Royal College of Obstetricians and Gynaecologists

Termination of Pregnancy for Fetal Abnormality

in England, Scotland and Wales

May 2010

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REPORT OF A WORKING PARTY

May 2010

Royal College of Obstetricians
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Remit and Membership

Remit of the Working Party

1. To review the Working Party Report, *Termination of Pregnancy for Fetal Abnormality in England, Wales and Scotland* (published in January 1996).
2. To review all evidence submitted to the Science and Technology Committee relating to the Abortion Act 1967.
3. To review all other relevant evidence relating to advances in antenatal screening and fetal and neonatal management, including corrective surgery.
4. To publish a report based on the Working Party's findings.

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Executive summary and recommendations

This report is intended to assist doctors and other health professionals to support women and their families when a fetal abnormality is diagnosed and to help women to decide, within the constraints of the law, whether or not to have the pregnancy terminated. It is designed to be explanatory rather than prescriptive and does not purport to give ethical guidance.

Since the last RCOG guidance on termination of pregnancy for fetal abnormality was issued in 1996, advances in the detection of congenital abnormalities have resulted in earlier diagnosis and clearer indications for the offer of termination of pregnancy. Improved imaging, with follow-up of specific abnormalities, has led to a better understanding of their natural history, a more accurate assessment of prognosis and better informed counselling. In addition, antenatal screening has expanded and improved and is now part of routine antenatal care.

The law relating to termination of pregnancy has not changed since 1990 although it has been tested in a number of specific cases. The 1967 Abortion Act, as amended, sets out the grounds and time limits for termination of pregnancy, as well as stating who can perform an abortion and where it can be performed. Termination of pregnancy for fetal abnormality may only be considered if there is a substantial risk that the child, if born, would suffer physical or mental abnormalities that would result in serious handicap. Termination for fetal abnormality will only be lawful, except in an emergency, when the two practitioners, who testify by signing the certificate of opinion form, believe in good faith that the grounds for termination of pregnancy are met.

There is no legal definition of substantial risk. Whether a risk will be regarded as substantial may vary with the seriousness and consequences of the likely disability. Likewise, there is no legal definition of serious handicap. An assessment of the seriousness of a fetal abnormality should be considered on a case-by-case basis, taking into account all available clinical information.

Technical improvements in diagnostic ultrasound continue to be made. More recently, three-dimensional ultrasound technology has been introduced for diagnostic purposes, although its exact role remains unclear. Magnetic resonance imaging can be effective as an adjunct to ultrasound in diagnosing and evaluating structural abnormalities, particularly those involving the fetal central nervous system. Progress in fetal diagnosis is improving knowledge of the natural history of many fetal disorders. While amniocentesis, chorionic villus sampling and fetal blood sampling remain standard methods for the diagnosis of aneuploidy, noninvasive techniques are being developed which should reduce the need for invasive procedures in the future.

Recommendations

1. All women should be provided with information about the purpose and potential outcomes of antenatal screening tests to detect fetal abnormalities and should have an opportunity to discuss their options, before the test is performed (section 6).
2. A robust management pathway must be in place to ensure that appropriate information and support are available. For most major fetal abnormalities, referral to a doctor with expertise in fetal medicine is recommended (section 6).
3. All practitioners performing fetal anomaly ultrasound screening should be trained to impart information about abnormal findings to women and a health professional should be available to provide immediate support to the woman and her partner (section 6).
4. Optimal care for women after a diagnosis of fetal abnormality relies on a multidisciplinary approach. Those involved should be clear about their own roles and should ensure that the woman is carefully guided along a planned care pathway by fully briefed and supportive staff (section 6).
5. All staff involved in the care of a woman or couple facing a possible termination of pregnancy must adopt a non-directive, non-judgemental and supportive approach (section 6).
6. It should not be assumed that, even in the presence of an obviously fatal fetal condition such as anencephaly, a woman will choose to have a termination. A decision to decline the offer of termination must be fully supported (section 6).
7. Live birth following termination of pregnancy before 21^{+6} weeks of gestation is very uncommon. Nevertheless, women and their partners should be counselled about this unlikely possibility and staff should be trained to deal with this eventuality (section 8).
8. Live birth becomes increasingly common after 22 weeks of gestation and, when a decision has been reached to terminate the pregnancy for a fetal abnormality after 21^{+6} weeks, feticide should be routinely offered. Where the fetal abnormality is not compatible with survival, termination of pregnancy without prior feticide may be preferred by some women. In such cases, the delivery management should be discussed and planned with the parents and all health professionals involved and a written care plan agreed before the termination takes place (section 8).
9. Where the fetal abnormality is not lethal and termination of pregnancy is being undertaken after 21^{+6} weeks of gestation, failure to perform feticide could result in live birth and survival, an outcome that contradicts the intention of the abortion. In such situations, the child should receive the neonatal support and intensive care that is in the child's best interest and its condition managed within published guidance for neonatal practice. A fetus born alive with abnormalities incompatible with life should be managed to maintain comfort and dignity during terminal care (section 8).
10. After a termination for fetal abnormality, well-organised follow-up care is essential (section 6).
11. The Working Party recognises the need for the National Health Service Fetal Anomaly Screening Programmes to be linked to databases that enable detection rates of specific congenital abnormalities to be monitored and the impact of the programmes to be evaluated. It is therefore recommended that these programmes are linked to systems which aim to provide continuous monitoring of the frequency, nature and outcomes of congenital anomalies in live or stillborn infants and fetuses in England, Scotland and

Wales. An appropriately funded and centrally coordinated system of congenital anomaly ascertainment that covers all parts of the country is essential (section 4).

12. Outcome data on children born with specific abnormalities are required to provide better information on natural history and prognosis. These data would enable a more accurate assignment of prognosis and better informed prenatal counselling in the future. The Working Party recommends that the envisaged 2-year data collection for preterm infants should be expanded to collect outcome data for infants with abnormalities (section 4).

13. Abortion statistics for England and Wales for 2008 report that 124 terminations for fetal anomalies (Ground E) were performed of pregnancies over 24 weeks of gestation. As numbers in most categories of abnormality were fewer than ten, the nature of the abnormalities is not disclosed and trends or patterns in termination cannot be determined. We recommend that such information is published in the Department of Health Abortion Statistics on a 3- and 6-year cycle (section 4).

1. Introduction

The Working Party was set up by the Royal College of Obstetricians and Gynaecologists in 2008 to produce updated guidance on the termination of pregnancy for fetal abnormality, taking into account changes that have occurred since the College report of 1996.[1]

The report is intended to assist doctors and other health professionals to support women and their families when a fetal abnormality is diagnosed and to help women to decide, within the constraints of the law, whether or not to have the pregnancy terminated. The report is also designed to help staff to provide appropriate care both for those women who elect to have an abortion as well as those who decide not to have the pregnancy terminated.

Over the 13 years since the last guidance was issued, there has been a range of developments in the detection and treatment of congenital abnormalities that has resulted in earlier diagnosis and clearer indications for the offer of termination of pregnancy. Data from improved imaging with follow-up of specific abnormalities has allowed a better understanding of the natural history of many fetal abnormalities and has resulted in a more accurate assessment of prognosis and better informed counselling. In addition, screening is now an integral part of routine antenatal care and most women accept the offer of screening. This has resulted in the development of clear auditable standards for fetal anomaly screening and better access for women.

The Department of Health's abortion statistics show that in 2008 there were 195 296 abortions to residents in England and Wales (18.2/1000 resident women aged 15–44 years).[2] The overall proportion of terminations with fetal abnormality is unknown since, before 24 weeks, this might not be the prime indication for the abortion. Of the total number of terminations, around 1% (1988) were performed under Section 1(1)(d), known as Ground E, of the Abortion Act (see section 2 of this report), namely that there was a substantial risk that, if the child were born, it would suffer physical or mental abnormalities that would result in serious handicap. However, despite improved antenatal screening programmes to detect fetal anomalies, there has been little change in the number of abortions carried out under Ground E over the past 5 years.

In 2008, for residents of England and Wales, 1308 of the 1988 (66%) terminations of pregnancy for fetal abnormality were performed before 20 weeks of gestation; 309 (16%) were carried out in the first 12 weeks. Terminations performed over 24 weeks for fetal anomaly have remained constant at 124–137/year between 2002 and 2008 (Figure 1).

About one-third (37%) of pregnancies terminated under Ground E were reported to be for chromosomal abnormalities. Trisomy 21 (Down syndrome) was the most common reported chromosomal abnormality and accounted for 22% of all Ground E cases. Structural abnormalities accounted for 48% of terminations in this group; most were for nervous system (24%) and musculoskeletal system abnormalities (7%).

Structural abnormalities constitute a major cause of mortality, accounting for about 23% of neonatal deaths and 16% of stillbirths in 2006.[3]

In Scotland, 13 817 abortions were carried out in 2008, which is a rate of 13.1/1000 women; of these, 152 (1.2%) were carried out under Ground E of the Abortion Act. Of these, 28 were for trisomy 21, 86 for other chromosomal anomalies and 38 for neural tube defects and other abnormalities.[4] In Scotland, abortion for fetal anomaly after 24 weeks is infrequent.

