

## in that case

Two-year-old Sarah is admitted to the paediatric ward with acute myeloblastic leukaemia. She is started on intensive chemotherapy but also requires a bone marrow transplant to optimise the chances of cure. Sarah has five siblings who are all tested for suitability as a donor. Fifteen-year-old Lucy, twelve-year-old Henry, ten-year-old Kerry and seven-year-old Sam are all found to be incompatible. Four-year-old Joshua is found to be compatible. Sarah's parents Brian and Philippa are told of the news and are eager for the transplant to proceed. The mortality of matched sibling donor marrow transplants is about 20%. The transplant procedure involves the donor undergoing a general anaesthetic and having bone marrow removed via needles inserted into the pelvic bone cavity. The procedure takes an hour and a half and the donor will have postoperative pain, which can occasionally persist. The marrow fully regenerates within two weeks. Joshua is scared of the hospital and needles.

## commentary

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### Parental Authority

In New Zealand children are regarded as consumers of Health and Disability services. Thus they enjoy the rights which attach to consumers, one of which is the right to refuse treatment. It follows that proper consent is required before a child is treated. But what is proper consent for a child? It is generally agreed that there is no longer an arbitrary age which can be fixed to denote competence to consent. The Gillick judgement offers an alternative set of criteria, notably that the child needs to have sufficient maturity to understand the treatment offered and the implications of accepting or refusing that treatment. The problem of assessing maturity is complex but it clearly does not apply in the case in question for at four years of age the implications of the treatment for both donor and recipient cannot be grasped. Had ten-year-old Kerry or even seven-year-old Sam been compatible siblings such problems would have figured. In the case of incompetent minors the responsibility of providing consent falls to the parents. The rationale for this is that the parents are assumed, not unreasonably, to be most likely to have the best interests of the patient at heart. The assumption that Brian and Philippa have four-year-old Joshua's best interests at heart has therefore to be tested. This presents the first major problem in the case.

### Conflict of Interest

There is a danger in transplantation medicine for the welfare of donors to be neglected in face of the parlous condition and grievous needs of the recipients. It would seem that the risks of explantation, apart from cases where vital organs are required, are always outstripped by risks in denying transplantation. The result is that the welfare of the donor might be regarded with less care than it ought. For this reason the Pittsburgh agreement lays down the rule of separation of clinical responsibility for donor and recipient. Thus the zeal of the clinician to rescue the dying cannot intrude upon the responsibility of the clinician to protect the living. But such a separation cannot be made in the case of Brian and Philippa as parents of both the potential donor and recipient. They are desperate not to lose two-year-old Sarah but they also love four-year-old Joshua. Nevertheless some short term suffering for Joshua will seem as little when compared with the denial of life to Sarah. In the long term, it seems, there is no question to be answered, the procedure must go ahead. But is such a determination a best interests judgement in the case of Joshua? It is only to make such judgements that the parents are entrusted with the responsibility to give consent. A judgement of this sort is not the same as a judgement of what is in Sarah's best interests, nor of the family's interests as a whole – even though Joshua is a member of it.

### Commodification of Children

In recent years there has been a fair amount of discussion of the commissioning of pregnancies in order to provide compatible tissue for suffering parents or siblings. This

practice has been condemned by some critics as an unethical practice insofar as it regards the foetus or the resultant child merely as a means to an end, a commodity produced for the convenience of others. As such it is degrading and unacceptable. If we assume that this is so, and there is some good sense in the claim, then we might ask what it is that merits the description 'commodification'. One important element is surely that the child in question has no control over what is done to her, and that those most naturally regarded as being responsible for her protection have vested interests in neglecting that responsibility, so treating the child with less respect than it deserves, *viz.* as a valuable commodity rather than a valued person. Do Brian and Philippa find themselves in such a position? It might be argued that permitting them to determine what should happen to Joshua is to put a foot on this slippery slope. On the other hand the identity of the existing child as Sarah's sibling marks Joshua off from simply being a commodity and this difference might be thought to have an important bearing on his best interests.

