

APPENDIX B: Script for use by decision coach

(Modified by Dr. Gregory Moore (MD, FRCPC) and Ms. Sharon Ding (BSc (c)) with permission from: Guillen *et al.* *J Pediatr* 2012;160:382-7. Dr. G. Moore is a neonatologist practicing at The Ottawa Hospital and the Children's Hospital of Eastern Ontario (Ottawa, ON, Canada) and routinely cares for extremely premature infants; Ms. S. Ding is a student employee at the Children's Hospital of Eastern Ontario Research Institute. Both Dr. G. Moore and Ms. S. Ding were the primary developers of the modified decision aid as well.)

Decision Aid User Guide:

- This is a sample script to provide information – of course it is expected that the user will need to alter the delivery of the consultation to better suit the situation of the patient and current circumstances. This script is by no means a standardized method of consultation; it is meant to be used only as a helpful reference.
- The script can be used with mothers facing premature delivery at 22-25 weeks GA
- Decision coaches may wish to use a flat surface or table during the decision coaching session. This may make it easier to present the cards to the patient. It may also facilitate placing certain cards side-by-side or in groups, if you so choose. Alternatively, provide the parents with a set of their own cards to use during the decision coaching sessions.
- The decision coach will be a healthcare provider trained to help the parents make the best decision for their infant. The decision coach should engage in a SDM process with the parents and exchange information about the risks and benefits of each option, clarify the values and preferences of the family, and consider the feasibility of each option under discussion. By using decision coaching with the decision aid, one should be able to ‘walk’ the parent(s) through the decision making process. (*See Section 6.0 of the Guideline for further details about the SDM process.*)

Introduction:

- I'm here to speak with you about extremely premature infants and the options you have in terms of care plans for your baby. My goal is to work with you to make the best possible care plan for your baby if it is born extremely prematurely. It will be important to talk about what is meaningful to you and what you value.
- I'm sorry to have to meet you in these difficult circumstances. There is **nothing you did to cause this situation** – it is not your fault – and I hope your pregnancy is able to continue.

- If anything is unclear or if you have a question anytime during our conversation today, you are always welcome to ask me to explain again or clarify.
- I might know better when it comes to medicine, but you know best for your own family and your own values, priorities and opinions. Our goal today is for me to give you information and for you to put that together with your knowledge of yourself/selves to make the decision that fits *you*.
- I am here so that we can make this decision together, but it is important to me that you understand this information, so you can make a decision that matches your preferences, beliefs and values.
- Have you had any previous experience with pre-term babies? May I ask about your current social and living situation?
- To help us in our discussion today, I will be using a decision aid. It's actually a deck of cards, with words, numbers, pictures and diagrams that will illustrate a lot of the things we will be talking about. I hope that our decision aid will make it easier for you to understand and remember the information I show you today.
- As you probably know, babies are usually born after 37-40 weeks gestation.
- This means that you are only a little past the half-way point in your pregnancy.
- Therefore your baby is very small and very fragile. Your baby is about the size of _____ (*i.e. 4 sticks of butter (~450g)*) and is only a little longer than the palm of your hand
- You can imagine then that from head to toe, your baby is fragile and your baby's organs are not ready to do their job. *Provide examples, such as:*
 - a. The lungs aren't ready to breathe in oxygen
 - b. The heart may not be ready to pump oxygen to the body
 - c. The brain isn't ready to coordinate all of the functions in the body
 - d. The skin is not ready to protect the body

Slide #1: Comparison Card

- From the top of this card, you can see that there are 2 broad options regarding the care of your baby if it is born extremely prematurely – palliative care or early intensive care. Do you know, generally speaking, what these two options mean? On the side of this card are different areas of information that can help parents decide which option is best for them and their baby. What would you like to hear about to start: one of the areas of information or one of the options regarding the care of your baby if it is born extremely prematurely?
- *Note: Health care provider can then repeatedly return to this card to allow the parent(s) to decide on what area of information or care option they'd like to discuss next.*

Slide: Early Intensive Care

There are some photographs on this card that you may find uncomfortable or difficult to look at. You do not have to look if you do not want to, and you are also free to ask me to stop at any time. All these photographs are real and have been donated by other parents to help parent(s) like you with your decision.

Pictures #1 & #3

- Some parents will choose early intensive care, or in other words, choose to have us be present in the delivery room and attempt to provide medical support to their baby.
- This is a picture of a baby born extremely prematurely, at about 24 weeks gestation, who has received early intensive care [*Extra details: gestation – 24+1 weeks, birth weight – 630g*].

Picture #2 (diagram)

- When your baby is born, that means that he/she may need a lot of help from the doctors/nurses. This is what we call “early intensive care” or “active resuscitation”.
 - a. That means he/she will get help breathing with a mask and/or a breathing tube and machine.
 - b. He/she may need to get medicine to get the heart started
 - c. He/she may need to have their chest pushed (chest compressions) to get the heart started
 - d. He/she will be surrounded by many machines and many people and it can be very scary
- Resuscitating can mean one or more of these things: (*point to terms at bottom of card & explain them briefly as needed*) How many of these will be necessary depends on the condition of your baby – sometimes if one of these doesn’t work, we will have to try more of these until we find one that works. Some parents may also choose the ones they’d like for us to try; it is up to you whether you want to make this choice. Otherwise, we will usually try each method that is available to us.
- Because these babies are so fragile, this means that even when we try early intensive care, not every baby will survive. But without early intensive care (and then further intensive care), none will survive.
- Early intensive care involves some procedures that cause some pain, whereas none of these procedures are used during palliative care. In both cases, we try to minimize any pain, but there is certainly the potential for much more pain if early intensive care is attempted and then followed with further intensive care. For example: (*provide examples of painful interventions – needles, IVs, ETTs, NGs, etc...*)
- If you choose early intensive care and your baby survives, your baby will likely be in the hospital for months. Some extremely premature infants will have continued medical care/support throughout their entire lives.
- Tending to an extremely premature baby from a parent and family’s perspective has its own challenges. We have many resources and supports to help you with any difficulties or questions you may have.

