

# Late Abortion: A Review of the Evidence

A briefing compiled by  
Pro-Choice Forum



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# Introduction

Abortion – in particular ‘late’ abortion - has been the subject of much recent media discussion. The emphasis of commentators has been that while early abortion, in the first 12 weeks of pregnancy, can be accepted as regrettable, but necessary, abortion at later stages should be considered very differently. ‘Late’ abortion been represented as a source of growing discomfort, and there have been numerous calls for the abortion law to be reconsidered in this light.

*Late Abortion: A Review of the Evidence* has been compiled in recognition of this discussion. It provides research-based evidence and statistical information to assist with the consideration of issues around late abortion. It is hoped that the evidence-driven approach taken will prove valuable to those considering this matter, and helps reasoned conclusions to be drawn in this difficult and challenging debate.

In particular, this briefing provides evidence relating to the following claims that have been made about why late abortion should be a particular cause for concern:

- That technological developments and new scientific knowledge – in the areas of neonatal care, understanding of fetal development, and antenatal screening – indicate that the upper time limit for legal abortion should be reviewed, and lowered.
- That the methods used in late abortion are horrific, and are also sometimes carried out in a way that leads to ‘botched’ abortions, where the fetus is born alive.
- That very late abortion, performed after 24 weeks on the grounds of fetal abnormality, is being provided in a way that breaches the current law.
- That a kind of legislative ‘trade off’ may be the best solution, in which abortion during the first trimester (12 weeks) would become available ‘on request’, but with greater restriction later in pregnancy. (Upper time limits of 18, 20 and 22 weeks have been mentioned). This is sometimes portrayed as a move to make British law more like that in Europe.

*Late Abortion: A Review of the Evidence* is also available at [www.prochoiceforum.org.uk](http://www.prochoiceforum.org.uk)

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Dr Ellie Lee, lecturer in social policy, University of Kent, and co-ordinator, Pro-Choice Forum, November 2004.

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# Key findings: a summary

## Abortion at 20 weeks or more: trends and statistics

- The percentage of all abortions performed at 20 or more weeks is small. It has remained at between 1 and 1.6 % of the total number of terminations for many years. In England and Wales in 2002 there were 175, 932 abortions of which 2,874 were performed at 20 weeks and above. Over the past two decades the number performed after 24 completed weeks has varied from 60 to 101.
- Proportionally more abortions to younger women occur at 20 or more weeks' gestation as compared to older women. In 2002, 2.3% of all abortions to women aged under-20 were at 20+ weeks, compared to 1.4% for those aged 30-39.
- The last decade or so has seen a significant switch from abortions provided by NHS establishments to those provided by non-NHS establishments but paid for by the NHS (NHS Agency). The outcome is that NHS hospitals now provide fewer abortions at 20+ weeks than a decade ago.
- In 2002 NHS agency abortions represented 60% of all 20+ week procedures. British Pregnancy Advisory Service (bpas) is the main provider of late abortions outside the NHS.

## Abortion methods in the second trimester

- The Department of Health and the Royal College of Obstetricians and Gynaecologists (RCOG) have clear guidelines for the provision of late abortion. Procedure to ensure the fetus is not delivered showing signs of life following abortion at 21 weeks and over is the subject of particular guidance.
- The incidence of live birth following an abortion procedure (so-called 'botched abortion') is very low. To date, this has been reported only in NHS hospitals.
- Abortion at 20 weeks and over can be provided surgically by dilatation and evacuation (D&E), or medically by induction of labour using mifepristone and prostaglandin. There have been considerable improvements to both methods over the past 30 years, especially to the latter.
- Serious complications resulting from abortion are now uncommon, but increase with gestation. In 2002, with medical abortions, complications were notified in 11/1000 cases at 20+ weeks, the most frequent complication being haemorrhage. With surgical abortions, complications were notified in 6/1000 at 20+ weeks. The most frequent complication was haemorrhage, but uterine perforation occurred in 2/1000 cases.

## Why women have late abortions

- There are four main categories of reasons for women having abortions late: failure to recognise the pregnancy earlier; delay in seeking abortion; diagnosis of fetal abnormality; delay in access to abortion because of unanticipated changes in the woman's circumstances.
- In the vast majority of cases (around 80 per cent) women undergoing abortion after 12 weeks, and in particular at 20 weeks or more, do not realise they need to seek abortion until they are three or four months pregnant.

### Case Study 1: A 17-year-old who failed to recognise she was pregnant until nearly 20 weeks gestation:

*I started on the pill about the end of August...I'd never been on the pill before, you're never quite sure about it and I didn't know what to expect anyway....When I'd been to the GP I'd worked out I was two months pregnant...then I went in to have the internal examination [at consultation] ...he was like, 'well actually...you're more like four and a half months pregnant'...and I hadn't known, 'cause I hadn't been having my periods normally.*

### Case Study 2: A woman in her 30s. Situation as reported by a bpas counsellor:

*A recent one, that was a planned pregnancy, very much wanted. She was about 23 weeks. And her husband said he was leaving her for her best friend. She just couldn't continue. She just couldn't have his baby. She just wept, and wept and wept.*

### Case Study 3: From correspondence posted on a website by a 19-year-old seeking an abortion in September 2004:

*Correspondent 1: I'm...13 weeks pregnant, I wasn't able to see my doctor until just the other week because I've been away....when I spoke to her she said the NHS would not give me a termination because I was over 8 weeks pregnant. She referred me to the BPAS who told me it would cost me £425....I simply cannot afford this....I told my doctor I could not afford it and she told me BPAS or a private clinic were my only choice..... Otherwise I have to keep the baby.*

*Correspondent 2: I had an abortion on the NHS at 18 weeks pregnant...they sent me up to London because no-one in my area would do it on moral grounds, but it happened...if it's any help to you, it's a BPAS clinic.*

*Correspondent 1: Thank you so much.... How did*

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*you get them to do this? My doctor just won't come up with suggestions, it seems I have to put things to her.*

### **Fetal sentience and the neurobiology of pain**

- Between 12 weeks' gestation and 40 weeks (birth), phenomenal changes occur in the fetus. While important milestones can be observed, the overriding impression is one of continual change - one period of development closes to open another frontier on biological maturation. This is also true for the immediate postnatal period
- The fetus is sensitive to touch from around seven weeks' gestation, and shortly afterwards can move its limbs. At this stage, movements are spinal reflex responses, not dependent on brain activity, and are therefore unlikely to contain any conscious component.
- It is only after 26 weeks that generalised movement begins to give way to more defined actions, reflecting the improved organisation within the nervous system. Birth and the time afterwards generate a massive increase in sensory input, helping the differentiation and creation of feeling, so that the feelings of hunger, for example, can be separated from feelings of cold.
- The anatomical structures necessary for pain (and the experience of other feelings) are in place at around 26 weeks' gestation. Some time remains, however, before pain can be experienced, since feelings and emotions are not given directly by the brain but arise from repeated experience, categorisation, memory and reconnection. The concept of 'fetal pain' should therefore be rejected.
- Unless we propose separate sentient stages for smiling or crying, findings in this area are relevant to the recent debate generated by 4-D ultrasound images of the fetus. They should lead to rejection of the implication arising from them that the fetus is sentient.

### **Fetal viability**

- Survival after birth at 24 to 28 or more weeks has improved since the early 1990s through developments in neonatal intensive care that include better provision of respiratory and circulatory support, surfactant usage and nutrition.
- There is no evidence of any increase in survival at gestations of 22 weeks or less, and survival at 23 weeks is still rare.
- Infants born in Great Britain and Ireland have survival rates of 0% at 21 weeks, and about 1% at 22 weeks, 11% at 23 weeks and 26% at 24 weeks.  
Severe long-term disability is frequent in premature infants that survive, and may be as high as 67% at 23 weeks, 38% at 24 weeks, and 20% at 25 weeks.
- Abortion providers recognise threshold viability by emphasising the importance of accurate determination of gestation, the psychological needs of the woman and her partner, and the use of methods for stopping the fetal heart *in utero*.
- Medical approaches towards the treatment of

pregnancies of 22-24 weeks reflect the circumstances of the pregnancy. Medical teams work hard to provide a standard of care that respects the choices made by women, takes into account their psychological needs, and which terminates the pregnancy as safely as possible.

### **Antenatal screening for chromosome, structural and genetic abnormalities**

- Antenatal screening and diagnosis for chromosome, structural and genetic abnormalities have developed significantly in the past 30 years in regard to accuracy and the range of conditions that can be tested for.
- Of screening for Down's syndrome, evidence suggests that a combination of ultrasound (at around 12 weeks gestation) and biochemical tests (at 12 -16 weeks) best achieves the goal of identifying a high proportion of women carrying an affected pregnancy while also minimising the number of 'false positives' (women who are identified as being at higher risk but who, after a diagnostic test, are found to have an unaffected fetus). Women who have a confirmed diagnosis will have progressed well into the second trimester. They then need time and support to make their reproductive decision.
- About one baby in 55 is born with a major structural abnormality (for example neural tube defects, renal anomalies). The optimal gestational age to screen for fetal abnormalities appears to be 20 weeks. Some may require further investigation. The woman will then need time to consider her decision. This will take the pregnancy beyond the 22nd week, and close to 24 weeks in some cases. Some conditions will require further monitoring in order to assess their significance. There are also problems that could not be predicted that can occur beyond 24 weeks, for example, major inter-cranial bleeds causing significant damage to the fetal brain.
- Screening for single gene disorders (for example thalassaemia and sickle cell disorder) can be performed at any time. In some cases it is performed prior to the beginning of pregnancy, for example testing for carrier status for Tay Sachs disease within the Ashkenazi Jewish population. However, experience suggests that in many populations and population subgroups women and couples are far more motivated to think about the issue once a pregnancy has begun.
- Programmes may be extended incrementally in the foreseeable future in response to technological improvements but there is little prospect of major changes.

### **Termination of pregnancy after prenatal diagnosis of fetal abnormality**

- Relatively few pregnancies are terminated on the ground that there is substantial risk that if the child were born it would suffer from physical or mental

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abnormalities as to be seriously handicapped. In 2003, of a total of 190,660 abortions for England and Wales, 1941 (1.02 per cent) were performed for this reason. Far more babies are born with abnormalities than affected pregnancies are terminated. (2-3% of births are affected, giving a figure of around 19, 500 births each year).

- The proportion of terminations for this reason increases in each age group: in 2002, 0.47% of terminations in women aged 20-24 were for an abnormality compared with 2.9% of those in women aged 40 or more, reflecting the well known association of fetal abnormality with maternal age.
- More than 60% of terminations for fetal abnormality take place before the end of the 19th week of pregnancy. Of those terminated after 20 weeks (35% in 2000 and 2001) the majority takes place before 24 weeks: 86% in 2000 and 83% in 2001. The timing of diagnoses and subsequent terminations is related to the gestation at which prenatal diagnosis is possible.
- Rates of abortion for fetal abnormality clearly reflect the severity of the condition, with most women choosing abortion for lethal conditions, and far fewer where the condition may be treatable. The conditions affecting the fetus leading to later abortions are those that are harder to diagnose antenatally. With cleft lip and palate only two of 558 reported cases were terminated pregnancies in 2001, with nine reported as stillborn.

### **Continental European legislation on abortion**

- Inside and outside the European Union abortion legislation varies widely. Abortion legislation ranges from the very restrictive in countries such as Ireland, Malta and Poland to being available on request in countries such as the Netherlands and Sweden.
- Recent analysis indicates that about one third of countries have abortion laws that allow abortion without restriction in the first trimester. There are variations in

limits relating to gestational stage after the first trimester.

- Women from countries with more restrictive legal regimes will travel to other countries with more liberal laws, often at great personal and financial cost, to obtain abortions. This includes women who travel from countries with laws that restrict the availability of abortion after 12 weeks. Around 10, 000 women from other countries have abortions in Britain each year.

### **Abortion in late pregnancy: legal issues**

- The position in English common law, and also under the Human Rights Act 1998, is that the fetus is not a legal person, and its interests cannot trump those of the pregnant woman.
- A general principle now guiding medical law in Britain is respect for the autonomy of the patient. Legal cases have determined that the pregnant woman cannot be forced to undergo unwanted medical treatment even if her life depended on it, and even if her refusal to do so will result in the death of the fetus.
- The restrictions on reproductive decision-making contained in the Abortion Act 1967 stand as an anomalous exception to the law in general, generating a marked legal inconsistency.
- Whatever position one takes in the abortion debate is uncomfortable. Fetal development from conception to birth offers no easy cut-off point for proponents on either side of the debate. There is substantial merit, however, in accepting that patient autonomy is paramount, since this provides a clear 'bright line' solution for health care professionals, and it fits with other legal principles.
- Legal recognition of reproductive autonomy need impose no obligation on health care professionals to act against their own morals. It does not mean disregarding the importance of fetal life but recognises that abortion decisions, like other procreative choices, are appropriately understood as private, and to be made by a woman in consultation with her doctor.

