

The Maltese Conjoined Twins

Two Views of Their Separation

Four months into their mother's pregnancy, an ultrasound scan of the twins publicly known only as "Jodie" and "Mary" revealed that the girls were conjoined, and it quickly became clear that the modest facilities near their family's home on the Mediterranean island of Gozo would be ill equipped to handle the complicated birth.¹ With the financial support of an existing arrangement between the Maltese government and the British National Health Service, their parents sought medical help in the United Kingdom, where further testing revealed that one of the twins might not survive the birth. As devout Roman Catholics, the parents refused to contemplate the possibility of abortion and on 8 August 2000, Jodie and Mary were born at St. Mary's Hospital in Manchester.

Lying on their backs, the girls' heads and upper bodies emerged at opposite ends of a torso that was joined from the base of the pelvis to the lower abdomen. Their spines were fused at the base, and their legs extended to the sides at right angles. Each twin had her own brain, heart, lungs, liver, and kidneys, and they shared a bladder that lay mostly in Jodie's abdomen.

Jodie was described as surprisingly bright and alert. She moved her limbs, squirmed, and appeared to have developmentally normal responses for her gestational age. Her brain appeared to be anatomically and functionally normal, and the same was true of her liver, lungs, kidneys, and heart, with one exception: Jodie's aorta fed into Mary's, circulating blood through Mary's body and back into Jodie through a united inferior vena cava.

Mary's condition was less hopeful from the start. Her brain was described by physicians as "primitive" because

of reduced cortical development, an incomplete corpus callosum, and a malformation in the hindbrain. Although her eyes were open and she was capable of reflexive movements, she could not cry because her lungs were severely underdeveloped and virtually devoid of functioning tissue. As a result, she was incapable of breathing on her own. Her heart was also abnormally large and had difficulty functioning properly. It was estimated to contribute less than 10 percent of Mary's circulatory requirements. Because of these circulatory incapacities, Mary relied entirely on Jodie's heart and lungs to oxygenate and circulate blood through both of their bodies.

In the days after their birth, specialists at St. Mary's were grim about the prognosis of the twins in their current condition. They estimated that Jodie's heart would fail under the excess strain in as little as six months. They also estimated that Mary had a 75 percent chance of developing hydrocephalus, which would be very difficult to treat in light of her abnormal abdominal cavity and cardiac abnormality. The prospect of persistent hypoxia in Mary increased the likelihood of further damaging her brain, and specialists also thought it could promote similar cell destruction in Jodie as well. Surgeons were very optimistic, however, that Jodie would have only a 5 to 6 percent chance of not surviving surgical separation, and they were confident that she would then be able to live out a normal life span with the most serious foreseeable complications limited to possible difficulties walking without support and controlling her bowels. They were certain, however, that Mary could not survive independently of her sister, and that separation would therefore directly cause her immediate death.

The twins' parents refused to consent to separation. They maintained that they loved each of their children equally, that both of their daughters had an equal right to life, and that they could not possibly kill one in order to allow the other to survive. They affirmed that they were content to place their faith in God and let His will decide the twins' future. Contemplating the possibility that the surgery would go ahead without their consent, they worried deeply about their ability to care for Jodie, both financially and personally, if she were to survive with serious disabilities. They are of modest means, and the facilities on their Mediterranean homeland could not provide the specialized care that the child might need. They said that the prospect of having to leave her in England, to be cared for by someone else, would break their hearts.

Continuing to feel that they could not, in good conscience, allow both twins to die in their care when they believed that one could be saved, the staff turned to the courts for permission to perform the surgical separation

without parental consent. On 25 August a family court judge issued a judgment authorizing the separation. On 22 September, that judgment was upheld by a three-judge court of appeals, and a week later the parents decided not to challenge the decision further. After a month of at times high-pitched public debate, and the rejection of a last minute legal appeal filed by an anti-abortion group, the operation to separate the twins began on 6 November. It ended some twenty hours later, early in the morning the following day. As expected, Mary did not survive the operation. As of this writing, Jodie was said to be breathing without support and feeding normally.

—Alex John London

1. Details of the twins' condition prior to surgery are drawn primarily from testimony given before the court of appeals, Royal Courts of Justice, 22 September 2000, Case No: B1/2000/2969.