Slide: Palliative Care

There are some photographs on this card that you may find uncomfortable or difficult to look at. You do not have to look if you do not want to, and you are also free to ask me to stop at any time. All these photographs are real and have been donated by other parents to help parent(s) like you with your decision.

Picture #1

- Some parents choose palliative care, which allows their baby to have a natural death.
- This is what will naturally happen to very premature babies if we do not try early intensive care.
- This is a picture of a baby born extremely prematurely, at about 23 weeks gestation, who has received palliative care after a brief attempt at resuscitation. *[Extra details: gestation – 23+3 weeks, birth weight – 343g, no response to about 5 minutes of resuscitation prior to palliative care]*
- The baby may cry or breathe immediately after birth, but this is not always the case. Some babies will move their limbs while others will not. The baby's colour may be pinkish or grayish soon after birth and then turn paler and bluish.

Pictures #2 & #3

- In this case, the doctors/nurses will be present in the delivery room to provide comfort to the baby and avoid any interventions that may cause pain or suffering. You will be able to have and hold your baby right away. To make sure your baby is comfortable, we can: put him/her in warm blankets, give small amounts of sugar water into his/her mouth, give additional pain-relieving medication if required, etc ... You can stay in the room with the baby for as long as you'd like and can come and go as needed.
- With palliative care, we expect that your baby will live for several hours or less, but we can't predict with 100% certainty. Having a baby of this age surviving beyond 12 hours is very unlikely. You can usually stay with your baby for as long as you'd like.
- We offer resources and supports to parents and families who have chosen palliative care in order to help them with any difficulties and answer their questions.

Slide: Comparison Chart ('Final' time)

- To help be certain you understand these two options, let's re-visit the chart summarizing and comparing some of the key information about early intensive care and palliative care.
 - Your baby has a chance to survive with early intensive care, but will definitely die if you choose palliative care.
 - If your baby survives after early intensive care and further intensive care, he/she is at risk for long-term disability. We say that disabilities are likely, but remember that disability can range anywhere from mild to major. Long-term disabilities are not possible for palliative care since your baby will not survive.
 - Your quality of life may be changed regardless of your decision; the effect on parents is variable. If your baby survives, he/she is likely to rate his/her quality of life quite well, but this is variable.
 - The mother's risk of healthcare problems in the long term or her risk of dying are not affected by the choice between palliative care or early intensive care should a live baby be born.
- In medicine we have a number of jobs. Two are: 1) to help you live as long as possible and; 2) to help you be as comfortable as possible. Unfortunately these two things don't always go together.
- There is no wrong choice. There is only the choice that is right for you, your baby and your family. Both early intensive care and palliative care are good and valid choices in this difficult situation.
- I want you to remember that there are also other options. Early intensive care and palliative care are just the 2 broad options. Feel free to ask me questions about ways we can personalize these options for you.
- Unfortunately, we cannot be 100% certain of what will happen as every baby, family and situation is different.

Slide: Quality of Life

- The quality of life of both the babies born very prematurely and the parents of these surviving children tend to vary with the situation and family.
- You can expect that there will be changes in your lifestyle and family function that comes not only from being a parent, but also from being the caregiver of a baby born extremely prematurely.
- Whether these changes affect you positively or negatively will depend on your circumstances and how you deal with these changes.
- For the child or teenager who was born extremely prematurely, there are some things to consider:
 - What are the effects of ongoing medical problems due to being born very prematurely?
 - How do they think they are affected by limits in their ability to perform everyday tasks?
- Some things to consider for the parent or caregiver of a child or teenager who was born extremely prematurely are:
 - How is their emotional health?
 - What sort of stress do they experience?
 - What happens to the family and marital bonds?
 - How much confidence do they have in their own parenting abilities?
- Would you be interested in talking more about any of these points (*point to bullets on card*)? We can discuss any that you would like to learn more about in further detail (*see Guideline for additional information as needed*).
- We encourage you to seek any support you need from us and from the social work team

Slide: Maternal impact - survival and long-term health problems

- Choosing either palliative care or early intensive care for your baby will not, in itself, have any direct impact on your chance of surviving or having long-term health problems
- Overall, the chance of a mother dying in any pregnancy is remote but the medical problems that lead to extremely premature births can affect a mother's health. *For example: pre-eclampsia can damage a woman's kidneys and brain.* Deciding to delay delivery in these situations creates the risk of the mother becoming progressively sicker and damaging parts of her body or even dying. We may recommend delivery the baby, no matter how extremely premature he/she is, in these situations.
- Now, decisions about the mode of delivery (meaning vaginal birth or C-section) can directly influence a mother's long term wellbeing. There is data to suggest that C-sections at extremely premature gestations can put a mother's future health and fertility at risk. This is due mostly to the fact that a certain type of C-section called a 'classical C-section' may have to be performed. This type of C-section may make it harder to get pregnant again. This is important because some extremely premature babies do not survive and subsequent difficulty getting pregnant would be distressing. Classical C-sections have a scar that is weaker and has an increased risk of rupturing in a future pregnancy. Some of these ruptures will occur before labour, with catastrophic effects. Elective C-sections are recommended in all future pregnancies after this type of C-section, and the surgery may be more challenging than usual. Every subsequent pregnancy would require more surgery.
- The data on the best mode of delivery for an extremely premature infant is limited and unclear. In 2014, two separate national advisory bodies stated that for extremely premature deliveries, "the present evidence suggests that caesarean delivery cannot be routinely recommended (UK, RCOG)" and "currently available data do not consistently support routine caesarean delivery to improve perinatal mortality (USA, SMFM AAP ACOG). The maternal-fetal medicine team needs to discuss with you whether there are potential benefits of a C-section for your baby and if so, whether they outweigh the potential risks to you.
- Just as parents can choose different levels of resuscitation for their extremely premature newborn, they can choose different levels of obstetric intervention. Active obstetric intervention would include the use of C-section. Passive obstetric intervention would focus on interventions known to optimise the newborn's condition after a vaginal birth, (such as steroids for lung maturity or leaving the membranes intact throughout labour) but would not include delivery by C-section. Passive obstetric intervention can be chosen along with neonatal resuscitation and early intensive care.
- To summarize, the choice of palliative care or early intensive care for your baby will not directly impact your health or chance of survival. However, choosing active obstetric intervention could impact your health, as it may result in you delivering by a classical C-section that carries additional long-term maternal risks.