### **Conclusions**

- Late abortion remains relatively rare. A modest reduction in the proportion of abortions carried out at a late gestational stage could be achieved through service modifications. In particular, if services at 18 weeks and over were made more accessible, it would likely have the effect of reducing the number performed at later weeks.
- The independent sector providers (primarily British Pregnancy Advisory Service) are now the main providers of late abortion. This raises issues in regard to accessibility, and also the training of relevant staff working in NHS hospitals in late abortion methods and procedures.
- Most women who seek abortion late do not realise they need to do so earlier. If abortion was made harder to access in later pregnancy than it is currently, the main outcomes would be that women would have abortions later still; would become 'abortion tourists' and seek abortion in another country; or would have to continue unwanted pregnancies.
- Many recent claims regarding the biological and psychological development of the fetus have misrepresented the findings of scientific research and the effects of technological innovation.
- If discussion about abortion is to be conducted in a way that takes full account of the effects of technology,

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it is important that developments in areas including fetal viability and detection of fetal abnormality are not exaggerated.

- If discussion is to be scientific, it is vital that emotive accounts are countered with discussion of evidence. This is especially relevant when, for example, assessing claims that are made on the basis of fetal images generated by 4-D ultrasound.
- Claims that British law should be made more like that of 'Europe' require clarification, since there are many types of law in different European countries. Some are more permissive, and others that are more restrictive have one very obvious outcome, in that they generate 'abortion tourism'.
- Those concerned with law and policy must consider the need for consistency in the law. There is a striking disparity between the overall trajectory of common law and medical law in Britain and European Human Rights law on the one hand, and the premises of British abortion law on the other. This could usefully be made the subject of informed debate.

The following people have contributed to *Late Abortion: A Review of the Evidence* and are available for further comment (contact [info@prochoiceforum.org.uk](mailto:info@prochoiceforum.org.uk) for further details)

- **Abortion at 20 weeks or more: trends and statistics**  
Dr Steve Clements, *Research Fellow, Centre for Sexual Health Research, University of Southampton*
- **Abortion methods in the second trimester**  
Zoe Coward, *Senior Press Officer, bpa*; David Paintin FRCOG, *Emeritus Reader in obstetrics and gynaecology, Imperial College School of Medicine*; Kate Paterson, *Consultant in Community Gynaecology, St Mary's Hospital Paddington*
- **Why women have late abortions**  
Dr Ellie Lee, *Lecturer in Social Policy, University of Kent*
- **Fetal sentience and the neurobiology of pain**  
Dr Stuart Derbyshire, *Assistant Professor of Radiology and Anesthesiology University of Pittsburgh Medical Center*
- **Fetal viability**  
Dr Rodney Rivers, *Reader in Paediatrics, Imperial College Faculty of Medicine*, Ellen Raphael, *who is Programme Manager, Sense About Science*; Laura Riley, *Director, Progress Educational Trust*
- **Antenatal screening for chromosome, structural and genetic abnormalities and Termination of pregnancy after prenatal diagnosis of fetal abnormality**  
Joanie Dimavicius, *Former Director, Antenatal Results and Choices*; John Gillott, *Policy Officer, Genetic Interest Group*; Helen Statham, *Senior Research Associate, Centre for Family Research, University of Cambridge*
- **Continental legislation on abortion**  
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- **Abortion in late pregnancy: legal issues**  
Professor Sally Sheldon, *Department of Law, University of Keele*

# Abortion at 20 or more weeks: trends and statistics

## Number and proportions of abortions notified at 20 or more weeks

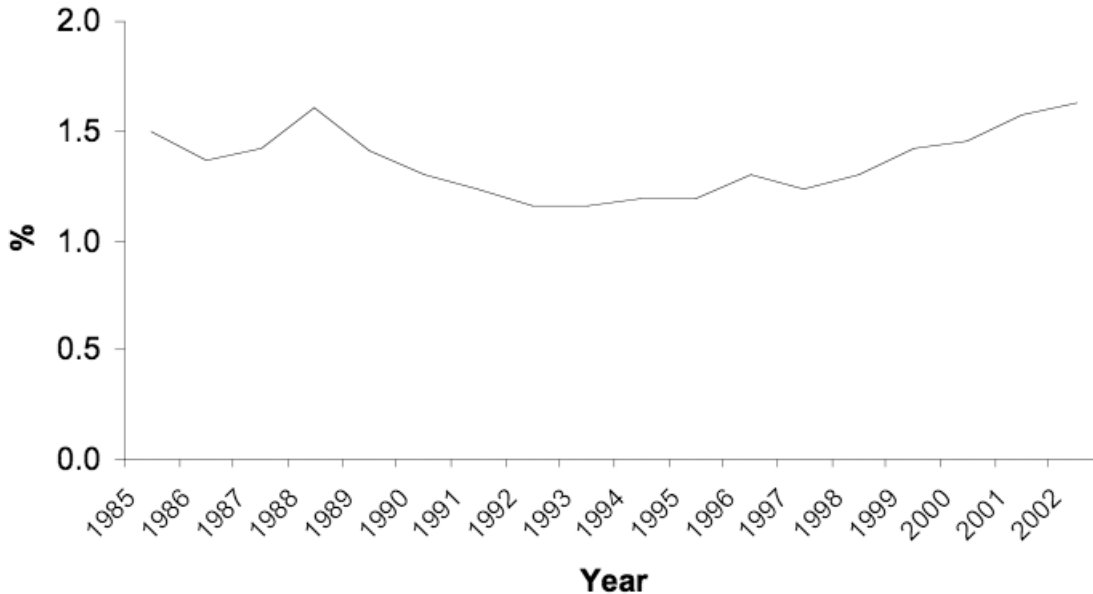


Figure 1: Percentage of all abortions occurring at 20 or more weeks

The percentage of all abortions performed at 20 weeks or more (20+) is small. It has remained at between 1 and 1.6 percent of the total number of terminations for many years. In 1985 there were 141,101 abortions, of which 2,116 abortions were performed at 20+ weeks. In 2002 the figures were 175,932 and 2,874 respectively.

All the above statistics are for residents of England and Wales. The number of abortions performed to non-residents at 20+ weeks has decreased from 2,316 in 1985 to 479 in 2002.

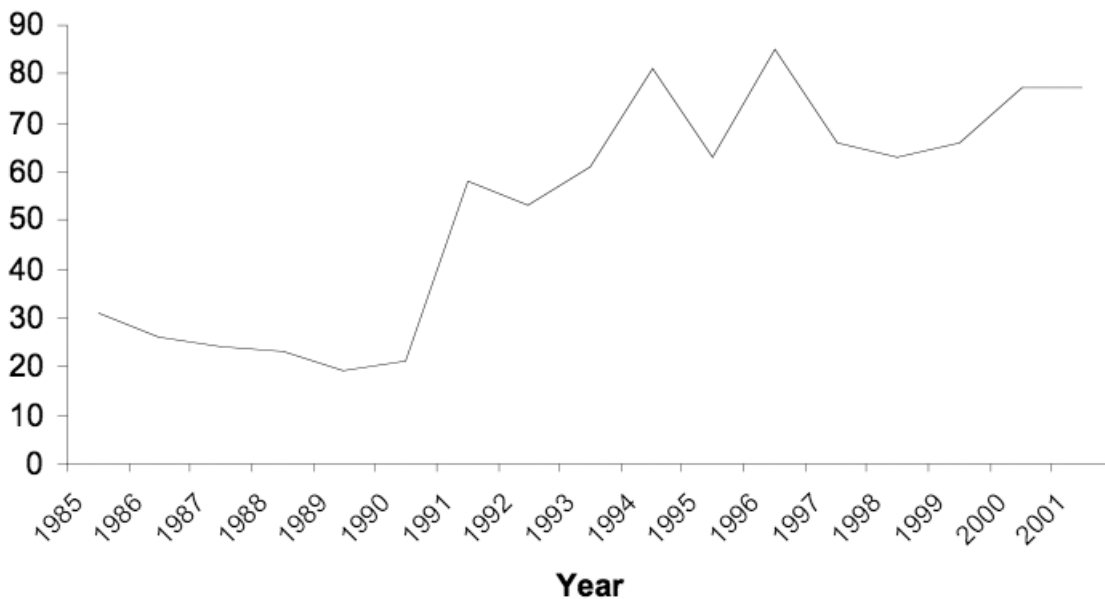


Figure 2: Number of abortions occurring at 25 or more weeks

In 1991 a 24-week limit was introduced for most abortions. Before and after this change to the law, the number of abortions performed at more than 24 weeks has been very small. In 1985, there were 31 such abortions and in 2002 there

were 77. Between 1991 and 2002, the number done after 24 completed weeks has varied from 60 to 101 with no clear rising trend. (If non-resident women are included the range is 74 in 1995 to 126 in 1999.)

The vast majority of these abortions are for fetal abnormality. The apparent rise in numbers after the law was changed in 1991 is accounted for by obstetric outcomes, previously registered as still-births, that are now notified as legal abortions, and by a very modest increase in terminations for serious but non-lethal abnormalities that were diagnosed with certainty only after 24 weeks.

For further discussion of late abortion for fetal abnormality, see sections 6 and 7.

### Grounds for abortion

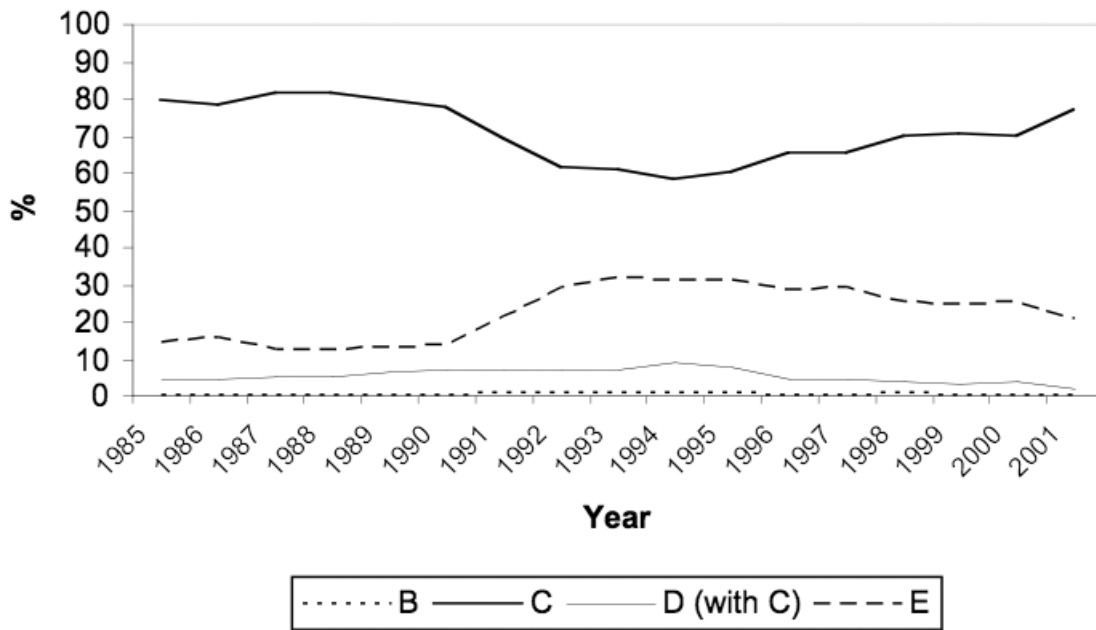


Figure 3: Grounds for abortion performed at 20 or more weeks

Note: D (with C) refers to abortions performed under Ground D only or both Grounds D and C

There are a number of grounds by which an abortion may be performed. In abortion notifications a single ground or a combination may be given. The following four categories are relevant:

B: ... to prevent grave permanent injury to the physical or mental health of the pregnant woman (no time limit and introduced in 1991)

C: ...risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman (24 week time limit).

D: ... risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of any existing child(ren) of the family of the pregnant women (24 week time limit).

E: ... there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped (no time limit).

The majority of 20+ week abortions are provided under Ground C (77% (2128) in 2001). The second most prevalent ground for abortion at 20+ weeks gestation is Ground E only (21% (581) in 2001) (See section 7).



