Counselling and management for anticipated extremely preterm birth

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Abstract
Counselling couples facing the birth of an extremely preterm infant is a complex and delicate task, entailing both challenges and opportunities. This revised position statement proposes using a prognosis-based approach that takes the best estimate of gestational age into account, along with additional factors, including estimated fetal weight, receipt of antenatal corticosteroids, singleton versus multiple pregnancy, fetal status and anomalies on ultrasound and place of birth. This statement updates data on survival in Canada, long-term neurodevelopmental disability at school age and quality of life, with focus on strategies to communicate effectively with parents. It also proposes a framework for determining the prognosis-based management option(s) to present to parents when initiating the decision-making process. This statement replaces the 2012 position statement.

Keywords: ANCS, Decision making, Extremely preterm infant, NDD, QOL, SDM

BACKGROUND
Early preterm birth poses medical, social and ethical challenges and opportunities. Although extremely preterm infants have high mortality and morbidity rates compared with term infants, prognostic uncertainty exists in each individual case [1]. This uncertainty accounts, in part, for the ethical challenges associated with determining what course of action is in the best interests of a particular newborn.

Some argue that extremely preterm infants deserve the same aggressive intensive care offered to older children with comparable risks of morbidity and mortality. Every infant, situation and family is unique and decisions regarding management can vary substantially among families [11-13].

There is no universal agreement on approach and management [4]. Parents and health care professionals (HCPs) each have their own personal and professional experiences, value systems and interpretations of relevant medical data shaping moral judgments regarding best interests. HCPs rank the quality of life (QOL) of adolescents born extremely preterm lower than parents and children with related disabilities rank it themselves [5]. Recent research has put emphasis on the role of the family in decision making, how to communicate with families and the importance of sharing QOL information with parents. Also, the survival of infants born at 22 weeks gestational age (GA) has been increasingly reported in the last few years [6][7]. HCPs must remember that most births involve the opportunity for a family to welcome a child into the world with hope, even one born extremely preterm.

This position statement provides updated recommendations to help HCPs, together with families, guide management of the anticipated birth of an extremely preterm infant. Statement objectives are to: review factors to consider in the decision-making process, provide a framework for engaging parents in the decision-making process and suggest levels of care based on the estimated risks of mortality and neurodevelopmental disability (NDD). It does not address obstetrical care of the mother in detail. For present purposes, the terms ‘parent’ and ‘family’ can refer to any person or couple expecting the birth of an infant or to those whose child has been born.
Recommendations focus on infants to be born between 22\textsuperscript{6} and 25\textsuperscript{6} weeks GA. Cases exist at any GA where a devastating congenital lesion, clinical situation or family circumstance leads to the consideration of palliative care. Nationally, palliative care is accepted as the usual approach when an infant is born ≤21 weeks GA.

**METHODS**

Search strategies were conducted between 2013 and 2015, using MEDLINE, EMBASE, Cochrane Database of Systematic Reviews and CENTRAL. Search terms included: outcomes (NDD at 4 to 8 years of age and QOL) for infants born extremely preterm; antenatal corticosteroid (ANCS) use and risks of maternal morbidity related to delivering preterm; and shared decision making and communication with parents. Regarding studies related to NDD, the age range of 4 to 8 years is more predictive of long-term disability than follow-up at an earlier age [8]. To ensure sufficient breadth of expertise, national stakeholders provided input through a consultation process, which included the use of validated tools. Definitions (GA, NDD, early intensive care and palliative care) can be found in the appendix.

**CARE OF THE MOTHER AT RISK FOR EXTREMELY PRETERM BIRTH**

**Assessing GA**

Ultrasound is the most accurate method for establishing GA (aside from in vitro fertilization) [9]. First trimester crown-rump length is the most accurate for dating within 3 to 8 days [9][10]. The degree of imprecision increases with advancing GA (± 10 days at 16 to 22 weeks and ± 2 weeks at 24 weeks) [11][13]. Despite these limitations, establishing an accurate GA is crucial for counselling, management and support of the family.