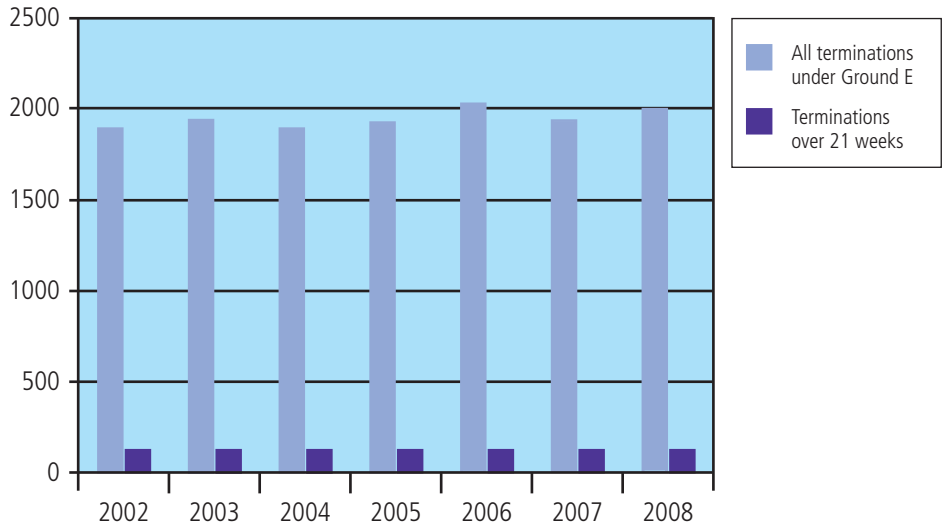

Figure 1 Legal abortions in England and Wales performed under Ground E, 2002–2008

2. Legal status of termination of pregnancy

The law governing termination of pregnancy by doctors is found in four different Acts of Parliament:

- The Offences Against The Person Act 1861
- The Infant Life (Preservation) Act 1929
- The Abortion Act 1967
- The Human Fertilisation and Embryology Act 1990.

The Offences Against The Person Act 1861, Section 58, prohibits the unlawful medical or surgical induction of a miscarriage.

The Infant Life (Preservation) Act 1929 makes it an offence to 'destroy the life of a child capable of being born alive but, in defence, specifies that no person shall be found guilty of an offence under this section unless it is proved that the act which caused the death of the child was not done in good faith for the purpose only of preserving the life of the woman'. If a woman had been pregnant for a period of 28 weeks or more, that 'shall be *prima facie* proof that she was at that time pregnant of a child capable of being born alive' but the Act does not define the gestation at which a less mature fetus has such capacity.

Compliance with the provisions of the Abortion Act 1967 in effect creates a series of defences to the Offences Against The Person Act and the Infant Life (Preservation) Act. This includes the legal requirement that a pregnancy can only be terminated by a registered medical practitioner where two registered medical practitioners are of the opinion, formed in good faith, (except in an emergency) that one of the stipulated grounds is met.

The Human Fertilisation and Embryology Act 1990 amended the 1967 Abortion Act. It introduced a time limit on most abortions of 24 weeks of gestation but permitted termination at any gestation on grounds of serious fetal anomaly.

The grounds for abortion are set out in Sections 1(1) (a)–(d) of the Abortion Act. The abortion notification form refers to these as Grounds A to G. The ground that there is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped is known as Ground E in practice and is referred to as Ground E in this report.

The defences today

Section 1 of the Abortion Act, as amended, contains the substance of the law:

Section 1(1)

Subject to the provisions of this Section, a person shall not be guilty of an offence under the law relating to abortion where a pregnancy is terminated by a registered medical practitioner if two registered medical practitioners are of the opinion, formed in good faith that:

(a) the pregnancy has not exceeded its 24th week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children or her family; or

(b) the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or

(c) the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or

(d) 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 (Ground E on the abortion notification form).

The Act draws a distinction between pregnancies of up to 24 weeks and those of later gestation. Pregnancies of up to 24 weeks of gestation can be terminated under Section 1(1)(a), since many doctors believe in good faith that the continuation of any pregnancy that a woman wishes to terminate involves a greater risk to her physical and mental health than its termination. Thus, up to 24 weeks, doctors dealing with fetal abnormality have the option of choosing either 1(1)(a) or 1(1)(d).

A pregnancy may be terminated at any stage for fetal abnormality under Section 1(1)(d) (Ground E), which specifies that there is a substantial risk that if the child was born it would suffer from such physical and mental abnormalities as to be severely handicapped.

What constitutes substantial risk and severe handicap is clearly germane to decisions about termination of pregnancy after 24 completed weeks of gestation. As discussed below, there is no legal definition of substantial risk or severe handicap.

Two practitioners believe in good faith

Each of the grounds for termination of pregnancy has to be believed by two medical practitioners in good faith and, if challenged, they would have to be able to persuade the court that their belief is honestly held. There has only been one prosecution of a doctor found not to hold a belief in good faith under the Abortion Act (R v. Smith).[5] In this case, the evidence indicated that the doctor failed to carry out an internal examination, had made no inquiries into the pregnant woman's personal situation and had not sought a second doctor's opinion. He was convicted on the grounds that he had not in good faith attempted to balance the risks of pregnancy and termination. To quote Lord Scarman: 'The question of good faith is essentially one for the jury to determine on the totality of the evidence. A medical view put forward in evidence by one or more doctors is no substitute for the verdict of the jury. An opinion may be absurd professionally and yet formed in good faith; conversely, an opinion may be one which a doctor could have entertained and yet in the particular circumstances of

the case may be found either to have been formed in bad faith or not to have been formed at all'.[5]

In practice, it will be much easier to establish that a belief was held in good faith if it seems to be reasonable. The legality of the procedure depends upon both doctors holding the belief in good faith. Thus, if it turns out that one of the two did not hold the requisite belief, the whole procedure will have been unlawful. In such cases, the termination would be unlawful and thereby would expose those participating in the termination to criminal prosecution.

Selective feticide

The law on selective feticide for a woman carrying more than one fetus was obscure until 1990, since the procedure involved the demise of a fetus but the woman remained pregnant. The Abortion Act now provides that the procedure must be treated as an abortion, so that it will be lawful only if one of the four statutory grounds is satisfied. Most specialists in this area believe that the continuation of multiple pregnancies could involve a greater risk to the woman than the termination of one of the fetuses and Ground 1(1)(a) is usually relied upon in pregnancies of under 24 weeks of gestation.

What happens if the fetus is born alive after termination of pregnancy?

A fetus that is born alive after termination of pregnancy is deemed to be a child, irrespective of the gestational age at birth, and should be registered as a live birth. Thus, before deciding on the means of terminating the pregnancy, it is important to define whether the fetus will be born alive; in practice, this means that doctors have to distinguish those capable of being born alive.

In law, a child is born alive when it is capable of maintaining an existence independent of its mother. In Rance v. Storr and Mid Downs Health Authority, the court followed a 19th century precedent and held that the child must be 'breathing and living by reason of its breathing through its own lungs alone, without deriving any of its living, or power of living, by or through any connection with its mother'.[6] This begs the question of how long the child needs to be able to survive by this means.

If it is anticipated that the fetus may die during the delivery process or that the child may die as a result of an abnormality that is incompatible with survival, some parents may request delivery without feticide. As a result, a child may be born alive and subsequently die after it has achieved a life of its own. In such situations, termination of pregnancy should only be undertaken after careful discussion between attending obstetric, midwifery and neonatal staff and the woman and her family, with all parties agreeing a written care plan before the termination takes place.

When a child dies following termination, the question arises as to whether a prosecution could be brought for murder or manslaughter. There is no binding authority on this point and there is nothing in the Abortion Act authorising the destruction of the child. The defence created by the Abortion Act provides that a doctor will not commit an offence 'under the law relating to abortion' but the words are too narrow to create a defence to a charge of murder or manslaughter. Within the terms of the Abortion Act, a doctor cannot be acting 'unlawfully', which is one of the necessary ingredients of the law of homicide.

If the child is born alive, there is little doubt that, whatever the intention of those who brought about its premature delivery and whatever the wishes of the woman or the doctor inducing delivery, the fetus becomes entitled to the legal protection available to any other child. This moment of transition alters the moral and legal status of the fetus/child and has been considered carefully in the Nuffield Council on Bioethics Working Group Report entitled *Critical Care Decisions in the Fetus and Newborn*.[7] In respect of the gestational age of any child at birth, there are situations in which the likely outcome in terms of death or later disability is such that active support would be considered inappropriate and that all care should be directed to the child's and the mother's comfort until the child dies. This report also clearly indicates that decisions concerning the type of care that is offered should be made on the basis of what is in the 'best interests' of the fetus/child and family and that at gestational ages below 24 completed weeks, the likely outcome is so poor that the wishes and views of the mother are critically important in these decisions. This applies equally to situations when a child is born with or without a serious congenital abnormality, such as one of sufficient seriousness to lead to termination. These recommendations have recently been considered and adopted in the development of a professional framework for care.[8]

Where the fetus is born alive following termination and is known to suffer from a condition that will lead directly to death shortly after birth, there is no compulsion on the part of the attending neonatal staff to instigate resuscitation and intensive care, which is not in the best interests of the child. Guidelines are in preparation for the conduct of perinatal palliative care in such situations (British Association of Perinatal Medicine). Where this is likely to happen, there should be careful discussion between attending obstetric, midwifery and neonatal staff and the woman and her family. Before the termination takes place, all parties should agree a written care plan and, in such situations, the Working Party believes that all parties act from their firm belief and in good faith within the terms of the Abortion Act.

A more difficult situation arises when the termination results in a liveborn child suffering from a condition for which the outcome is predicted to be very poor but for whom survival is likely in the first instance. Such children should receive the neonatal support, including resuscitation, and intensive care that is in their best interests, as judged by the criteria usually applied to their condition. Events taking place before birth are unlikely to be relevant to the determination of their best interests.

Once a child is established in neonatal care, the situations in which the neonatal team would consider offering discontinuation of neonatal supportive care are described within the Royal College of Paediatrics and Child Health document, *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*.[9] In practice, in neonatal care, one of three grounds drives the decision to move to palliative care, namely:

1. The 'no chance' situation: the child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Treatment to sustain life is inappropriate.

