

Peter Saunders reflects on our attitudes to those with special needs

Photo is posed by a model and does not refer to the article
Photo: Down's Syndrome Association

Bearing burdens

When I was a final year medical student, a baby was admitted onto the paediatric surgical ward with duodenal atresia. A relatively straightforward operation would have saved her but, because she had Down's Syndrome, her parents opted not to treat. She was left alone in a side room, given large doses of morphine and effectively starved and dehydrated to death.

Some years later, when I was a senior registrar in general surgery, a woman in her 50s (again with Down's Syndrome) presented with obstructive jaundice secondary to a tumour of the Ampulla of Vater. The necessary Whipple's procedure, which involves removing duodenum, gall bladder, bile duct and half the pancreas, was a major undertaking, but there was no question in the minds of her family that she should receive the best care available. In fact she tolerated the procedure well and made an excellent recovery.

I have often reflected on these two cases and the different attitudes of the families involved. But treatment decisions like these may be consigned to history very shortly if current trends continue.

The number of Down's Syndrome pregnancies is increasing. There were 1,067 in England and Wales in 1989 but by 2002 this had risen to 1,433, mainly due to the fact that women are delaying having children until an age when the risk of having a child with this condition is higher. But despite this the number of Down's Syndrome babies *born alive* each year has actually *fallen* from 750 to around 600 over the same period. This is because our society is increasingly taking the view that it is better if children with this condition are not born at all. In 2002 around 800 Down's Syndrome babies, 56% of the total, were aborted. But the number would have been much higher if more had been diagnosed before birth.¹

Prenatal screening by ultrasound or maternal blood tests can raise suspicion of Down's Syndrome, but a firm diagnosis can only be made through tissue diagnosis, either at 10-12 weeks by chorionic villus

sampling (CVS), or at 16-20 weeks by amniocentesis. Currently 92% of all Down's Syndrome babies diagnosed before birth are aborted, but the government has plans under a new Human Genetics Commission consultation called *Choosing the Future*² to make prenatal screening much more widely available. If it concludes as anticipated, we can expect the number of children born with Down's Syndrome each year to fall to well less than 100. We can also expect to see fewer children born with a large range of other genetic abnormalities.

There is no doubt that bringing up a child with special needs involves substantial emotional and financial cost, and yet at the very heart of the Christian gospel is the Lord Jesus who chose to lay down his life to meet our own 'special needs'. The Apostle Paul tells us that Christ died for us 'when we were powerless' (Romans 5:6) and that 'bearing one another's burdens' is at the very heart of Christian morality (Galatians 6:1). For Christian doctors bearing burdens involves not only providing the best medical care for the most vulnerable members of our society, but also supporting their families in the long haul, being prepared to speak out when they are being treated unjustly and doing what we can to oppose unjust and discriminatory legislation and health policy.

On 17 April 2005 I will be part of a small team running the London marathon to support those with Down's Syndrome and their families.³ But all of us are part of a much larger team called in a whole variety of ways to engage in the fight for these very special people and others in a similar position of vulnerability. Let's pray that we fight these battles well.

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1. www.smd.qmul.ac.uk/wolfson/Indscr/INDCSRreport.pdf
2. Saunders P. *Choosing the Future*. *Triple Helix* 2005; Winter:4
3. See www.justgiving.com/petersaunders