Slide: Things that affect survival and the risk of disability (use when discussing GA specific survival and disability rates)

- There are some things that may either improve or worsen your baby's situation. Compared to the average expected survival or disability rates, here are just a few things that can improve or worsen survival or the risk of disability.
 - We know that the further along in pregnancy that you are, the better the chances the baby will survive and not have long-term disability. Every day helps.
 - We know that babies who are bigger/heavier for their gestational age do better than babies who are smaller/lighter for their gestational age.
 - We know that when moms receive 2 doses of steroids 12 hours prior to the delivery, their babies do better than when moms have not been given steroids (*institution dependent – your institution may not provide steroids to parents <24 weeks gestation*). Though having both doses is likely most helpful, having any amount of steroids prior to the delivery may help.
 - We don't know why, but we know that girls do better than boys.
 - We know that babies who are singletons do better than babies who are born as multiples.
 - There are also things that we can see in an ultrasound, like missing amniotic fluid for weeks, that may help us to predict your baby's chances.
 - Furthermore, some clinical things, like an infection in the mom's uterus, may also change the situation.
- *For the higher weight (every 100 g), steroids given, female gender and singleton status, they reduce the risk of death or disability by the equivalent of about 1 week worth gestation.*
- These are some things to consider, but are by no means the only things we should consider; however, just because your baby has all the positive things or all the negative things does not mean that he/she will/will not survive or will/will not be disabled. Every baby is different.
- Please remember that all these numbers we are talking about are 'estimates'. For your baby, either he/she will or won't survive and either he/she will or won't have a long term disability. We can't predict this; we can only estimate the chance of survival and risk of disability.

Slide: Survival – 22 weeks

Front:

- Here are 100 babies. These are the babies who were given early intensive care at less than or equal to 22 weeks. On average, at your 22 weeks gestation, 19 out of 100 babies will live – that's the babies in red; 81 out of 100 will die – that's the babies in white.
- But, these aren't exact numbers. It's our best estimate, but as you can see here (*point to 'range'*) the survival could be as low as 11 out of 100 or as high as 29 out of 100.
- [*If parents want further understanding of the estimates, the following can be discussed:* we use something called a 95% confidence interval or CI to tell you the accuracy of our estimate: This means that we are 95% sure, or confident, that your baby's chance of survival is in this interval or range. (Another way to think about it is that 95 out of 100 babies will have survival chances in this interval, and the remaining 5 out of 100 will have survival chances outside of this interval.) For this card and your GA, the 95% CI runs from 11 out of 100 to 29 out of 100 babies surviving.]
- As you can tell from these numbers, the accuracy of our estimates is definitely not perfect.
- Remember that this number is an estimate of what might happen if we looked at 100 babies. We saw that 13 out of 70 babies given early intensive care *actually* survived in the past. We cannot be certain that this will happen every time.
- These numbers are from the Canadian Neonatal Network and the years 2010-2013.

Back:

- Here in Ottawa, from 2010-2014, we had very few attempts at early intensive care for babies born at less than or equal to 22 weeks and of these attempts, no babies survived. Therefore, we cannot tell you the true chance of survival for these babies in Ottawa.

Slide: Disability – 22 weeks

- If your baby survives to go home, he/she may have some problems later on.
- These problems or disabilities can be major or possibly major, or there may be mild or no problems.

Pictograph #1

- Here again are the 100 surviving babies at 4 to 8 years of age. On this card are the major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 22 weeks and survive.
- On average, 25 out of 100 surviving babies will have a major disability at 4 to 8 years of age, shown in red. As with the survival numbers, you can see that there isn't an exact number (*point out 'range'*). The babies in white, which is 75 out of 100 surviving babies, will have no disability, a mild disability, or a possibly major disability.

Pictograph #2

- Here are the same 100 surviving babies. This time we will add the babies with possibly major disabilities to the ones we saw with the major disabilities. These are the possibly major to

major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 22 weeks and survive.

- On average, 42 out of 100 surviving babies at 4 to 8 years of age will have a possibly major to major disability, shown in red. You can see again that there isn't an exact number (*point out 'range'*). The babies in white, which is 58 out of 100 surviving babies, will have either mild or no disability.
- Remember that this is what we think might happen in 100 babies based on what we saw with **only 12** babies.