2. The 'no purpose' situation. Although the child may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it.

3. The 'unbearable' situation. The child and/or family feels that, in the face of progressive and irreversible illness, further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment, irrespective of the medical opinion that it may be of some benefit.

Conclusions

- The law relating to terminations within the UK is described within The Offences Against The Person Act 1861, The Infant Life Preservation Act 1929 and the Abortion Act 1967, as amended by the Human Fertilisation and Embryology Act 1990. The amended Abortion Act sets out the legal framework within which an abortion may be legally carried out and, in effect, creates a series of defences to prosecution under the former two Acts.
- What constitutes a serious handicap becomes a particular issue for doctors when termination of pregnancy is likely to take place after 24 weeks of gestation, when abortion is no longer lawful under Ground 1(1)(a) of the Abortion Act.
- Termination for fetal abnormality will only be lawful when two registered medical practitioners are of the opinion, formed in good faith, that the grounds for termination of pregnancy are met; in the final analysis a jury would have to determine that these beliefs are appropriate on the totality of the evidence.
- A fetus born alive after termination for a fetal abnormality is deemed to be a child and must be treated in his or her best interests and managed within published guidance for neonatal practice. A fetus born alive with abnormalities incompatible with long-term survival should be managed to maintain comfort and dignity during terminal care.

3. Definition of substantial risk and serious handicap

When a fetal abnormality has been detected, the pregnancy can be terminated before 24 weeks of gestation under Ground 1(1)(a) of the Abortion Act but after 24 weeks of gestation it can only be carried out if there is a substantial risk that the child if born would be seriously handicapped. Thus, much of the discussion around late termination of pregnancy for fetal anomalies has focussed on what constitutes a substantial risk of serious handicap.

Substantial risk

There is no legal definition of what comprises a 'substantial' risk. Whether a risk is substantial depends upon factors such as the nature and severity of the condition and the timing of diagnosis, as well as the likelihood of the event occurring.

It has been argued that, since neither substantial risk nor serious handicap is defined, each can be interpreted on a largely subjective basis. As a result, it would be difficult if not impossible to demonstrate that a decision to terminate the pregnancy was not taken in good faith.[10] It has also been suggested that, if the doctor's mistake is factual, for example, if they thought the risk was 50% when it was 25%, 'their honest beliefs' (good faith) will protect them under the Act. The same commentator suggests that, if their mistake is not factual but rather whether the 25% is a 'substantial' risk, their 'good faith' will not protect them under the Act if a court takes the view that that is a misinterpretation of the Act. They will, simply, have misdirected themselves in law.

Serious handicap

The law does not define serious handicap. The view has been expressed that 'provided the condition is not trivial, or readily correctable, or will merely lead to the child being disadvantaged, the law will allow doctors scope for determining the seriousness of a condition. At a minimum it is suggested a "serious handicap" would require the child to have physical or mental disability which would cause significant suffering or long-term impairment of their ability to function in society. The most serious genetic or other conditions which manifest themselves at birth or almost immediately thereafter are by and large likely to fall within the scope of Section 1(1)(d)'.[11]

The authorities dealt with a case in which a curate of the Church of England sought judicial review of a failure to prosecute after an abortion was carried out on a fetus with a cleft palate. The challenge was adjourned when the local police agreed to reinvestigate the case but this resulted in a decision from the West Mercia Chief Crown Prosecutor as follows:

> 'I consider that both doctors concluded that there was a substantial risk of abnormalities that would amount to the child being seriously handicapped. The evidence shows that these two doctors did form this opinion and formed it in good faith. In these circumstances, I have decided there was insufficient evidence for a realistic

prospect of conviction and there should be no charges against either of the doctors.'

This falls short of saying that a cleft palate constitutes a serious handicap, the test being that the doctors formed the view in good faith that there was a substantial risk of serious handicap.

The 1996 RCOG report[1] drew attention to the World Health Organization's definition of disability: 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.[12] It quoted a scale of severity of disability and those with disability at the higher points of the scale would be considered by most people to be seriously handicapped. These include the following two categories:

- assisted performance: the need for a helping hand; that is, the individual can perform the activity or sustain the behaviour, whether augmented by aids or not, only with some assistance from another person
- dependent performance: complete dependence on the presence of another person; that is, the individual can perform the activity or sustain the behaviour but only when someone is with him or her most of the time.[12]

The 1996 RCOG report also provided helpful guidance on the scaling of severity, noting that both the size of risk and the gravity of the abnormality are important. Our advice is that doctors should continue to weigh up the following factors when reaching a decision:

- the potential for effective treatment, either *in utero* or after birth
- on the part of the child, the probable degree of self-awareness and of ability to communicate with others
- the suffering that would be experienced
- the probability of being able to live alone and to be self-supportive as an adult
- on the part of society, the extent to which actions performed by individuals without disability that are essential for health would have to be provided by others.[1]

Doctors will be better able to demonstrate that their opinions were formed in good faith if they have sought advice from appropriate specialists. These may not be obstetricians but may be specialists in the management of the particular condition. For example, in the case of cleft palate, the woman should be referred to the surgical team that specialises in its treatment. In other cases, the appropriate specialist may be a neonatologist, paediatrician or neurologist. If it is their opinion on which reliance is based, it may be appropriate for them to provide one of the signatures under the Act. In complex cases, it may be appropriate to hold a multidisciplinary team meeting.

A further issue unresolved by the law concerns the time when the handicap will manifest itself. Children born with a correctable congenital abnormality, such as diaphragmatic hernia, may be deemed to be seriously handicapped until they receive effective surgical treatment; others suffering from a genetic condition, such as Huntington's disease, are unlikely to manifest the condition until later in life.

The Working Party sees little reason to change the current law regarding the definition of serious abnormality and concludes that it would be unrealistic to produce a definitive list of conditions that constitute serious handicap. Precise definition is impractical for two reasons. Firstly, sufficiently advanced diagnostic techniques capable of accurately defining abnormalities or of predicting the seriousness of outcomes are not currently available. Secondly, the

consequences of an abnormality are difficult to predict, not only for the fetus in terms of viability or residual disability but also in relation to the impact in childhood as well as on the family into which the child would be born.

Conclusions

- There is no legal definition of substantial risk. Whether a risk will be a matter of substance may vary with the seriousness and consequences of the likely disability.
- There is no legal definition of serious handicap – nor is it clear whether the disability has to be present at birth or will qualify if it is something that will afflict the child later in life.
- The Working Party sees little reason to change the current law regarding the definition of serious abnormality and concludes that it would be unrealistic to produce a definitive list of conditions that constitute serious handicap. An assessment of the seriousness of a fetal abnormality should be considered on a case-by-case appraisal, taking into account all available clinical information.
- In cases of doubt the Working Party recommends that obstetricians seek advice from maternal-fetal medicine specialists and where decision making is not straight forward, colleagues who specialise in treating the conditions in question, and in appropriate cases request them to counsel the parents.

4. The diagnosis of fetal abnormality

Since the previous guidance in 1996,[1] antenatal screening for fetal abnormalities is more widespread, the performance of ultrasound in detecting fetal anomalies has improved and the natural history of many fetal anomalies is better understood. There is some evidence that the detection of trisomy 21 is occurring earlier in pregnancy.[13]

The UK National Screening Committee (UKNSC) now makes UK-wide screening policies and each country determines how best these policies should be implemented.[14] A Fetal Anomaly Screening Programme Centre has been established to ensure access to screening for trisomy 21 and other fetal abnormalities.[15] The remit of the Centre is to set standards for doctors and other professionals engaged in ultrasound scanning and biochemical testing for fetal anomalies and to oversee the implementation of a screening programme conforming to an agreed level of quality. An integral part of the programme is the provision of information for women.

Detection of fetal abnormalities and assessment of risk of serious handicap

The suspicion of a fetal abnormality may be suggested by a family history, for example, of cystic fibrosis. Alternatively, an abnormality may be detected by chance when a routine scan is performed for another reason; for example, because of concerns about fetal growth or clinical suspicion of hydramnios. Most fetal abnormalities are detected as a result of routine screening for trisomy 21 and ultrasound screening for major structural abnormalities, such as neural tube defects.

All women are offered screening for trisomy 21. The test recommended by the UKNSC[14] and the National Institute for Health and Clinical Excellence (NICE)[16] is based on nuchal translucency and serum markers, usually by 14 weeks of pregnancy. Women are also offered a minimum of two ultrasound scans. The first is an early scan, undertaken after 8 weeks of gestation for dating the pregnancy and confirming viability and, increasingly, screening for trisomy 21; gross fetal abnormalities may also be detected. The second scan undertaken between 18^{+0} and 20^{+6} weeks of pregnancy is to detect major structural anomalies. The objectives of this ultrasound scan are two-fold: first, to identify abnormalities associated with severe morbidity or that are incompatible with life, so that women and their partners can be offered a choice, within the constraints of the law, as to whether or not to have the pregnancy terminated; second, to detect abnormalities which require early intervention following delivery or which may benefit, in a small number of cases, from intrauterine treatment.

