



## CPS position statement for prenatal counselling before a premature birth: Simple rules for complicated decisions

[Annie Janvier](#), MD PhD FRCPC,<sup>1</sup> [Keith J Barrington](#), MB ChB,<sup>2</sup> [Khalid Aziz](#), MA MEd(IT) FRCPC FAAP,<sup>3</sup> [Eduardo Bancalari](#), MD,<sup>4</sup> [Daniel Batton](#), MD,<sup>5</sup> [Carlo Bellieni](#), MD,<sup>6</sup> [Brahim Bensouda](#), MD,<sup>7</sup> [Carlos Blanco](#), MD PhD FRCPI,<sup>8</sup> [Po-Yin Cheung](#), MBBS PhD FRCP,<sup>9</sup> [Felicia Cohn](#), PhD,<sup>10</sup> [Thierry Daboval](#), MD FRCPC FAAP MSc,<sup>11</sup> [Peter Davis](#), MD FRACP,<sup>12</sup> [Eugene Dempsey](#), ChB,<sup>13</sup> [Amélie Dupont-Thibodeau](#), MD PhD(c),<sup>14</sup> [Emanuela Ferretti](#), MD FRCPC,<sup>15</sup> [Barbara Farlow](#), BEng MBA,<sup>16</sup> [Matteo Fontana](#), MD,<sup>17</sup> [Etienne Fortin-Pellerin](#), MD,<sup>18</sup> [Aviva Goldberg](#), MD MA,<sup>19</sup> [Thor Willy Ruud Hansen](#), MD PhD MHA FAAP,<sup>20</sup> [Marlyse Haward](#), MD,<sup>21</sup> [Lajos Kovacs](#), MD FRCPC FAAP,<sup>22</sup> [Anie Lapointe](#), MD FRCPC,<sup>23</sup> [John Lantos](#), MD,<sup>24</sup> [Colin Morley](#), MD,<sup>25</sup> [Ahmed Moussa](#), MD,<sup>26</sup> [Gabriel Musante](#), MD MSc,<sup>27</sup> [Sophie Nadeau](#), MD,<sup>28</sup> [Colm PF O'Donnell](#), MB MRCP MRCPCH FRACP FJFICMI PhD,<sup>29</sup> [Kristina Orfali](#), PhD,<sup>30</sup> [Antoine Payot](#), MD PhD,<sup>31</sup> [C Anthony Ryan](#), MB ChB,<sup>32</sup> [Guilherme Sant'Anna](#), MD PhD,<sup>33</sup> [Ola D Saugstad](#), MD PhD FRCPE,<sup>34</sup> [Sadath Sayeed](#), JD MD,<sup>35</sup> [Theophil A Stokes](#), MD,<sup>36</sup> and [Eduard Verhagen](#), MD PhD JD<sup>37</sup>

<sup>1</sup>Pediatrics and clinical ethics, Université de Montréal and Centre Hospitalier Universitaire (CHU) Sainte-Justine;

<sup>2</sup>Pediatrics, Université de Montréal, Montreal, Quebec;

<sup>3</sup>Pediatrics, University of Alberta, Royal Alexandra Hospital Neonatal Intensive Care Unit, Edmonton, Alberta;

<sup>4</sup>Pediatrics, Obstetrics and Gynecology, University of Miami, Division of Neonatology, University of Miami Health System, Miami, Florida;

<sup>5</sup>Neonatology, Southern Illinois University School of Medicine, Carbondale, Illinois, USA;

<sup>6</sup>Neonatal Intensive Care, Siena University Hospital, Siena, Italy and the Bioethical Committee of the Italian Pediatric Society;

<sup>7</sup>Pediatrics, McGill University, Montreal, Quebec;

<sup>8</sup>Pediatrics, National Maternity Hospital Dublin, National Children's Research Centre, Our Lady's Children's Hospital, Dublin, Ireland;

<sup>9</sup>Departments of Pediatrics, Pharmacology and Surgery, University of Alberta, Edmonton, Alberta;