### Best Interests and Hypothetical Consent

A case might be made for the view that it is in Joshua's best interests to be treated as a donor of bone marrow. Though the treatment is not indicated for him by any condition from which he suffers nevertheless failure to treat him thus might have adverse health outcomes for him. Identifying these outcomes is related to the possibility of creating hypothetical consents for children such as already exist in some psychiatric interventions where the patient is not competent to consent to treatment for his own benefit but for which he will nevertheless be grateful after the event – the so-called 'thank you tomorrow' justification. The case would go as follows: Joshua cannot now understand that his sister's life is put in jeopardy if some of his tissue is not used to treat her leukaemia. Nevertheless her chances of survival will be greatly and uniquely enhanced by Joshua's role in the transplantation. If he is not consented into the procedure he is likely to learn later in life that his sister's death, which we now know is more likely to occur if he does not donate, was partly due to the fact that out of concern for his short term suffering she was denied lifesaving treatment. Such knowledge would not contribute to his sense of wellbeing,

which gain would outweigh the short term suffering involved in the donation process.

### Best Interests and Treatment Failure

The picture is not as simple as outlined. What happens to the claimed net benefit for Joshua if the treatment fails? We might claim that even if the donation is not a success the knowledge that he was part of the effort to do everything possible to save his sister's life, when there was thought to be a good chance of this occurring, would still contribute to his sense of wellbeing. However, there are at least two possible scenarios to account for here. The first would be the situation where the transplantation procedure failed simply because, due to the compromised immune system produced as a preparation for the bone marrow transplantation, Sarah failed to fight off an infection which was fatal. In such a case Joshua could live with the knowledge that he was part of the heroic efforts made to give his sister a life. The chances are that he would resent the fact that out of concern for his welfare he was not permitted to play such a role as a consequence of which Sarah died. This would constitute good grounds for a 'thank you tomorrow' consent. The second scenario is more problematic. One of the dangers of bone marrow transplantation is the possibility of graft/host disease in which the transplanted immune system rejects the body into which it is transplanted and kills the patient. In such cases the patient's death is caused not by the disease which is being treated, nor by an opportunistic infection but rather by the transplanted tissue. Would living with the knowledge that, indirectly, he was so responsible for his sister's death contribute to Joshua's sense of wellbeing? There is no way in which we can be secure in our answer to this question.

### Conclusion

It would be mistaken to rule out the use of Joshua's bone marrow as unethical simply because of the impossibility of his providing a proper consent. On the other hand it would be unacceptable for his bone marrow to be donated simply on the strength of his parents' wishes. The use of the concept of a hypothetical consent helps to address the ethical issues the case presents. Such a procedure demands sensitive weighing of the potential risks and benefits. On balance it will probably be thought that the probabilities of benefit for Joshua outweigh those of risk or harm and on that basis the decision not to proceed would be unethical. Of course

we have to be able to live with uncertainties in making a decision either way in this case. Further, each case must be considered on its own merits. The foregoing arguments might not succeed if the clinicians were to be seeking to remove a kidney, or if Joshua's health was already compromised in some relevant way so making the procedure more hazardous, and so on.

## commentary

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The United Nations General Assembly adopted the Convention on the Rights of the Child (UNCROC) in 1989, following a decade of activity to develop an international convention aimed at promoting and protecting children's human rights. New Zealand was an initial signatory to the Convention, but took the formal step of ratification in March 1993. This step confirmed our Government's acceptance of the obligations imposed upon it by UNCROC<sup>1</sup> and demonstrated its willingness to work towards compliance with agreed international standards. However, while UNCROC is the pre-eminent embodiment of children's rights, it does not override our domestic law. Nevertheless UNCROC has had an influential impact on decision-making in various legal cases concerning children (for example, in the deportation of illegal immigrants who have NZ born children, and in custody and access cases concerning relocation matters). Its use in other fields is sadly lacking. Article 42 of UNCROC imposes an obligation on the Government to actively promote the Convention to adults and children alike. Yet there is a general lack of awareness of the Convention amongst professional groups, and amongst children below the age of 18 years whose rights it is meant to be promoting.

The case scenario concerns the paediatric care and treatment of a two year old child (Sarah) with acute myeloblastic leukaemia. The scenario is complicated by the fact that her four year old brother (Joshua) is a compatible donor for a bone marrow transplant. The United Nations Convention on the Rights of the Child incorporates several Articles which have relevance to their situation. While UNCROC does not provide an answer as to whether or not the transplant procedure should go ahead, consideration of the relevant

Articles does help to tease out the rights of each child within these grave family circumstances.

Article 3(1) requires that all actions concerning children and young people shall take full account of their best interests. This is consistent with our domestic law – s23 of the Guardianship Act 1968 requires the Court to 'regard the welfare of the child as the first and paramount consideration.'