The use of ultrasound to screen for fetal abnormalities at 18^{+0}–20^{+6} weeks results in variable detection rates, depending on the type of abnormality. A literature survey carried out for the NHS fetal anomaly ultrasound programme cited detection rates in the UK for specific conditions shown in Table 1, together with prevalence rates for these conditions.[17]

Table 1. Detection rates for specific conditions (adapted from NHS Fetal Anomaly Ultrasound Screening Programme Study: Literature Survey, June 2007)[17]

Condition	Rate of detection (%)	Frequency/10 000 (*n*)
Anencephaly	98	2.3–6.4
Spina bifida	90	4.3–7.9
Major cardiac abnormalities	50	2.6
Diaphragmatic hernia	60	0.24–4.0
Gastroschisis	98	3.0–4.0
Exomphalos	80	3.3
Bilateral renal agenesis	84	1.8
Lethal skeletal dysplasia	60	0.8
Cleft lip	75	7.0–13.0

The overall detection rates for ultrasound screening are 83% for abnormalities incompatible with life, 50% for serious abnormalities where survival is possible and 16% for those requiring immediate care after birth.[16]

Once a screening scan has identified a potential abnormality and the woman has been referred to a fetal medicine specialist for a second opinion, diagnostic accuracy appears to improve substantially. Although the literature largely focuses on missed lesions, it is the certainty of diagnosis that is important for determining prognosis and providing critical information to women and their partners confronted by a decision of whether or not to have the pregnancy terminated.

Prognosis

An accurate diagnosis is needed for the severity of the condition to be assessed and the prognosis determined. This is reasonably clear-cut when the condition is deemed fatal and many such conditions will be identified before 22 weeks. It is when the anomaly is more likely to result in morbidity than mortality that problems in defining severity arise. To acquire better outcome information on infants with specific congenital abnormalities, routine follow-up is required, such as the 2-year data collection recommended for premature infants.[18]

Termination of pregnancy for specific fetal abnormalities after 24 weeks

Annual statistics are available for abortions in England and Wales.[2] However, information on the specific fetal abnormalities for which terminations of pregnancy are carried out after 24 weeks of gestation is limited. This is because of the small numbers recorded in each category: if the number is fewer than ten (including zero), information is not made available because of confidentiality concerns that individual women or health professionals may be identifiable. In 2008, 124 terminations were carried out after 24 weeks (Table 2). Further details for specific groups of abnormalities are highlighted below.

Table 2. Legal abortions: principal medical condition for abortions performed under Ground E, England and Wales residents, 2008

ICD-10 code[1]	Condition	Total (*n*)	Over 24 weeks of gestation (*n*)
Total, Ground E alone or with any other		**1998**	**124**
Q00–Q89	**Congenital malformations total**	**956**	**85**
Q00–O07	**Nervous system total**	**477**	**42**
Q00	Anencephaly	172	–
Q01	Encephalocele	20	–
Q03	Hydrocephalus	33	–
Q04	Other malformations of the brain	75	21
Q05	Spina bifida	118	–
Q02,Q06,Q07	Other	59	11
Q10–Q89	**Other congenital malformations total**	**479**	**43**
Q20–Q28	Cardiovascular system	124	17
Q30–Q34	Respiratory system	10	–
Q60–Q64	Urinary system	101	14
Q65–79	Musculoskeletal system	147	–
Q10–Q18,Q35–56,Q80–Q89	Other	97	–
Q90–Q99	**Chromosomal abnormalities total**	**739**	**27**
Q90	Down syndrome	436	–
Q901–Q913	Edwards syndrome	143	–
Q914–Q917	Patau syndrome	61	–
Q92–Q99	Other	99	–
	Other conditions total	**293**	**12**
P00–P04	Fetus affected by maternal factors	99	–
P05–P08	Fetal disorders relating to maternal gestation and growth	15	–
P832–P833	Hydrops fetalis not due to haemolytic disease	27	–
Z80–Z84	Family history of heritable disorder	140	–
	Other[2]	12	–

[1] ICD-10 codes are taken from the International Statistical Classification of Diseases and Related Health Problems (10th Revision) published by the World Health Organization (WHO); figures for specific groups shown only where there are 10 or more cases in total.

[2] Includes cases where insufficient detail was available to allocate an ICD10 code at time of publication; fewer than 10 cases (0–9) or where a presented figure would reveal a suppressed value.

Abnormalities of the central nervous system

Abnormalities of the central nervous system (CNS) such as severe hydrocephalus, serious structural brain abnormalities (such as holoprosencephaly, schizencephaly) and thoracic or high lumbar neural tube defects are relatively straightforward to diagnose. However, the outcome for other CNS abnormalities (such as mild to moderate ventriculomegaly) is much less certain and further investigations will be required to refine the diagnosis. This may mean that decisions based on optimal information cannot be made before 24 weeks of gestation. In 2008, one-third of terminations undertaken beyond 24 weeks were for abnormalities of the central

nervous system (42/124). This is likely to reflect the greater certainty that the abnormality would result in serious handicap. However, the accurate diagnosis and determination of prognosis for conditions such as isolated agenesis of the corpus callosum or mild ventriculomegaly can pose problems due to difficulties in accurately detecting additional CNS abnormalities and the variable regression or progression which necessitates the need for a repeat scan several weeks after the initial diagnosis. This can result in delayed diagnosis.

Severe cardiac abnormalities

Severe cardiac abnormalities have a reasonably predictable outcome. Once an abnormality has been identified, paediatric cardiologists can offer fairly accurate information on whether the anomaly can be corrected (to normal anatomy) or whether a palliative procedure is required, with the much greater risk of long term morbidity. In 2008, there were 17 late terminations in this group.

Renal abnormalities

Renal abnormalities can present late in pregnancy with severe oligohydramnios. Occasionally, biochemical testing of fetal urine can point to renal impairment but the accuracy of prediction is problematic and testing is not possible in the absence of a dilated urinary tract. There were 14 terminations in this group in 2008.

Musculoskeletal abnormalities

Musculoskeletal abnormalities can pose particular diagnostic and counselling problems. Although many skeletal abnormalities are lethal, isolated absent or abnormal limbs and other skeletal dysplasias, such as achondroplasia, are often shocking to parents but not always associated with 'severe' handicap. There were fewer than ten late terminations in the musculoskeletal group in 2008 and 58 in the 6-year period 2003–2008.

Other structural abnormalities

Other structural abnormalities, such as facial clefting, can be distressing for parents. Whereas isolated cleft lips can usually be repaired with minimal long-term consequences, combined cleft palate and lip can be more problematic.

Chromosomal abnormalities

Chromosomal abnormalities detected at amniocentesis or chorionic villus sampling are usually diagnosed and decisions made by 24 weeks. However, late diagnosis may arise following either late booking or late manifestation of clinical features arising from an underlying abnormality such as hydramnios in duodenal atresia (associated with trisomy 21) or fetal growth restriction (associated with trisomy 18). A fetus with a structural abnormality associated with a chromosome abnormality is likely to have a poorer prognosis. In 2008, 27 late terminations were performed for chromosomal abnormalities. Table 3 shows terminations for chromosomal abnormalities between 2003 and 2006.

Table 3. Abortions performed under Ground E over 24 weeks of gestation for chromosomal anomalies, 2003–2008

ICD-10 code	Condition	Over 24 weeks of gestation (*n*)
Q90–Q99	Chromosomal abnormalities total	156
Q90	Down syndrome (trisomy 21)	56
Q910–Q913	Edwards syndrome (trisomy 18)	32
Q914–Q917	Patau syndrome (trisomy 13)	15
Q92–Q99	Other	53

Decision to terminate a pregnancy

While the above list is not exhaustive, it illustrates some of the issues facing doctors deciding whether there are legal grounds for termination. However, an additional dynamic is gestational age. For example, the decision to terminate a fetus with a severe isolated limb abnormality after 24 weeks clearly raises greater dilemmas than termination at an earlier stage of pregnancy.

The national statistics suggest that, although there has been little change in the overall number of pregnancies terminated for CNS abnormalities between 1996 and 2008, there have been fewer terminations for hydrocephalus. This may be due to earlier diagnosis, the availability of better diagnostic and prognostic information (in some cases from fetal magnetic resonance imaging) and/or a more conservative approach to pregnancy termination after 24 weeks of gestation. Conversely, there seems to be an increase in terminations for cardiac abnormalities, probably reflecting the increasing emphasis on ultrasound screening for cardiac abnormalities and improving expertise in diagnostic fetal echocardiography.

Conclusions

- The suspicion of an abnormality may arise as a result of fetal anomaly screening, by chance at the time of a scan carried out for clinical reasons or because there is a known family history.
- A woman with findings suggesting a fetal anomaly should be referred to a person or centre with expertise in fetal medicine. Units without a fetal medicine specialist should refer women to the nearest unit with fetal medicine expertise.

RECOMMENDATIONS

- The Working Party recognises the need for the National Health Service Fetal Anomaly Screening Programmes to be linked to databases that enable detection rates of specific congenital abnormalities to be monitored and the impact of the programmes to be evaluated. It is therefore recommended that these programmes are linked to systems which aim to provide continuous monitoring of the frequency, nature and outcomes of congenital anomalies in live or stillborn infants and fetuses in England, Scotland and Wales. An appropriately funded and centrally coordinated system of congenital anomaly ascertainment that covers all parts of the country is essential.

- Outcome data on children born with specific abnormalities are required to provide better information on natural history and prognosis. These data would enable a more accurate assignment of prognosis and better informed prenatal counselling in the future. The Working Party recommends that the envisaged 2-year data collection for preterm infants should be expanded to collect outcome data for infants with abnormalities.
- Abortion statistics for England and Wales for 2008 report that 124 terminations for fetal anomalies (Ground E) were performed over 24 weeks of gestation. As numbers in most categories of abnormality were fewer than ten, the nature of the abnormalities is not disclosed and trends or patterns in termination cannot be determined. We recommend that such information is published in the Department of Health Abortion Statistics on a 3- and 6-year cycle.

