



The Joseph Case

Joseph has Fanconi's anaemia. He has some minor abnormalities of his hands but the main problem is with his bone marrow, which does not produce enough red cells, white cells or platelets. By the age of seven, Joseph's blood counts have started to fall significantly and he is prone to bleeding and infections. These could prove fatal and Joseph will need a bone marrow or stem cell transplant if he is to survive.

His parents have dedicated all of the past seven years to caring for Joseph. His mother would like to have another child and his father is keen to use IVF (in vitro fertilisation), with embryo selection, to make sure the baby will have the same tissue type as Joseph. They hope that cord blood can be harvested at the time of the baby's birth and used to provide stem cells for the transplant that Joseph desperately needs.

Joseph's mother does become pregnant through IVF with selection of a tissue-matched embryo. The embryo is also tested to make sure it does not carry the genetic defect which causes Fanconi anaemia. The family arrange for cord blood to be collected at the time of the baby's birth and to be frozen in a cord blood bank until the time of Joseph's transplant. Unfortunately the birth does not go as planned. Joseph's mother suffers an antenatal haemorrhage and goes into early labour. Because of the haemorrhage and emergency delivery, very little cord blood can be collected. The cell count will not be enough for Joseph's transplant.

With medication and ongoing hospital treatment, Joseph may survive another few years. His new baby sister, Sarah, will be able to donate bone marrow for him when she is of the right age and size to have her bone marrow harvested in theatre under general anaesthetic. The small amount of cord blood stem cells retrieved can be used to 'top up' this bone marrow and provide a large enough dose for Joseph's transplant.

The family must now wait for Sarah to become old enough to have this procedure.

Discussion issues

- Should parents be allowed to genetically select their children?

- In the UK it is now legal to select a tissue-matched embryo, if an older child has a serious or life-threatening illness. Who should decide which illnesses this is allowed for?

- The same technique was used in this case to make sure that the embryo did not carry the genetic defect which leads to Fanconi anaemia. If you feel it is unethical to genetically select an embryo for their tissue-type (i.e. to help an existing child), do you think it is acceptable for parents to select an embryo which does not carry a life-threatening or serious condition (i.e. so that the new child is not ill)?

- Again, who decides which illnesses fall into this category? What about conditions that are not life-threatening but a parent may wish to avoid in future children, e.g. achondroplasia (dwarfism) or albinism (absence of skin pigmentation)?

- What do you think about the discarding of embryos created during the process that are not needed (either not a tissue match, or carry the genetic condition)?

- The cord blood collection unfortunately did not work out as planned. Baby Sarah will now need to undergo an operation to donate bone marrow. As a small child she has no right to refuse this. It is right that her parents should be the ones to give consent on her behalf? Or should someone else make the decision, such as a court?

- Bone marrow transplants are very risky procedures with a mortality risk of approximately 30% for Fanconi anaemia. What if the transplant doesn't go well for Joseph? Do you think that Sarah could carry any psychological issues from this in the future if she is unable to 'save' her brother?

- What do you think of the term 'Saviour Siblings' that is commonly used (mostly by the press) to label children such as Sarah?