## Age

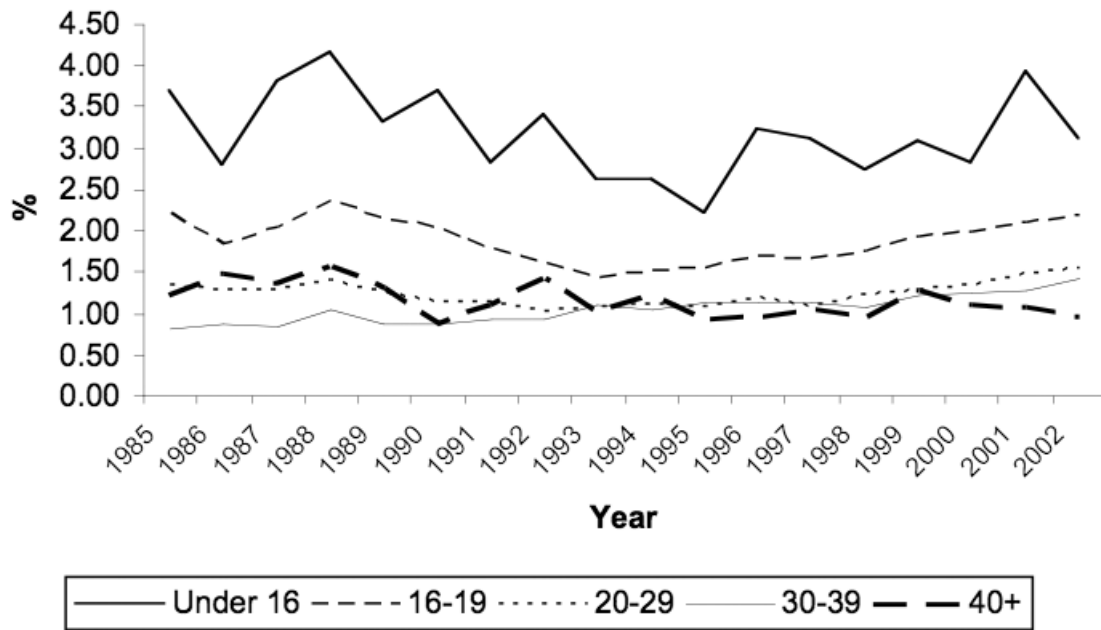


Figure 4: Percentage of 20+ week abortions by age group

Proportionally more abortions to younger women occur at 20+ weeks as compared to older women. In 2002, 3.1% of abortions to women aged under-16, and 2.2% of abortions to women aged 16-19, were performed at 20+ weeks (2.3% of all abortions to all women aged under 20) as compared to 1.4% for those aged 30-39.

## Method (see section 2 for further discussion)

At 20+ weeks there has been an increase in surgical abortions, rising from 30% in 1994 to 63% in 1998. Thereafter the percentage of surgical abortions has remained at the same level. (Additional note: there has also been an increase in the percentage of early medical abortions, from 1% in 1996 to 5% in 2001 at 9-12 weeks. The percentage under 9 weeks has increased from 11% in 1996 to 20% in 2001).

## Provider

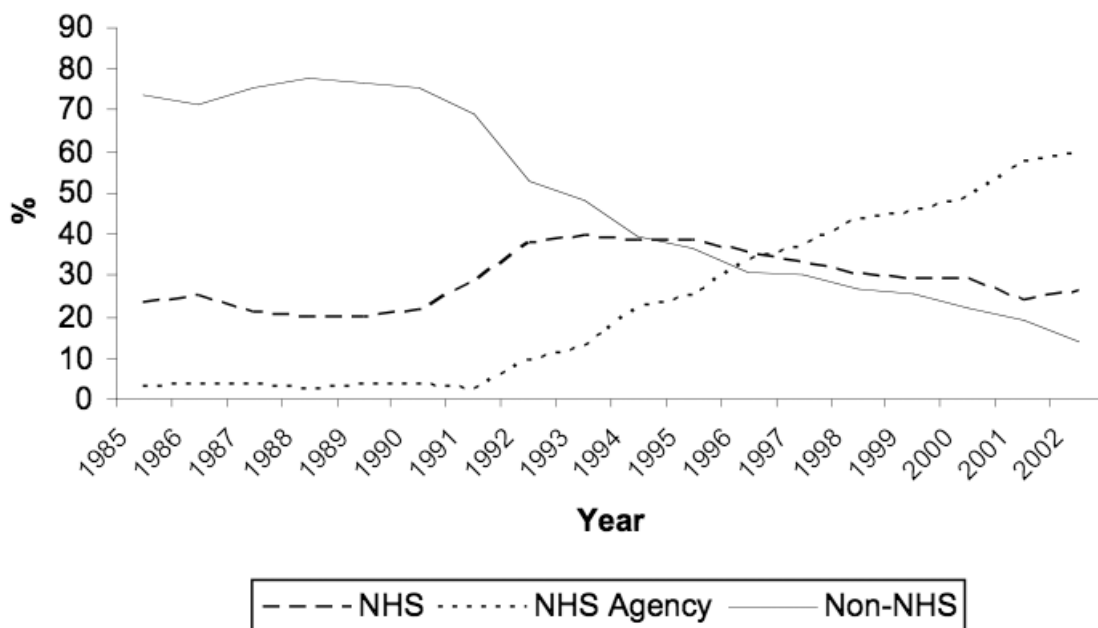


Figure 5: Providers of 20+ week abortions

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The proportion of 20+ week abortions funded by the NHS has increased significantly. In 1985, non-NHS abortions (privately funded) represented 74% of all 20+ week abortions, a figure that remained fairly constant until 1991 (69%). The percentage then fell, to 14% in 2002.

The last decade or so has seen a significant switch from abortions provided by NHS establishments, to those provided by non-NHS establishments but paid for by the NHS (NHS Agency, primarily bpas). In 1985, NHS agency abortions represented 3% of all 20+ week abortions, a figure that remained fairly constant until 1991 (2%). Since then the percentage increased, to 60% in 2002. (See sheet 3 for further discussion).

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# Abortion methods in the second trimester

## Introduction: current guidelines on late abortion services

The Department of Health has regulations<sup>1</sup> and the Royal College of Obstetricians and Gynaecologists (RCOG) has clear guidelines<sup>2</sup> relating to all aspects of abortion practice. Guidelines include information on treatment methods for all gestation bands, and on how to deal with complications. All abortions must take place in NHS hospitals or in places approved by the Secretary of State (the limit in approved places is 24 weeks). For second trimester abortions guidelines state that:

*It is essential to have an agreed multidisciplinary management plan prior to late termination, taking account of issues such as conscientious objection. The multidisciplinary team should include, where appropriate, obstetricians, neonatologists, midwives and nursing staff.*

In managing complications for second trimester abortions there is clear advice on additional treatment and regimens for drug administration.

## Current practice in late abortion services

There are two main methods of vaginal abortion in the second trimester. One is surgical, by dilatation and evacuation (D&E), and the other is medical, by the induction of labour with mifepristone and prostaglandin.

### Surgical abortion

Dilatation and evacuation is always preceded by treatment that softens and dilates the cervical canal. From 13 to 18 weeks, this begins three to four hours before the abortion by giving misoprostol tablets either by mouth or in the vagina. After 18 weeks, a hydroscopic dilating device (a short thin rod of material that swells as water is absorbed) is placed in the cervical canal six to 12 hours before the abortion, and misoprostol may be added an hour or so later to enhance the effect. Then, under general anaesthesia, the cervix is dilated further, and the fetus and placenta are removed in fragments with special forceps.

### Medical abortion

Medical abortion is induced by giving the progesterone-blocking agent mifepristone by mouth, and about 36 hours later vaginal tablets of the prostaglandin misoprostol. Mifepristone softens the cervix and makes the uterus more sensitive to the prostaglandin. Misoprostol induces uterine contractions that dilate the cervix and expel the fetus. The process usually takes six to 12 hours and resembles a late miscarriage. In the

non-NHS sector, all medical abortions at 20 weeks and over are supervised by a midwife.

## Developments in abortion care

There have been considerable improvements in abortion methods over the last 30 years. Medical abortion has seen the most change. In the late 1970s, uterine contractions were induced by the trans-cervical or intra-amniotic injection of naturally occurring prostaglandins. In the 1980s, these agents were superseded by the vaginal administration of modified prostaglandin gemeprost. More recently, the abortion process has been made swifter and less painful by the introduction of oral mifepristone followed 24-36 hours later by vaginal misoprostol. This regimen has now become standard practice.

The surgical method, D&E, was developed in the 1970s by specialist gynaecologists working semi-independently in this country and in the USA. In the USA, cervical preparation has always been routine, usually by one or more insertions of laminaria (hydroscopic dilators obtained from seaweed) over a period of 24 hours; local rather than general anaesthesia tends to be used. In England, until recent years, D&E between 13 and 18 weeks was done under general anaesthesia without any cervical preparation and, at later gestations, by the two-stage method. This involved two general anaesthetics given 24 hours apart. During the first stage, the cervix was dilated just wide enough to allow feticide by pulling down and cutting the umbilical cord. The feticide facilitated the abortion the following day by softening of the cervix and making the fetal tissues easier to remove. In recent years, British gynaecologists have adopted routine cervical preparation before all second trimester abortions by D&E (as described above) and the two-stage method is seldom used.

The NHS usually provides late abortions medically whereas the independent providers tend to use D&E (although the medical method is available in the independent sector). Given a choice, most women prefer abortion by D&E because they avoid the pain of the medically-induced uterine contractions and the experience of expelling an intact dead fetus.

Serious complications are uncommon, but increase with gestation with both methods. In 2002, with medical abortions, complications were notified in 8/1000 at 13-19 weeks, and in 11/1000 at 20 or more weeks, the most frequent being haemorrhage. With surgical abortions, complications were notified in 3/1000 at 13-19 weeks and in 6/1000 at 20 or more weeks; the most frequent complication was haemorrhage but uterine perforation occurred in about 1/1000 at 13 to 19 weeks and in

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2/1000 at 20 or more weeks. Perforation is particularly serious because it often necessitates immediate abdominal surgery, and because it leaves a scar in the uterus than could rupture in a future wanted pregnancy<sup>3</sup>.

### **Feticide**

RCOG guidance on termination of pregnancy for fetal abnormality emphasises that a legal abortion should not result in a live birth<sup>4</sup>. The same document also states that for “terminations after 21 weeks, the method chosen should ensure that the fetus is born dead.” This is achieved by making sure that the fetal heart is stopped before medical abortion is initiated. This is done either by the injection into the fetal heart of potassium chloride or by the intra-amniotic injection of concentrated urea (both types of injection are guided by ultrasound). When abortion is surgical this is not needed, as there is no risk of a live birth due to the nature of the procedure.

### **Issues around fetal viability**

RCOG guidelines are clear that the management of fetuses and newborn infants at the threshold of viability should be in accordance with the British Association of Perinatal Medicine’s Framework for Practice<sup>5</sup>. At the time of writing it is professionally acceptable not to attempt to support life in fetuses below the threshold of viability (see section 5). It is extremely important to distinguish between physiological movements and signs of life, as well as being aware that observed movements may be of a reflex nature and not necessarily signs of life or viability.

### **Reports on so-called “botched abortions”**

Every effort is taken to ensure that late second trimester abortions do not result in live births and reported incidences are extremely rare. These procedures can be extremely upsetting, not only for the woman but also for the attendant medical and nursing staff. This is why there are clear guidelines from the RCOG and the Department of Health on the practice of late abortions (see above).

When, very rarely, an abortion results in a viable birth, NHS hospitals and independent abortion providers

are required (by law) to have arrangements in place for such an emergency. Independent abortion providers, as a condition of their licence, have to have neonatal equipment on site, or have to be within 30 minutes of a hospital that is willing to provide emergency cover if necessary.

In June 2004 there were several media reports on so called “botched” abortions within the NHS. These reports often failed to mention that cases being referred to dated back over 20 years with the most recent occurring in the late 1990s. It is very unfortunate that reporting has taken place with so little regard being paid to such facts, or for the feelings of women who might undergo a late abortion.

The provision of late second trimester terminations requires medical and nursing staff willing to provide this service. Such staff must have special training and a caseload that is sufficient to maintain their skills. Most NHS gynaecological units now deal with only a small number of second trimester abortions (see section 1). Medical methods predominate in the NHS because the same skills are also used for managing miscarriages and pre-term labour. Few NHS gynaecologists have had an opportunity to be trained to perform abortion by D&E. In contrast, there is a group of gynaecologists in the independent sector who specialise in D&E and terminate many pregnancies by this method each year. The independent sector also offers a choice of medical or surgical methods for late second trimester abortion, something that is not possible in most NHS hospitals.

There is a need to consider how late abortion services should be provided, and how training should be organised, in order to ensure the possibility of the fetus showing signs of life following abortion is reduced even further.

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# Why women have late abortions

Recent discussion about late abortion has paid little attention to the reasons why women terminate pregnancies at this stage, or to their personal experience when doing so.

## Reported reasons for abortion requests in the second trimester

Women who have terminations in the second trimester fall into four categories:

1. Those who fail to recognise the pregnancy earlier because of: irregular, infrequent periods; failed contraception (particularly with methods that can cause amenorrhoea or irregular bleeding); and denial of pregnancy (sometimes associated with occasional episodes of bleeding that are interpreted as menstruation).
2. Those who delay seeking abortion because of: indecision; apprehension (difficulty in confiding in parents or partner); failure of anticipated emotional or economic support (from family, partner, and employer); and unanticipated change in socio-economic circumstances (with her partner, parents, or others dependent on her as a carer).
3. Those for whom the fetus is found to be seriously abnormal as a result of routine screening, or because of maternal infection that is known to be teratogenic (causes abnormality). (See sections 6 and 7 for further discussion).
4. Those who experience difficulty in accessing abortion because: the GP is unwilling to refer; the local NHS services are inadequate (long waits for assessment and treatment); the local NHS service does not terminate under ground C after 12 weeks; and/or the woman is unable to afford treatment in the independent sector.