**Place of care**

Rates of neonatal mortality and morbidity decrease when extremely preterm infants are born at tertiary perinatal centres rather than at nontertiary centres [14]. Transferring women at risk for extremely preterm birth to tertiary perinatal centres improves maternal care and offers opportunities for counselling by maternal–fetal medicine specialists and neonatologists. When transfer is not possible and delivery at a nontertiary centre is expected, management decisions for mother and infant need to consider availability of resources and the possible limitations of setting and local expertise when determining the infant’s prognosis.

**Antenatal corticosteroids**

Debate continues concerning the benefits of administering ANCS to mothers during pregnancies before 24 weeks GA because they were excluded from studies reported in the National Institutes of Health’s consensus statement [15]. Since then, animal data [16] and several large retrospective cohort studies have suggested that ANCS use improves survival rates for infants <24 weeks GA [17]-[20]. ANCS should be offered to women at risk for extremely preterm birth at ≥22 weeks GA when early intensive care is a management option. The timing of ANCS administration can be a challenge because the chance of delivering extremely preterm is difficult to estimate and the maximal period of efficacy for ANCS is reached within 7 days of the last dose [21]. Although some trials of repeated ANCS have suggested potential for harm to the fetus and mother, one recent systematic review showed lower risk for respiratory distress syndrome and other neonatal morbidities in infants born after mothers received one or more courses of ANCS, without evidence of harm in later childhood [22][23].

**Mode of delivery**

Three recent statements concluded that current evidence does not consistently support routine caesarean sections to improve neonatal outcome in extremely preterm births [1][24][25]. Caesarean sections at an extremely early GA carry significant risks for the mother, particularly when they involve a classical incision [26]-[31]. Parents and obstetrical HCPs should decide jointly on optimal mode of delivery by carefully weighing the potential short- and long-term risks (including that of in utero fetal demise) against benefits.

**FACTORS TO CONSIDER IN DECISION MAKING AROUND MANAGEMENT**

Many medical and nonmedical factors inform the management of extremely preterm infants. Relying on GA alone to predict outcome and generate recommendations for management is erroneous. Medical considerations include the risk estimates for infant mortality and NDD and QOL in the longer term [32]. Explaining the limitations of current data clearly and truthfully to expectant parents is necessary.

**Survival**

One systematic review of survival focused on infants weighing <1000 g or <28 weeks GA at birth [33]. Out of 51 studies, large variation in survival rates was found, particularly depending on the denominator used. Variation was also possibly caused by differences in
baseline risk, antenatal and postnatal therapies and/or approaches to withholding or withdrawing life-sustaining interventions. The last two variables depend on individual HCPs and/or variation in approved practices in a particular society [7]. Such potential for selection bias underlines the need for HCPs to understand the limitations of survival data and acknowledge them during discussions with parents.

The most relevant data for parents in Canada are population-specific (i.e., Canadian) and, ideally, based on local institution rates. Between 2010 and 2015, the units providing data to the Canadian Neonatal Network (CNN) recorded a total of 3830 live births at <26 weeks GA. Table 1 shows survival data to time of discharge from the neonatal intensive care unit (NICU) (stillbirths excluded). CNN reports data for babies born at ≤22 weeks GA as a group. Survival at <22 weeks GA is extremely rare, with four reported survivors at <22 weeks GA within the stated time frame (P. Chan, personal communication). The CNN website (www.canadianneonatalnetwork.org) provides up-to-date data.