Slide: Major Disability “Breakdown” – 22 weeks

Breakdown Overview

- When doctors talk about long term “problems” or “disabilities” in children who were born extremely prematurely, they are usually referring to 4 specific problems:
 - Cognitive Delay – this means how is your child able to learn, think, talk (*give examples if you wish*)
 - Cerebral Palsy – this is the name we give when there is a problem with the way the brain tells the nerves that tell the muscles how to move. It can be as mild as problems with fine motor skills such as writing, or as severe as not being able to walk or move properly
 - Vision Impairment – the ability to see
 - Hearing Impairment – the ability to hear
- We can categorize these 4 disabilities individually as major or possibly major to major. (*show the titles of the 2 cards*)

[Note for healthcare providers: “major disabilities” refers to severe neurodevelopmental impairments, defined as follows:

Severe Definitions

- A severe cognitive delay means an IQ greater than 3 standard deviations below the average. For these children, it means they will require highly specialized schooling in order to achieve basic communication and self-care.*
- Severe cerebral palsy usually means the inability to walk. For these children, it means they usually require a wheelchair for transportation.*
- Severe vision impairment means no useful vision. For these children, it means they are blind.*
- Severe hearing impairment means deafness that cannot be corrected, with hearing aids, for example. For these children, it means they are deaf.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the major disabilities with the patient, as discussed in the above definitions. **)*

Major Disability Breakdown

- These are the major disability rates of 4 to 8 year old children who were born extremely prematurely at 22 weeks.

- For cognitive delay only: Out of the 10 surviving babies born at 22 weeks that we looked at, only one had major cognitive delay. Keep in mind that this is just what we saw in those 10 babies, and 10 is a very small number of babies.
- For vision impairment only: Out of the 9 surviving babies born at 22 weeks that we looked at, only one had major vision impairment. Again, keep in mind that this is just what we saw in those 9 babies and 9 is a very small number of babies.
- For cerebral palsy and hearing impairment only: Out of the 9 surviving babies born at 22 weeks that we looked at, none had major cerebral palsy/a major hearing impairment. This does not mean that the chance is zero for all babies, and it certainly is NOT zero. This is just what we saw in those 9 babies, and 9 is a very small number of babies.

Slide: Possibly Major to Major Disability “Breakdown” – 22 weeks

[Note for healthcare providers: “possibly major to major disabilities” refers to moderate-to-severe neurodevelopmental impairments, with “moderate” defined as follows:

Moderate Definitions

- *A moderate cognitive delay means an IQ 2-3 standard deviations below the average. For these children, it means they have serious school challenges (e.g. unlikely to finish high school), and/or may have to repeat years.*
- *Moderate cerebral palsy means difficulty with movement and walking. For these children, it means they usually walk with a support aid (e.g. cane) or with the help of a wheeled device.*
- *Moderate vision impairment means impaired vision, but does not mean blindness.*
- *Moderate hearing impairment means deafness that can be corrected, with hearing aids, for example.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the possibly major disabilities with their patients, as discussed in the above definitions. **)*

- Remember that possibly major to major disability rates include children that fall in one or more of the possibly major or the major categories.

Possibly Major to Major Disability Breakdown

- These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely at 22 weeks. The babies in red have possibly major to major disability, and the babies in white have mild or no disability. Remember that children having mild or no disability may or may not be (what we call) “normal”.
- For cognitive delay and cerebral palsy only: Out of the 10 surviving babies born at 22 weeks that we looked at, only 1 had a possibly major to major cognitive delay/cerebral palsy. Remember that this is just what we saw in 10 babies, and 10 is a very small number of babies.
- For vision impairment only: Out of the 9 surviving babies born at 22 weeks that we looked at, 4 had a possibly major to major vision impairment. Remember that this is just what we saw in 9 babies, and 9 is a very small number of babies.
- For hearing impairment only: Out of the 9 surviving babies born at 22 weeks that we looked at, none had a possibly major to major hearing impairment. But this still does not mean that

the chance is zero for all babies. This is just what we saw in 9 babies, which is a very small number of babies.

- Again, please keep in mind that all the numbers on this card came from what we saw in 9 or 10 babies born at 22 weeks who survived.

Disability Breakdown Summary

- Some children will have only 1 problem, and some children will have all 4 problems.
- Unfortunately, we can't predict which baby will have which and how many of these problems.

Slide: Survival – 23 weeks

Front:

- Here are 100 babies. These are babies who received early intensive care at 23 weeks.
- From the Canadian Neonatal Network, we know that on average, at your 23 weeks gestation, 40 out of 100 babies will live – that's the green babies; 60 out of 100 babies will die – that's the white babies.
- But, these aren't exact numbers. It's our best estimate, but as you can see here (*point to 'range'*) the survival could be as low as 34 out of 100 or as high as 45 out of 100.
- *[If parents want further understanding of the estimates, the following can be discussed:* we use something called a 95% confidence interval or CI to tell you the accuracy of our estimate: This means that we are 95% sure, or confident, that your baby's chance of survival is in this interval or range. (Another way to think about it is that 95 out of 100 babies will have survival chances in this interval, and the remaining 5 out of 100 will have survival chances outside of this interval.) For this card and your GA, the 95% CI runs from 34 out of 100 to 45 out of 100 babies surviving.]
- As you can tell from these numbers, the accuracy of our estimates is definitely not perfect. Remember that these numbers are an estimate of what might happen in the future based on what we saw happen in the past.

Back:

- In Ottawa, from 2010-2014, on average, 31 out of 100 babies receiving early intensive care at 23 weeks will live – that's the babies in green; 69 out of 100 will die – that's the babies in white.
- But, again these aren't exact numbers. It's our best estimate and you can see (*point to 'range'*) that the survival could be as low as 14 out of 100 or as high as 56 out of 100.
- Remember that this number is an estimate of what might happen if we looked at 100 babies. We saw that 5 out of 16 babies given early intensive care *actually* survived in the past 5 years here in Ottawa. We cannot be certain that this will happen every time.

Slide: Disability – 23 weeks

- If your baby survives to go home, he/she may have some problems later on.
- These problems or disabilities can be major or possibly major, or there may be mild or no problems.

