Supporting parents’ choices after prenatal diagnosis

Jane Fisher
‘Diagnoses and Dilemmas’ London 9/9/13
‘The consequences of a decision to terminate an abnormal pregnancy remain with parents forever. It is always very hard, but how we come to terms with the loss of that baby depends to a large extent on how we are treated from the time that an abnormality is discovered’

• Quote from SATFA’s first Annual review 1988/89
ARC provides information and support to parents:

- making decisions before, during and after antenatal testing
- dealing with worrying screening results
- when fetal anomaly is suggested or diagnosed
- making decisions about the future of the pregnancy
- coping with the aftermath of their decisions

*continued support is offered whatever decision is made*
What ARC offers

• Independent source of information and safe confidential space

• Opportunity to explore their options and consider potential outcomes

• Individualised support
Dealing with anxiety

‘It’s such a stressful time, I hope the results on Thursday are clear, but that still makes me think that could there still be something wrong even if they’re clear. I don’t really want to feel like this until it’s born; it’s a nightmare’

Email from father – awaiting CVS results after raised nuchal translucency

‘Apparently my PAPP-A is very low so they are going to scan me at 28 weeks – that seems a lifetime away.’

Helpline call
Earlier diagnosis

NDSCR Report 2011 – prenatal diagnosis

• 1211 cases of T21
  810 (67%) diagnosed after 1\textsuperscript{st} trimester screening
  303 (25%) diagnosed after 2\textsuperscript{nd} trimester screening
  62 (5%) diagnosed after ultrasound

• 468 cases of T18
  327 (70%) diagnosed after 1\textsuperscript{st} trimester screening
  53 (11%) diagnosed after 2\textsuperscript{nd} trimester screening
  61 (13%) diagnosed after ultrasound

• 171 cases of T13
  93 (54%) diagnosed after 1\textsuperscript{st} trimester screening
  28 (16%) diagnosed after 2\textsuperscript{nd} trimester screening
  40 (23%) diagnosed after ultrasound
'Available now!
A safe, non-invasive test that measures fetal cells present in the mother's blood to produce a 99% accurate Down Syndrome screening result.

Available from 10 weeks gestation, simply attend our centre for an accurate dating scan, provide a small blood sample and receive your result in under 15 days.'

• Numerous private clinics and consultants now offering ‘the Harmony ® Prenatal Test’.
• Costs vary from £400 - £800
• CVS or amniocentesis required to confirm result
Impact of a prenatal diagnosis

• ‘five seconds later she said the words that would change our lives forever. I couldn’t quite take it in. My husband went white and grabbed my hand.’

• ‘...the lady then said she had seen a heart defect and that we had to go to another hospital to see a doctor who was expert in heart defects. All of a sudden carrying my baby now felt terrifying. It didn’t matter what I did now, nothing would take this away from me.’

• ‘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.’
• ‘Oh my tiny baby... we saw you on the screen when we went for our scan and squeezed each others hands with excitement. I wish I could keep that feeling; those pitiful few minutes when you were all ours, a limitless horizon of potential that at this point just meant joyful anticipation.’

ARC News
'We felt so alone – this is something that nobody speaks about. Our midwife was lovely, but she said we were the first couple she knew to have a diagnosis like this. I found it comforting to receive the ARC booklet because it was a proper printed publication it made us feel that other people must go through this.'
Continuing after a diagnosis

For the parents:

- Feelings about a ‘different’ pregnancy and a changed relationship with a different baby
- Fears and concerns about practical aspects of care
- Worries about the health of the baby
- Strain of adjusting to an ever changing scenario
- Preparing for the birth
- Preparing for afterwards: no baby OR the reality of an ill baby

Statham, Solomou and Green 2001
Ending the pregnancy

‘The thought of having to give birth and not be able to bring my baby home was absolutely devastating. On top of the complete emotional turmoil I was suffering, I now had to cope with the thought of going through a painful labour with no reward. I hadn’t been pregnant before so the thought terrified me.’

ARC News
## DH abortion statistics 2012: ‘Ground E’

<table>
<thead>
<tr>
<th>Gestation</th>
<th>&lt;13</th>
<th>13-14</th>
<th>15-16</th>
<th>17-19</th>
<th>20-21</th>
<th>&gt;22</th>
</tr>
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<tbody>
<tr>
<td>Total</td>
<td>2692</td>
<td>386</td>
<td>795</td>
<td>353</td>
<td>283</td>
<td>482</td>
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<tr>
<td>Surgical (%)</td>
<td>25</td>
<td>55</td>
<td>43</td>
<td>20</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Medical (%)</td>
<td>75</td>
<td>45</td>
<td>57</td>
<td>80</td>
<td>90</td>
<td>99</td>
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</table>
Choice of TFA method

• Medical and surgical termination of pregnancy conducted according to RCOG guidelines appear to have comparable outcomes. Wherever possible women should be offered the choice of method.