The reasons why women have abortions late are, in other words, almost entirely beyond their own control. In most cases – available evidence suggests at least 80% – women terminating pregnancies late do not realise they need to request abortion until they are more than three to four months pregnant. This major proportion of the demand for late abortion will continue, therefore, regardless of changes to the abortion service<sup>1,2</sup>.

## Comments by women about their need for late abortion

A University of Southampton study of the experience of young women<sup>3</sup> indicates how some of the factors listed above result in second trimester abortions:

Age 17, abortion at 20 weeks:

*'Cause I started on the pill about the end of August...I'd never been on the pill before, you're never quite sure about it and I didn't know what to expect anyway....When I'd been to the GP I'd worked out I was two months pregnant...then I went in to have the internal examination [at consultation]...he was like, 'well actually...you're more like four and a half months pregnant'...and I hadn't known, 'cause I hadn't been having my periods normally.*

Age 17. Pregnancy confirmed at eight weeks, abortion at 19 weeks:

*I told my partner...he seemed all right with it as well. But then I started getting mixed feelings about whether or not I should keep it and I started coming up with all the reasons in my head...it's happened to my mum before and my mum's got seven kids, so...I just thought 'I can't bring a child into the world the way things are at the moment, 'cause I ain't working, I'm still at home, I've got no support or nothing'...it's from there it started to change.*

An on-going study<sup>4</sup>, including interviews with staff working for abortion providers, highlights the experience of women more generally:

*We often get them when they don't realise they are that advanced. Especially where they have been for the morning-after pill. They just do not think they could be pregnant. And when their periods don't come they just think it's because the pill has messed them up. They think it just can't be that [pregnancy]. We get quite a lot like that.*

*A recent one, that was a planned pregnancy, very much wanted. She was about 23 weeks. And her husband said he was leaving her for her best friend. She just couldn't continue. She just couldn't have his baby. She just wept and wept and wept.*

The following are comments from such staff about the situation under the current law<sup>4</sup>:

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*Last week ...there was a young woman, just about to go to University.... She was convinced she was about 14 weeks pregnant. But she was 28... Her mum was here to support her. I remember her going out of here, up the steps, I asked if she wanted to talk, she said no, she just wanted to get out. She got to the top of the steps and she just fell to her knees, and howled. Her mum just held her. It was absolutely awful.*

*We see women that we have to turn away. I hate it when that happens. We all do...The doctor has already said the scan is showing its more than 24 weeks. Not one of us would volunteer for that job...it's the worse thing in the world to do.. You have the women who say "well I can't, I can't go home and tell my mum" or "I can't have this baby I am going to kill myself".*

### **Delay due to how the NHS provides legal abortion**

Most measures indicate that abortion, generally, has become easier for women to access over recent years<sup>3,5</sup>. But some barriers to access remain. In some areas only just over two-thirds of procedures are NHS funded. More than one quarter of women still wait more than three weeks from referral to procedure. This means some women undergo abortion later than should have been possible, and have to accept the consequent increase in the risk of complications.

There is no research that addresses in detail the specific issue of service provision at 20-24 weeks. What evidence there is indicates that: it is increasingly common for NHS hospitals to offer only early abortion, and for agency agreements to be put in place to deal with later procedures; provision at 20-24 weeks is now mostly dealt with by the independent sector; NHS gynaecologists perceive the abortion service to be less than adequate at later gestations<sup>3</sup>. As a result, women may find it difficult to obtain abortion at this stage, and where they can, may experience delays (for example, a referral at 19 weeks will lead to a procedure at 21 or 22 weeks).

### **What women say**

Women's self-reported experience suggests that abortion is more accessible than in the past but that women continue to experience delays:

*I went to the hospital for a scan...I had to go to [another town] for an abortion....when I found out I was pregnant I was three months, but by the time they organised the abortion and everything I was... four months<sup>3</sup>.*

Some women are (rightly or wrongly) given the impression that abortion later in pregnancy may not be available, and/or will not be funded by the NHS locally:

*She [the doctor] was saying it would be too big, they [the local hospital] wouldn't do an abortion...That's why I thought we'll just have to do it private...find the money....It made me really upset. (Age 17. Sought abortion at 13 weeks gestation, and had a termination at 15 weeks. Her boyfriend had to borrow the £600 needed for a private procedure from friends)<sup>3</sup>.*

The following exchange, posted on a website in September 2004, refers to the development in the organisation of the abortion service, whereby local NHS hospitals increasingly provide procedures only up to a specified time limit, with later procedures provided through contract arrangements with independent sector providers:

*Correspondent 1: I'm 19 and 13 weeks pregnant, I wasn't able to see my doctor until just the other week because I've been away....when I spoke to her she said the NHS would not give me a termination because I was over 8 weeks pregnant. She referred me to the BPAS who told me it would cost me £425....I simply cannot afford this....I told my doctor I could not afford it and she told me BPAS or a private clinic were my only choice..... Otherwise I have to keep the baby.*

*Correspondent 2: I had an abortion on the NHS at 18 weeks pregnant...they sent me up to London because no-one in my area would do it on moral grounds, but it happened...if it's any help to you, it's a BPAS clinic.*

*Correspondent 1: Thankyou so much.... How did you get them to do this? My doctor just won't come up with suggestions, it seems I have to put things to her<sup>6</sup>.*

### **Conclusions**

Most women who have late abortions, for reasons beyond their own control, do not realise earlier in pregnancy that they would need to consider termination. Any discussion of second trimester abortion must be based on this reality.

Some pregnancies are terminated later than they could have been because of practical difficulties accessing abortion in the second trimester. The proportion having late abortions would decrease modestly if abortion was more accessible, with assessment within three to five days of referral, the abortion itself after a further three to five days, and if self-referral was possible.

A lower legal time limit for abortion would have an inescapable practical effect. A larger number of women than is currently the case would either have to continue an unwanted pregnancy and give birth, or seek abortion in another country.

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# Fetal sentience and the neurobiology of pain

## Introduction

The British media have recently engaged in discussion of fetal development. Much of this discussion has strongly implied that the fetus is highly developed at an earlier stage of gestation than previously assumed. Provoked by graphic images of the fetus generated by 4-D ultrasonography, it has been reported that fetuses at 15 to 22 weeks gestation can 'walk', 'cry' and 'smile'. There is the implication that the fetus is not merely moving particular muscles but is responding emotionally and cognitively, and is aware.

This implication has previously been the subject of extensive research and discussion with respect to pain. The question of fetal pain has been central to debate about the point at which the fetus can be considered sentient<sup>1, 3, 5, 9, 10, 13, 14</sup>. Whether the fetus feels pain is critically dependent upon the presence of sentience or awareness. If the fetus is not aware, then any response to injury, or other threat to fetal integrity, is merely reactive. Unless we propose separate sentient states for smiling, crying, and pain, it is likely that debate and investigations regarding fetal pain will be relevant to fetal sentience in general and to the current conjecture that 4-D images of the fetus indicate fetal sentience.

## What is pain?

Most of us think of pain as being similar to a fire alarm with injury activating a pain pathway (the 'cable'), which triggers a pain centre (the 'alarm') somewhere in the brain. This model of pain is known as 'specificity theory' and was first proposed by Rene Descartes almost 350 years ago. For Descartes, nerve filaments were activated by the fast moving particles of a noxious stimulus (such as a fire) creating a disturbance that passed directly to a central point in the brain. In the modern interpretation, nerve filaments have been replaced by dedicated pain fibre systems that pass into the spinal cord and ascend into the thalamus of the brain before being relayed to the primary sensory cortex, which is part of the outer rippled part of the brain.

This conception was thrown into serious doubt by observations made half a century ago. In 1955 it was reported that injury signals are not transmitted to the brain via a single dedicated pathway but by multiple pathways, each with distinctive features including different speeds of transmission and terminations within the brain<sup>15</sup>. Modern imaging techniques have confirmed variable brain terminations from noxious input<sup>6, 7, 8, 16</sup>. Rather than a single pain centre there is a pain network, which includes structures that lie below the cortex (the

outer rippled part of the brain) such as thalamus, as well as large areas of the cortex, widely believed to be responsible for the higher processes of thought and feeling<sup>2</sup>.

Specificity theory oversimplifies the biology of pain but it also renders the psychology problematic. Thinking of pain as being like a fire alarm suggests that the actual experience rests not with the person but with the event. Pain is defined in terms of a stimulus that is deemed to be painful because it elicits the response of pain. To put that more simply, pain is defined as pain and the content of the experience is lost<sup>7</sup>.

## The neurobiology of a fetus

From about seven weeks gestation, fetal skin contains free nerve endings responsible for initial registration of noxious stimulation. These cells reach maturity at 24-28 weeks gestation<sup>11</sup>.

Some projections from the developing spinal cord also reach the thalamus (the lower 'alarm') of the brain at about seven weeks gestation but at this point the thalamus is very immature. It is not yet ready to 'ring'. There is no indication of the cell structure and organisation that will gradually be observed from around 20 weeks gestation<sup>12</sup>.

The very first projections from the thalamus towards the cortex (the higher 'alarm') are apparent from about 12-16 weeks gestation but these are projections into the subplate. The subplate is a 'waiting compartment' where fibres accumulate and mature before penetrating the cortical plate developing above. Like the lobby of a theatre or the car park of a stadium, interactions in the subplate are random and un-coordinated until direction towards a seat is provided.

The thalamic connections do not penetrate the cortical plate, making it to their 'seats', until 26 weeks gestation. In rudimentary form, the 'alarm' is complete but important development remains.

Starting at 28 weeks there is massive relocation of subplate fibres into the cortical plate. Even after that point the cortical plate undergoes tremendous growth increasing in volume by 50% between 29 weeks and term when the characteristic layers, the 'seat ordering', of the cortex appear.

Development continues after birth, expressed fundamentally by the increasing size of the human brain, but actual neuronal activity in the neonate undergoes important maturation during the first year of life. The neuronal function of the cerebral cortex, including somatosensory, prefrontal and anterior cingulate regions, increase by a third from birth to 18 months<sup>4</sup> and these are

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brain regions that have been consistently associated with sentience and pain experience<sup>2, 5, 6, 7, 8, 16</sup>.

To summarise, fetal development is profound in both speed and extent. Between 12 weeks gestation and 40 weeks (normal birth) quite phenomenal changes occur. While important milestones can be observed the overriding impression is one of continual change - one period of development closes to open another frontier of biological maturation. This is also true for the immediate postnatal period.

### **Response or sentience?**

Consistent with the biological development described, sensitivity to touch begins at around seven weeks gestation. Touching the mouth, for example, will result in a bending of the head. Such movements are spinal reflex responses, not dependent on brain activity, and therefore unlikely to contain any conscious component.

Shortly after the development of sensitivity, repeated skin stimulation results in hyperexcitability and a generalised movement of all limbs. This hyperexcitability indicates the immature nature of the fetal nervous system. It is only after 26 weeks that generalised movement begins to give way to more defined actions, reflecting the improved organisation within the nervous system. Infants delivered at 26-31 weeks, for example, show coordinated facial actions in response to heel prick that are not present in more premature infants.

Observations of premature infants provide important information on the development of the human nervous system but might not be a useful guide to fetal experience. The womb and outside world are very different places and what happens at birth is important<sup>14</sup>. The environment of the womb consists of warmth, buoyancy and a cushion of fluid to prevent tactile stimulation. The placenta provides a chemical environment to encourage sleep and suppress higher cortical activation. Inside the womb there is little to be gained from alertness and motion, which can only cause the expenditure of energy with little possibility of escape or other advantage. In contrast to the buffered fetal environment, the intense tactile stimulation of birth triggers behavioural activity and wakefulness and marks the transition from laying down brain tissue to also organising that tissue with regards to the world now rudely thrust upon it.

At birth and afterwards there is massive increase in sensory input and this acts as a form of 'neuronal crowd control'. Repeated sensory input during this critical period of development results in generation and stabilisation of functional brain circuits with unused pathways being eliminated. This internal organisation of inputs helps the differentiation and creation of feeling so that the feeling of hunger, for example, can be separated from feelings of cold. The organisation of feeling and thought, however, is as dependent upon information from the outside as it is upon the structure of the inside. When mummy points to a spot and asks, 'what's that?' she is beginning the process of enabling an internal discrimination and with it experience.

Pain is not merely the response to physical injury or disease but is a higher order experience including emotional, cognitive (thinking) and sensory components. Fitzgerald - among the foremost neurological researchers in this area- commented to the UK Department of Health in 1995 that, "...true pain experience [develops] postnatally along with memory, anxiety and other cognitive brain functions"<sup>10</sup>, which reflects the fact that brain development is not just about hooking 'alarms' up to 'buttons' but is about enabling subjective experience<sup>5, 13</sup>. Pain depends as much on the latter as the former.

### **Conclusion**

There is some consensus that the anatomical structures necessary for pain are in place around 26 weeks gestation, but some time remains before pain can really be experienced. Pain is much more than working sensory receptors connected to a brain. When we feel pain it is an experience we have spent a good portion of our psychological development learning to recognise. This feeling is not given directly by our brain but is made through repeated experience, categorisation, memory and reconnection. This development is obviously dependent upon the presence of a sufficiently developed neural system, the human brain, but the content of that experience is dependent upon elements that lie outside the human brain and beyond the womb. The concept of 'fetal pain' presupposes this developmental process and should be rejected.