5. Technological and other developments in the diagnosis of fetal abnormalities

There have been a number of developments in the detection of congenital abnormalities in the last 10 years of potential relevance to the timing of and indication for termination of pregnancy.

Earlier diagnosis

Recent research has focused on the diagnosis of fetal abnormalities at an earlier gestation. While some structural abnormalities will be detected early, it remains the case that the majority will only be identified on an anomaly scan at 18^{+0} to 20^{+6} weeks. Early diagnosis has potential benefits: termination is safer the earlier it is performed and there may be greater access to surgical termination, which some women prefer.

Improved diagnosis

Two-dimensional (2-D) ultrasonography remains the mainstay of noninvasive fetal diagnosis. However, new imaging modalities can provide additional information although in many cases this will not necessarily lead to a more certain diagnosis. The capability to produce three-dimensional (3-D) images is becoming a standard feature on many new ultrasound machines, although its precise role remains controversial. What is clear is that, for some abnormalities, particularly those involving external structures (most notably the face), 3-D imaging can sometimes be helpful for counselling, as the parents can more easily understand a 3-D than a 2-D image and hence may be in a better position to appreciate the physical impact of the abnormality. However, as the small number of studies assessing the ability of 3-D imaging to detect fetal abnormality compared with 2-D imaging have found no added benefit (and some abnormalities were missed or misdiagnosed),[19,20] it is unlikely that 3-D ultrasound will become the main fetal imaging modality. As a complement to 2-D imaging, there are data suggesting that 3-D contributes useful information concerning skeletal dysplasia, abnormalities of the extremities and face, the assessment of organ volume and in the determination of the upper level of bony abnormality in spina bifida.

Magnetic resonance imaging (MRI) has become another useful adjunct to 2-D ultrasonography. The development of magnetic resonance sequences to allow rapid image acquisition has reduced movement artefact and meant that detailed images of the fetus can be obtained. A number of cohort studies suggest that MRI is most likely to be useful in the diagnosis of fetal neurological abnormalities. In particular, MRI provides information about gyral patterning, the structure of the corpus callosum and cortical thickness that is not provided so well by 2-D ultrasound.[21] As a result, it has been suggested that MRI can be used in conjunction with ultrasound and that it will change the diagnosis in up to 30% of cases with suspected CNS abnormalities. MRI has also been suggested as a useful technique for imaging the fetal chest and understanding the anatomy of large neck lesions. Although MRI is routinely performed

in centres taking referrals for fetal CNS complications, its true impact on prenatal diagnosis still needs to be established.

Natural history of fetal abnormalities

Information from improved imaging and from postnatal follow-up studies has led to a greater understanding of the natural history of many fetal abnormalities permitting a more accurate assignment of prognosis for some fetal defects and better informed parental counselling. A factor contributing to the improved understanding of prognosis has been the multidisciplinary approach to clinical management and counselling. In many units, parents will receive information not only from consultants with a special interest in fetal medicine, midwives and neonatologists but also, when relevant, from paediatric surgeons, neurologists, cardiologists and geneticists.

Congenital cystic adenomatoid malformations (CCAMs) and diaphragmatic hernias are examples of conditions where counselling has changed as a result of improved knowledge about outcome. Initially, large CCAMs causing mediastinal shift were thought to be associated with a poor outcome but, as more data have accumulated, it has become apparent that many will 'regress' as pregnancy continues and outcome is generally good.[22] Congenital diaphragmatic hernias are associated with pulmonary hypoplasia and a significant risk of postnatal mortality, although recent descriptions of ultrasonographic ratios that reflect lung size and correlate with outcome have helped to advise parents on the likely outcome for their fetus based on the degree of pulmonary hypoplasia.[23]

Prenatal diagnostic techniques

Amniocentesis/chorion villus sampling

Obtaining fetal cells from amniotic fluid (amniocentesis), placenta (chorionic villus sampling) or fetal blood by inserting a needle under ultrasound guidance are recognised methods for diagnosing chromosomal or genetic abnormalities. Technological advances mean that it is possible to diagnose some aneuploidies such as trisomy 21, within 24–48 hours using the polymerase chain reaction or fluorescence *in situ* hybridisation. In the future, it seems likely that techniques involving rapid assessment of the whole genome, such as array comparative genomic hybridisation, will greatly increase the amount of information that can be obtained from a single sample but this raises concerns about false positive rates and counselling parents with newly detected submicroscopic chromosomal imbalances.[22] A barrier to implementation of new techniques for prenatal diagnosis is the lack of data about their performance; in this context case–control or randomised controlled trials need to be encouraged and participants reassured that recruitment will not affect access to termination of pregnancy where appropriate.

Non-invasive methods

Research has been carried out into the development of noninvasive methods to avoid the risk of losing a potentially normal baby as a result of invasive diagnostic prenatal procedures. A method that already has some clinical utility involves the detection of cell free, fetal-specific segments of DNA (free fetal DNA or ffDNA) in the maternal circulation. Analysis of ffDNA is used clinically for fetal sexing or determination of fetal blood group.[24] High-throughput DNA sequencing techniques make it possible that, in the future, ffDNA could be analysed for detection of fetal aneuploidy or single gene disorders.

Treatment options

A number of interventions are currently performed in specialist centres to improve fetal outcome following *in utero* diagnosis of fetal pathology. These include transfusion of red blood cells for treatment of fetal anaemia and laser ablation of placental anastomoses in monochorionic twins with the twin-to-twin transfusion syndrome. An alternative approach to fetal therapy is the administration of drugs to the woman to achieve a transplacental effect; the most common examples include the use of steroids to induce maturation of the fetal lungs before preterm delivery, maternal steroids and immunoglobulin to treat fetal alloimmune thrombocytopenia and maternal anti-arrhythmics to treat fetal arrhythmias.

Of particular relevance are procedures that offer the potential of improving the fetal or neonatal outcome in serious (or major) abnormalities (by reducing mortality and/or morbidity), thereby offering parents an alternative to termination or continuation of pregnancy with postnatal management. Three such procedures are currently being evaluated as part of research protocols:

- *in utero* closure of spina bifida during the second trimester of pregnancy by performing a maternal hysterotomy. Initial animal studies suggested that early closure protected the exposed spinal cord from trauma and the neurotoxic effects of amniotic fluid and improved neurological function. These observations have yet to be replicated in the human[25]
- endoscopic placement of a balloon inflated in the fetal trachea to improve lung growth and improve outcome with congenital diaphragmatic hernia[22]
- percutaneous vesicoamniotic shunting in male fetuses with presumed posterior urethral valves.[26]

Finally, there are a number of research groups investigating the possibility of treating fetuses with monogenic disorders such as haemophilia, ornithine transcarbamylase deficiency and muscular dystrophy using gene or stem cell therapy, with the aim of achieving a permanent cure or amelioration of postnatal disease severity.[27] It is likely to be some years before such interventions become clinically relevant.

Conclusions

- Technical improvements in ultrasound equipment continue to be made – more recently, 3-D ultrasound technology has been introduced for diagnostic purposes, although its exact role remains unclear.
- MRI can be effective as an adjunct to ultrasound in diagnosing and evaluating structural abnormalities, particularly those involving the fetal central nervous system.
- Experience from fetal diagnosis is leading to a better understanding of the natural history of many fetal disorders which previously were derived principally from postnatal observations. This has improved prognostic information available for parents.
- While amniocentesis, chorionic villus sampling and fetal blood sampling remain standard methods for the diagnosis of aneuploidy, noninvasive techniques are being developed which should reduce the need for invasive procedures in the future.
- *In utero* treatment of some structural abnormalities has been practised for a number of years but it is recognised that such interventions need to be tested in well-designed prospective studies to establish their effectiveness.

6. Management following a diagnosis of a fetal abnormality

Current national guidelines recommend that routine screening for trisomy 21 should be performed before 14 completed weeks of pregnancy to allow early decisions to be made, including whether to have an invasive diagnostic test and, if fetal aneuploidy is confirmed, whether to have the pregnancy terminated.[16] Increased nuchal translucency before 14 weeks of gestation is also associated with conditions other than aneuploidy, such as congenital cardiac abnormalities.

Information for women about antenatal screening

Screening for trisomy 21 and fetal anomalies is universally offered to women, who must be provided with accurate information and the opportunity to discuss the purpose and potential outcomes of all antenatal screening tests so that they may decide whether to accept or decline the tests. The provision of information and pre-test discussions should be scheduled early enough to enable a woman to have time to decide whether to have screening. Nationally produced written information on antenatal screening is available and has been translated into several languages.

Fetal anomaly screening using ultrasound scanning at 18^{+0} days to 20^{+6} weeks is offered to all women.[28] However, there have been concerns that women are not made fully aware of the potential implications of the scan before it is carried out. To ensure that information is available to all women, a published set of standards is being developed by the NHS Fetal Anomaly Screening Centre and this document should be released in 2010. Even when women are well-informed about the purpose of tests including scans, the emotional impact of a diagnosis of abnormality is highly significant and causes considerable distress.

The shock of any prenatal diagnosis of fetal abnormality makes it hard for women to take in the information that they need to assimilate to make potentially life-changing decisions. It is essential, therefore, when a diagnosis is made, to have well-planned and well-coordinated care pathways in place in all units.

Communication of findings from chorionic villus sampling and amniocentesis

Some women will undergo invasive diagnostic procedures for chromosomal or genetic abnormalities following an abnormal fetal anomaly screening test or because of family history. Whatever the reason, a positive test result will lead to difficult decisions about the future of the pregnancy. How and when the results will be delivered should be agreed before the test is performed and the professional responsible should be suitably trained to discuss difficult information with patients.