Pictograph #1

- Here again are the 100 surviving babies at 4 to 8 years of age. On this card are the major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 23 weeks and survive.
- On average, 11 out of 100 surviving babies will have a major disability at 4 to 8 years of age, shown in green. As with the survival numbers, you can see that there isn't an exact number (*point out 'range'*). The babies in white, which is 89 out of 100 surviving babies, will have no disability, a mild disability, or a possibly major disability.

Pictograph #2

- Here are the same surviving 100 babies. This time we will add the babies with possibly major disabilities to the ones we saw with the major disability. These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 23 weeks and survive.
- On average, 38 out of 100 surviving babies at 4 to 8 years of age will have a possibly major to major disability, shown in green. You can see again that there isn't an exact number (*point out 'range'*). The babies in white, which is 62 out of 100 surviving babies, will have either mild or no disability.

Slide: Major Disability “Breakdown” – 23 weeks

Breakdown Overview

- When doctors talk about long term “problems” or “disabilities” in children who were born extremely prematurely, they are usually referring to 4 specific:
 - a. Cognitive Delay – this means how is your child able to learn, think, talk (*give examples if you wish*)
 - b. Cerebral Palsy – this is the name we give when there is a problem with the way the brain tells the nerves that tell the muscles how to move. It can be as mild as problems with fine motor skills such as writing, or as severe as not being able to walk or move properly
 - c. Vision Impairment – the ability to see
 - d. Hearing Impairment – the ability to hear
- We can categorize these 4 disabilities individually as major or possibly major to major.
(*Show the titles of the 2 cards*)

[Note for healthcare providers: “major disabilities” refers to severe neurodevelopmental impairments, defined as follows:

Severe Definitions

- *A severe cognitive delay means an IQ greater than 3 standard deviations below the average. For these children, it means they will require highly specialized schooling in order to achieve basic communication and self-care.*
- *Severe cerebral palsy usually means the inability to walk. For these children, it means they usually require a wheelchair for transportation.*
- *Severe vision impairment means no useful vision. For these children, it means they are blind.*
- *Severe hearing impairment means deafness that cannot be corrected, with hearing aids, for example. For these children, it means they are deaf.]*

(Healthcare providers are encouraged to share the outcomes of each of the major disabilities with their patients, as discussed in the above definitions. **)**

Major Disability Breakdown

- These are the major disability rates of 4 to 8 year old children who were born extremely prematurely at 23 weeks. The babies in green have major disability, and the babies in white have possibly major, mild or no disability.
- For these 100 4 to 8 year old children who were given early intensive care at 23 weeks and survived, on average, there will be ____ (*input appropriate number*) out of 100 with major _____ (*name of impairment*). But, this isn't an exact number. We have the 'range' running from ____ (*input appropriate number*) out of 100 babies to ____ (*input appropriate number*) out of 100 babies having major _____ (*name of impairment*) (*point out the 'range' on top of the horizontal array*). (*Do this for all four morbidities: cognitive delay, cerebral palsy, vision impairment, and hearing impairment*)

Slide: Possibly major to Major Disability "Breakdown" – 23 weeks

[Note for healthcare providers: "possibly major to major disabilities" refers to moderate-to-severe neurodevelopmental impairments, with "moderate" defined as follows:

Moderate Definitions

- *A moderate cognitive delay means an IQ 2-3 standard deviations below the average. For these children, it means they have serious school challenges (e.g. unlikely to finish high school), and/or may have to repeat years.*
- *Moderate cerebral palsy means difficulty with movement and walking. For these children, it means they usually walk with a support aid (e.g. cane) or with the help of a wheeled device.*
- *Moderate vision impairment means impaired vision, but does not mean blindness.*
- *Moderate hearing impairment means deafness that can be corrected, with hearing aids, for example.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the possibly major to major disabilities with their patients, as discussed in the definitions above. **)*

- Remember that possibly major to major disability rates include children that fall in one or more of the possibly major or major categories.

Possibly Major to Major Disability Breakdown

- These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely babies at 23 weeks. The babies in green have possibly major to major disability, and the babies in white have mild or no disability. Remember that children having mild or no disability may or may not be (what we call) "normal".
- For these 100 4 to 8 year old children who were given early intensive care at 23 weeks and survived, on average there will be ____ (*input appropriate number*) out of 100 with possibly major to major _____ (*name of impairment*). But, this isn't an exact number. The 'range' runs from ____ (*input appropriate number*) out of 100 babies having possibly major to major _____ (*name of impairment*) to ____ (*input appropriate number*) out of 100 babies having possibly major to major _____ (*name of impairment*) (*point out the 'range' on top of the horizontal array*). (*Do this for all four morbidities: cognitive delay, cerebral palsy, vision impairment, and hearing impairment*)

Disability Breakdown Summary

- Some children will have only 1 problem, and some children will have all 4 problems.

Unfortunately, we can't predict which baby will have which and how many of these problems.

Slide: Survival – 24 weeks

Front:

- Here are 100 babies. These are the babies who received early intensive care at 24 weeks.
- The Canadian Neonatal Network tells us that on average, at your 24 weeks gestation, 61 out of 100 babies will live— that's the purple babies; 39 out of 100 will die – that's the white babies.
- But, these aren't exact numbers. It's our best estimate, but as you can see here (*point to 'range'*) the survival could be as low as 58 out of 100 and as high as 65 out of 100.
- *[If parents want further understanding of the estimates, the following can be discussed:* we use something called a 95% confidence interval or CI to tell you the accuracy of our estimate: This means that we are 95% sure, or confident, that your baby's chance of survival is in this interval or range. (Another way to think about it is that 95 out of 100 babies will have survival chances in this interval, and the remaining 5 out of 100 will have survival chances outside of this interval.) For this card and your GA, the 95% CI runs from 58 out of 100 to 65 out of 100 babies surviving.] As you can tell from these numbers, the accuracy of our estimates is definitely not perfect. Remember that this number is an estimate of what might happen in the future based on what we saw happen in the past.