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# Fetal Viability

## Threshold viability

A fetus is considered 'viable' when, if born, it has a chance of long-term survival if given neonatal intensive care. Infants born in Great Britain and Ireland have survival rates of 0% at 21 weeks, and about 1% at 22 weeks, 11% at 23 weeks and 26% at 24 weeks<sup>1</sup>.

The British Association of Perinatal Medicine (BAPM) considers that infants born at 22-<28 weeks gestation (approximately equivalent to 500 to 1000g.) have "threshold viability", though in developed countries this term is more often used in reference to infants of <26 weeks<sup>2</sup>. Severe long-term disability is frequent in infants with threshold viability that survive, and may be as high as 67% at 23 weeks, 38% at 24 weeks, and 20% at 25 weeks<sup>3,4</sup>.

Women with wanted pregnancies in premature labour at 22-28 weeks can expect that the medical team will consult with them and their partners, and that treatment decisions will be based on their child's best interests.

The RCOG advises that it is professionally acceptable not to attempt to support life in fetuses expelled before 22 weeks gestation. They emphasise that "it is extremely important to distinguish between physiological movements and signs of life, as well as being aware that observed movements may be of a reflex nature and not necessarily signs of life and viability"<sup>5</sup>.

The BAPM guidelines are careful to state that women should be counselled to ensure that their expectations of fetal viability are "appropriate and realistic", because survival rates at such early gestations are very poor. Threshold viability needs to be understood as the earliest starting point for possible medical intervention for women with wanted pregnancies who are in premature labour. Not all immature infants will be treated and the outcomes for infants born at 22-24 weeks gestation are very poor.

## Improvements in the survival of infants with threshold viability since the early 1990s

Many studies of infants with threshold viability have been published in the last 25 years. Most involve relatively small numbers of infants, particularly at 24 weeks or less, and differences between the design of the studies make changes over time difficult to assess.

Although survival after birth at 24 to 28 or more weeks has improved since the early 1990s, through improvements in neonatal intensive care that include better provision of respiratory and circulatory support, surfactant usage and nutrition<sup>6</sup>, there is no evidence of any increase in survival at gestations of 22 weeks or less<sup>7,8</sup>

and survival at 23 weeks is still rare. The inability of the fetal lungs to expand, and to permit oxygen transfer, prevents survival before 22-23 weeks and cannot be overcome with the technology currently available. It is apparent that neonatal intensive care cannot completely replicate the intra-uterine environment.

There is no clear evidence that there has been any reduction in long-term disability among the survivors of infants born at 24 weeks or more.

## Relevance for abortion services

Abortion providers recognise threshold viability by emphasising the importance of accurate determination of gestation, the psychological needs of the woman and her partner, and the use of methods for stopping the fetal heart *in utero*.

Where women are to undergo abortion, gestation has to be determined as accurately as possible. This means considering the date of the first day of the last normal menstrual period, the regularity and duration of the menstrual cycle, any records of clinical assessments of uterine size, and any ultrasound measurements of the fetus.

No method of assessment is completely reliable – an irregular menstrual cycle makes the date of the last period unreliable (conception occurs 14 days *before* the first missed period); clinical assessment has an error of about plus or minus 2 weeks; ultrasound scanning (because fetuses vary in size at a given gestation) has an accuracy of about  $\pm 5$  days up to 12 weeks and  $\pm 12$  days at 24 weeks. An ultrasound scan is routine whenever abortion is being considered at 18 or more weeks. Most gynaecologists regard a fetal biparietal skull diameter of more than 56 to 60 mm as evidence that a fetus has reached 24 weeks but this cautious approach ignores the considerable variation between fetuses of the same age, and results in some women being refused abortions that would, in fact, have been within the law.

The Royal College of Obstetricians and Gynaecologists states:

*[F]or all terminations at gestational age of more than 21 weeks and six days, the method chosen should ensure that the fetus is born dead. This should be undertaken by an appropriately trained practitioner. Intra-cardiac potassium chloride is the recommended method and the dose chosen should ensure that fetal asystole [no heartbeat] has been achieved. It should be confirmed by observing the fetal heart by an ultrasound scan for five minutes. Additionally, it is*

*mandatory to confirm asystole by an ultrasound scan 30-60 minutes after the procedure. Consideration can be given to abolishing fetal movements by the instillation of anaesthetic and/or muscle relaxant agents immediately prior to potassium chloride administration<sup>5</sup>.*

Guidelines also state that, “parents must receive sympathetic and supportive counselling before and especially after the procedure.” When the abortion is for lethal fetal abnormality, and parents may request not to

have feticide, the RCOG recommends that “discussion must take place within the appropriate [medical] team, and [that] the patient’s wishes and agreement are sought in the management of the fetus after birth.”

Medical approaches towards the treatment of pregnancies at 22-24 weeks reflect the circumstances of the pregnancy. Medical teams work hard to provide a standard of care that respects the choices made by women, takes into account their psychological needs, and which terminates the pregnancy as safely as possible.

## Appendix

Fetal viability in the UK and Ireland, with health outcomes at age 2.5 years

Data in the table below are taken from the EPICure study<sup>1,2</sup> published in 2000 and 2003. This is the most recently available study of UK and Irish premature birth outcomes. The data for the study were collected between March-December 1995 and included all live births in UK and Ireland. A new study by EPICure is expected in 2005.

<b>N (% live births)</b>	<b>21 weeks</b>	<b>22 weeks</b>	<b>23 weeks</b>	<b>24 weeks</b>	<b>Total</b>
<b>*Live births N</b>	104	138	241	382	865
<b>*Died in delivery room</b>	101 (97%)	116 (84%)	110 (46%)	84 (22%)	411 (47%)
<b>**Admitted for intensive care</b>	3 (3%)	22 (16%)	131 (54%)	298 (78%)	454 (53%)
<b>Died in Neonatal Intensive Care Unit</b>	3 (3%)	20 (15%)	105 (44%)	198 (52%)	326 (38%)
<b>Survived to discharge</b>	0 (0%)	2 (1%)	26 (10%)	100 (26%)	128 (15%)
<b>Deaths post-discharge</b>	N/A	0 (0%)	1 (0.4%)	2 (0.5%)	3 (0.3%)
<b>Lost to follow-up</b>	N/A	0 (0%)	0 (0%)	1 (0.3%)	1 (0.1%)
<b>***Severe disability</b>	N/A	1 (0.7%)	8 (3%)	24 (6%)	33 (4%)
<b>Disability (not severe)</b>	N/A	0 (0%)	6 (2%)	28 (7%)	34 (4%)
<b>Survivors without identified disability at 2.5 years old (% live births*)</b>	N/A	1 (0.7%)	11 (5%)	45 (12%)	57 (7%)

\* Gestation based on ‘working’ estimate on labour ward

\*\* Gestation confirmed post-natally

\*\*\* The authors’ state: A severe disability is one that is expected to render the child dependent, with severe problems into later life. In the severe category we classified children with cerebral palsy who were not likely to be mobile, children whose development was very behind what we would have expected and children with severe hearing and sight problems.

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## Key points emerging from study

### Survival

Of the 865 live births of up to 24 weeks gestation recorded in the UK and Ireland between March- Dec 1995, 47% died in the delivery room and 38% died in neonatal intensive care units. 15% of all the survivors in the study were able to leave hospital, however a further 0.3% of these died at home afterwards.

### Disability

Of the infants who were able to leave hospital, 52% had some level of disability (26% had severe disability; 26% less severe disabilities.) The 33 children with severe disabilities had, in the main, cerebral palsy or other neurological problems or developmental delay, though a small number of these have problems in several areas. Development was slightly delayed for the whole group with an average score of about 85% for both their motor and learning skills at 2.5 years. Being born at 23 weeks was not worse than being born at 24 weeks for disability or development, but survival was much less likely at 23 weeks compared to 24 weeks.

### Growth at 2.5 years old

Children in the EPICure group tended to be smaller and lighter than full-term children in early childhood, although most measurements fall in the normal range. For example, average weight is about 3 pounds less than the average for the general population. Very few studies have looked at growth in later childhood, but there is a tendency for premature babies to slowly catch up with children born at full term.

### Medical Problems

The commonest medical problems in premature babies are related to the chest; about 45% of the children needed help with medicine to relieve wheeze and cough, and many of these children were said to have asthma.

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# Antenatal screening for chromosome, structural and genetic anomalies

## Introduction

Antenatal screening services are typically offered during pregnancy with the aim of detecting those who are at raised risk of having a child with a specific condition. Women who are so identified are then offered a definitive diagnostic test that involves an invasive procedure. This is only offered to women at higher risk because it carries a small (approximately 1%) risk of miscarriage.

Provision of antenatal screening and diagnosis services has, historically, developed in an ad-hoc way. The services available for pregnant women have varied according to the interests of local health professionals, the demands of local women, and local service providers' decisions about funding. As technologies developed, they were accompanied by increasing media interest. Access to those tests perceived as better became increasingly subject to ability to pay.

The important changes in antenatal screening in the last decade have included: developments in methods of screening for chromosome anomalies; the introduction of universal screening for Down's syndrome; improved technologies for detecting structural anomalies; and the implementation of screening for sickle cell disorder and thalassaemia.

## Screening for Down's syndrome

Screening for Down's syndrome has developed partly in response to consumer demand. There are two methods of screening: an ultrasound scan to measure the nuchal translucency (NT), a fluid area at the back of the fetal neck, and maternal serum testing which measures biochemistry. These are offered in various combinations. Evidence suggests that a combination of ultrasound and a number of biochemical tests best achieves the goal of identifying a high proportion of women carrying an affected pregnancy while also minimising the number of 'false positives'- women who are identified as being at higher risk but who after a diagnostic test are found to have an unaffected fetus. In order to ensure equity of access, in April 2001 the Minister for Public Health announced that all women would be offered screening for Down's syndrome that would meet specified standards by April 2004.

Ultrasound to measure the size of the fluid area at the back of the fetal neck is performed towards the end of the first trimester of pregnancy. Biochemical tests are performed at the end of the first trimester and also in the second. In the latter case a blood sample is taken at about 16 weeks' gestation and tested for various proteins and hormones. A computer algorithm calculates the likelihood of an affected pregnancy by combining the woman's age,

the gestation of the fetus and the results of the biochemistry.

The results are available within 10 days. Currently about 5% of women will screen positive, which is defined by a likelihood of 1 in 250 or a higher risk that the baby would be born with Down's syndrome. These women will be offered a diagnostic procedure, amniocentesis, within three working days of receipt of the test result. Diagnostic results should then be available within 14 days.

The woman may be 19-20 weeks pregnant by the time she has a confirmed diagnosis. She then needs time and support to make her reproductive decision.

## Fetal Anomaly Scanning

About one baby in 55 is born with a major structural abnormality and structural abnormalities outnumber all the single gene defects. A fall in the perinatal mortality rate is due mainly to the termination of pregnancies affected by fetal anomalies. The optimal gestational age to screen for fetal abnormalities appears to be 20 weeks.

Current scanning protocols include:

- Neural tube defects
- Hydrocephalus
- Cardiovascular anomalies
- Abdominal wall defects
- Major renal anomalies
- Major limb abnormalities

Discussions of the implications of a scan with an obstetrician should happen within one working day. If indicated, referral to a tertiary centre with maternal fetal medicine specialists should be offered within two working days<sup>1</sup>.

Ultrasound can be diagnostic of specific conditions, e.g. anencephaly, and in this case the results are known immediately. The 20-week anomaly scan can also identify conditions that will require further testing or continued monitoring. For example, conditions such as cleft palate may be an indication of a major chromosome abnormality and may indicate the need for an amniocentesis. Results of such tests should be available within 14 working days of receipt of a specimen by the laboratory. The woman will then need time to consider her decision. This will take the pregnancy beyond the 22nd week, and close to 24 weeks in some cases.

Other conditions will require further monitoring in order to assess their significance. For example borderline ventriculomegaly (10mm) will not in itself cause damage to the fetus. But if, through regular monitoring, it is observed that the lateral ventricle has increased to >15mm

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then major problems in the development of the brain will occur. In such cases it is essential that the pregnancy be monitored so that if changes occur an accurate diagnosis and prognosis can be given to the woman, without pressure of time. Other problems, which could not be predicted, can occur beyond 24 weeks, for example, major inter-cranial bleeds causing significant damage to the fetal brain.

### **Screening for single gene disorders**

In some cases women and families are aware of their increased risk of having a child with a genetic condition. This may be because there is a known family history of the condition, or because the couple already has an affected child. A number of genetic conditions, however, including some of the (relatively) more common ones, typically occur to women without a family history. The classic example is provided by recessive conditions, which affect a child with healthy parents, who are both unaffected carriers. When two carriers have a child, there is a one in four chance that the child will be affected.