Following the diagnosis of a chromosomal abnormality, the woman concerned should be offered a consultation with her obstetrician as soon as possible to discuss the results and her options. Better implementation of screening tests is likely to result in an increase in first-trimester diagnoses of aneuploidy and other abnormalities, which will lead to more women being offered an earlier surgical termination of pregnancy. There is, however, no evidence that earlier termination of pregnancy lessens the emotional impact of the pregnancy loss.

Communication of findings from ultrasound

Regardless of how a fetal abnormality is detected, it is essential that there is a clearly defined care pathway to ensure that appropriate information and support are available. Figure 2 shows the screening pathway for a woman with a scan with suspected fetal anomaly detected at 18–20 weeks.

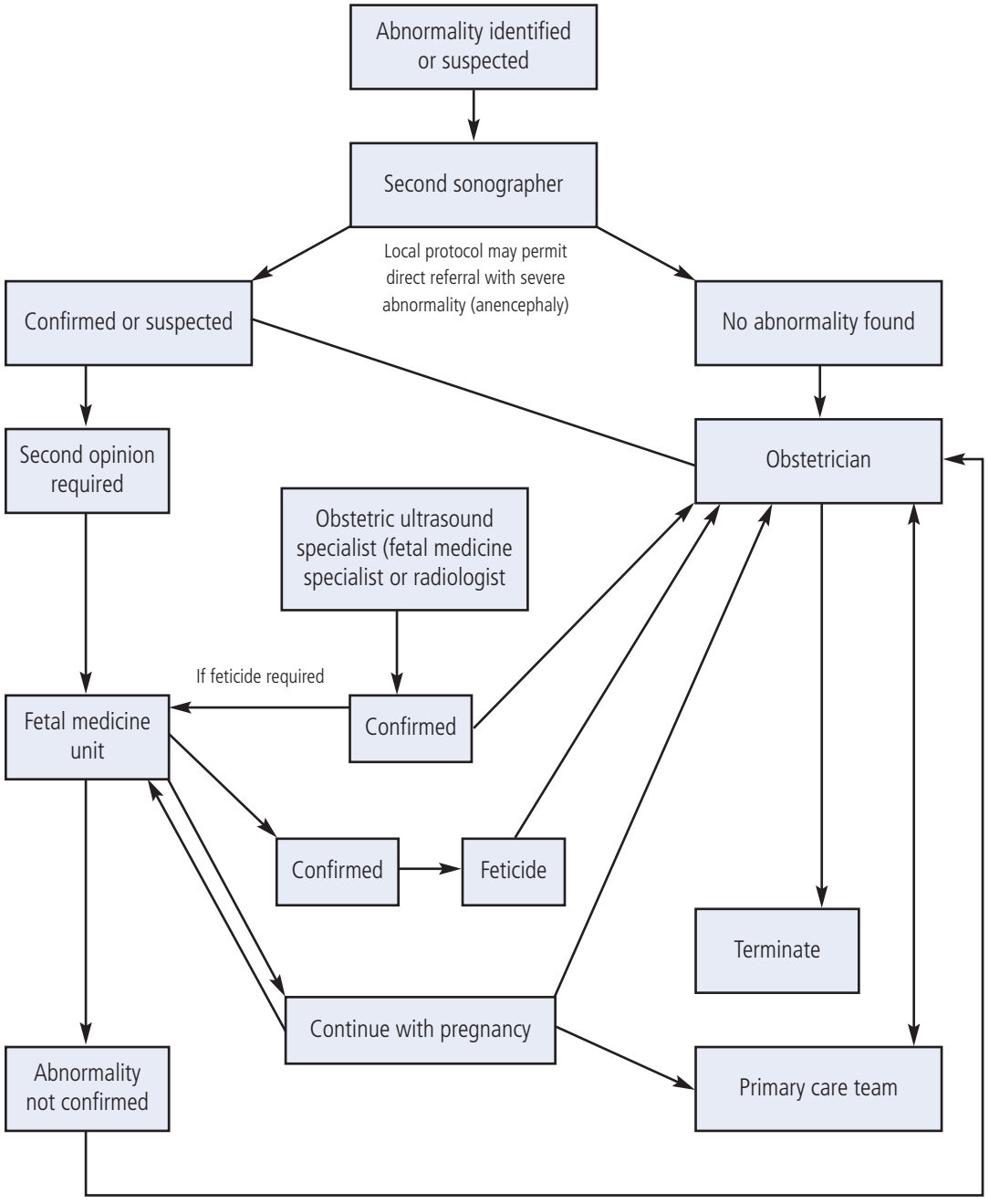

Figure 2 Screening pathways for ultrasound diagnosis

If the scan reveals either a suspected or confirmed abnormality, the woman should be informed by the sonographer at the time of the scan. It is essential that all practitioners performing fetal anomaly ultrasound screening should be trained to communicate abnormal findings to women, as such information is likely to have significant emotional impact.

Usually, sonographers will ask a senior sonographer colleague to confirm findings and this should be done immediately. If an abnormality is confirmed or suspected, referral is usually required, although some obvious major fetal abnormalities, such as anencephaly, may not require a second opinion (this should be decided by local guidelines).

For women who have been given distressing news about their baby during the scan, there should be a health professional available to provide immediate support.

In the case of a suspected abnormality, women should be seen for a second opinion by an expert in fetal ultrasound, such as a fetal medicine specialist. An appointment should be arranged as soon as possible and ideally within three working days. Any delay in receiving more information about the abnormality and its implications will be distressing for women and this should be acknowledged.

If the specialist cannot confirm the abnormality and is confident that the fetus is developing normally, the woman should still be referred to her obstetrician for further discussion, because the significance, from the woman's perspective, of a temporary 'false positive' and the associated residual anxiety should not be underestimated and support and explanation will be required.

Once an abnormality has been confirmed, arrangements should be made for the woman to see an expert who has knowledge about the prognosis of the abnormality and the options available. For most abnormalities, this will be a fetal medicine expert, although some women may want to discuss their decision further with their local obstetrician.

When an offer of termination is deemed appropriate

The decision to end what is usually a wanted pregnancy is extremely difficult and painful for most parents. The severity of the prognosis has a major bearing on their decision making. Women and their partners will need as much information as possible on the implications of the diagnosis. The prognosis can include a great deal of uncertainty. Obstetricians are not always best placed to advise on outcomes after birth and, in some situations, input from other medical specialists, such as paediatricians, paediatric surgeons, geneticists and neonatologists, may be required to ensure a more comprehensive and balanced approach. Agreement on the diagnosis and as precise a prognosis as possible provides the woman with the best available information on which to make her decision when she is counselled by the fetal medicine specialist or subspecialist.

Counselling and support

The decision-making process for women and their partners after the diagnosis of fetal abnormality is a difficult one. They must try to absorb the medical information they have been given, while in a state of emotional shock and distress, and work out a way forward that they can best live with. In such sensitive circumstances, women and their partners must receive appropriate counselling and support from the healthcare practitioners involved. All staff involved in the care of a woman or couple facing a possible termination of pregnancy must adopt a non-directive, non-judgemental and supportive approach. The use of appropriate literature and the

availability of help from non-directive external agencies, such as Antenatal Results and Choices, is extremely helpful.

After the diagnosis, the woman will need help to understand and explore the issues and options that are open to her and be given the time she needs to decide how to proceed. She must not feel pressurised to make a quick decision but, once a decision has been, made the procedure should be organised with minimal delay. Although usually there will be no time pressure put on her decision making, there may be occasions when the pregnancy is approaching 24 weeks of gestation when, because of existing legislation, a rapid decision will have to be reached. In this instance, the reasons must be sensitively outlined and the added distress this may cause acknowledged. Table 4 illustrates the complexity of making a diagnosis and the steps taken before a decision is reached.

Table 4. Steps in diagnosis of fetal abnormality

Condition	Procedure
Anencephaly at 13 weeks	Confirmed by second sonographer Counselled by local obstetrician No referral to fetal medicine specialist Surgical termination of pregnancy at 13^{+} weeks
Isolated unilateral multicystic kidney	Confirmed by local fetal medicine specialist Normal contralateral kidney Counselled by local fetal medicine specialist and/or local paediatrician (including formulation of a postnatal management plan) Follow-up arranged at 32 weeks Postnatal investigations confirmed an isolated multicystic kidney
Isolated ventriculomegaly at 20 weeks (atrium 11 mm)	Counselled by local fetal medicine specialist Declined karyotyping Scan 2 weeks later by fetal medicine specialist showed that the ventriculomegaly had progressed (13 mm) Referred to fetal medicine subspecialist Amniocentesis – normal karyotype, infection screen negative Fetal MRI at 24 weeks showed abnormal gyral development Counselled by paediatric neurologists Feticide and medical termination of pregnancy at 25 weeks
Multiple non-lethal anomalies at 21 weeks (including cardiac outflow tract anomaly)	Referred to fetal medicine subspecialist Amniocentesis: normal karyotype, no evidence of 22q deletion No syndrome match established from dysmorphology databases Multidisciplinary group (fetal medicine subspecialist, neonatologist, paediatric surgeon, geneticist) discuss case and conclude the grounds for termination of pregnancy under Ground E are met; feticide and medical termination of pregnancy

Care of a woman who decides to continue with her pregnancy

The decision by the woman to continue her pregnancy must be fully supported and it should not be assumed that, even in the presence of an obviously fatal fetal condition, a woman will choose to have a termination. If she wishes to continue with the pregnancy, she should be

managed either at the fetal medicine unit (depending on the abnormality) or in conjunction with her referring obstetrician. Some women will choose to continue the pregnancy with the option of palliative care after delivery and this decision must be respected, supported and an individualised care plan agreed. Other women will decline termination for non-lethal conditions and will need referral to specialists such as paediatricians, paediatric surgeons or neonatologists. The baby may need to be born in a centre with immediate access to a range of paediatric specialists, such as cardiologist or paediatric surgeons. In either instance, a coordinated care pathway needs to be established and women should have easy access to a designated health professional throughout the pregnancy. It will be helpful to provide her with details of any relevant parent support organisations. Regardless of the nature of the abnormality, it will also be necessary to ensure that the woman's needs as an expectant mother are not overlooked. Antenatal care should be arranged so that she does not have to wait with others where pregnancies are straightforward. She should also be offered one-to-one antenatal sessions tailored to her specific needs.