Table 1. Survival rates in Canada in 2010 to 2015

<table>
<thead>
<tr>
<th>GA (weeks + days)</th>
<th>Number of live births (n)</th>
<th>Infants who received palliative care at birth (n, [% of live births])</th>
<th>Infants who received early intensive care at birth (n, [% of live births])</th>
<th>Delivery room deaths in newborns who received early intensive care (n, [%])</th>
<th>Survivors to NICU discharge in newborns who received early intensive care (n, [%]; 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤22 + 6</td>
<td>332</td>
<td>226 (68%)</td>
<td>106 (32%)</td>
<td>56 (53%)</td>
<td>19 (18%; 11, 25%)</td>
</tr>
<tr>
<td>23 + 0–23 + 6</td>
<td>723</td>
<td>196 (27%)</td>
<td>527 (73%)</td>
<td>82 (16%)</td>
<td>218 (41%; 37, 45%)</td>
</tr>
<tr>
<td>24 + 0–24 + 6</td>
<td>1200</td>
<td>68 (6%)</td>
<td>1132 (94%)</td>
<td>26 (2%)</td>
<td>753 (67%; 64, 70%)</td>
</tr>
<tr>
<td>25 + 0–25 + 6</td>
<td>1575</td>
<td>24 (1.5%)</td>
<td>1551 (98.5%)</td>
<td>66 (4%)</td>
<td>1225 (79%; 78, 80%)</td>
</tr>
</tbody>
</table>

CI Confidence interval; GA Gestational age; NICU Neonatal intensive care unit

**Neurodevelopmental disability at school age**

One recent systematic review and meta-analysis included nine high quality cohorts [34]. Table 2 summarizes the findings. While there was no statistically significant difference in the risk for severe NDD by week of GA, there was a statistically significant reduction of 6% in the risk of moderate-to-severe NDD with each increasing week of GA. The most commonly observed condition is cognitive impairment, followed by cerebral palsy. Vision and hearing deficits occur less frequently.
The limitations of these data must be understood by HCPs and parents. They include: small sample sizes with wide confidence intervals at 22 and 23 weeks GA, an unknown number of children with one versus multiple impairments, variation in the definition and labelling of NDD by HCPs (especially ‘severe’ versus ‘moderate’) that may not reflect parents’ views or reality, no information on mild or other types of impairment (e.g., behavioural) and the lack of correlation between degree of NDD and QOL [5]. One example demonstrates such limitations clearly: A child with severe cognitive impairment and severe cerebral palsy and a child with isolated uncorrectable deafness would both be classified as having severe NDD.

**Health status and QOL**
A systematic review performed in 2013 assessed the self-reported QOL of adolescents and adults who were extremely low birth weight (ELBW) or very low birth weight (VLBW) infants [9][35][40]. Nearly all studies showed no significant difference in self-rated QOL scores for former ELBW/VLBW infants compared with full-term counterparts. Both groups rated their QOL as good. However, using self-reported data prevented severely disabled individuals from participating in some studies. Two additional limitations are that no studies focused solely on infants born at 22 to 25 weeks GA and the data drawn from VLBW/ELBW infants born in the 1970 to 1995 time period are probably inapplicable to babies born today [41]. One study providing a breakdown by GA found no significant difference in QOL scores among adolescents born at 23 to 27 weeks GA [40]. While the broad results suggest that most former VLBW/ELBW infants rate their QOL as ‘good’ in adolescence/young adulthood, the individual QOL measures vary considerably.

**Parental QOL**
A systematic review performed in 2013 used different reporting time frames and tools to evaluate QOL in the caregivers of children born VLBW or ELBW [42][53]. The time frames ranged from 1 to 25 years after delivery, with mothers completing the vast majority of evaluations. Most studies reported increased levels of parent stress and a negative impact on family functioning and finances for parents of children born as VLBW/ELBW infants compared with parents of children born at term. Some effects did improve over time. One study [47] following these children into early adulthood found that parents felt that their experience improved family bonds, enhanced parental self-perception and improved their parenting abilities. The effects of having a VLBW/ELBW infant on divorce rate are equivocal. Despite finding an overall negative impact compared with term controls, many parents of these children did not report distress or an additional burden of care. Overall, the QOL of parents appears to be highly individualized and dependent on specific family situations and characteristics.

**Prognostic uncertainty**
Although survival rates are improving and the chances of surviving without moderate-to-severe NDD increase with each incremental week of GA, such benefits can be off-set by other prognostic factors. These variables include: birth weight (in 100 g increments), singleton (versus multiple) birth, the provision of ANCS therapy,
and gender (with male infants disadvantaged) [54][55]. Each of these factors can alter outcome by as much as an additional week of gestation.