Screening for single gene disorders therefore has a similar rationale to screening for Down's syndrome and fetal anomaly: women may be at raised risk, in this case a significantly raised risk, of having a child with a genetic condition but may also be unaware of this. In the case of a recessive condition the initial screen will involve offering women and their partners themselves a genetic test. If both are carriers the risk of an affected child will be one in four and an invasive test on the fetus will then be offered.

The test on the couple could be performed at any time. In some cases it is performed prior to the beginning of pregnancy, for example testing for Tay Sachs disease within the Ashkenazi Jewish population. However, experience suggests that in many populations and population subgroups women and couples are far more motivated to think about the issue once a pregnancy has begun.

Currently, the principal national antenatal genetic screening programme is for the haemoglobinopathies - thalassaemia and sickle cell disorder, conditions that mainly affect people who have originated from Africa, the Caribbean, the Middle East, Asia and the Mediterranean. The policy for antenatal screening in England is for the phased implementation of a programme that will eventually offer screening to all women as a part of early antenatal care. Debate continues on whether other programmes should be developed. In 1999, the Health

Technology Assessment programme recommended universal antenatal screening for Cystic Fibrosis. The National Screening Committee has not agreed this, although debate continues. Similarly, debate continues on whether and how to implement screening for fragile X syndrome, a condition which causes learning difficulties largely, but not exclusively, in boys.

### **Screening programmes and women's choices**

Research continues on how to provide screening in ways that ensure that women make informed choices. It is unavoidable that whilst screening provides reassurance for the majority it will create anxiety for some. Evidence suggests that although anxiety is raised in women receiving false positive screening results this mostly falls on receipt of subsequent reassuring results although some residual anxiety does remain. If the pregnancy is affected the anxiety is considered a price worth paying for the reproductive choice offered. That 94% of women who have a prenatal diagnosis of Down's syndrome choose to terminate the pregnancy would suggest that screening offers women reproductive choices which they value<sup>2</sup>.

### **Future developments**

There is little likelihood that screening tests will change dramatically in the foreseeable future. Programmes to detect genetic abnormalities may be extended incrementally. Ultrasound equipment has improved, enabling clearer images, and this may continue. There has been research about the possibility of collecting fetal cells from maternal blood as a means of offering risk-free diagnosis at early gestations, but this is unlikely to be available in the foreseeable future as a consistent, replicable diagnostic tool.

The National Screening Committee is committed to setting standards for all antenatal screening programmes which can be audited and published. The aim of all the programmes is to have lower false positive rates and higher detection rates. Work by the NSC to improve patient understanding and professional practice includes: DIPEX, a web-based information source supported by the NSC; 'Informed Choice', a training programme for health professionals; and training for sonographers in communication provided by the charity Antenatal Results and Choices.

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# Termination of pregnancy after prenatal diagnosis of fetal abnormality

Abortion late in the second trimester, and after 24 weeks, may be performed, “when there is a substantial risk that if the child was born it would suffer from physical or mental abnormalities as to be seriously handicapped” (Ground E, Abortion Act 1967, as amended by the 1990 Human Fertilisation and Embryology Act). Comment below summarises research, and government statistics, about abortion for this reason.

## Background

Relatively few pregnancies are terminated at any gestational stage under Ground E of the Abortion Act. Numbers have remained almost unchanged over many years, both in absolute values and relative to the total number of terminations. In 2003, of a total of 190,660 abortions for England and Wales 1941 (1.02 per cent) were performed under Ground E<sup>1</sup>.

It is not just older women who find their pregnancy is affected. In 2002, 87 women aged under-19 were reported as terminating a pregnancy under Ground E. However, the proportion of terminations carried out under Ground E increases in each age group: in 2002, 0.47% of terminations in women aged 20-24 were for an abnormality compared with 2.9% of those in women aged 40 or more<sup>2</sup>.

Contrary to popular perception, only 20% of terminations follow a diagnosis of Down’s syndrome (Table 1). More than half of ‘other’ chromosome anomalies for which pregnancies are terminated are lethal, and over a third of central nervous system (CNS) anomalies are for anencephaly, where the forebrain fails to develop and there can be no cerebral function. Other pregnancies are terminated because of a range of problems including serious cardiac, renal, respiratory, genetic or facial abnormalities, and because of intra-uterine infections and anomalies of fetal growth<sup>2,3,4</sup>.

Table 1 Proportion of terminations carried out for particular anomalies

Year (total terminations)	N (%) Down’s syndrome	N (%) other chromosome anomalies	N (%) anomalies of the brain and central nervous system	N (%) cardiovascular anomalies	N (%) terminations because of family history of fetal abnormality
2000 (1833)	348 (19.0)	269 (14.4)	460 (25.1)	120 (6.5)	138 (7.5)
2001 (1722)	347 (20.1)	244 (14.2)	411 (23.9)	110 (6.4)	113 (6.6)
2002 (1894)	382 (20.2)	325 (17.2)	411 (21.7)	106 (5.6)	103 (5.4)

Far more babies are born with abnormalities than are affected pregnancies terminated. (For all notifiable abnormalities recorded in the registers, 20% resulted in terminations in each year between 1999 and 2001, and 80% were associated with pregnancies that continued to the birth of a malformed baby; of these, between 2.6 and 3.5% were stillborn and a further 8-9% died in the neonatal period)<sup>5,6,7</sup>.

Termination rates reflect the severity of the condition, with most parents choosing abortion for abnormalities such as anencephaly, which can only be lethal, and decreasing numbers for conditions where outcome and treatment may be more successful. (For example, with cleft lip and palate only two of 558 reported cases were terminated pregnancies in 2001, with nine reported as stillborn<sup>7</sup>.) (See below for further discussion of decision-making following diagnosis of fetal abnormality).

## Timing

More than 60% of terminations for fetal abnormality take place before the end of the 19th week of pregnancy (Table 2)<sup>2,3,4</sup>. Of those terminated after 20 weeks (35% in 2000 and 2001) the majority takes place before 24 weeks: 86% in 2000 and 83% in 2001. The timing of diagnoses and subsequent terminations is related to the gestation at which pre-natal diagnosis is possible. For most women, results of routine tests and anomaly scanning are known in the mid to late second trimester.

Table 2 Gestation at termination after prenatal diagnosis

Year	< 12 weeks	13-19 weeks	All > 20 weeks	Only those > 24 weeks
<b>2000</b>	267 (14.6%)	908 (49.5%)	658 (35.9%)	94 (5.1%)
<b>2001</b>	290 (16.8%)	836 (48.5%)	596 (34.6%)	101 (5.9%)
<b>2002</b>	Data not available	Data not available	Data not available	114 (6.0%)

Very few terminations are done after 24 weeks. Office for National Statistics (ONS) figures for 2000 – 2002 allow for some exploration of the reasons for these later terminations (Table 3)

Table 3 Proportions of terminations carried out after 24 weeks for a range of conditions

Year N <sup>6</sup>	% DS <sup>1</sup>		%AN <sup>2</sup>		% HC <sup>3</sup>		%CV <sup>4</sup>		% GP <sup>5</sup>	
	total	> 24 weeks	total	> 24 weeks	total	> 24 weeks	total	> 24 weeks	total	> 24 weeks
<b>2000</b> 1833	19.0	5	9.5	3.2	2.3	18.1	6.5	8.5	0.87	8.5
<b>2001</b> 1722	20.1	11	8.6	2.0	2.6	4.0	6.4	15.0	0.13	7.0
<b>2002</b> 1894	20.2	6.14	7.4	1.8	1.8	8.0	5.6	11.4	0.26	1.8

<sup>1</sup>Down's syndrome; <sup>2</sup>Anencephaly; <sup>3</sup>Hydrocephalus; <sup>4</sup>Cardiovascular system; <sup>5</sup>Factors related to gestation and growth

<sup>6</sup>Total terminations performed under Ground E

Conditions that are clearly diagnosable are more likely to be terminated before 24 weeks. For example, 19 – 20% of all terminations are for Down's syndrome (DS), but only 5 to 11% of those after 24 weeks. Similarly anencephaly (AN) accounts for approximately 8% of all terminations but only 2% of those carried out later. Conditions that are harder to diagnose, that are more likely to need referral to fetal medicine centres, and which may require more careful and prolonged monitoring, such as hydrocephalus (HC) and cardiovascular problems (CV), are relatively more prevalent among later terminations. Terminations because of problems of fetal growth (GP) are rare overall, but constituted 8.5% of post 24-week terminations in 2000.

Reasons for late diagnosis include when fetal growth is very slow; the coincidental late diagnosis of a major brain anomaly at a scan undertaken because of other concerns about the pregnancy (and which was later diagnosed as associated Down's syndrome); fetal heart abnormalities requiring monitoring over time to assess the prognosis; and the postponement of a selective termination of one twin with a lethal chromosome anomaly to allow the healthy twin the optimal chance of survival<sup>8</sup>. Decisions later in the pregnancy are particularly harrowing for parents.

### Decision-making

All research and clinical experience confirms the numbing shock that parents feel when told of a fetal abnormality and the distress involved in making the decision about the outcome of the pregnancy<sup>9</sup>. Once a diagnosis has been made, parents lose what they had believed to be a normal pregnancy, whatever the abnormality and whatever decision they subsequently

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make. Recent reviews of research have confirmed there is limited information available to show how the difficult decision about pregnancy outcome is made<sup>9, 10</sup>. The important factors described by parents appear to be:

- the severity of the abnormality and the impact this would have on the child, on themselves as potential carers, and on other immediate family members (including children not yet born) and
- their prior attitudes and beliefs about abortion.

Severity may be judged differently by parents, depending on their experiences and attitudes. For some, the condition may need to be lethal for a termination to be considered; for most, a condition associated with learning disability is perceived as more serious than one requiring surgical intervention. Individuals with direct experience of conditions, either personally or in close family or friends, make a variety of choices: some parents with one child with Down's syndrome would not consider testing in a subsequent pregnancy, others would seek out early diagnosis with the intention of termination if another child was affected. Most parents who themselves were born with facial clefts would not consider that diagnosis in a child as a reason for termination, but others would. While prior attitudes and beliefs are very important, some parents do make decisions that differ from those they had believed they would make: some who never believed they would terminate find the reality of a diagnosis such that they do decide not to continue with the pregnancy and vice-versa. It is believed that some parents are not offered tests and the option of termination because of presumptions that their religious beliefs do not allow termination. In reality parents of many faiths undergo termination including Catholics, Jews, Muslims, and Hindus<sup>8</sup>.

### **Health professionals' views**

A recent unpublished study comprising interviews with doctors and midwives working in four English fetal medicine units focussed on late diagnosis and termination<sup>11</sup>. Practitioners broadly supported the current law: specifically it was perceived as allowing parents the time to make and be sure of their decision, allowing themselves time to ensure diagnostic certainty and thus prevent early decisions based on inadequate or incomplete information, and allowing healthy babies in multiple pregnancies to be given the best chance if selective termination could be carried out late in the pregnancy. Fetal medicine specialists were clear that in the third trimester, they made all decisions about the offer of a termination and that, only then, could parents decide. Decision-making was onerous for professionals and presented them with ethical dilemmas. All the professionals felt that these decisions could only be made only in collaboration with colleagues, and that each case was unique - it was necessary to take account of how this particular anomaly was affecting this particular pregnancy.

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# Continental European legislation on abortion

There are currently calls for legal abortion provision in England, Wales and Scotland (but not Northern Ireland) to become more like the continental experience, of making abortions in the first trimester easy to obtain, and later ones more difficult. Specific proposals include bringing down the upper time limit from 24 to 22 or 18 weeks.

## What is a model of continental European legislation?

Inside and outside the European Union abortion legislation varies widely. It reflects the social, political, religious and cultural background of the different countries on the European continent. Abortion legislation ranges from the very restrictive in countries like Ireland, Malta and Poland to being available on request in countries like the Netherlands and Sweden. In Malta it is prohibited in all circumstances. In Ireland abortion is in principle available only on grounds of saving the woman's life, but there is no readily available information<sup>1</sup>. In Poland abortion is in theory legal on the grounds of the woman's life, preserving her physical and mental health, rape, incest or fetal impairment, but its availability is limited in the public sector by conscientious objections from hospital administrations and medical staff. As a result underground private abortion services are "robust in Poland, as is abortion "tourism", abortion by Polish women who travel to neighbouring countries"<sup>2</sup>.

In autumn 2000 the International Planned Parenthood Federation European Network (IPPF EN) published a comprehensive review in its magazine *Choices* of grounds on which abortion is permitted in 37 countries of its member associations in West, East and Central Europe<sup>3</sup>. The IPPF EN analysis indicates that 26 of the 37 countries reviewed have abortion laws that "allow the procedures without restrictions" in the first trimester. Since this review was published a referendum held in Switzerland in June 2002 backed a Parliamentary measure to allow abortions within the first 12 weeks of pregnancy<sup>4</sup>. This definition of 'on request' includes those countries (Albania, Belgium, France, Germany, Hungary, Italy) where the law requires any woman seeking an abortion to state that she is in a condition of "distress or something similar"<sup>5</sup>.