Care of a woman who decides to have a termination of pregnancy

Once the decision to terminate the pregnancy has been reached, the method and place should be discussed, together with a view about whether feticide is required. Most women will be unaware that, within the NHS, medical abortion induced by drugs is the procedure usually offered after 14 weeks of gestation. The prospect of labouring to deliver a dead fetus will be difficult for many and discussions about the procedure will require sensitive handling by experienced staff. Although the prospect of labour in these circumstances is especially daunting, some women gain some satisfaction from having given birth and have welcomed the chance to see and hold their baby.

Pre-termination discussions will include how and where the procedure will be managed, the options regarding pain relief and whether the woman might want to see the baby and have mementos such as photographs and hand and footprints. She will also need information about the postnatal period, including physical implications for her and the possibility of a postmortem examination being performed. She will need to be made aware of information from a postmortem that may be relevant for a subsequent pregnancy. These discussions are likely to be distressing for the woman and her partner so they should be handled by a suitably skilled and trained member of staff.

Wherever the termination is to take place, the woman should be given a private room with facilities for her partner to stay. Women who decide to have a surgical procedure will need to be prepared for the possibility that this may be performed on a gynaecological ward or at a day clinic, where they will be alongside women undergoing other types of procedures, including termination of pregnancies for non-medical reasons.

If it is considered likely, on the basis of the non-lethal nature of the anomaly and the gestational age, that feticide is appropriate, a referral to a fetal medicine specialist or subspecialist with competence in feticide will be required. The termination would usually be undertaken at the referring obstetric unit. However, because not all units will be able to undertake feticide, some women will have to travel a considerable distance for this to be performed and make the return journey after the procedure. Staff should be aware of the emotional distress this can cause and should ensure that support is available and that travel arrangements are practical.

It is essential for all relevant staff, both at the referral unit and the fetal medicine unit, to be aware of the woman's history and the management plans, so that inadvertent inappropriate remarks can be avoided as well as the need for the woman to explain her situation repeatedly to different staff members.

Post-termination care

Well-organised follow-up care is essential after a termination for fetal abnormality. Anecdotal feedback from Antenatal Results and Choices indicates that this is an area of care that some women find lacking. Good communication with primary care is necessary to ensure that the woman's general practitioner is well-informed and that she is offered a home visit by a community midwife.[29]

The post-termination follow-up appointment needs careful management, as many women find it difficult to return to the hospital and this will be exacerbated if they are asked to wait in a busy antenatal clinic with expectant mothers.

At the post-termination follow-up appointment with the obstetrician the autopsy findings will be discussed and the risk of recurrence clarified. It may be necessary to obtain genetic advice. An appointment to discuss postmortem results needs to be arranged as soon as possible and any unavoidable delays should be explained to women and their partners and the stress this causes acknowledged. Many women will be very anxious about this appointment because of the implications it may have for subsequent pregnancies. The drawing up of a provisional plan for prenatal diagnosis in a subsequent pregnancy should be envisaged.

Subsequent pregnancy will be anxiety laden for most women and will require sensitive management, with a care plan agreed as early in the pregnancy as possible.

When termination is not offered

There may be a situation when an abnormality is diagnosed and the clinician does not consider that termination would meet the criteria of the law but the woman requests it. If the diagnosis is made before 24 weeks, the woman may be entitled to a termination under an alternative Ground in the Abortion Act and if the attending clinician feels unable to support this for reasons of personal conviction, she must be offered a referral to a colleague or another centre as quickly as possible for assessment as to whether termination meets the legal requirements. If the diagnosis is made after 24 weeks, the woman should be given access to a second opinion and if she is still not offered a termination she should be offered counselling.

The importance of continuity of care

Optimal care for women after a diagnosis of fetal abnormality relies on a multidisciplinary approach. All involved in the process should be clear on their role and make sure that the women and her partner are carefully guided along a planned care pathway by fully briefed and supportive staff. This is particularly important when care is divided between local and tertiary units and clear lines of communication must always be in place. This communication must include primary care as it is essential that the woman's general practitioner and community midwife are informed that the pregnancy is not continuing so that support can be offered to the woman once she returns home. Standard antenatal care is often not suitable for women with a diagnosis of fetal anomaly.[30]

Conclusions

- All women should be provided with information on the purpose and potential outcomes of the antenatal screening tests to detect fetal abnormalities and should have an opportunity to discuss their options, before the test is performed.
- Although the majority of fetal abnormalities are identified through fetal anomaly screening, some are detected during the course of an ultrasound examination for other reasons. No matter how the abnormality is detected, there must be a robust pathway in place to ensure that appropriate information and support are available.
- All practitioners performing fetal anomaly ultrasound screening should be trained to impart information about abnormal findings to women and a health professional should be available to provide immediate support to the woman and her partner.
- Optimal care for women after a diagnosis of fetal abnormality relies on a multidisciplinary approach. Those involved should be clear about their own roles and should sure that the woman is carefully guided along a planned care pathway by fully briefed and supportive staff.
- All staff involved in the care of a woman or couple facing a possible termination of pregnancy must adopt a non-directive, non-judgemental and supportive approach.
- It should not be assumed that, even in the presence of an obviously fatal fetal condition such as anencephaly, a woman will choose to have a termination. A decision to decline termination must be fully supported.
- After a termination for fetal abnormality, well-organised follow-up care is essential.

7. Methods of termination of pregnancy

Termination of pregnancy can be performed surgically before 15 weeks of pregnancy, when uterine evacuation can usually be achieved by vacuum aspiration with an appropriate-sized curette after cervical preparation with misoprostol or gemeprost. After this gestational age, fetal size precludes complete aspiration and dilatation and evacuation (D&E) becomes necessary. The RCOG only recommends D&E when undertaken by specialist practitioners with access to the necessary instruments and who have a sufficiently large caseload to maintain their skill.[31] Medical termination is performed by mifeprostone (200 mg) followed 36–48 hours later by either misoprostol or gemeprost.[31] To our knowledge, there have been no trials comparing the effectiveness or acceptability of current medical and surgical techniques after 13 weeks of gestation.

Risks of termination increase with gestational age, particularly with medical termination; complication rates (haemorrhage, uterine perforation and/or sepsis up to the time of discharge from the place of termination) increase from 5/1000 medical procedures at 10–12 weeks to 16/1000 at 20 weeks of gestation and over.[2] Most terminations after 12 weeks of pregnancy are performed surgically either within NHS hospitals or funded by the NHS in the independent sector (Table 5). The situation is very different when only terminations performed under Ground E are considered (Figure 3). This may reflect the value placed on having an intact fetus to perform postmortem examination, especially in euploid cases. However, it may also reflect the limited availability of D&E within the NHS, where the vast majority of terminations of pregnancy under Ground E are conducted. Almost all second-trimester abortions in Scotland, for whatever reason, are carried out medically rather than surgically.

Table 5. Legal abortions (all Grounds) 2008; gestation weeks by provider and method

Gestation weeks	Abortions (*n*)	Purchaser			Method	
		NHS funded		Privately funded	Medical	Surgical
		NHS hospital	Independent sector			
9–12	55 964	51	45	4	15	85
13–19	16 101	30	64	6	24	76
20–23	2 765	27	67	6	25	75
≥ 24	124	100	0	0	89	11

Conclusions

Medical and surgical termination of pregnancy conducted according to RCOG guidance,[31] appear to have comparable outcomes. Wherever possible, women should be offered the choice of method.

Medical termination offers the opportunity for pathological examination of an intact fetus. This may be critically important where the finding of unrecognised structural anomalies may amend the prenatal diagnosis and alter recurrence risk.

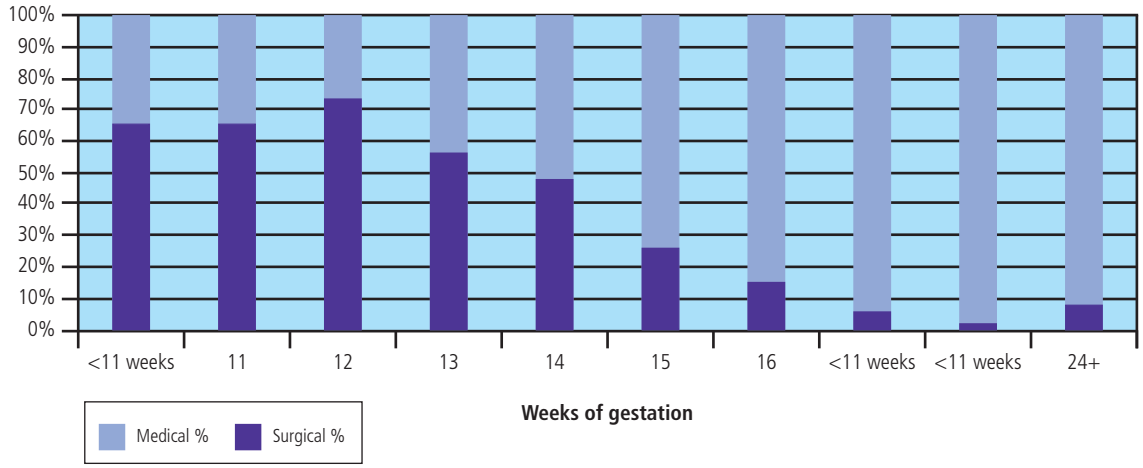

Figure 3 Ground E terminations of pregnancy by gestation and method, 2008

8. Feticide

When undertaking a termination of pregnancy, the intention is that the fetus should not survive and that the process of abortion should achieve this.[1] Death may occur before delivery, either by the procedure undertaken by an obstetrician (feticide) or as a consequence of a compromised fetus being unable to tolerate induced labour. Death may also occur after birth either because of the severity of the abnormality for which termination was performed or because of extreme prematurity (or both).

