the patient’s wishes whatever the outcome. If the patient survives the surgery but will die postoperatively without being given blood, the surgeon who disagrees with this approach should take local advice. If there is a clinical consensus that the (now incapacitated) patient’s wishes should be overridden, the Court of Protection (CoP) may be approached at any hour of the day and provides a valuable impartial decision. However, powerful evidence will be required to persuade the court that a patient’s competent wish to refuse blood can be overruled and this is unlikely to happen.

Adult patients anticipating such a time when they may lack capacity can make arrangements to avoid being given a specified treatment that they choose not to have. This can be done by making an ‘advance decision’, which is a statutory construct that has evolved from the ‘living wills’ and ‘advance directives’ that were created by the common law. The statute that created advance decisions is the Mental Capacity Act 2005 (MCA).

Advance decisions may in some circumstances be informal and for less contentious issues (e.g. deciding in advance to refuse the placement of a nasogastric tube) they will usually be respected without clinical difficulty. Unsurprisingly, advance decisions to refuse life-saving treatment must conform precisely to the requirements of the MCA; they are only valid if the patient has verified that the decision is to apply even if his or her life is at risk. Furthermore, the decision must be in writing, signed and acknowledged by the patient as well as a witness (MCA 2005, section 25). Alternatively, the patient may have created a lasting power of attorney (LPA), a legal document empowering another adult to refuse the life-saving treatment on the patient’s behalf. Again, for a LPA to be effective in authorising the refusal of consent for life-saving treatment, strict formalities must be observed (MCA 2005, section 11).

Crucially, advance decisions enabled in these ways are valid only if they are applicable to the clinical circumstances in which the decision needs to be taken. One such circumstance when the advance decision of patients who now lack capacity must be scrutinised is their requirement of a blood transfusion.

Where the need for transfusion will accompany an elective operation, there is ample time to resolve the question as to whether an advance decision or LPA remains valid. If the patient has capacity, the refusal communicated by the advance decision/LPA becomes irrelevant since the contemporary decision of a competent patient automatically overrides any of their previous legal arrangements. More usually, the patient will not have capacity so it is a matter of fact as to whether the documents remain valid. If there is any doubt, the procedure must be postponed until the uncertainty is resolved.

However, elective surgery where blood transfusion may benefit the patient’s health (but where it is not anticipated...
that life threatening emergencies will be encountered poses rather different problems for the surgeon. This is particularly so when confronted with an incapacitated patient accompanied by friends and relatives who assert that the patient would refuse blood if only he or she had capacity to do so. In this situation, the formalities of an advance decision to refuse life saving treatment are not required to create a valid refusal of treatment. If the clinician can be satisfied that the reported oral decision that was made by the patient remains valid, then such an 'advance statement' can be relied on. Nevertheless, the surgeon must make further enquiries before concluding that the informant recounts accurately the now incapacitated patient's wishes.

Where possible, you should establish to what extent the reports of the patient's views reflects a general opinion on blood transfusion as opposed to statements that he or she made with the intention of confronting the clinical situation with which the patient is now faced. You should seek reliable evidence of an explicit decision to refuse the proposed transfusion, again, in the specific clinical circumstances that now prevail. A report that the patient had a 'general aversion' to blood transfusion is not enough. It is also important to elicit evidence that the patient, when stating his or her views to the informant, understood the foreseeable consequences of refusing transfusion. Finally, can the informant be sure that the patient had capacity to make this statement when it was made and was he or she free of coercion?

Even after an exhaustive enquiry, the surgeon may still be left uncertain as to whether during a period of capacity, the patient would have refused blood transfusion related to his or her elective surgery. In the absence of evidence for an advance statement, the surgeon should proceed as if there were none. If it is believed that such a statement was made, reasonable steps should be taken to find out what the decision was. If it is quite clear that a statement was made, then it would be wrong to speculate that the statement is invalidated by coercion or undue influence unless there is tangible evidence to support such a contention.

The situation is somewhat easier if the incapacitated patient arrives with a written declaration, ostensibly produced during a time that he or she was competent. In this situation, your enquiry will concentrate on the circumstances under which these words were written and as to whether there are any doubts over the authenticity of the document. Again, when refusing life saving transfusion, only an advance decision made valid by the formalities of the MCA is sufficient.

In urgent circumstances, where surgery necessitating blood transfusion is required within 24 hours (but not immediately), there is less time to verify the validity of advance arrangements but if this can be done, they should be complied with. In the absence of these formal documents, other contextual evidence should be gathered, which will help you decide whether transfusion will be in the best interests of the incompetent patient.