Five countries (UK, Cyprus, Finland, Iceland and Luxembourg) allow abortion on what is defined as broad 'socio-economic grounds'.

## Gestational limits

The *Choices* review points out that the majority of countries where abortion is available 'on request' have a

gestational limit, usually of 12 weeks. But calculation of this period varies from the date of the last menstrual period or from the estimated date of conception. Calculated from the last menstrual period the gestational limit is "12 weeks in 17 of the countries with the most liberal laws and 14 weeks in another five countries... 90 days in Italy, 18 weeks in Sweden and 24 weeks (or foetal viability) in the Netherlands"<sup>6</sup>.

The abortion law in the Netherlands, which has one of the lowest abortion rates in the world, permits abortion "virtually on request at any time between implantation and viability if performed by a physician in a hospital licensed to perform abortions"<sup>7</sup>. In Sweden abortion is legal, "on a wide variety of grounds, including on request, up to 18 weeks of gestation... for pregnancies between 12 and 18 weeks of gestation, the pregnant woman is required to discuss the abortion with a social worker; after 18 weeks permission must be obtained from the National Board of Health and Welfare"<sup>8</sup>.

Statistics from IPPF EN<sup>9</sup> indicate that four countries (Georgia, Kyrgyzstan, Moldova and Ukraine) have 28 weeks as the upper time limit for abortion on a broad range of indications. Other European countries permitting abortion on request in the first trimester allow later abortions only on specific grounds (for example, the woman's life and health, fetal impairment): 24 weeks (Greece), 22 weeks (Albania, Latvia, Lithuania, Russian Federation), 21 weeks (Estonia), 20 weeks (Bulgaria) 18 weeks (Norway). Belgium and UK have no upper time limit for abortion for fetal impairment.

## Abortion 'tourism'

Women who cannot obtain legal abortion in their own countries will – at whatever stage in their pregnancy – travel at great personal and financial cost to other countries. Polish women travel to Austria, Belarus, Belgium, the Czech Republic, Germany, the Netherlands, Lithuania, the Russian Federation, Slovakia and the Ukraine<sup>10</sup>. Women from the Irish Republic and Northern Ireland travel to England.

Figures published by the UK Office of National Statistics (ONS)<sup>11</sup> show that, in 2002, 9,453 non-resident women obtained legal abortions in the UK (9,100 in 2003). This figure has remained between 9,000 and 10,000 in each year since 1995<sup>12</sup>. Of the 9,453 women who came in 2002, 6,522 were from the Irish Republic and 1,391 from Northern Ireland. Of the remaining 1,540, 176 came from France (199 in 2001) and 302 (389 in 2001) from Italy, both countries with limited availability of second trimester abortion. Fifteen women (12 in 2001) came from Poland.

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Analysis of the gestational age of the pregnancies shows a higher proportion of later terminations among non-resident women, compared with resident women in England and Wales. For non-resident women in 2002 just under 15% of terminations took place between 13 and 19 weeks (1,408) compared with 11% of terminations for resident women in England and Wales<sup>13</sup>. And 5% of non-resident women had terminations at over 20 weeks (479), compared with 2% of resident women<sup>14</sup>. In 2002 an encouraging trend among women from Northern Ireland is a significant increase in terminations under 9 weeks (59.4% in 2002 compared to 39.2% in 2001), with a slight reduction in the percentage of terminations over 13 weeks – 14% in 2001 to 13% in 2002<sup>15</sup>.

The Netherlands, like the UK, allows non-resident women to obtain legal abortions in its country. The UN

Population Division estimates that a “sizeable proportion” of women undergoing induced abortion in the Netherlands, are foreign-born<sup>16</sup>.

### **Conclusions**

There is a great variety in types of European legislation.

Making abortion more difficult at whatever stage in the pregnancy does not reduce women’s needs.

Women will travel to other countries to seek the safe, legal abortion procedures denied to them at home, whether it is a legal abortion at any stage of the pregnancy or at a later stage of the pregnancy.

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# Abortion in late pregnancy: legal issues

Professor Ronald Dworkin has suggested that, with the exception of a small number of extremists, there is broad agreement that while fetal life deserves respect, its protection cannot take priority over the rights of the pregnant woman<sup>1</sup>. This correctly captures the position at English common law and also under the Human Rights Act 1998: namely that the fetus is not a legal person, and its interests cannot trump those of the pregnant woman. The restrictions on reproductive decision-making contained in the Abortion Act 1967 stand as an anomalous exception to this broadly accepted general principle. Any further restriction to the availability of legal abortion can only exacerbate this unfortunate inconsistency. Indeed, from a legal point of view, more consistency might be achieved by further liberalisation of the law regulating abortion.

## Patient Autonomy and Medical Law

Recent years have witnessed a widely applauded shift in medical practice. The old attitude of 'doctor knows best' paternalism has been increasingly replaced by recognition of patient autonomy. This shift has been recognised in the legal principles regulating medical practice. Thus children have been granted increased rights to decide on their own medical treatment<sup>2</sup> and the courts have emphasised that it is not sufficient for doctors merely to accord with practices accepted by their peers if they are not to fall foul of the law of negligence. Rather their actions must be objectively justifiable, and be capable of 'withstanding logical analysis'<sup>3</sup>.

Most significantly, it has been accepted that adult patients must have control over their own medical treatment. As our most senior judges have noted:

*[A] medical practitioner must comply with clear instructions given by an adult of sound mind as to the treatment to be given or not given...whether those instructions are rational or irrational<sup>4</sup>.*

*[T]he existence of the patient's right to make his own decision, which may be seen as a basic human right, (is) protected by the common law<sup>5</sup>.*

*[I]f the patient is capable of making a decision on whether to permit treatment...his choice must be obeyed even if on any objective view it is contrary to his best interests<sup>6</sup>.*

## The regulation of pregnancy

In accordance with this more general trend, the importance of ensuring the woman's autonomy in pregnancy and childbirth is an entrenched principle of English law<sup>7</sup>. Like the competent adult man, a competent female patient cannot be forced to undergo unwanted

medical treatment, even if her life depends upon it. The fact that she is pregnant, even with a full term viable fetus, makes no difference. The importance which English law attaches to patient autonomy has led the Court of Appeal to decide that a competent adult woman's right to refuse a caesarean section, even if that decision would inevitably result in the death of her fetus, is absolute<sup>8</sup>. Judicial commitment to a pregnant woman's right of self-determination is unambiguous:

*[P]regnancy ... does not diminish (a woman's) entitlement to decide whether or not to undergo medical treatment...Her right is not reduced or diminished merely because her decision to exercise it may appear morally repugnant<sup>9</sup>.*

Such adherence to the autonomy of the pregnant woman is also accepted within the medical community. The Royal College of Obstetricians and Gynaecologists' guidelines provide that clinicians must honour an advance directive specifying refusal of treatment during pregnancy, even if this is at the expense of the fetus<sup>10</sup>. And a British Medical Authority spokesman has suggested that: "[T]he fact that a woman has moral obligations to her fetus does not mean the health professionals or the courts can compel her to fulfil them"<sup>11</sup>.

A Health Service Circular has expressly stated that a competent woman is entitled to make a decision which will lead to the death or serious handicap of her fetus even if her choice, "...is so outrageous in its defiance of logic or of accepted moral standards that no sensible person who had applied his mind to the question to be decided could have arrived at it"<sup>12</sup>.

This clear and consistent approach means that the worst excesses of some other jurisdictions have been avoided. Unlike in the USA, pregnant women have not been criminalized for their actions during pregnancy. Neither can they be made civilly liable for them<sup>13</sup>. And the courts have refused to accept that a fetus can be made a 'ward of court' where this would involve restricting the freedom of action of the pregnant woman<sup>14</sup>.

## The regulation of abortion

In this context, the severe constraints placed on women's autonomy in termination decisions are an anachronistic remnant of the attitudes of a previous age. If the common law principle of self-determination requires an individual's choice about her medical treatment to be respected even where her decision will end the life of a 36-week-old fetus, it seems entirely illogical to subject pregnant

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women who wish to terminate pregnancies of much shorter gestation to the stringent qualifying conditions in the Abortion Act 1967.

Two arguments, which might be made in favour of distinguishing abortion from the general trend towards recognising patient autonomy, should be mentioned, though they are not compelling. Firstly, scarce resources and the inevitability of rationing are often cited as reasons to reject the very concept of a 'right' to any particular treatment<sup>15</sup>. But since the average abortion costs less than £300<sup>16</sup> and the health care provided during an average pregnancy cost £1700<sup>17</sup> there is no economic justification for limiting access to abortion.

Secondly, of course, in termination decisions, we are concerned not just with the well being of the pregnant woman, but also that of the fetus. However, whatever moral significance we may attach to it, the fetus is not a legal person. It has been consistently affirmed in common law that "[t]he foetus cannot, in English law ... have any right of its own at least until it is born and has a separate existence from the mother"<sup>18</sup>. This is likewise the position under the Human Rights Act (1998). While the European Convention states that, "everyone's right to life shall be protected by law", the European Court of Human Rights has rejected an understanding which would include the fetus as enjoying a 'right to life'. As the European Commission of Human Rights has noted:

*The 'life' of the foetus is intimately connected with, and cannot be regarded in isolation from, the life of the pregnant woman. If article 2 were held to cover the foetus and its protection under this article were, in the absence of any express limitation, seen as absolute, an abortion would have to be considered as prohibited even where the continuance of the pregnancy would involve a serious risk to the life of the pregnant woman. This would mean that the 'unborn life' of the foetus would be regarded as being of a higher value than the life of the pregnant woman<sup>19</sup>.*

This reasoning has recently been confirmed in *Vo v France*<sup>20</sup>. As a Court of Appeal judge has summarised: "on its true construction Article 2 is apt only to apply to persons already born and cannot apply to a foetus"<sup>21</sup>.

### **Conclusion: the merits of consistency**

Whatever position one takes in the abortion debate is uncomfortable, fetal development from conception to birth offering no easy cut off point for proponents on either side of the debate. But there is substantial merit in accepting that patient autonomy is paramount and that it mandates the possibility of termination very late into pregnancy. The paramountcy of patient autonomy provides a clear 'bright line' solution for health care professionals, and it fits with other common law principles and the Human Rights Act (1998). And of course it should be noted that this imposes no obligation on health care professionals to act against their own morals, given the right of conscientious objection, enshrined in the 1967 Abortion Act.

Allowing liberal access to abortion does not mean disregarding the importance of fetal life (just as recognising patient autonomy to refuse life-saving treatment does not involve devaluing the importance of human life). It does, however, recognise that abortion decisions, like other procreative choices, are appropriately understood as private ones for an individual to make in consultation with her doctor. And, of course, it involves trusting women to make the best decisions for themselves and for those close to them. That this will not lead to frequent recourse to abortion late in pregnancy is clearly demonstrated by the recent history of abortion practice in the UK. Late abortion is not a pleasant experience for anyone concerned, but it needs to exist as a last resort for a small number of women who feel that, for whatever reasons, it is the best option for them and their families.

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# References

## Section 1 – Abortion at 20 or more weeks: trends and statistics

All data are taken from ONS statistics.

## Section 2 – Abortion methods in the second trimester

- 1 Private and Voluntary Care (England) Regulations. 2001. Section 41, Termination of pregnancies; Department of Health. 2002. Procedures for the Approval of Independent Sector Places for the Termination of Pregnancy (Oct. 1999).
- 2 RCOG. 2004 (September). *The Care of Women Requesting Induced Abortion. Evidence based clinical guidelines number 7*. London: Royal College of Obstetricians and Gynaecologists.
- 3 ONS. 2002. Abortion Statistics, England and Wales, AB No 28, Table 14. The Stationery Office: London.
- 4 RCOG. 1996 (January). *Termination of pregnancy for fetal abnormality in England, Wales and Scotland*; RCOG. 1998 (March). Report of the RCOG Ethics Committee, *Late termination of pregnancy for fetal abnormality: A consideration of the law and ethics*.
- 5 The British Association of Perinatal Medicine Memorandum. 1999 (November). *Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice*.