Back:

- From 2010-2014, in Ottawa, on average, 59 out of 100 babies receiving early intensive care at 24 weeks will live – that's the babies in purple; 41 out of 100 will die – that's the babies in white.
- But again, these aren't exact numbers. It's our best estimate and you can see (*point to 'range'*) that the survival could be as low as 43 out of 100 or as high as 73 out of 100.
- Remember that this number is an estimate of what might happen if we looked at 100 babies. We saw that 23 out of 39 babies given early intensive care *actually* survived in the past 5 years here in Ottawa. We cannot be certain that this will happen every time.

Slide: Disability – 24 weeks

- If your baby survives to go home, he/she may have some problems later on.
- These problems or disabilities can be major or possibly major, or there may be mild or no problems.

Pictograph #1

- Here again are the 100 surviving babies at 4 to 8 years of age. On this card are the major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 24 weeks and survive.
- On average, 18 out of 100 surviving babies will have a major disability at 4 to 8 years of age, shown in purple. As with the survival numbers, you can see that there isn't an exact number (*point out 'range'*). The babies in white, which is 82 out of 100 surviving babies, will have no disability, a mild disability, or a possibly major disability.

Pictograph #2

- Here are the same 100 surviving babies. This time we will add the babies with possibly major disabilities to the ones we saw with the major disabilities. These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 24 weeks and survive.
- On average, 28 out of 100 surviving babies at 4 to 8 years of age will have a possibly major to major disability, shown in purple. You can see again that there isn't an exact number (*point out 'range'*). The babies in white, which is 72 out of 100 surviving babies, will have either mild or no disability.

Slide: Major Disability “Breakdown” – 24 weeks

Breakdown Overview

- When doctors talk about long term “problems” or “disabilities” in children who were born extremely prematurely, they are usually referring to 4 specific problems:
 - a. Cognitive Delay – this means how is your child able to learn, think, talk (*give examples if you wish*)
 - b. Cerebral Palsy – this is the name we give when there is a problem with the way the brain tells the nerves that tell the muscles how to move. It can be as mild as problems with fine motor skills such as writing, or as severe as not being able to walk or move properly
 - c. Vision Impairment – the ability to see
 - d. Hearing Impairment – the ability to hear
- We can categorize these 4 disabilities individually as major or possibly major to major. (*Show the titles of the 2 cards*)

[Note for healthcare providers: “major disabilities” refers to severe neurodevelopmental impairments, defined as follows:

Severe Definitions

- *A severe cognitive delay means an IQ greater than 3 standard deviations below the average. For these children, it means they will require highly specialized schooling in order to achieve basic communication and self-care.*
- *Severe cerebral palsy usually means the inability to walk. For these children, it means they usually require a wheelchair for transportation.*
- *Severe vision impairment means no useful vision. For these children, it means they are blind.*
- *Severe hearing impairment means deafness that cannot be corrected, with hearing aids, for example. For these children, it means they are deaf.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the major disabilities with their patients, as discussed in the above definitions. **)*

Major Disability Breakdown

- These are the major disability rates of 4 to 8 year old children who were born extremely prematurely at 24 weeks. The babies in purple have major disability, and the babies in white have possibly major, mild or no disability.

- For these 100 4 to 8 year old children who were given early intensive care at 24 weeks and survived, on average there will be ____ (*input appropriate number*) out of 100 with major _____ (*name of impairment*). But, this isn't an exact number. Our 'range' is from ____ (*input appropriate number*) out of 100 babies having a major _____ (*name of impairment*) to ____ (*input appropriate number*) out of 100 babies having a major _____ (*name of impairment*) (*point out the 'range' on top of the horizontal array*). (*Do this for all four morbidities: cognitive delay, cerebral palsy, vision impairment, and hearing impairment*)

Slide: Possibly Major to Major Disability "Breakdown" – 24 weeks

[Note for healthcare providers: "possibly major to major disabilities" refers to moderate-to-severe neurodevelopmental impairments, with "moderate" defined as follows:

Moderate Definitions

- A moderate cognitive delay means an IQ 2-3 standard deviations below the average. For these children, it means they have serious school challenges (e.g. unlikely to finish high school), and/or may have to repeat years.*
- Moderate cerebral palsy means difficulty with movement and walking. For these children, it means they usually walk with a support aid (e.g. cane) or with the help of a wheeled device.*
- Moderate vision impairment means impaired vision, but does not mean blindness.*
- Moderate hearing impairment means deafness that can be corrected, with hearing aids, for example.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the possibly major disabilities with their patients, as discussed in the above definitions. **)*

- Remember that possibly major to major disability rates include children that fall in one or more of the possibly major or major categories.

Possibly major to Major Disability Breakdown

- These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely at 24 weeks. The babies in purple have possibly major to major disability, and the babies in white have mild or no disability. Remember that children having mild or no disability may or may not be (what we call) "normal".
- For these 100 4 to 8 year old children who were given early intensive care at 24 weeks and survived, on average there will be ____ (*input appropriate number*) out of 100 with possibly major to major _____ (*name of impairment*). But, this isn't an exact number. The 'range' is from ____ (*input appropriate number*) out of 100 babies having possibly major to major _____ (*name of impairment*) to ____ (*input appropriate number*) out of 100 babies having possibly major to major _____ (*name of impairment*) (*point out the 'range' on top of the horizontal array*). (*Do this for all four morbidities: cognitive delay, cerebral palsy, vision impairment, and hearing impairment*)

Disability Breakdown Summary

- Some children will have only 1 problem, and some children will have all 4 problems. Unfortunately, we can't predict which baby will have which and how many of these problems.