<sup>10</sup>University of California, Irvine, Kaiser Permanente Orange County, California, and American Society for Bioethics, USA;

<sup>11</sup>University of Ottawa, Children Hospital of Eastern Ontario, Ottawa, Ontario;

<sup>12</sup>Neonatal Medicine, Royal Women's Hospital, Victoria, Australia;

<sup>13</sup>Cork University Maternity Hospital and Department of Paediatrics & Child Health, University College Cork, Cork, Ireland;

<sup>14</sup>CHU Sainte-Justine, Montreal, Quebec;

<sup>15</sup>Pediatrics, University of Ottawa, The Ottawa Hospital/Children's Hospital of Eastern Ontario, Ottawa, Ontario;

<sup>16</sup>The DeVeber for Bioethics and Social Research, Patients for Patients' Safety Canada;

<sup>17</sup>Neonatal and Pediatric Intensive Care Unit, Children's Hospital of Lucerne, Lucerne, Switzerland;

<sup>18</sup>Pediatrics, Université de Sherbrooke, CHU de Sherbrooke, Sherbrooke, Québec;

<sup>19</sup>Department of Pediatrics and Child Health, University of Manitoba e-Health Services, Winnipeg, Manitoba;

<sup>20</sup>Oslo University, Oslo, Norway;

<sup>21</sup>Albert Einstein College of Medicine, Children's Hospital at Montefiore, Bronx, New York, USA, Montefiore-Einstein Bioethics Committee;

<sup>22</sup>Pediatrics, McGill University, Jewish General Hospital;

<sup>23</sup>CHU Sainte-Justine, Montreal, Quebec;

<sup>24</sup>Children's Mercy Bioethics Center, Children's Mercy Hospital, Kansas City, Kansas, USA;

<sup>25</sup>Neonatal Medicine, Royal Women's and Royal Children's Hospitals, Melbourne, Australia;

<sup>26</sup>Pediatrics, CHU Sainte-Justine, Montreal, Quebec;

<sup>27</sup>Newborn Services, Maternal & Child Department, Hospital Universitario Austral, Pilar, Argentina;

<sup>28</sup>Pediatrics, Université Laval, CHU de l'Université Laval, Québec, Québec;

<sup>29</sup>Pediatrics, University College Dublin, The National Maternity Hospital, National Children's Research Centre, Dublin, Ireland;

<sup>30</sup>Bioethics in Pediatrics, Columbia University, New York, New York, USA;

<sup>31</sup>Pediatrics and clinical ethics, University of Montreal, CHU Sainte-Justine;

<sup>32</sup>Pediatrics, Cork University, Cork, Ireland;

<sup>33</sup>Pediatrics, McGill University, Montreal, Quebec;

<sup>34</sup>Pediatrics, Oslo University Hospital, University of Oslo, Oslo, Norway;

<sup>35</sup>Global Health and Social Medicine and Pediatrics, Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts;

<sup>36</sup>Pediatrics, Walter Reed National Military Medical Center, Uniformed Services University of the Health Sciences, Bethesda, Maryland, USA;

<sup>37</sup>Pediatrics, Neonatologist, Director of Pediatrics, University Medical Center Groningen, Groningen, Netherlands

Correspondence: Dr Keith J Barrington, Pediatrics, Université de Montréal, 3175 chemin Côte-Sainte-Catherine, Montreal, Quebec H3T 1C5. Telephone 514-345-4931 ext 5929, fax 514-345-4822, e-mail [keith.barrington@umontreal.ca](mailto:keith.barrington@umontreal.ca)

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In 2007, the Fetus and Newborn Committee of the Canadian Paediatric Society indicated that the 1994 position statement ‘Management of the woman with threatened birth of an infant of extremely low gestational age’ (1) needed revision. During a collegial process, which included an extensive review of the literature on the subject, the following important points were made:

- Gestational age (GA) estimates are inaccurate and, therefore, cannot be used as though they are precise to make life and death recommendations.
- Estimates of GA should not be used alone but should be used in conjunction with other prognostic indicators.
- Any position statement should emphasize communication and how to interact with parents, focusing on how to personalize antenatal consultation, shared decision making and ensuring that the life trajectory of the child (both at birth and in the neonatal intensive care unit [NICU]) is optimized.
- Information shared with parents, in addition to estimates of survival and long- and short-term morbidity, should include evidence about quality of life, and the experience of parents and children in and after the NICU.

