

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

Christian Medical Fellowship

Question 1

In the majority of cases of serious fetal abnormalities, the fetus is not at risk of intrauterine death and hence measures to *sustain* the life of the fetus are not necessary. In the relatively rare case where the fetus is at risk of intrauterine death, we believe that medical treatment should be given to the fetus if it is likely to bring substantial benefit relative to the risks. At the present state of knowledge fetal surgery appears to have a low success rate, although medical interventions, for example for fetal heart arrhythmias, may be life-saving. In all cases the likely benefits of any treatment should be balanced against its burdens and risks. The balancing of benefits and risks must be undertaken honestly and openly in consultation with the parents and the uncertainties of predicting future outcome should be highlighted. In the majority of cases there is considerable inaccuracy in the prediction of future neurological and cognitive outcome because the precise nature, and severity of future impairments cannot be known, and outcome depends on a range of contingencies including new medical treatments, preventive measures and social support for disabled people which are constantly being refined. It is important that these uncertainties are spelt out honestly though they are extremely hard for parents to come to terms with as they are faced with difficult decisions on action to be taken or not taken. In addition women's and couples' views, values and circumstances differ considerably, depending on their own upbringing, attitudes to disability and previous life experiences.

The fundamental goals of medicine have always been to relieve symptoms, to preserve life and where possible to restore to health, and these should remain the essential aims of neonatal and fetal medicine. We would add to this the old adage: '*To cure sometimes, to relieve often, to comfort always - this is our work. This is the first and great commandment. And the second is like unto it - Thou shalt treat thy patient as thou wouldest thyself be treated.*' The goals for the newborn baby are much greater than merely 'sustaining life'.

We believe that it is very rarely appropriate to treat a fetus against the wishes of the pregnant woman because any act to treat the fetus involves breaching the bodily integrity of the mother. We therefore support present case law and practice in this area.¹ However it is important to ensure that the opinions, desires and concerns of the pregnant woman are fully informed, explored and discussed.

¹ Royal College of Obstetricians and Gynaecologists. *A Consideration of the Law and Ethics in Relation to Court Authorised Intervention.* London: RCOG, 1994

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In particular we believe that:

- a) Experienced health professionals should give sufficient time for full discussion of relevant accurate information about fetal anomalies and prognoses with the pregnant woman and her partner.
- b) Alternative treatments and management options between the extremes of intensive treatment and fetal termination should be explored.
- c) Women and their partners should be offered a wider range of sources of information, including the option of speaking to other families with children affected by similar conditions, and sufficient time for reflection.
- d) In the case of antenatally diagnosed fetal abnormalities, it is particularly important that obstetric, genetic where necessary, and neonatal medical teams co-operate closely together to ensure that consistent information and a coordinated range of management options are communicated clearly to the pregnant woman and her partner.

It is important to recognise the role of social factors and attitudes in the decisions that parents make regarding the option of termination. Parents frequently feel covert pressure to choose in favour of a termination of an impaired fetus because of perceived deficiencies in social, financial and psychological support for families with disabled children.

The only situation in which treatment of the fetus against the wishes of the mother might be appropriate is if she is clearly incompetent to give consent to treatment because of psychiatric illness or learning disability. In this case we believe that treatment might be justified if it was clearly in the best interest of the fetus, that is that the benefits of treatment clearly outweigh its burdens and risks. Even so, we believe that attempts should be made to obtain the assent of the mother when legally valid consent cannot be provided.

Question 2

It is impossible to give precise answers to these broadly-based and generic questions. We believe it is unhelpful to focus attention solely on the prolongation of life. The focus should be on whether intensive medical or surgical *treatment* is appropriate. This depends critically on the unique constellation of clinical, social and personal features of each individual case, the uncertainties in long-term outcome and includes the family and social context.

We believe that the primary aim of the treating clinician, in discussion with the parents, is always to act in the best interests of the individual child. This involves, in principle, striking a balance between the likely benefits of invasive and intensive treatment against the risks and harms which that treatment carries for the individual child. The benefits which intensive treatment can

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bring include long-term survival but also the likelihood and degree to which health can be restored. Since the precise balancing process includes a range of personal values, goals and attitudes and a range of uncertainties about future outcome, it is essential that, wherever possible, the parents should be fully informed and encouraged to participate with health professionals in the process of weighing the benefits of treatment against its burdens and risks.