A Separate Peace

BY ALEX JOHN LONDON

One of the most difficult aspects of this tragic case is that even the best responses to it seem deeply troubling. Combined with the fact that the issues on which it turns are as emotionally charged as they are complex, it can be very tempting to say that, ultimately, this is an intimate matter that should be left to the private discretion of what appear to be loving and very genuinely concerned parents. Nor would it be wise to disparage two very powerful motives that animate this position: a genuine compassion for the people whose lives are most deeply affected by the case, and a principled concern to resist setting a precedent that would unfairly intrude on the legitimate authority of parents to make important health care deci-

sions for their children. At the same time, however, the sphere of legitimate parental discretion is not unlimited, and whether or not the decision to separate Mary and Jodie represents such a dangerous intrusion hinges crucially in this case on the interests of the children whose very lives are at issue. As anguishing as it may be, there do seem to be clear and compelling reasons to support separating *these* twins, and embracing this conclusion need not diminish the compassion we feel for this family, nor our

complement of vital organs. The central difficulty was that Mary's lungs were so severely underdeveloped that they did not function and her individual cardiac output was insufficient to meet her needs. Had she been born a singleton, Mary would not have survived long after birth, and it was clear that she would not be able to survive if separated. Even when she was joined to her sister, Mary's prospects were not bright.

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substantive commitment to protecting parental rights.

The special way in which Mary and Jodie were physically conjoined makes this case unique in several respects. Unlike previous high-profile cases in which a pair of conjoined twins shared a single major organ, Mary and Jodie each had their own

other cause—by a growth or a structural abnormality—and if the risks associated with correcting that problem were the same as those she would face in the surgical separation, then it would be difficult to justify not performing the surgery. Even liberal democratic nations that strive to respect the faith traditions of their citizens

have traditionally imposed limits on the extent to which religious convictions may guide medical decision-making if they threaten the life of a child. In Jodie's case, the threat she faced without surgery was profound and her chances of surviving the operation appeared to be good. Moreover, if she survived the initial trauma of the surgery it was very likely that she could live out a normal life span, even if with some restricted mobility or other physical impairment. In contrast, the bleakness of Mary's condition was such that if she were being supported by artificial means rather than by Jodie, it likely would have been permissible at some point to withdraw such support (whether mechanical or nutritional), even though it would also have resulted directly in her death.

Of course, Jodie did not suffer from a growth or a mere structural abnormality; the heart in her chest beat also for the heart that could not sustain Mary, a task that it could not long endure. The very conditions that sustained Mary's life also directly threatened Jodie's, and the risks that Jodie endured from supporting her sister were far greater than the risks she would face in surgical separation. Mary's condition was heartrending because she would have eventually succumbed to her substantial physical deficits, either because of the toll they would take on her directly, or because of the toll they would take on her sister. But although it is profoundly sad that Mary could not be sustained by the underdeveloped organs of her body, it would have been profoundly unfair to require Jodie to sacrifice her own existence in order to make up for this misfortune. To leave the twins conjoined would have delayed Mary's inevitable demise by exacting from Jodie a sacrifice greater than ought morally to be demanded of her.

It is difficult to see how Mary's right to life could encompass a right to the organs and life of her sister as well, especially in light of her very grim prospects even with that support. Furthermore, even if we assume

that each twin has a right to some means to support her life, there appear to have been alternative means of supporting Mary that would not have compromised Jodie's right to her own life in the process. During the appeals court hearing, a surgeon was asked whether it would be possible to perform the operation and then immediately connect Mary to a heart and lung machine, thereby preventing her death. The surgeon responded that such a measure was technically possible but would be unusual since these machines are supposed to provide temporary support within the context of a potentially resolvable abnormality. Thus even if we assume that both twins have a right to some means to support their lives, Mary could have received artificial support instead of depending on Jodie. Further, such a right would only strengthen the argument for providing Jodie unrestricted use of her own vital functions. Unless Mary had a moral entitlement to the use of Jodie's vital organs as the sole source of her inevitably doomed existence, it would have been unfair not to attempt to free Jodie from the mortal sacrifice being exacted from her by that role. The fact that caregivers would not ordinarily contemplate providing life support to an infant in Mary's condition should not thereby shift the burden of doing so to Jodie.