In October 2012, a new position statement, ‘Counselling and management for anticipated extremely preterm birth’ (2), was published by the Canadian Paediatric Society, which we found to be extremely disappointing because it did not incorporate many of the above points. Since 1994, our knowledge regarding both the survival rates of extremely preterm infants (3–5) and the quality of life of those survivors has substantially improved (6–13). We have also learned more about what parents want to know when they are facing the delivery of an extremely premature infant (14–16), as well as their experiences in the NICU (17) and the impact on families in the long term (18,19). Disturbingly, we have also learned that preterm infants are routinely denied life-sustaining treatment, even when their prognosis is better than that of other patients who routinely receive such treatment (2,20–28). None of this evidence was included in the new statement.

The statement supposes that all of the medical staff involved with these decisions need to be given simple rules (21). We reject this premise. When decisions are complicated, decision making must be nuanced. There is no other clinical situation in which doctors avoid responsibility for life-and-death decisions by proposing and following simple and scientifically flawed algorithms (21). We are concerned that several recommendations are unsupported by any of the literature that was cited. We are also concerned about the lack of an explicit ethical underpinning for the recommendations.

In our opinion, the limitations of the 2012 policy statement are as follows:

- The recommendations for intervention thresholds, based on completed weeks of gestation (which are inaccurate), are not rational. There is no discussion of how these particular thresholds were chosen compared with other possible thresholds.
- The literature review is incomplete, with significant gaps. It should be systematic and the criteria for selecting different references explicit. There are several large population-based cohort studies that are not referenced (29), whereas others are included, but not their latest published data (30). A database study showing a very small increase in mortality between one and five years of age among extremely preterm infants is quoted (31), with no indication of why this reference was chosen over many hundreds of other potential studies.
- There is scarce acknowledgement of the importance of quality of life, and no recognition of the data showing that quality of life is not related to GA (12).
- There are significant errors in several quotations of the literature. For example, all of the values in Table 2 are incorrect; also, the proportions of children from the Epicure study with severely abnormal outcome and from the Australian cohort are incorrectly quoted.

- Different long-term outcome measures are treated as though they were equivalent. One of the studies referenced for Table 2 included all grades of cerebral palsy as severe disability, while another only included ‘severe’ cerebral palsy; one study included infants with a two-year Bayley Mental Development Index (MDI) >2 SDs below the mean, while another only if the MDI was >3 SDs below the mean.
- The definitions of severe disability are not appropriate; a low Bayley MDI score at two years of age is not a disability, and many infants with low two-year scores experience no disability in the long term. If followed and evaluated for their cognitive function later in life, there is no difference between infants of GAs between 23 and 26 weeks.
- The Grading of Recommendations Assessment, Development and Evaluation (GRADE) system requires an explicit systematic review of all of the evidence, the construction of ‘summary of findings tables’, an exhaustive process of rating the quality of the evidence and, finally, the creation of recommendations (32). Most of these steps were omitted; only the terms for strong or weak recommendation are used, which is defined by the GRADE working group as “the extent to which one can be confident that the desirable effects of an intervention outweigh its undesirable effects” (33); such a distinction is meaningless without performing all of the previous steps, and is not relevant to ethical decision making concerning life-sustaining interventions.

