

This response was submitted to the call for evidence by the Nuffield Council on Bioethics on *Emerging techniques to prevent inherited mitochondrial disorders: ethical issues* between January 2012 and February 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

### **Anonymous 8**

I am a 25 year old woman and I carry the MELAS mitochondrial gene. Luckily I have not presented any symptoms of the condition thus far. My sister is turning 30 this year and hers is a much different, more upsetting story. She does present symptoms of MELAS. I have watched as she suffers from and seen the consequences of seizures which she now takes daily, I have seen my sister go from a vibrant young actress to barely being able to form sentences, I have seen my sister complain of not being able to hear what people are saying, although they are speaking loudly and her hearing aids are in. These are only a few of many problems she has faced and continues to face. Things will not get better, they will only get worse. She watches as her friends have left home, found careers, got engaged, got married. She also has to watch me, her younger sister, follow this path too and at one point that seemed to be where she could be headed. Due to her condition taking over her whole life and due to the dementia element that has begun taking over her whole personality, my sister's chance at that path has been stolen.

2. I have decided to not have children. Although the early years of my sister's life were better and there were happier times for her, for me to bring a child in to the world who may suffer what she has, is unimaginable. However, if these procedures being discussed were permitted for treatment, I would consider conceiving and giving birth to a child who would not suffer the impacts of a mitochondrial disorder. I would inform them that their mitochondria were healthy and that all their other genes came from their mum and dad. I would also tell them had that procedure not been done; there may have been more serious implications to their life. If and when I am ready to have a child and if this treatment was not offered within the UK, I would go further afield. Knowing this treatment was available could potentially change my current mind-set. It could create for me (and many other men and women) a chance to experience what is supposed to be an amazing time in a person's life, pregnancy, rather than the bleak picture I have of it now.

3. It is vital that these procedures are permitted for treatment and I think it would be unethical to not allow them to go ahead. Although my sister struggles the most, this condition not only affects her but has had a large impact on our family as a whole. My parents are selfless and have given their all, mentally and physically to care for their daughter, while running a business and maintaining a marriage, let alone having any time for themselves. Having grown up and watched our family story unfold, I understand I have a bias view but this procedure is here to change for good, mitochondrial stories like this one. I struggle to understand why IVF is permitted yet there may be an ethical issue with this procedure.

4. I will get older and I will still carry the MELAS mitochondrial gene but what I don't want to do is to raise a son/daughter and see bit by bit their personalities and lives be taken from them as I have done with my sister, Laura.