Particular concern and care should be applied to conditions in which the benefits of invasive or intensive treatment are excessively limited or restricted, and conditions in which the burdens or risks of invasive treatment are enhanced.

Conditions in which the benefits of treatment are restricted include extreme prematurity of 22-23 weeks gestation, lethal dysmorphic and other syndromes which are inconsistent with long term survival, progressive degenerative or neoplastic disorders, major congenital or acquired brain injury leading to grossly diminished life expectancy, and very severe congenital malformations which are not amenable to treatment or amelioration.

Conditions in which the burdens or risks of treatment may be excessive include extreme prematurity where there is severe congenital or acquired lung pathology necessitating very prolonged mechanical ventilation, severe congenital malformations which require repeated and major surgical intervention, and rare conditions such as epidermolysis bullosa which are associated with difficulty in achieving adequate pain relief and symptom control.

In the complex task of balancing likely benefits against risks of treatments we believe that health professionals are sometimes inappropriately influenced by feelings of personal responsibility or guilt where their own medical interventions have apparently led to the survival of an individual with impairments. It is important that health professionals are not subjected to explicit or implicit pressure to ensure that fetuses or babies who are likely to be disabled do not survive. In all discussions about the likely impact of future disabilities health professionals should openly and honestly involve the parents and recognise their unique contribution, perspective and expertise.

The purpose of commencing intensive life support methods including mechanical ventilation is not to prolong life indefinitely where there is no prospect of recovery. Instead its primary aim should be to support the critically ill individual while they return to health. Hence the withdrawal of intensive life support may be appropriate if recovery is not possible. We believe that the intention in withdrawing life-support is not to bring death, but rather to withdraw futile treatment, although it is possible to foresee that death may occur as a result of this action. If, as sometimes happens, the baby does not

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die following the withdrawal of life support, then compassionate caring, with provision of feeds and symptom relief, should be continued.

The withdrawal of intensive treatment because its burdens exceed its benefits does not imply that the intrinsic value of the baby's life is reduced. No one is able to make a final judgement on the value of another life. We are not able to decide whether a life is futile or not. We do however have a responsibility to decide whether intensive treatment is futile or not.

Section 2

Regarding option 1 – the moral status of the fetus

The Consultation paper tends to conflate moral with legal status, although these have quite different implications. In UK law, the fetus is not recognised as 'a person' and has no legal rights throughout the 40 or more weeks of pregnancy, except for one right after 24 weeks gestation - protection from termination of pregnancy. This right to life is, however, qualified in that:

- a) termination is allowed at any stage up to term if there is a 'substantial risk' of 'serious handicap' or if the mother's life is at risk.²
- b) in 2002 for example, although 2,753 abortions between the 20th and the 24th week were recorded, gestational ages may be under-estimated in records to allow abortions after 24 weeks.³
- c) as discussed above, practitioners are advised to respect women's refusal of interventions during pregnancy and labour, including interventions intended to save the life of the fetus.⁴

It is notable that the Consultation Paper refers to fetal life in terms of its being actively 'sustained' or 'prolonged' by medical care. It would be more balanced to acknowledge that in most instances fetal life continues independently of medical care, and that in many cases medical intervention in fetal life is intended not to sustain but to end fetal life.

Despite the lack of legal rights, in our view as Christian health professionals and in the view of the majority of adults in our society, the fetus has an intrinsic moral status as a member of the human family.

We believe that the current wording of the UK law under which termination may legally be performed because of a perceived risk of 'serious handicap' at any stage of pregnancy until term is unhelpful. There has been widespread public concern and debate over the possibility that late feticide may

² Abortion Act 1967 s1(1)

³ Times 2003; 8 September

⁴ RCOG 1994. *Art Cit* (ref 26)

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occasionally be performed in the UK for relatively minor congenital malformations. The absence of legal guidance for professionals and parents on the nature or severity of fetal abnormality for which termination would be regarded as legal, causes an unnecessary burden of anxiety and uncertainty on all relevant parties. The parents of a mature fetus who are offered the possibility of late feticide may be intensely distressed and even outraged by the suggestion. On the other hand health professionals may sense a legal duty to inform parents of the option of late feticide because of the possibility of subsequent litigation if parents are not informed.