One Canadian graphic tool uses a combination of birth weight and GA to predict survival, without short-term morbidity, to hospital discharge [56]. Other prognostic factors include the number of days into the week of gestation (e.g., 23¹ versus 23⁶) [57] and birth outside a tertiary perinatal centre. Finally, the clinical course of the extremely preterm infant in the NICU also influences long-term outcomes. Intracranial bleeding, periventricular leukomalacia, retinopathy of prematurity, bronchopulmonary dysplasia, sepsis, days on mechanical ventilation and nutrition (feeding human milk) appear to influence outcomes [58][62]. Other clinical diagnoses, parental socioeconomic status and post-discharge interventions can also influence outcomes but a detailed review of such factors is beyond the scope of this statement.

ANTENATAL COUNSELLING AND DECISION MAKING

Communicating with parents

Parents facing the birth of an extremely preterm infant should, ideally, have several opportunities to meet with HCPs to share information and consider a care plan, particularly as pregnancy progresses or new information becomes available. Many parents report feeling distressed, disempowered and grief-stricken when faced with the possibility of delivering extremely preterm [63]. Qualitative studies report a degree of ‘disconnect’ between the information HCPs provide and what parents recall [64][65].

Providing written information improves parental understanding and recall [66]. Consistency and accuracy in provided information is crucial for expectant parents. Communication between obstetrical and neonatal teams concerning consultations, along with clear documentation of the joint plan in the mother’s medical chart, promotes consistency and adherence to the plan [24]. Communicating with parents about periviability, potential outcomes and difficult decisions requires specialized training [67][69]; trainees must demonstrate expert competence before performing consultations without supervision. Involving trained peer counsellors may provide further support to parents.

Shared decision making

Shared decision making (SDM) is the best approach for preference-sensitive decisions, which include those made when no clear evidence supports one treatment over another, options have different inherent benefits/risks, or parental values are involved. SDM can mitigate parental grief around end-of-life decisions, enhance knowledge of and satisfaction with care, aid decision making that is consistent with parental values and foster collaboration with medical teams [70]-[73].

Key steps in the SDM process include: identifying the decision to be made (choice talk), reviewing the options (option talk), and providing support for deciding what matters most to the parents (decision talk) [74]. The HCP’s expertise lies in recognizing major biological and medical factors influencing survival and long-term prognosis, while the family knows most about the socioenvironmental and familial characteristics that will influence their infant’s outcomes (e.g., finances, resource availability, support from extended family). Such characteristics are difficult to measure but must all be considered in the SDM process.

Most parents wish for an SDM ‘model’ during antenatal consultations, a practice strongly recommended in the perinatal setting [63][75][76]. Some parents prefer a more directive approach or recommendation. The approach with each family should be individualized and based on their expressed needs and wishes. Formal training in SDM helps HCPs to optimize parental engagement in an informed decision-making process [65]. The parents’ expectations regarding their own role in decision making can never be assumed. Some parents are reluctant to carry the burden of decision making, while others want to be involved but do not know how [77].