The RCOG currently recommends feticide for terminations over 21^{+6} weeks.[32] The only exception to this rule is when the fetal abnormality itself is so severe as to make early neonatal death inevitable irrespective of the gestation at delivery.[32] No specific examples were given but it is reasonable to assume that anencephaly would fulfil this criterion.

Information exists on live birth and survival rates of fetuses born after spontaneous preterm labour between 22^{+0} and 25^{+6} weeks of gestation in 1995 in the UK (Table 6). In the Epicure study, 11% of 2122 fetuses believed to be 20–22 weeks of gestation were born alive, of which two (0.1%) survived to discharge. For those born at 23 weeks, live birth and survival rates increased to 39% and 4%, respectively.[33]

Table 6. Live birth and intensive care admission rates after spontaneous preterm birth at less than 26 weeks of pregnancy, UK, 1995

Gestation (weeks)	Births (*n*)	Live births		Died in delivery room (%)	Admitted to NICU		Survived to discharge (%)[b]
		(*n*)	(%)		(*n*)	(%)[a]	
≤ 21	2122	104	11	93	3	3	0
22		138			17	12	9
23	622	241	39	50	121	50	20
24	637	382	60	18	313	82	34
25	633	424	67	8	389	92	52

[a] Percentage of all live births

[b] Percentage of admissions to neonatal intensive care units (NICU)

Wyldes and Tonks reported data on livebirth rates in terminations for fetal abnormality in the West Midlands between the years 1995 and 2004.[34] Overall, 102 of the 3189 (3.2%) fetuses were born alive, of which 36% survived 1 hour or less and 6% for 6 or more hours. Livebirth rates between 20 and 23 weeks of gestation are shown in Table 7. The number and proportion of live births at or over 22 weeks decreased over the period of study from 10% to 16% in 1995–1997 to 2% in 2004. No such decline was seen in cases less than 22 weeks.[34] The proportion of live births at 20–21 weeks did not vary with type of fetal abnormality (5% for chromosomal abnormality, 3% for multiple structural abnormalities, 4% for renal abnormalities and 7% for cardiac abnormalities).[34]

Table 7. Livebirth rates after termination of pregnancy for fetal abnormality in West Midlands, 1995–2004

Gestation (weeks)	Live births		
	(*n*)	(%)	(95% confidence interval)
20	404	3.5	1.7–5.2
21	429	5.4	3.2–7.5
22	235	6.4	3.3–9.5
23	154	9.7	5.1–14.4

Prevalence of feticide

Information on feticide is routinely collected for all terminations in England and Wales. The proportion of abortions performed under Ground E preceded by feticide for the years 2005–2008 is shown in Table 8. This includes selective terminations where the ground for abortion was Ground E. From this it can be seen that feticide is undertaken for a significant number of abortions before 22 weeks of gestation. However, feticide is not performed for some Ground E abortions over 21^{+6} weeks. It is not known whether this relates to a decision not to offer the procedure on the part of the clinician or whether the procedure was offered but declined by the woman. Because of the Office for National Statistics guidance on disclosure of abortion statistics, whereby information from 'unsafe' cells (those with less than ten cases) is suppressed,[35] it is not known what proportion of these late abortions were performed for anomalies where early neonatal death was thought to be inevitable.[2]

Table 8. Proportion of terminations for fetal abnormality preceded by feticide (residents of England and Wales, 2005–2008)

Year	Total[a]	Gestation (weeks)						
		< 16	16–19	20	21	22	23	≥ 24
2005	1916	2	3	17	35	72	81	–[b]
2006	2036	1	3	13	30	72	88	–[b]
2007	1939	2	–[b]	9	23	74	82	–[b]
2008	1988	2	–[b]	11	25	65	88	92

[a] All terminations for fetal abnormality

[b] Percentages are suppressed where based on totals less than 10

Attitudes to feticide

There has been little research on health professionals' and parents' views on feticide as part of termination of pregnancy for fetal anomaly. While many professionals will find the procedure stressful, most agree that feticide will prevent parents and labour ward staff from facing the agony of neonatal distress and pain.[36,37] Statham *et al.*[38] and Graham *et al.*[39] have documented differences among fetal medicine specialists concerning abnormalities for which they personally would offer termination after fetal viability. With respect to decisions about feticide, Statham *et al.*[38] reported that the overriding consideration of fetal medicine specialists was staying within the law. However, both studies identified specialists who were more flexible about

offering feticide after 21+6 weeks of gestation where the anomaly was considered to be incompatible with survival.[38,39]

Procedure for feticide

Parents must receive sympathetic and supportive counselling before and particularly after the procedure. Feticide should be performed by an appropriately trained practitioner (and always under consultant supervision) under aseptic conditions and continuous ultrasound guidance.

Intracardiac potassium chloride (KCl) is the recommended method to ensure fetal asystole.[32] After aspiration of fetal blood to confirm correct placement of the needle, 2–3 ml strong (15%) KCl is injected into a cardiac ventricle. A repeat injection may be required if asystole has not occurred after 30–60 seconds. Asystole should be documented for at least 2 minutes and a scan repeated after 30–60 minutes to ensure fetal demise. In a series of 239 cases of feticide using this technique, between 20+5 and 37+5 weeks of gestation, there were no failures (live births);[40] asystole was confirmed in all cases within 2 minutes of the initial injection, with no woman requiring a second needle insertion and no maternal complications. The mean volume of KCl required was 4.7 ml (range 2–10 ml).[40] Although KCl can be administered via the umbilical route after cordocentesis, failures have been recorded.[41,42] Fetal demise may also be induced by intra-amniotic or intrathoracic injection of digoxin (up to 1 mg) and by umbilical venous or intracardiac injection of 1% lignocaine (up to 30 ml).[43] Neither procedure, however, consistently induces fetal demise.[1,43,44]

Selective termination in monochorionic twins with a discordant fetal abnormality is particularly challenging because of the risk of embolisation of potassium to the healthy fetus through placental vascular anastomoses. In addition, acute haemorrhage of the survivor into the dead co-twin can result in death or neurological injury. To avoid these complications, selective feticide of the affected twin should be performed by a vascular occlusion procedure such as radiofrequency ablation, bipolar cord coagulation, laser cord coagulation or cord ligation. The optimal surgical approach remains undetermined and is dependent upon gestational age and available expertise (occlusion is available in a limited number of fetal medicine centres). Fetal demise of the remaining twin remains a significant risk.[46]

Conclusions

- Live birth following medical termination of pregnancy before 21+6 weeks of gestation is very uncommon. Nevertheless, women and their partners should be counselled about this unlikely possibility and staff should be trained to deal with this eventuality.
- Instances of recorded live birth and survival increase as gestation at birth extends from 22 weeks. In accordance with prior RCOG guidance, feticide should be routinely offered from 21+6 weeks of gestation. Where the fetal abnormality is not compatible with survival, termination of pregnancy without prior feticide may be preferred by some women. In such cases, delivery management should be discussed and planned with the parents and all health professionals involved and a written care plan agreed before termination takes place.
- Where the fetal abnormality is not lethal and termination of pregnancy is being undertaken after 22 weeks of gestation, failure to perform feticide could result in live birth and survival, an outcome that contradicts the intention of the abortion. In such situations, the child should receive the neonatal support and intensive care that is in the child's best interest and its condition managed within published guidance for neonatal practice.

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Glossary

2-D	two-dimensional
3-D	three-dimensional
CCAM	congenital cystic adenomatoid malformations
CMACE	Centre for Maternal and Child Enquiries
CNS	central nervous system
D&E	dilatation and evacuation
consultant with a special interest in fetal medicine	A consultant who has completed an medicine Advanced Training Skills Module in Fetal Medicine (or has the equivalent training)*
fetal medicine subspecialist consultant	A consultant who has successfully completed subspecialty training in maternal and fetal medicine and has been awarded a Certificate of Completion of Training (CCT) in the subspecialty and who devotes at least half, and probably more, of their working time to the subspecialty*
feticide	A procedure to stop the fetal heart and cause the demise of the fetus in the uterus
ffDNA	cell-free, fetal-specific segments of deoxyribonucleic acid
Ground E	Section 1(1)(d) of the Abortion Act 1967
KCl	potassium chloride
MRI	magnetic resonance imaging
NICE	National Institute for Health and Clinical Excellence
previable fetus	A baby in the uterus before the stage of viability, usually taken to be 23 weeks or less
RCOG	Royal College of Obstetricians and Gynaecologists
SANDS	Stillbirth and neonatal death charity
trisomy 21	Down syndrome
UKNSC	UK National Screening Committee

* These definitions are explained in Royal College of Obstetricians and Gynaecologists. *The Future Workforce in Obstetrics and Gynaecology in England and Wales. Working Party Report*. London: RCOG; 2009.

Attention is also drawn to the glossary entitled 'Medical Terms Explained' available on the RCOG website [www.rcog.org.uk/womens-health/patient-information/medical-terms-explained].