## A WAY FORWARD

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We have learned enough about decisions for extremely premature babies that simple guidelines are no longer needed. Decisions in the perinatal period should be made in a manner similar to decisions for any other patient. All health care providers should be adequately educated in ethical decision making and in communicating with families. In very high-risk situations, both before and after birth, when dealing with incompetent babies and young infants, the ethical principles are very similar. A statement to help doctors in these situations should ideally have the following characteristics:

- Explain that decision making should be personalized in terms of communication style, information needs and decision-making style of the parents in the best interest of their child.
- Recommend that all patients are considered individually, and that care is family-centred and personalized.
- Acknowledge that transfer to a tertiary care centre and administration of antenatal steroids do not mandate either institution of life-sustaining interventions or an operative delivery by Cesarean section.
- State that infants born at extremely low GAs have a reduced survival and increased risks of adverse long-term outcomes, but that survivors generally have a good quality of life.
- Explain that decision making for the extremely preterm infant should be an ongoing dialogue with parents, and that if new information becomes available, especially at the time of birth, decisions should be re-evaluated.
- Encourage caregivers to share information that includes the quality of life, and the life experiences of preterm infants and their families both during and after their NICU stay. This information should be balanced and include what some children cannot do because of disabilities, but also what they and their families can do.
- Discuss the timing of death. The average age at death of neonates who die in the NICU has been increasing. The consequences of intensive care before death should be accounted for in ethical considerations. Re-evaluation of the appropriateness of life-sustaining interventions during the NICU stay to reduce the burdens of care is at least as important for this group of patients as the initial decision to actively intervene.
- Recognize the limitations of ‘disability categorization’. For preterm infants, some disabilities that are labelled ‘minor’ in the medical literature, such as behavioural problems, may be considerably more difficult for some families to cope with than ‘severe’ disabilities, such as correctable deafness or ambulant cerebral palsy. The categorization of some impairments as major (eg, cerebral palsy) and others as minor (eg, behavioural problems) by health care practitioners has implied value judgements that may not be shared by families.

- Avoid conflating death and disability. Guidelines and ‘calculators’ for decision making tend to conflate survival and disability (2,34). Survival and disability do not have the same meaning for families. Quantifying ‘survival without disability’ to make a single dichotomous outcome helps the design of research projects, but conflating them in the clinical setting should be avoided because it sends an ambiguous and unclear message. Parents should be informed of the possibility of survival and disabilities separately.
- Mention adaptation and coping of families: The meaning of disability (and not just the risks of disabilities) and the impact on families should be included in the discussions.

## CONCLUSION

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There is no easy way to make decisions regarding life and death. However, guidelines for such decisions should at least start with accurate facts. Classifying infants according to inaccurate estimates of completed seven-day periods of GA is inappropriate because it ignores facts about the inaccuracy of GA assessments or the range of outcomes within each GA strata (21). It also sets arbitrary limits on parental participation in shared decision making by framing the decisions that are offered to them based on these inaccurate conclusions drawn from meaningless GA categories.

Information related to survival and outcomes, including quality of life, should be personalized, following an analysis of the risks for a particular infant and taking into account all of the relevant medical characteristics. A shared decision must then incorporate and be consistent with the values and desires of the parents and the best interest of their child. The limitations of the evidence should be an incentive to examine each case in a personalized fashion (35). Given our wide range of uncertainties about any baby in the first hours of life, the morally appropriate approach is to establish individualized goals of care with each family for each baby.

Finally, a position statement proposing recommendations for withholding or withdrawing life sustaining interventions should be explicit about what criteria have been used to make those recommendations. Are these criteria based on a low survival rate? If yes, what is considered to be too low a survival? Are they based on the burden of interventions? If yes, then state which interventions, and how the burden is to be evaluated and by whom? If the criteria are based on the likelihood of survival with unacceptable outcomes, then state what outcomes are considered to be worse than death, and why, and to whom?

The Canadian Paediatric Society is an important and respected body that has done much to promote the health and well-being of Canadian children, and its statements have influence around the world. Unfortunately this position statement does not reflect best practice in ethical decision making regarding very high-risk deliveries. It is based on premises that may prejudice the outcomes of extremely preterm birth and limit the scope of ethical decision making in individual cases. The authors of this commentary respectfully request that this position statement be withdrawn, or revised based on input from the wider neonatal community and from parents, and that the Canadian Paediatric Society continues to fulfill its mission to advocate for all children, including preterm infants.

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