Decision aids for parents facing imminent preterm birth have been developed [78][79]. Decision ‘coaching’, where a trained HCP provides parents with individualized, nondirective guidance, is often used in conjunction with other decision aids to facilitate SDM [80][81]. Table 3 lists strategies for communicating effectively with parents, engaging parents in decision making, clarifying their values and preferences and guiding the prenatal consultation [64][62][68]. SDM is the goal but may not always be possible due to clinical circumstances (e.g., a rapidly progressing labour, or when narcotics or a prescribed medication heavily alter a mother’s level of consciousness).
<table>
<thead>
<tr>
<th>Consultation phases</th>
<th>Key points</th>
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| To prepare for consultation                                  | • Speak with the mother’s HCP, obtain all relevant information regarding maternal and fetal health  
  • Ensure use of interpretive services by a professional translator, if required                                                                 |
| Creation of a comfortable environment                        | • Make sure to talk with both parents, if feasible  
  • Make sure the consult is not disturbed (e.g., turn pager to vibrate, close the door or curtains, let the nurse know)  
  • Sit down, shake hands (if appropriate) and introduce yourself first, slowly and clearly  
  • Demonstrate openness to communication with and involvement of parents  
  • Ask about participants (e.g., use names, including the infant’s name, if known, and if parents agree you can use it)                                                                 |
| Assess parental knowledge of prematurity issues, along with perspectives, concerns, expectations, needs and preferences | • Ask what they know about prematurity  
  • Make sure you understand and acknowledge their values, perspectives and concerns (e.g., cultural/social background, religious beliefs, family structure)  
  • Adjust ways of communicating information to respect their values and preferences  
  • Support their involvement in decision making with inclusive wording (e.g., ‘How can I support you?’; ‘We can make this decision together’) |
| During consultation                                           | • Typically, parents want to know about likelihood of survival, risk of NDD (with related challenges and opportunities), what medical problems might be encountered, possible treatments, what a preterm baby looks like, what it is like to be in the NICU, what happens after birth, how to manage breastfeeding, and their own role in the NICU (with explanations) |
| Ensure factors that are important to parents are discussed (e.g., Ask what is important to them) | • Present parents with the choices they need to make, clearly and accurately  
  • Offer appropriate management options based on the clinical situation                                                                                                  |
| Discuss different choices or options                          | • Include both positive and negative aspects of care, pros and cons of the options, treatable and untreatable conditions  
  • Disclose potential outcomes according to parental preferences:  
    – Use grading words (majority, most, significant, some, a minority) and numbers when possible (6 out of 10, rather than 60%) |

Table 3. Strategies to facilitate communication with expectant parents during a prenatal consultation (to reorder and adapt as needed)
Use a consistent denominator when presenting different options, outcomes or event rates, to make the information easier to understand, interpret or compare (XX out of 10, 100 or 1000). For example, saying ‘Out of 100 babies, 20 will die, 20 will survive with NDD, and 60 will survive with no NDD,’ is better than saying 20 out of 100 for one outcome, then 1 out of 5 for another. Disclose uncertainty (i.e., the limits of statistics when applied to a particular baby).

### Additional strategies to build trust

- Allow parents to lead the conversation:
  - Use their verbal, nonverbal cues to pace discussion
  - Ask how you can support them
  - Invite them to share how they see the situation
  - Use open-ended questions (‘How…?’; ‘Could you tell me more?’, ‘Can you describe…?’)
  - Always ask whether parents have questions or need clarification
- Listen for concerns and emotions, and be empathetic and supportive:
  - Validate the difficulty of their situation
  - Use a soft voice, allow silences, use appropriate touch
  - Acknowledge and be sensitive to emotional reactions and concerns
  - Support parental needs and values
- Answer questions and be sure parents have received and understand the information to the extent they want to
- Maintain eye contact with both parents
- Offer time to think and reflect
- Avoid interrupting. Be quiet as parents describe perspectives, values or preferences

**Note:** Obtaining informed consent for a management plan requires—at a minimum—sharing accurate information tailored to the parents’ needs regarding the risk of death and NDD, and the opportunity of having a surviving child with or without NDD.

### Show compassion and acknowledge parental distress

- Reassure parents that they did not do anything to cause preterm birth
- Confirm the uniqueness of their family and of the unborn baby
- Acknowledge their baby as a being, not a GA
- Provide value-neutral information (i.e., by including the positives of having an infant they can love and cherish)
- Be honest

### Concluding the consultation

- Provide support and give parents realistic hope
  - Validate their situation as very difficult and their reactions as understandable
  - Tell them that every hour, day and week that the pregnancy continues (with baby and mom in stable condition) has positive effects
• Make sure they know that they are not alone
• Make sure they understand that you are there to provide more information and answer new questions
• Invite them to write their questions down as they think of them, for next time
• Meet with parents the following day, if possible, or at any time after the initial consultation

*Adapted with permission from ref. [89]

HCP Health care professional; NDD neurodevelopmental disability; NICUNeonatal intensive care unit

MANAGEMENT DECISIONS, INCLUDING ETHICAL CONSIDERATIONS

Depending on an infant’s prognosis, HCPs usually present parents with one or two broad management options during a prenatal consultation: early intensive care (with ongoing re-evaluation) and/or palliative care. Prognosis is based on all available information at the time of consultation and helps determine what management options are proposed.