In major tertiary centres it is not uncommon to find physical juxtaposition of fetal medicine units, in which late feticides are performed because of a diagnosis of a major fetal impairment, with neonatal intensive care units in which extremely preterm or impaired newborns are receiving intensive treatment. This juxtaposition of health care services in which contradictory activities are undertaken, can raise emotions of profound ambiguity and distress amongst health professionals and parents.

We understand that the legal limits of abortion are beyond the Working Party's terms of reference. However, we believe that a detailed review of this aspect of the legal framework for late abortion should be recommended and that guidelines should be developed following wide consultation. We see no moral difference between the fetus at 24 weeks gestation and a newborn infant at the same gestational age, and therefore hold that late feticide should not be legal.

In contrast to the fetus, under UK law every baby, including the extremely preterm and profoundly impaired, possesses all the human rights documented in the 1989 UN Convention on the Rights of the Child (more than are noted in the Consultation Paper on p28). These legal rights complement and validate the baby's moral status as a member of the human family.⁵ The contemporary moral status of the extremely preterm or severely impaired baby is an important question that should be addressed by the Working Party.

The dominant model for contemporary bioethics puts emphasis on individual autonomy and a utilitarian summation of consequences, frequently couched in terms of the minimisation of individual 'suffering'. This model inevitably tends to devalue the moral significance of both fetuses and newborn infants and erodes respect for the intimate emotional interdependence between babies and parents. John Harris asserts that babies cannot value their own life, and therefore their life has reduced significance.⁶ Peter Singer and others regard babies as non-persons (without human rights) because they lack certain characteristics. These supposed 'ethically relevant' characteristics include

⁵ UNCRC. *1989 UN Convention on the Rights of the Child*. New York: UN, 1989

⁶ Harris J. *The Value of Life*. London: Routledge and Kegan Paul, 1985

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consciousness, the capacity for physical, social and mental interaction with other beings, having conscious preferences for continued life and having enjoyable experiences. Additionally having relationships to others – relatives, for instance, who will grieve over your death are included as proof of a worthwhile life.⁷ At the same time the simplistic equation of disability with 'suffering' implies that only survival free of physical and cognitive impairment is to be regarded as a reasonable outcome of medical intervention.

In contrast, clinical experience indicates that the majority of parents relate to their premature or critically ill newborn baby as a unique, precious member of their family and the wider human community; an individual, with a history, an identity and a name; not as an object but a person to be treated with gentleness and respect; an irreplaceable, beloved child.^{8,9,10}

It is often assumed by ethicists and others that babies are entirely passive recipients of care from health professionals and parents. However, there is increasing evidence that many premature babies actively interact with caregivers and with their environment. They demonstrate preferences for certain positive experiences and attempt to avoid negative ones¹¹ suggesting that, in some senses, the premature baby can be considered as an active participant rather than a merely passive 'consumer' of care. In the same way there is increasing evidence that the mature fetus interacts with its environment in the uterus, and has a range of sensory and cognitive abilities.^{12,13} We believe that the Working Party could contribute to the current rather abstract understanding of the moral status of babies and fetuses by drawing public attention to recent empirical research about their behaviour and interactions.

Regarding option 2 – acting and omitting to act

The analysis of medical care in terms of acts and omissions is an unhelpful way of considering the morality of treatment decisions. The underlying implication is that a decision to omit treatment is morally equivalent to intentional killing. Similarly it is implied that a decision not to kill a fetus is equivalent to a decision to 'sustain' its life. This assumes a purely consequentialist or utilitarian ethical framework. We believe that the intentional killing of newborn infants is always wrong whereas providing palliative care whilst withholding futile treatment may be entirely appropriate. The moral integrity and intentions of

⁷ Singer P. *Rethinking Life and Death*. Oxford: Oxford University Press, 1995

⁸ Wyatt J. *Matters of Life and Death*. Leicester: Inter-Varsity Press, 1998: 167-8

⁹ Alderson P, Hawthorne J and Killen M. Are premature babies citizens with rights? *Journal of Social Sciences* 2005: (in press)

¹⁰ Alderson P, Hawthorne J, Killen M. The participation rights of premature babies. *International Journal of Children's Rights* 2005: (in press)

¹¹ Als H. 'Reading the Premature Infant' in Goldson E. (ed) *Nurturing the Premature Infant*. New York: Oxford University Press, 1999: 18-85

¹² Commission of Inquiry into Fetal Sentience. *Human Sentience Before Birth*. London: CARE, 1996.