In a 2014 High Court application, a 65-year-old woman (LM), who had been a Jehovah's Witness since the 1970s, experienced bleeding from her duodenal ulcer. She had been found wandering and confused outside her home. Her haemoglobin level was 57g/l on presentation. Discussing her plight with the gastroenterologists, she was adamant that she did not want treatment with any blood products; they were sure that she had full capacity to make this decision and that she was aware that she could die without blood transfusion. LM had received other medical treatment over the years and her adherence to her faith, together with her steadfast refusal of blood in any circumstances, had been documented in her notes.

The conversation with the gastroenterologists was recorded in the notes but no formal advance decision to refuse life saving treatment existed. Similarly, LM had not created a LPA enabling refusal of life saving treatment.

Three days following LM's discussion with the gastroenterologists, she deteriorated, requiring intubation, ventilation and sedation. Henceforth, she lacked capacity for further decision making. Her clinicians felt that transfusion would improve but not guarantee her chances of survival. Perhaps anxious that this lady had not provided a valid advance decision to refuse a life saving blood transfusion, the clinicians approached the CoP, seeking a declaration that withholding transfusion would be lawful in her case.

The court heard from Mr R, a representative of her congregation, who had known her for 40 years and who brought with him letters from 5 other members of her religious group who knew her. R described LM as a formerly active member of the congregation, who fully subscribed to the tenets of the faith (including those opposing blood transfusion) and had taught them to others. Her beliefs on this matter had been consistent. The trust's position was that LM had made her wishes known, even with the knowledge of impending death. When considering her now, incapacitated, the trust did not feel that transfusion was in her best interests since it would be an affront to her established wishes.

The court found that LM had capacity during her early admission to decide whether to accept or refuse a transfusion, and that the advance decision she took prior to losing her capacity (to refuse transfusion) was both valid and applicable to her later more serious condition, when she had lost her capacity. It was therefore lawful to withhold transfusion.

LM died on the day of the judgement.

The judge also noted that he would have granted a declaration even if she had not made a valid applicable decision since on the facts presented to the court, both from her congregation and the clinicians, a transfusion would not have been in her best interests. This was because her wishes and feelings as well as her longstanding beliefs and values carried determinative weight. It was also relevant that the transfusion might not have been effective in saving her life.

This judgement serves to reinforce the principles of the MCA. Adults are presumed to have capacity but this may be challenged by clinicians should they suspect otherwise. The facts show that LM's clinicians tested her capacity and found it intact.

Adult patients with capacity are entitled to defend themselves against any clinical intervention they choose to
avoid, even if death may result. LM took the opportunity, while she had capacity, to assert her intentions to avoid transfusion. When dealing with a patient who lacks capacity, the MCA obliges us to consider (as far as we can ascertain) any past and present wishes expressed by the patient, together with any beliefs and values that would be likely to influence his or her decision. In so considering her comments made when talking to the gastroenterologists, the trust concluded that transfusion would not be in her best interests.

Perhaps regrettably, LM was not prompted at that stage to make an advance decision to refuse life saving blood transfusion. If she had done so, her clinicians, it seems, would have been content to rely on it when she finally lost her capacity owing to the progression of her illness. Nevertheless, with the assistance of the CoP (which exists precisely for this eventuality), LM’s informal assertions refusing blood were given full weight. Even in their absence, the court made it clear that pleadings from her congregation (together with previous refusals documented in her notes) would have been sufficient to allow the declaration to be made that blood transfusion would not have been in her best interests.

This case provides authority for asserting both that (i) an advance decision to refuse blood transfusion gives both surgeons and their patients some certainty that blood transfusion will be withheld in the prescribed circumstances, and that (ii) in the absence of such a formal document, recourse to the CoP with substantial informal evidence of the patient’s wishes and beliefs can achieve the same result. We should view the CoP as providing an immense benefit to both surgeons and citizens, ensuring that the tensions between preserving life and respecting wishes are adjudicated independently.

Finally, when surgery and transfusion are required immediately, within perhaps the next 15 minutes, there is no time for detailed enquiries. If the evidence in front of you makes you believe that this adult has certainly refused transfusion, preferring death to blood, then you should respect this wish. However, bear in mind that no surgeon in England has ever faced the criticism of a court for saving a patient’s life by giving blood in these circumstances. The presumption that life is preferable to death remains strong in our legal system and can only be rebutted by a surgeon’s certainty that the patient would rather have died. This conviction is hard to achieve in 15 minutes.

References