When the HCP determines that both early intensive and palliative care are options, parents should be engaged in SDM and their decisions regarding appropriate care for their infant supported. When there is a typical approach to care, present it to parents together with the reasons why other options may (or may not) apply to their particular circumstances. Throughout the process, parents should be encouraged to express their thoughts and opinions. Listen, be sure that parents understand the information provided, and seek consent to proceed. Ideally, the decision-making process occurs over time, with HCPs and parents able to acknowledge, articulate and manage varying degrees of prognostic uncertainty.

Some difficult clinical issues have no universal answers, which is why parental involvement, ethics-based discussion and personal reflection are such important aspects of care. What factors initially determine whether to offer parents both early intensive or palliative care options or recommend one option over another? What outcomes are relevant to this decision? What predicted likelihood of death justifies the noninitiation of intensive care? What severity and/or predicted likelihood of NDD could justify noninitiation of intensive care? What predicted likelihood of survival justifies over-ruling a family’s request for palliative care? Clearly, these and other difficult questions exist in many cases. The clinical picture, HCP experience and parental involvement all inform the decision-making process, and Table 4 suggests a framework for key deliberations.
A lower limit where palliative care will be recommended by HCPs is typical practice, just as there is an upper limit where they will recommend early intensive care. A parent may disagree with the option that is recommended. Given the lack of a moral authority regarding standard of care in this complex area, a ‘non-recommended’ option is sometimes instituted after further informed discussion, time to think and conflict resolution [32][87]. There are also cases where parents and HCPs cannot reach consensus about an infant’s care management. While HCPs are responsible for exploring management options with parents, this obligation does not necessarily extend to offering treatments that are clearly outside the usual local level of care. In such situations, consider seeking a second opinion from a colleague and/or support from an ethics consultation, or applying for an institutional board review to determine the infant’s and family’s best interests.

When extremely preterm infants are born outside of a tertiary care centre, consultation via phone or video with a neonatologist can help to focus management options and care planning based on setting, resources and local expertise.

When the care plan is uncertain or when the plan is to provide early intensive care, a neonatal team capable of caring for the infant and facilitating management decisions should be present at the birth. After the birth of an extremely preterm infant, there are often several opportunities to learn more about the infant’s prognosis and to re-evaluate care plans. The provision of palliative care (chosen before or after birth) mandates the presence of HCPs who can oversee individualized comfort measures, including keeping the infant warm and minimizing discomfort and pain. Give parents opportunities to hold and spend as much time with their infant as desired. Also, be sure they are
aware of the possibility that their infant may survive despite noninitiation or discontinuation of life-sustaining therapies, although such cases are extremely rare. Comfort measures are essential for any dying infant, and bereavement care and options to create memories (e.g., footprints, handprints, photographs) should always be provided for parents in such situations.

**RECOMMENDATIONS**

The quality of evidence reviewed for this statement is nearly all low or very low, such that almost all recommendations stem from expert opinion and consensus [88]. With the exception of research on ANCS, the literature provides relatively indirect evidence to support recommendations. Recommendations have not been graded for evidence. Difficult, preference-sensitive and value-based decisions are often made in this area of care.

- When a pregnant woman is at risk of giving birth between 22⁰ and 25⁶ weeks GA, the primary HCP should consult with a maternal–fetal medicine specialist. Transfer to a tertiary perinatal centre is recommended.

- Parents facing the birth of an extremely preterm infant should have the opportunity for face-to-face discussions with their obstetrical HCP as well as a consultation with a neonatologist or paediatrician. When circumstances permit, parents should be able to meet with these HCPs on more than one occasion.

- Parents must receive individualized, accurate information about their infant’s anticipated likelihood of survival and potential long-term outcomes. For each case, the HCP must explain the degree of prognostic uncertainty and the limitation of data.