This line of reasoning brings into focus an important alternative view of the surgical separation. In separating the twins, the support that Jodie gave to Mary could have been replaced by functionally equivalent mechanical supports. But if it would have been permissible to withdraw mechanical support from Mary because it was futile, then it also was permissible to refrain from employing it in the first place. For those who reserve the term "killing" for acts that cause death in a morally impermissible manner, then, this operation could reasonably be described as a case of attempting to aid Jodie while refraining from prolonging Mary's life artificially. If the decision was made to forgo initiating artificial life support measures for Mary,

it is because her condition was tragically irreversible.

When giving equal consideration to the life of each twin, therefore, we must recognize the inevitability of Mary's demise, the intensely intimate way in which her living directly endangered the life of her sister, that there was no way to free Jodie from this danger other than by separating her from Mary, and that with the unrestricted and independent use of her own vital functions, Jodie's prospects are bright. Given the unique circumstances of this case, the only way to free Jodie from the most immediate threat to her life was to discontinue the support she provided to Mary by separating them surgically. Coming to Jodie's aid in this way killed Mary, but it did not wrong her morally.

Even as Jodie's recovery continues, she and her family face an uncertain future. In the years to come, Jodie will require skin grafts and additional corrective surgeries, and her parents will have to grapple with the loss of one child and the special challenges of caring for the other. One thing is certain, however. Whether these challenges are ultimately daunting and insurmountable, or more tractable and surmountable, will depend on the ability of the communities so vocally divided over this case to come together and support Jodie and her parents in its aftermath.

Hubris in the Court

BY LORI P. KNOWLES

The physical, ethical, and legal drama in which Jodie, Mary, and their parents found themselves was one of those tragic cases in which all the possible outcomes are awful. Separating the twins

and killing Mary in the process, and not operating and apparently allowing both children to die, both have profound moral costs, and there can be legitimate disagreement among thoughtful people about which is the better course of action. In my opinion, however, it would have been better to respect the parents' religious objection and not to operate.

The primary reasons for respecting the parents' decisions in a case like this are twofold. First, the courts have no superior moral authority, access to facts, or legal jurisdiction that would justify replacing the parents as ultimate decisionmaker. Second, practical issues such as quality of life and social consequences may not be relevant in the legal sphere but are crucial to reaching a morally just decision.

The law requires that courts determine in every case what facts form the basis of a reasoned legal opinion; there can be no decision without resolving the facts on which the decision rests. In the twins' case, medical facts form the foundation for the court's decision, yet there exists no medical certainty. For example, while doctors first predicted that Jodie and Mary could live conjoined for only three to six months at the time of trial, by the time of appeal just a month later, they acknowledged that the girls might live conjoined for as long as three years. If the revised estimate was correct (and clearly, that estimate could change again in the coming years), it's conceivable that in a few years improved medical technology might have permitted the toddlers to be safely separated. The nature of medical uncertainty mandates caution where the basis for a legal decision is dependent on medical facts.

British courts are constrained in making decisions with respect to medical interventions on children to a "best interests" test: only interventions that are in the best interest of the child can be ordered. Considerations such as parental inconvenience are not directly relevant, although they may indirectly affect the child's

best interests. Leaving aside quality of life considerations, a decision to separate Jodie from Mary was arguably in Jodie's best interests, but that decision could not be made independently from a decision to separate Mary from Jodie, and it was clearly not in Mary's best interests. The actions are one and the same: saving Jodie was killing Mary. Since they could not be meaningfully distinguished, the action of separation could not be justified under the best interests test because it would never be in Mary's best interest (unless you believe Mary might have been better off dead).

When faced with novel situations, a court must draw analogies to or distinctions from similar decided cases. Yet since all other paradigmatic life and death decisions concern physically unconnected people, truly helpful analogies to the twins' case do not exist. Jodie and Mary's corporeal connection was the central fact at trial,

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and attempts to draw analogies to cases involving separate persons could only obfuscate that fact and confuse the legal reasoning. Few have recognized this. In order to circumvent the reality that saving Jodie and killing Mary were results of the same action, the courts and commentators have looked for analogies that would permit them to characterize the action of killing Mary as something else. For example, the decision to operate and thereby kill Mary was characterized as akin to a legitimate use of the court's power to step into the shoes of the parent to promote the child's well-being over a parental objection. It was also suggested that separating Mary was not actually an action of "killing" but merely a "withdrawal of life support." Finally, it was argued that Mary's right to life was less than a full right—that it would not entitle her

to the same protections afforded all persons born alive.