Article 5 respects the rights and responsibilities of parents to provide guidance for the child which is appropriate to his or her evolving capacities. Sarah's parents are apparently eager for the transplant to proceed, but they have to weigh both Sarah and Joshua's rights. Clearly the transplant is not without risk (however slight) and discomfort to Joshua; but this must be balanced with the more optimal outcome for Sarah by the transplant proceeding.

Article 12 assures each child of their right to express their opinion freely and to have that opinion taken into account in any matter or procedure affecting the child. Sarah's and Joshua's young ages should not inhibit the ascertainment of their views, as there is now considerable research affirming the contribution children of even young ages can make to decision-making processes. We are already aware of Joshua's understandable fear of hospital and needles – clearly this would need to be worked through with him prior to any decision being made. There are no details in the case scenario concerning Sarah's views and feelings, but her need for information and consultation in an age-appropriate fashion should not be overlooked.

Article 24 recognises the right of each child to the highest standard of health and medical care attainable.

Regardless of UNCROC, s25 of the Guardianship Act enables a parent to give consent to any medical or surgical procedure to be carried out on their child(ren). Thus the consent of Sarah and Joshua's parents will enable the transplant to proceed legally. Nevertheless, what UNCROC does is remind us that the rights of each individual child should be taken into account by the parents and health care providers. This will enable a fuller picture to emerge within this family context on which to base the ultimate decision. The Convention is intended to be read holistically, thus facilitating the weighing up of principles and options in an

informed fashion by all the key players. In this respect UNCROC, like the Code of Health and Disability Consumer's Rights and the Gillick principle, has rejected the more paternalistic 'status-based' approach (of s25) in favour of an 'understanding-based' approach to children's competence to participate in health-care decision making. This approach is currently also being adopted in the draft New Zealand Standards for the Welfare of Children and Young People in Healthcare Facilities. Based on national and international documents (like UNCROC) the Standards will promote the welfare of children and young people in healthcare settings and will undoubtedly have relevance for situations like those featured in the case scenario.

#### Notes

1. New Zealand did however enter three reservations to UNCROC concerning: the non-provision of benefits to children unlawfully in NZ; employment law in respect of children; and the continued mixing of juvenile and adult prisoners.

## commentary

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There are a number of quite difficult ethical issues arising in a case such as this. We must make the assumption that, at the time this case was under consideration, there was clear current evidence that allogeneic bone marrow transplant (BMT) offered a distinct long term survival for this patient over alternative modalities available. This may not always be clear in this rapidly evolving field. I will focus on two areas related to the donor that will or should dominate the ethical thinking of the therapeutic team looking after Sarah.

First, the issue of informed consent for the donor. It would have been easier if the match had been with the older two siblings, but the fact that the only suitable donor was 4 years old need not be a great handicap. The parents can consent the child to the procedure even given that Joshua's interests would have been of secondary importance to the patient's at the time. We can foresee that more problems would have arisen if the consent to be a 'life-saving' donor had been withheld, and the patient subsequently died of the disease without BMT. The impact that this knowledge would have had on Joshua when he was older would under 'normal'

circumstances be devastating. Parental counselling for consent would raise this issue – amongst others that serve the best interests of the donor, who is, after all, not sick and yet is to be subjected to a potentially harmful and certainly scary procedure.

Second, of paramount importance is the need to recognize that there is a duty of care to Joshua as the donor. The objectivity needed to provide this cannot be held by the team looking after Sarah, and nor can it be by her parents. It is our policy in allogeneic BMT that, as soon as the donor has been identified, even before confirmatory testing is undertaken, that all health and counselling issues related to the donor are transferred completely to an independent specialist with experience in the field and who has no direct involvement in the care of the patient. If necessary, for example in smaller centres, this may mean the involvement of a unit from another centre. This specialist will be responsible for the consent counselling, medical and other evaluation and all other issues, even including those of advocacy, pertinent to the donor. Apart from the obvious procedure-related issues, it must be borne in mind that much of the treatment-related morbidity and mortality that BMT has for the patient relates to graft-versus-host disease and many a donor in the past has taken this knowledge badly after the event. The opinions and advice of the 'donor's physician' will be recorded appropriately and will show transparently that, at all stages, the best interests of the donor have been served without undue pressures being applied. Even with the best will in the world, the therapeutic team looking after the recipient can not provide such objective opinions and advice. Normally, of course, we would expect the transplant to proceed in a case such as this, especially as this type of live organ donation has the advantage that the tissue removed is readily renewed. A happy outcome would be contributed to by such proper and due attention to the donor's interests.