- When both early intensive care and palliative care are considered to be equal care options, the management plan should be decided upon after engaging in a SDM process with parents. The SDM process should be ongoing as the pregnancy continues.

- HCPs should consider using a decision aid, decision coaching and parent information handouts to facilitate parental involvement and understanding throughout the SDM process.

- The maternal–fetal medicine specialist, neonatologist, nurse caring for the mother and other HCPs involved in the circle of care, must communicate directly with each other and with parents to ensure clear understanding of the management plan, avoid conflicting information and enhance care. Ideally, such conversations should take place at the bedside to allow all pertinent information to inform the decision-making process. The plan must be clearly documented and revised if the plan changes.

- ANCS should be given between 22⁰ and 25⁶ weeks GA when early intensive care is a management option and, in the opinion of the obstetrical HCP, the risk of extremely preterm birth is high.

- The HCP and team most capable of managing an extremely preterm infant should attend delivery, regardless of the management plan chosen.

- When prenatal maternal transfer is not possible, the HCP at the referring centre should initiate a consultation with a neonatologist (by phone or via telemedicine) to review management options and receive guidance about the decision-making process with the parents. Early intensive care or palliative care should be offered, based on estimation of prognosis and the resources available. The management plan should be finalized after discussion between HCP at the referring centre and parents.

- When an extremely preterm infant is born but no decision has been reached regarding the management plan (e.g., circumstances prevented SDM antenatally or parents could not yet decide), the infant should usually receive early intensive care until SDM or further discussion with the parents can occur. This recommendation does not apply for infants considered extremely likely to die or to experience severe NDD, or when the setting, resources (including personnel) or local expertise do not allow for the adequate provision of early intensive care.

- All extremely preterm infants who do not receive early intensive care, or for whom early intensive care is not successful, must receive compassionate palliative care, including warmth and pain relief.

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Appendix

Definitions

Gestational age
This statement uses the definition of GA from the WHO’s International Classification of Diseases, 10th revision, as days and weeks completed since the first day of the last menstrual period. Thus, “22 weeks” refers to the period between 22 weeks 0 days (22°) and 22 weeks 6 days (22°). An extremely preterm birth refers to one occurring between 22 weeks 0 days (22°) and 25 weeks 6 days (25°).

Neurodevelopmental disability
This statement uses definitions of NDD that are consistent with those used in the landmark EPICure cohort report. Though definitely not all-encompassing, they represent the main disabilities perceived by HCPs and parents as creating lifelong, potentially difficult challenges for children and families [8][90][91]. Severe NDD renders a child highly dependent on caregivers and includes one or more of the following conditions: severe cerebral palsy (unable to walk or able to walk short distances with a walker); severe cognitive deficit (>3 standard deviations below the mean on a

standardized intelligence test, leading to major challenges with learning, communication or interpersonal relationships); blindness or severely impaired vision; or profound hearing loss that cannot be corrected. Moderate NDD implies that a child is likely able to achieve some measure of independence, and includes one or more of the following conditions: moderate cerebral palsy (difficulty with walking or another part of movement); moderate cognitive impairment (2 to 3 standard deviations below the mean on a standardized intelligence test, leading to some challenges with learning, communication or interpersonal relationships); impaired vision without blindness; or correctable hearing loss. Moderate-to-severe NDD includes one or more of the disabilities described above.

Early intensive care
Usually, early intensive care aims at achieving infant survival, though it can also offer time (a ‘trial’ of intensive care) to assess, in consultation with parents, the most appropriate course for surviving infants. Early intensive care may be synonymous with resuscitation and involve life-sustaining interventions, such as positive pressure ventilation (including continuous positive airway pressure), intubation and ventilation, chest compressions, or administering intravenous fluids and epinephrine.

Palliative or comfort care
Palliative or comfort care aims at achieving comfort but not curing. This form of care includes drying, swaddling, cuddling and skin-to-skin contact with the infant, and may include giving oral sucrose, medications to sedate or manage pain, oral fluids or milk. Extremely preterm infants receiving comfort care will die within minutes to days of birth.

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