Slide: Survival – 25 weeks

Front:

- Here are 100 babies. These are the babies who received early intensive care at 25 weeks.
- From the Canadian Neonatal Network, we know that on average, at your 25 weeks gestation, 79 out of 100 babies will live – that's the orange babies; 21 out of 100 babies will die – that's the white babies.
- But, these aren't exact numbers. It's our best estimate, but as you can see here (*point to 'range'*) the survival could be as low as 77 out of 100 or as high as 82 out of 100.
- *[If parents want further understanding of the estimates, the following can be discussed:* we use something called a 95% confidence interval or CI to tell you the accuracy of the prediction: This means that we are 95% sure, or confident, that your baby's chance of survival is in this interval or range. (Another way to think about it is that 95 out of 100 babies will have survival chances in this interval, and the remaining 5 out of 100 will have survival chances outside of this interval.) For this card and your GA, the 95% CI runs from 77 out of 100 to 82 out of 100 babies surviving.]
- As you can tell from these numbers, the accuracy of our estimates is definitely not perfect. Remember that this number is an estimate of what might happen in the future based on what we saw happen in the past.

Back:

- In Ottawa, from 2010-2014, on average, 67 out of 100 babies receiving early intensive care at 25 weeks will live – that's the babies in orange; 33 out of 100 will die – that's the babies in white.
- But again, these aren't exact numbers. It's our best estimate and you can see (*point to 'range'*) that the survival could be as low as 54 out of 100 or as high as 77 out of 100.
- Remember that this number is an estimate of what might happen if we looked at 100 babies. We saw that 40 out of 60 babies given early intensive care *actually* survived in the past 5 years here in Ottawa. We cannot be certain that this will happen every time.

Slide: Disability – 25 weeks

- If your baby survives to go home, he/she may have some problems later on.
- These problems or disabilities can be major or possibly major or there may be mild or no problems.

Pictograph #1

- Here again are the 100 surviving babies at 4 to 8 years of age. On this card are the major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 25 weeks and survive.
- On average, 13 out of 100 surviving babies will have a major disability at 4 to 8 years of age, shown in orange. As with the survival numbers, you can see that there isn't an exact number (*point out 'range'*). The babies in white, which is 87 out of 100 surviving babies, will have no disability, a mild disability, or a possibly major disability.

Pictograph #2

- Here are the same 100 babies. This time we will add the babies with possibly major disabilities to the ones we saw with the major disabilities. These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care at 25 weeks and survive.
- On average, 24 out of 100 surviving babies at 4 to 8 years of age will have a possibly major to major disability, shown in orange. You can see again that there isn't an exact number (*point out 'range'*). The babies in white, which is 76 out of 100 surviving babies, will have either mild or no disability.

Slide: Major Disability “Breakdown” – 25 weeks

Breakdown Overview

- When doctors talk about long term “problems” or “disabilities” in children who were born extremely prematurely, they are usually referring to 4 specific problems:
 - a. Cognitive Delay – this means how is your child able to learn, think, talk (*give examples if you wish*)
 - b. Cerebral Palsy – this is the name we give when there is a problem with the way the brain tells the nerves that tell the muscles how to move. It can be as mild as problems with fine motor skills such as writing, or as severe as not being able to walk or move properly
 - c. Vision Impairment – the ability to see
 - d. Hearing Impairment – the ability to hear
- We can categorize these 4 disabilities individually as major or possibly major to major. (*Show the titles of the 2 cards*)

[Note for healthcare providers: “major disabilities” refers to severe neurodevelopmental impairments, defined as follows:

Severe Definitions

- *A severe cognitive delay means an IQ greater than 3 standard deviations below the average. For these children, it means they will require highly specialized schooling in order to achieve basic communication and self-care.*
- *Severe cerebral palsy usually means the inability to walk. For these children, it means they usually require a wheelchair for transportation.*
- *Severe vision impairment means no useful vision. For these children, it means they are blind.*
- *Severe hearing impairment means deafness that cannot be corrected, with hearing aids, for example. For these children, it means they are deaf.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the major disabilities with their patients, as discussed in the above definitions. **)*

Major Disability Breakdown

- These are the major disability rates of 4 to 8 year old children who were born extremely prematurely at 25 weeks. The babies in orange have major disabilities, and the babies in white have moderate, mild or no disabilities.
- For these 100 4 to 8 year old children who were given early intensive care at 25 weeks and survived, on average there will be ____ (*input appropriate number*) out of 100 with major _____ (*name of impairment*). But, this isn't an exact number. The 'range' runs from ____ (*input appropriate number*) out of 100 babies to ____ (*input appropriate number*) out of 100 babies will have major _____ (*name of impairment*) (*point out the 'range' on top of the horizontal array*). (*Do this for all four morbidities: cognitive delay, cerebral palsy, vision impairment, and hearing impairment*)

Slide: Possibly Major to Major Disability “Breakdown” – 25 weeks

[Note for healthcare providers: “possibly major to major disabilities” refers to moderate-to-severe neurodevelopmental impairments, with “moderate” defined as follows:

Moderate Definitions

- *A moderate cognitive delay means an IQ 2-3 standard deviations below the average. For these children, it means they have serious school challenges (e.g. unlikely to finish high school), and/or may have to repeat years.*
- *Moderate cerebral palsy means difficulty with movement and walking. For these children, it means they usually walk with a support aid (e.g. cane) or with the help of a wheeled device.*
- *Moderate vision impairment means impaired vision, but does not mean blindness.*
- *Moderate hearing impairment means deafness that can be corrected, with hearing aids, for example.]*

*(**Healthcare providers are encouraged to share the outcomes of each of the possibly major disabilities with their patients, as discussed in the above definitions. **)*

- Remember that possibly major to major disability rates include children that fall in one or more of the possibly major or major categories.