¹³ McCullagh P. *Fetal Sentience*. London: All-Party Parliamentary Pro-Life Group, 1996

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the health professionals and the parents are of central importance in any ethical dilemma at the beginning of life.

Regarding option 3 – questions about the quality of life

See section (d) under background information (p9) for discussion of Quality of Life issues.

Question 4

Regarding number 1 – quality of life

As argued in section (d) of background information (p9), we believe that the concept of 'Quality of Life' (QoL) is beset with logical and practical difficulties, particularly when applied to a newborn or young child. It is entirely appropriate that greater attention should be paid to the *subjective experience* and perceptions of newborn infants, particularly those who are undergoing intensive medical care. This is an area of active research, for example in studies of neonatal responses to painful stimuli, and it is likely to make major contributions in improving the quality of medical and nursing care at the beginning of life. We believe this is an important area for the Working Party to highlight and in which to encourage further research. Similarly we believe that empirical investigation of the subjective experiences of older children, adolescents and adults who are survivors of neonatal intensive care is an important area for ongoing research.

We support research into the causation, nature, severity and consequences of neurological, behavioural and cognitive impairments in those who are survivors of neonatal intensive care. On the other hand we oppose the concept that an individual's actual or predicted QoL can be assessed by an external observer, and we believe that this approach is incoherent, misleading and counter-productive. See background section (d) for further discussion of QoL issues.

In summary we believe that attention must be paid to the recording and assessment of the subjective life experiences of babies, children and adults who have undergone neonatal intensive care. The Working Party might investigate how future surveys could be designed to take greater account of children's, young people's and parents' unique and diverse views, and to reflect these more realistically. However we believe that unthinking use of so-called QoL measures by health professionals and policy makers is unhelpful, misleading and counter-productive.

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Regarding number 2 - Religious and spiritual influences

It is important to recognise that every individual has a worldview – a set of presuppositions and ‘beliefs’ that informs their actions and decisions. Hence those professionals and parents who profess no religious convictions still hold to fundamental beliefs and assumptions which play the role of a religious belief. Fundamental beliefs may be contestable, but they must be respected and recognised.

The parents’ opinions about their child’s treatment should not be marginalised on the basis that it is rooted in a religious worldview. Parents’ decisions, particularly if they are strongly opposed by the doctors, need to be tactfully explored in discussion with the parents. It may well be appropriate to involve a member of the couples’ faith community, the hospital chaplain or other faith representative. It is therefore important that these ‘chaplains’ are given the opportunity to become properly informed and opportunities for special training may need to be provided. The health care professionals involved may also opportunities for review and discussion.

From a general perspective it is worth noting that over 70% of UK citizens put ‘Christian’ as their religion in the 2001 Census. Therefore it must be recognised that Christian values and beliefs continue to play a dominant role in our society, and that all health professionals should be aware of and sensitive to this faith perspective. The secular – and utilitarian – ethical agenda that often appears to drive new legislation and guidance in the UK is out of step with the beliefs of the public. Health professionals must be careful not to impose their own rationalistic and enlightenment-based perspectives on their patients.

Regarding number 3 - Mass media

It is obvious that the mass media can play an important role in educating parents and the general public on the scientific, clinical, social and personal background to these ethical dilemmas. However the media can inadvertently perpetuate prejudices and stereotypes about the lives of disabled children and adults, and it is important that the perspective and interests of disabled children and adults themselves are reflected in programme-making. In addition sensationalist and inaccurate media portrayals can cause genuine distress to parents whose children are currently undergoing intensive care. It is important to work out ways by which both the media and the internet can be used to promote responsible public discussion and understanding.