## Section 3 – Reasons for abortion late in the second trimester

- 1 George, Anne and Randall, Sarah. 1996. 'Late presentation for abortion. *The British Journal of Family Planning* 22:12-15.
- 2 Alberman, E. and Dennis, KJ. (eds.). 1984. *Late abortion in England and Wales: Report of a national confidential study*. Royal College of Obstetricians and Gynaecologists: London. See also [http://www.guttmacher.com/pubs/ab\\_slides.html](http://www.guttmacher.com/pubs/ab_slides.html)
- 3 This refers to research carried out for a study about young women and abortion. Lee, E., Ingham, R., Clements, S. and Stone, N. 2004. *A Matter of Choice? National Variation in Teenage Pregnancy, Abortion and Motherhood*. York: Joseph Rowntree Foundation.
- 4 Centre for Sexual Health Research, University of Southampton. 'Young Women's Experience of Abortion in the Second Trimester' (on-going research project).
- 5 All-Party Parliamentary Pro-Choice & Sexual Health Group. 2004. *NHS Abortion Services, A Report of Primary Care Trusts Carried out by Voice for Choice*.
- 6 Comment posted on <http://www.livejournal.com> (20.9.2004)

## Section 4 – Fetal sentience and the neurobiology of pain

- 1 Anand KJS. and Hickey PR. 1987. 'Pain and its effects in the human neonate and fetus'. *New England Journal of Medicine* 317: 1321-1329.
- 2 Baars BJ, Ramsay TZ, and Laureys S. 2003. 'Brain, conscious experience and the observing self'. *Trends in Neurosciences* 26: 671-675.
- 3 Benatar, D. and Benatar, M. 2001. 'A pain in the fetus: toward ending confusion about fetal pain'. *Bioethics* 15: 57-76.
- 4 Chugani HT, and Phelps ME. 1986. 'Maturational changes in cerebral function in infants determined by 18FDG positron emission tomography'. *Science* 231: 840-843.
- 5 Derbyshire SWG. 1999. 'Locating the beginnings of pain'. *Bioethics* 13: 1-31.
- 6 Derbyshire SWG. 2000. 'Exploring the pain "neuromatrix" '. *Current Review of Pain* 6: 467-477.
- 7 Derbyshire SWG. 2002. 'Measuring our natural painkiller'. *Trends in Neuroscience* 25: 65-66.
- 8 Derbyshire SWG. 2003. 'Review and meta-analysis of neuroimaging data reveals differential activation from upper and lower gastrointestinal distension'. *American Journal of Gastroenterology* 98: 12-20.
- 9 Derbyshire SWG. 2003. 'Fetal Pain – A Look at the Evidence'. *American Pain Society Bulletin*, ed. P. Vicente, APS Illinois 13: 1-12.
- 10 Fitzgerald M. 1995 (May). 'Foetal pain: an update of current scientific knowledge'. A paper for the Department of Health.
- 11 Fitzgerald M. 1987. 'The prenatal growth of fine diameter afferents into the rat spinal cord - a transganglionic study'. *Journal of Comparative Neurology* 261: 98-104.

- 
- 12 Hevner RF. 2000. 'Development of connections in the human visual system during fetal mid-gestation: a DiI-tracing study'. *Journal of Neuropathology and Experimental Neurology* 59: 385-92.
  - 13 Lloyd-Thomas AR, and Fitzgerald M. 1996. 'Reflex responses do not necessarily signify pain'. *British Medical Journal* 313: 797-798.
  - 14 Mellor DJ, Tamara J, Diesch TJ, Gunn AJ, and Bennet L. 2004. 'The importance of 'awareness' for understanding fetal pain'. *Brain Research Reviews* (in press).
  - 15 Kerr DIB, Haugen FP, Melzack R. 1955. 'Responses evoked in the brainstem by tooth stimulation'. *American Journal of Physiology* 183: 253-258.
  - 16 Vogt BA, Berger GR, and Derbyshire SWG. 2003. 'Structural and functional dichotomy of human midcingulate cortex'. *European Journal of Neuroscience* 18: 3134-3144.

## Section 5 – Fetal Viability

- 1 Costeloe K, Hennesy E, and Gibson, AT. 2000. 'The EPICure Study: Outcomes to discharge from hospital for infants born at the threshold of viability'. *Pediatrics* 106(4):659- 671.
- 2 British Association of Perinatal Medicine. 2000 (July) Memorandum. <http://www.bapm.org/documents/publications/threshold.pdf>
- 3 NS Wood et al. 2003 (November). 'The EPICure study: growth and associated problems in children born at 25 weeks of gestational age or less'. *Archives of Diseases in Childhood, Fetal and Neonatal Edition* 88(6): F492-50.
- 4 Tin W, Wariyar U, Hey E. 1997. 'Changing prognosis for babies of less than 28 weeks' gestation in the north of England between 1983 and 1994'. *British Medical Journal* 314:107-11.
- 5 RCOG. *Further issues relating to late abortion: fetal viability and registration of births and deaths*. [www.rcog.org.uk/main pages.asp?Page ID=768](http://www.rcog.org.uk/main pages.asp?Page ID=768)

See also:

- RCOG Report *Termination of pregnancy for fetal abnormality in England, Wales and Scotland* (Jan 1996); Joint Report of the RCOG/RCPCH *Guidelines for screening, diagnosis and management of fetal abnormalities* (Dec 1997); Report of the RCOG Ethics Committee *Late termination of pregnancy for fetal abnormality: A consideration of the law and ethics* (Mar 1998); The British Association of Perinatal Medicine Memorandum, November 1999 - *Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice*; RCOG Evidence –based Guideline No 8. 2004. *The care of women requesting induced abortion (2004)*.
- 6 Morrison J.J. and J.M. Rennie. 1997. 'Clinical, scientific and ethical aspects of fetal and neonatal care at extremely preterm periods of gestation'. *British Journal of Obstetrics and Gynaecology* 104(4):1341-1350.
  - 7 Evans D.J. and M.I. Levene. 2001. 'Evidence of selection bias in preterm survival studies: systematic review'. *Archives of Diseases of Childhood, Fetal and Neonatal Edition* 84:F79-F84.
  - 8 Macfarlane P.L., Wood S., Bennett J. 2003 (May). 'Non-viable delivery at 20-23 weeks gestation: observations and signs of life after birth'. *Archives of Diseases in Childhood, Fetal and Neonatal Edition* 883:F199-F202.

## Section 6 – Antenatal screening for chromosomal, structural and genetic anomalies

- 1 RCOG, *Ultrasound Screening for Fetal Abnormalities*, 1997 and 2000.
- 2 [www.smd.qmul.ac.uk/wolfson/ndscr](http://www.smd.qmul.ac.uk/wolfson/ndscr) National Down's Syndrome Cytogenetic Register

Online sources of information

Useful online sources of information on conditions and policy include:

[www.nsc.nhs.uk/antenatal\\_screen/antenatal\\_screen\\_ind.htm](http://www.nsc.nhs.uk/antenatal_screen/antenatal_screen_ind.htm)  
[www.nelh.nhs.uk/screening/antenatal\\_pps/antenatal.html](http://www.nelh.nhs.uk/screening/antenatal_pps/antenatal.html)  
[www.arc-uk.org](http://www.arc-uk.org)  
[www.antenataltesting.info](http://www.antenataltesting.info)

## Section 7 – Termination of pregnancy after prenatal diagnosis of fetal abnormality

- 1 ONS. 2003. [www.publications.doh.gov.uk/public/sb0414.htm](http://www.publications.doh.gov.uk/public/sb0414.htm).
- 2 ONS. 2002. <http://www.publications.doh.gov.uk/public/sb0323.pdf>.
- 3 ONS. 2000. [http://www.statistics.gov.uk/downloads/theme\\_health/AB27/AB\\_No27\\_V1.pdf](http://www.statistics.gov.uk/downloads/theme_health/AB27/AB_No27_V1.pdf).
- 4 ONS. 2001. [http://www.statistics.gov.uk/downloads/theme\\_health/AB28\\_2001/AB28\\_2001.pdf](http://www.statistics.gov.uk/downloads/theme_health/AB28_2001/AB28_2001.pdf).
- 5 ONS. 1999. Congenital Anomaly Statistics notifications - 1999: England and Wales - summary table.
- 6 ONS. 2000. Congenital Anomaly Statistics notifications - 2000: England and Wales - summary table.
- 7 ONS. 2001. Congenital Anomaly Statistics notifications - 2001: England and Wales - summary table.
- 8 Statham, H., W. Solomou, and J.M. Green. 2001. *When a baby has an abnormality: a study of parents' experiences*.

- 
- Centre for Family Research, University of Cambridge: Cambridge.
- 9 Statham, H. 2002. 'Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences'. *Fetal and Maternal Medicine Review* 13: 213-247.
- 10 Marteau, T.M. and E. Dormandy. 2001. 'Facilitating informed choice in prenatal testing: How well are we doing?' *American Journal of Medical Genetics* 106: 185-190.
- 11 Statham, H., W. Solomou, and JM. Green. 2001. *When a baby has an abnormality: a study of parents' experiences*. Centre for Family Research, University of Cambridge: Cambridge.

## Section 8 – Continental European legislation on abortion

- 1 United Nations Population Division. 2002 (June). *Abortion Policies: A Global Review* (Ireland Country Profile). New York.
- 2 United Nations Population Division. 2002 (June). *Abortion Policies: A Global Review* (Poland Country Profile). New York.
- 3 Confalone, N. 2000 (Autumn). 'Abortion legislation in Europe'. *Choices*. London: International Planned Parenthood European Network Vol 28, No 2: 2-7.
- 4 'Swiss legalise abortion'. www.news.bbc.co.uk 2 June 2002
- 5 Confalone, N. 2000 (Autumn). 'Abortion legislation in Europe'. *Choices*. London: International Planned Parenthood European Network Vol 28, No 2: 2-7.
- 6 Confalone, N. 2000 (Autumn). 'Abortion legislation in Europe'. *Choices*. London: International Planned Parenthood European Network Vol 28, No 2: 5.
- 7 United Nations Population Division. 2002 (June). *Abortion Policies: A Global Review* (Netherlands Country Profile). New York.
- 8 United Nations Population Division. 2002 (June). *Abortion Policies: A Global Review* (Sweden Country Profile). New York.
- 9 IPPF European Network. 2004 (February). 'Abortion Legislation in Europe'. Brussels: IPPF.
- 10 United Nations Population Division. 2002 (June). *Abortion Policies: A Global Review* (Poland Country Profile). New York.
- 11 ONS. 2004 (July). *Statistical Bulletin, Abortion Statistics*, 'Legal abortions: non-residents' (Table 15).
- 12 ONS. 2004 (July). *Statistical Bulletin, Abortion Statistics*, para 3.3.
- 13 ONS. 2004 (July). *Statistical Bulletin, Abortion Statistics* (Table 3 Legal abortions by (i) purchaser (ii) statutory grounds (iii) gestation weeks (iv) procedure (v) marital status (vi) ethnicity (vii) parity (viii) previous miscarriages (ix) previous abortions 1999-2002, England and Wales, residents).
- 14 ONS. 2004 (July). *Statistical Bulletin, Abortion Statistics* (Table 3 Legal abortions by (i) purchaser (ii) statutory grounds (iii) gestation weeks (iv) procedure (v) marital status (vi) ethnicity (vii) parity (viii) previous miscarriages (ix) previous abortions 1999-2002, England and Wales, residents).
- 15 Figures provided by the Northern Ireland Family Planning Association (nifpa), August 2004
- 16 United Nations Population Division. 2002 (June). *Abortion Policies: A Global Review* (Netherlands Country Profile). New York.

## Section 9 – Abortion in Late Pregnancy: Legal Issues

- 1 Dworkin, R. 1993. *Life's Dominion: an Argument about Abortion and Euthanasia*. London: Harper Collins.
- 2 *Gillick*
- 3 *Bolitho*
- 4 Sir Thomas Bingham M.R. in the Court of Appeal judgment in *Airedale N.H.S. Trust v Bland* [1993] AC 789 at 808.
- 5 Lord Scarman, [*Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* 1985] 1 All ER 643 p. 649
- 6 Lord Mustill, *Bland* at 891.
- 7 Dept. of Health. 1993. *Changing Childbirth*.
- 8 *St. George's Healthcare N.H.S. Trust v S* [1998] 3 WLR 936, *Re MB*
- 9 *St. George's Healthcare N.H.S. Trust v S* [1998] 3 WLR 936 at 957
- 10 [1998] 3 WLR 936 at p, 95
- 11 Dyer, C. 1998. 'Trusts Face Damages after Forcing Women to have Caesareans'. *British Medical Journal* 316: 1477.
- 12 Department of Health. 1999 (19<sup>th</sup> February). *Consent to Treatment: Summary of Legal Rulings* HSC 1999/031, p.6.
- 13 Congenital Disability (Civil) Liability Act (1976). An exception is made for injury occasioned via negligent driving, on the basis that it would be unfair to deny the future child access to compensation derived from the woman's insurance company.

- 
- 14 *Re F (in utero)* [1988] Fam. 122
- 15 See further Morgan, D. 1996. 'Health Rights, Ethics and Justice : The Opportunity Costs of Rhetoric', in McLean, S. *Contemporary Issues in Law, Medicine and Ethics*. Aldershot: Dartmouth 15-27.
- 16 BPAS Price List, 1999
- 17 Audit Commission. 1997. *First Class Delivery: Improving Maternity Services in England and Wales*. Abingdon: Audit Commission Publications.
- 18 *Paton v Trustees of the BPAS*; [1979] QB 276, per Sir George Baker P at 279), affirmed in *Re F (in utero)* [1988] Fam. 122; *Burton v Islington HA* [1993] QB 204; *Attorney General's Reference (No. 3 of 1994)* [1998] AC 245.
- 19 *Paton v. United Kingdom* (1980) 3 E.H.R.R. 408, at 415.
- 20 *Vo v France*. 'Application no. 53924/00'
- 21 Balcombe L.J. in *Re F (in utero)* [1988] Fam. 122, at 142.