

## **Antenatal Results and Choices**

### **Later terminations for fetal abnormality The parental perspective**

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ARC

## **ARC**

- First launched 1988 as SATFA – **Support After Termination For Abnormality**
- In 1992 changed name to **Support Around Termination For Abnormality**
- Changed again to ARC – **Antenatal Results and Choices** in 1998 as more and more enquiries involved questions about testing

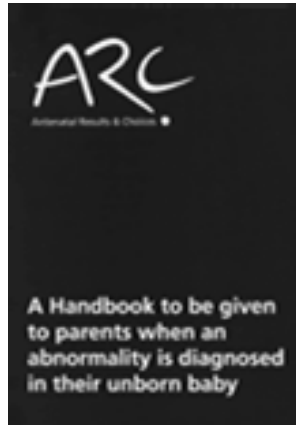
### **ARC provides information and support to parents:**

- making decisions before, during and after antenatal testing
- who are told that their unborn baby has an abnormality
- making decisions about the future of the pregnancy
- continued support is offered whatever decision is made

### **ARC provides support through:**

- a national helpline
- a national support network
- a website
- moderated email support groups
- a range of literature for parents, families and health professionals
- professional training
- informing policy

## ARC Handbook



## Office of National Statistics

- 186,416 terminations (2005)
- Of those 1,916 (approx 1%) were for fetal abnormality\*
- 23% after diagnosis of Down's syndrome
- 77% after diagnosis of other conditions
- 137 after 24 weeks

\* 'When there is substantial risk that if the child was born it would suffer from physical or mental abnormalities as to be seriously handicapped' (Clause E Abortion Act 1967)

## Antenatal tests

| What?  | When?                          |
|--|--------------------------------|
| <i>Early ultrasound scans</i>  |                                |
| Fetal viability scan   | 6 – 10 weeks                   |
| Dating scan  | 10 – 12 weeks                  |
| <i>Screening tests</i>   |                                |
| Sickle cell & thalassaemia blood test                                    | 8 – 10 weeks                   |
| Nuchal translucency (NT) scan (DS)                                       | 11 – 13 weeks                  |
| Combined test (DS)<br>(NT and blood tests)                               | 11 – 13 weeks                  |
| Integrated test (DS)<br>(NT and blood tests<br>then further blood tests) | 11 – 13 weeks<br>16 – 20 weeks |
| Serum screening (DS)<br>(blood tests)                                    | 16 – 20 weeks                  |
| Mid pregnancy scan*  | 18 – 22 weeks                  |
| <i>Diagnostic tests</i>  |                                |
| Chorionic villus sampling (CVS)  | 11 – 13 weeks                  |
| Amniocentesis  | 16 – 24 weeks                  |
| Mid pregnancy scan*  | 18 – 22 weeks                  |

## The impact of diagnosis

*'My husband and I felt everything crumble around us in the face of that news. Convictions previously held and decisions previously made seemed superficial and hastily arrived at now that the reality of the situation was upon us.'*

## The decision to terminate

*'It was the most difficult decision I have ever had to make and I feel the gravity and enormity of the responsibility was glossed over by one or two professionals... for us it wasn't an inevitable consequence. It was something we gave a lot of thought to, and a decision we both found very difficult. Whilst we don't regret the decision, we still regret aspects of the process of the decision.'*

[www.dipex.org](http://www.dipex.org)

## The decision to terminate

*'But how, as... a human being you make those sorts of decisions, you know, 'Do I stick a needle in my baby's heart and kill him now? Do I give birth to him and then sort of hope that he doesn't die, have a heart attack and drop dead at the age of five, you know? Or, if he survives it all, which is the best you hope for, how will he live with the burden of this knowledge of this terrible incurable thing? ...'*

## The decision to terminate

*'...And I remember sort of going round in circles in my head between these things, ...And thinking, what am I going to choose, you know? Which of these three just awful, very different scenarios is the one that I feel I could live with, or that I could choose him to have to live with?'*

## The need for time

*'I don't think we did take it all in. I think we came home - even the leaflets and things - it felt like it wasn't, 'real'. It was just, and that there was so much information and, there was almost a sense of - not urgency but they wanted us to make decisions quite quickly - and I mean obviously medically they knew exactly what was wrong, and exactly, you know, what we were faced with - but for us, it was a huge thing to decide.'*

*DIPEX interview*

## The need for time

- *'I've just had my CVS result which is positive for Down's syndrome. I'm just over 12 weeks so they've said the deadline for a surgical termination is tomorrow – I just don't know what to do.'*

Centre for Family Research Cambridge  
Obstetric factors: Impact on emotional well-being

## No impact

- gestational age
- type of malformation
- method of termination
- reproductive history
- 'cultural' religious beliefs

Statham, Solomou & Green.

*When a baby has an abnormality: A study of parents' experiences. (2001)*  
University of Cambridge, Centre for Family Research; Mother & Infant Unit, University of Leeds

## The mid-pregnancy scan

*'It was a sunny morning three days before Christmas when we went for our 22-week scan, excited about seeing our baby, confirming the sex and hopefully getting some good pictures for the grandparents...*

*...tears started rolling down my cheeks...my head was spinning... how can all these things be wrong? The sonographer said we should go to another hospital for further scans.'*

## The need for time

*'It wasn't until I saw the consultant that I decided to end the pregnancy. It was evident from all the scans and advice I had received that George's condition was extremely serious, but during the four weeks I had tried to cling on to a glimmer of hope that things wouldn't be that bad in the end.'*

## **The need for information**

*'We were referred to another hospital and after a difficult two-day wait we were given the awful diagnosis that the baby had ruptured posterior urethral valves. We were told we could continue with the pregnancy regardless, terminate or wait for three weeks for a follow up scan. We were in a state of shock but decided to wait for further news.'*

## **What parents say**

*'Now a year on I have accepted my decision. I just regret I had to be the one to make it.'*

## **Pressure to make a decision**

*'We decided that because of all the other problems that our baby had as well as Down's syndrome it wasn't fair to bring him into the world when his quality of life would have been so poor. I literally had one day to decide. I didn't want to have to make that decision and I wish someone could have decided for me.'*

## **Pressure to make a decision**

*'My baby has Edward's syndrome and they have told me because I'm nearly 24 weeks I have to decide quickly if I want a termination otherwise a panel of experts has to meet to authorise the procedure.'*

## **After a diagnosis of fetal abnormality parents need:**

- Information
- Time to consider their options
- Individualised support

## **Antenatal Results and Choices**

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