It is notable that media interest tends to focus on the most intractable and unusual individual ethical dilemmas, so called ‘hard cases’. These cases, often presented in a polarised and unhelpful way, may end up shaping public debate and discussions about policy, leading to bad – or unnecessary – laws and

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professional guidelines. We believe that these hard cases should not be the main factor that shapes the discussion and development of good medical practice.

Question 5

As discussed above we do not think that the QoL concept is helpful. We believe that it would be preferable to put assessment under two separate headings. Firstly, an assessment of *current subjective experience* of the newborn or child, based on detailed observations of indicators of sensory awareness, expressions of pain and distress, response to human interactions etc. In this process the opinions and experiences of the parents and family in interacting with their child should be given due weight. Secondly, the senior medical professionals responsible for the case should provide an estimate of the *prognosis* for later neurological cognitive and behavioural functioning, based on objective information derived from diagnostic procedures such as brain imaging, and other pathological investigations, whilst openly recognising and discussing the inevitable uncertainty and probabilistic nature of any opinion.

We believe that the individuals who should carry primary responsibility for making life-sustaining treatment decisions are the senior doctor who carries professional responsibility for the care of the baby (or the pregnant mother in the case of a fetus), and the mother and father. It is important health professionals recognise that their attitudes towards life-saving treatment are frequently different from those of parents. In a large study of parents of extremely low birth weight children, parents of term children, neonatologists and neonatal nurses in Canada, Streiner and colleagues demonstrated systematic differences in attitudes, with parents, both of term and extremely low birth weight children, more in favour of life-sustaining treatment than professionals.¹⁴ We would agree with the BMA¹⁵ that 'Where there is genuine uncertainty about which treatment option would be of most clinical benefit, parents are usually best placed and equipped to weigh the evidence and apply it to their child's own circumstances'.

We believe that it is unhelpful if direct responsibility for decisions about life-sustaining treatments are diffused to a wider group of individuals or to a committee, although discussion of the case details with a wider group of experienced professionals or a clinical ethics committee may be helpful. In the case of conflicting views between professionals and parents, every attempt should be made to find a 'compromise' solution to which all parties can agree. Involvement of other professionals, including counsellors or mediators may be

¹⁴ Streiner DL *et al.* Attitudes of parents and health care professionals toward active treatment of extremely premature infants. *Paediatrics* 2001;108:152-17

¹⁵ British Medical Association. *Withholding and withdrawing life-prolonging medical treatment. Guidance for decision-making*. London: BMA 2001 p.34.

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helpful, and on occasion even transfer to an alternative hospital seems preferable to involvement of the Courts.

We believe that recourse to the Courts should be a last resort. It is unfortunate that the adversarial nature of our court system seems inevitably to emphasise and exacerbate conflict between clinicians and parents. To our knowledge, with only one exception, all the relevant UK Court judgements, involving conflicts between parents and doctors over the care of a child, have upheld the clinicians' views against the parents'. Hence parents should be warned about this, and not be led to expect that the Courts will give equal weight to parental and to medical views. We believe that it is generally not helpful for these intensely painful and personal cases to be held in public, as the media attention and discussion add to the distress of both parents and professionals. The law should be involved in as few cases as possible and only as a last resort. It is the purpose of the law to define what one is permitted to do without suffering legal penalty. It is not its role to say what should be done.

Question 6

Advances in medical technology and changes in social values have tended can raise parents' expectations that it is their right and even their moral duty to have 'perfect' children, who will pose the least disruption to parents' lives and the least burden and economic cost to families and society. In this social context there is a tendency for moral choices to become more closely identified with economic and utilitarian considerations. These social and economic forces may tend to validate the moral belief that it is in the best interests of the fetus with moderately severe physical or cognitive impairments not to be born. The Consultation Paper asserts that '*in 1998 it cost £125,000 "to bring up" a child with severe disability, which was at least three times more than the amount required for a child without disability*'. This bald statement is an example of the negative evaluation of children described in 3(c). It does not allow for the great individual differences between parents with a normal child including those who choose to pay far more than £125,000 in childcare, clothing, leisure/entertainment and schooling costs, compared with parents who have very few resources. A comparison might be made with extra cost and 'burden' on parents of bringing up a child who is exceptionally gifted and who requires extra educational input. The statement in the Consultation Paper appears to put an economic value on an individual disabled life, rather than focussing on the political and economic decisions which underlie such calculations. Many disabled people argue that better education and employment opportunities would enable them to repay in income tax the investments which society had made in their earlier care.