The courts have the power to interfere with parental decisions that are patently against the accepted standards for a child's physical and medical well-being. There is, however, a qualitative difference between the twins' case and cases in which courts order intervention into harmful parental decisions. The twins' parents objected to the operation that would help Jodie precisely because that very operation would certainly *kill* Mary, a fact not disputed by the doctors. The decision to deny permission for an action that would kill their child was perfectly within the scope of their parental authority. Suppose, for example, a child is a suitable organ donor for a sibling. If the parents did not want to subject one child to an operation to save the other, the courts would not order the surgery. In fact, one person may never be legally sacri-

ficed for another. While those in favor of separating the twins have focused on the sacrifice that "should not be required of Jodie," this obfuscates a central legal fact: we do not believe that anyone should have to give up his or her life to save another. Therefore, while Jodie should not be sacrificed for Mary, neither should Mary be sacrificed for Jodie.

Others have argued that because Mary was dependent on Jodie's circulatory system for survival, the separation of Jodie from Mary is analogous to the removal of Mary's life support. However, there are important differences between the withdrawal of life support and Mary and Jodie's physical connection. Generally, in cases of withdrawal of life support, that support has been put in place by hospital personnel and acts as a barrier to prevent a death caused by an underlying

condition. But the support Jodie's system provided Mary was not put in place by the doctors, and therefore the decision to remove it was not theirs. Perhaps even more critically, withdrawal of life support is made in the interests of the patient, not with the interests of *others* as the rationale.

Some have highlighted the inevitability of Mary's death and claimed that the operation would simply hasten her death while potentially permitting Jodie to live longer. Lest we forget that death is inevitable for everyone, this should not be a compelling argument. In our society, we do not permit people to hasten the death of even terminally ill patients—especially not without their consent. Neither parents nor doctors may cause the death of a child simply because the child's life will be short or difficult. What seems to be operating behind the inevitability argument are judgments about the relative quality and worth of Mary's and Jodie's lives.

If we accept that both Mary and Jodie had equal rights to life, then we could not take Mary's life even to save Jodie's. Consequently, much of the commentary has focused directly or indirectly on characterizing Mary's life as less worthwhile than Jodie's. This characterization was explicit at the trial level, where one question be-

fore the court was whether Mary was a "person." However, in face of the seemingly irrefutable fact of Mary's personhood (she was born with a functioning if impaired brain), more subtle attacks on her status are present in the language used to describe her condition. Mary's brain was described as primitive and her status akin to that of a parasite—descriptions that allow one to see Mary both as a non-person and as morally blameworthy. Such language permits us to see Mary as less than a very ill disabled baby and provides the emotional distance needed to sanction her killing.

While we may make decisions about saving people based on the quality of their lives, we do not make decisions about killing people based on their quality of life. We do not decide to take a person's life because her quality of life will be low any more than we decide to kill those who require too much aid or too many resources to live. Quality of life is relevant when we are deciding whether we should keep someone alive. Keeping in mind that quality of life determinations are subjective by their very nature, descriptions of Jodie's quality of life have been almost uniformly optimistic. But Jodie will have to undergo multiple surgeries, including reconstructive rectal, abdominal, and

vaginal surgery. She may be incontinent and permanently unable to walk without assistance. Equally important, should she return to Gozo with her parents, she may be socially ostracized for the rest of her life, as I understand that some island inhabitants believe that those who are physically disabled in this life are being punished for sins in past lives. These issues are anything but irrelevant.

It is much easier to take action in the face of impending tragedy than to feel impotent. Doctors, in particular, because they have been taught to save lives and fight death, will inevitably be drawn to do *something*. This is familiar to us at both ends of the life spectrum: in heroic efforts to save children who are ultimately tremendously disabled, and in heroic efforts to save those who are terminally ill or dying from old age. Sometimes, however, a recognition of our limits, and a sensitivity to those who cannot simply walk away after a decision is rendered, mandate that, difficult as it may be, doing nothing may be the best thing to do. As the courts and the physicians had no moral or legal authority to make the decision whether to separate Jodie and Mary, they should have left it with those closest to the children—the parents.