• Improving access to and counseling for both methods of termination will allow expanded choices for women. Including a discussion of a woman's emotional coping style will help women choose the method that will result in optimal coping and grief resolution.

ARC Survey – what was offered?

<table>
<thead>
<tr>
<th></th>
<th>&lt;15 weeks</th>
<th>&gt;15 weeks</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical only</td>
<td>45 (43%)</td>
<td>216 (87%)</td>
<td>261 (74%)</td>
</tr>
<tr>
<td>Surgical only</td>
<td>22 (21%)</td>
<td>4 (2%)</td>
<td>26 (8%)</td>
</tr>
<tr>
<td>Both</td>
<td>35 (34%)</td>
<td>15 (6%)</td>
<td>50 (14%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (1%)</td>
<td>13 (5%)</td>
<td>14 (4%)</td>
</tr>
<tr>
<td>Total</td>
<td>104</td>
<td>248</td>
<td>351</td>
</tr>
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</table>

- Of women offered a choice 60% (n=30) had a surgical TFA. Women who had a surgical TFA were more likely to feel it was right for them.
## ARC survey on choice of method

<table>
<thead>
<tr>
<th>Indication</th>
<th>Medical Only</th>
<th>Surgical Only</th>
<th>Both</th>
<th>Don’t know</th>
<th>Medical</th>
<th>Surgical</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chromosomal</td>
<td>142 (54.4)</td>
<td>13 (50.0)</td>
<td>32 (64.0)</td>
<td>8 (57.1)</td>
<td>153 (55.6)</td>
<td>35 (52.2)</td>
<td>7 (77.8)</td>
</tr>
<tr>
<td>Structural</td>
<td>117 (44.8)</td>
<td>13 (50.0)</td>
<td>18 (36.0)</td>
<td>5 (35.7)</td>
<td>119 (43.3)</td>
<td>32 (47.8)</td>
<td>2 (22.2)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (0.8)</td>
<td>0</td>
<td>0</td>
<td>1 (7.1)</td>
<td>3 (1.1)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>261 (100.0)</td>
<td>26 (100.0)</td>
<td>50 (100.0)</td>
<td>14 (100.0)</td>
<td>275 (100.0)</td>
<td>67 (100.0)</td>
<td>9 (100.0)</td>
</tr>
</tbody>
</table>
ARC Survey on choice of method

‘I would have had to wait days until cvs results were back by which time I would have been past what I was informed was the deadline for surgical termination at my hospital.’

T13 12/40

‘I asked for surgical but was told I could not have this as the cut off was 13 and I was 13+2.’

T13
What was helpful?

It was a very peaceful time although stressful. I was in a private room. The midwife treated me very well, we were able to stay overnight with Jacob before we left. T21 17/20 MTOP

The friendliness and compassion of the staff and the clarity of the explanations and information given. Everyone was very considerate of us and kept us informed throughout the process. Structural anomalies 22/40 MTOP

I had an allocated specialist midwife who gave us the initial news, sat in with us during the cvs and gave us the confirmed diagnosis as well as offered support afterwards. She wasn't present when I was admitted for the actual procedure but we contacted her after the weekend in hospital and she visited and helped arrange the surgical termination. T21 14/40 STOP
What was unhelpful?

We weren't offered a choice of termination method - only medical – and although in the end I may well have chosen to have a medical termination, I think it would have been helpful to have known we had a choice and been able to discuss the pros and cons of the different methods.

*T21 14/40 MTOP*

I also thought I would have a surgical termination it was a shock to be induced and have the baby on a labour ward where there were healthy babies been born.

*T21 14/40 MTOP*

Having the termination in day surgery unit where they were not well equipped to deal with my emotional state.

*T21 13/40 STOP*
The challenges to providing choice of method

‘An increasing number of gynaecologists are opting out of providing STOP, especially after 12 weeks of gestation, thereby severely compromising training opportunities within the NHS: the RCOG Advanced Training Skills Module (ATSM) in Abortion Care has a compulsory element covering MTOP at early and late gestations, but only up to 14 weeks of gestation for STOP.’

What might help parents after prenatal diagnosis?

• As much information as possible about prognosis
• Information about all options
• Acknowledgement of uncertainty and distress
• Time and space to make decisions
• Compassionate and non-judgmental attitude from all staff
• Signposting to appropriate external information and support
• Continuity of care and follow up
How ARC can help

ARC professional training

www.arc-uk.org

Confidential support

0207 713 7486  info@arc-uk.org
‘This was the most dreadful thing we have ever been through in our lives. The grief, the emotional pain and the shock were overpowering. But even through this truly terrible time we felt a sense of gratitude that we had the choice to end the pregnancy. We felt and still feel that we made the right decision for us, but also, importantly, for her.’

ARC News
Thank you!

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