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Economic pressures colour social perceptions of disability, disabled children and of children generally, and can therefore exacerbate anxieties about the risks of impairment. As mentioned above, parents and children who live with disability tend to report more positive, accepting and pragmatic responses compared with practitioners and potential parents with little direct experience of disability. The Consultation Paper (p20) seems to assume a purely negative effect of disabled children on their families, but there is little empirical evidence to support this. Peter Rosenbaum and colleagues in Ontario have found no correlation between assessed severity of disability and indices of maternal stress. Similarly Pinelli, in a study of the families of extremely low birthweight adults, found no differences in marital disharmony, mood, anxiety, social support, depression or mother's physical or mental health, compared with controls.¹⁶ Health professionals and parents frequently express anxieties about the negative effects of impaired children on healthy siblings, implying that siblings are passive objects who are 'damaged' by the presence of a disabled child. In contrast, the empirical evidence suggests that siblings are active agents who frequently make a positive contribution towards caring for children with impairments and also report advantages of learning to live with disability as a family. In summary, economic considerations should never be an explicit or even implicit part of any treatment decisions regarding individual fetuses or the newborn.

Question 7

We do not believe that QALYs are a helpful or informative way of assessing the likely benefits of interventions at the beginning of life. See replies to questions 4 and 6 above.

Question 8

We believe that further guidelines would be of assistance to health professionals. However we do not believe that guidelines should be 'directive', but rather 'advisory' – and flexible enough to recognise that each situation is different. Directive protocols tend to assume that 'one size fits all' and in this respect are unhelpful. Senior and experienced health professionals must have the clinical freedom to treat patients in a manner that they genuinely believe is in their patient's best interests.

No. We believe this would be unhelpful and dangerous. Setting a limit makes the erroneous assumption that lack of resuscitation will inevitably result in the death of the infant. In some cases a child will continue to live but with a much greater risk of neurological impairment. A clinical decision to withhold initial care, followed by a decision to commence treatment some minutes or hours

¹⁶ Pinelli JM *et al.* Comparison of maternal health and burden of illness in families of extremely low birth weight and normal birth weight subjects at young adulthood. *Pediatr Res* 2005 [abstract available on www.abstracts2view.com/pas/]

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later (as is documented may occur currently in Holland) risks increasing the rate of neurological impairment and subsequent morbidity. An arbitrary limit on resuscitation also ignores the steady improvement seen over the last 30 years in the prospects for extremely small babies and the likelihood that further advances in clinical care, including new brain protective treatments, will be forthcoming in the next decade. Hence prescriptive guidelines may well impede medical progress in the care of extremely vulnerable babies. A further major problem with prescriptive guidelines based on gestational age is that, in routine clinical practice, the precise gestational age is often uncertain and in most clinical situations an error in gestational age of ± 2 weeks is accepted. Hence normal clinical uncertainty and errors in gestational age assessment may have profound and potentially damaging consequences. Again, senior and experienced health professionals must have the clinical freedom to act in their patient's best interests.

Question 9

We believe that current legislation governing the medical care of babies and children is satisfactory and that new legislation is not necessary.

We believe that the current wording of the UK law under which termination may legally be performed because of a 'substantial risk' of 'serious handicap' at any stage of pregnancy until term is unhelpful. The absence of legal guidance for professionals and parents on the nature or severity of fetal abnormality for which termination would be regarded as legal causes an unnecessary burden of anxiety and uncertainty on all relevant parties. In cases where significant abnormalities are detected late in pregnancy, health professionals currently perceive a legal duty to inform parents of the legality of late feticide, because of the possibility of subsequent litigation otherwise. As referred to above, we would support a detailed review of current legal framework for abortion beyond 24 weeks and the development of guidelines following wide consultation.