Possibly Major to Major Disability Breakdown

- These are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely at 25 weeks. The babies in orange have possibly major to major disabilities, and the babies in white have mild or no disabilities. Remember that children having mild or no disabilities may or may not be (what we call) “normal”.
- For these 100 4 to 8 year old children who were given early intensive care at 25 weeks and survived, on average there will be ____ (*input appropriate number*) out of 100 with moderate-to-severe _____ (*name of impairment*). But, this isn't an exact number. The 'range' runs from ____ (*input appropriate number*) out of 100 babies to ____ (*input appropriate number*) out of 100 babies having possibly major to major _____ (*name of impairment*) (*point out the CI on top of the horizontal array*). (*Do this for all four morbidities: cognitive delay, cerebral palsy, vision impairment, and hearing impairment*)

Disability Breakdown Summary

- Some children will have only 1 problem, and some children will have all 4 problems.

- Unfortunately, we can't predict which baby will have which and how many of these problems.

Slide: Survival Overview (Increases by Gestational Age) (use this card if a comparison between different GA weeks is desired by the parents or deemed necessary by the practitioner)

- On this card are the survival rates for babies at different gestations: from less than or equal to 22 weeks to 25 weeks (*point to dark blue bars and “weeks of gestation” axis*), and also the survival rate for term babies (*point to light blue bar*).
- Let's say 100 babies were given early intensive care. This graph shows, for each gestational week, how many babies out of those 100 may survive.
- As you can see, the dark blue bar gets taller as the number of weeks gets bigger. More babies survive at higher gestational ages. In other words, each extra week (and, in fact, day) your baby stays inside of you, gives him/her a better chance of surviving.
- The light blue bar shows how many babies who were born at term survive: this is about 99.99% or very close to 100 out of 100.

Slide: Major Disability Overview (use this card if a comparison between different GA weeks is desired by the parents or deemed necessary by the practitioner)

- If your baby survives to go home, he/she may have some problems later on. I'd like you to keep in mind during our discussion that even for a baby born at term, the chance of having a problem or ‘disability’ is about 4%. However, the chance of these disabilities is definitely greater for babies born extremely prematurely.
- A disability is a problem that may affect thinking, communicating, learning, moving, seeing, and/or hearing. We are only talking about specific disabilities and I will define them for you shortly. There can be other disabilities (like autism or attention-deficit disorder) but we don't have as good data on these disabilities.
- The disabilities can be considered major, according to the medical community. We define a major disability as a disability that is highly likely to make your child very dependent on you for their whole life. Again, we'll cover the specific definitions shortly.
- On this card are the major disability rates of 4 to 8 year old children who were born extremely prematurely. These are the babies who receive early intensive care and survive; they are from around the world.
- This card shows disability for the different gestations: from 22 weeks to 25 weeks. This graph shows, for each gestational week, how many babies out of 100 may have major disabilities if they are given early intensive care and survive.
- You have to remember that, no matter what we estimate right now, if your baby survives he/she either will or won't have major disability. The estimate just tells you the approximate chance that he/she will have major disability.
- You might think that as the number of weeks gets bigger, the number of babies with major disability decreases. However, after carefully looking at the data, we cannot say for certain that the chance of major disability goes down when the gestation increases. There is no

proven statistical significance that being born at a higher gestational age means less major disability in a surviving child.

- In other words, because our estimates aren't perfectly accurate, we can't say that the blue bars get shorter as the number of weeks gets bigger.
- The other thing we don't know from these statistics is what number of surviving children will have only one of these major disability versus what number will have more than one of them.

Slide: Possibly Major to Major Disability Overview (*use this card if a comparison between different GA weeks is desired by the parents or deemed necessary by the practitioner*)

- On this card are the possibly major to major disability rates of 4 to 8 year old children who were born extremely prematurely. Again, these are the babies who receive early intensive care and survive; they are from around the world.
- Surviving children with a possibly major disability will likely reach a reasonable degree of independence. We don't have the statistics for possibly major disabilities by themselves, so the data you see includes those children with possibly major and/or major disability(s).
- This card shows disability for the different gestations: from 22 weeks to 25 weeks. This graph shows, for each gestational week, how many babies out of 100 may have possibly major to major disability if they are given early intensive care and survive.
- You can see that as you go up from one week of gestation to another, the height of the blue bar goes down – the number of babies with possibly major to major disability decreases. In fact, it is statistically proven that for each extra week of gestation, the chance of possibly major to major disability goes down about 6%, or the blue bar gets shorter by about 6 babies out of 100. This decrease in the chance of possibly major to major disability is due to a decrease in the rate of possibly major disability.

Summary:

- Extremely premature babies can have many other problems. And these other problems can also affect whether or not they will survive and whether or not they will grow and develop normally.
- We can't predict with 100% certainty which baby will survive and which baby, if he/she survives, will not have any problems.
- It is important that you think about what matters most to you and your family; every situation is different, and what is right for you may be different than what is right for another family.
- While "early intensive care" and "palliative care" are the two broad options, we can also explore other options or discuss these two options more specifically to your preferences.
- You are welcome to discuss any options with me at any time.
- You may also consider discussing what we have talked about today with anyone else whose opinion matters to you.
- Remember that there is no 'right' answer, only what is best for you and your baby.
- I encourage you to write down any questions you may have and ask me anything you have any doubts about.
- You are not alone in this decision; we are all here to help you and to provide you with all the information that you need to make a decision that will best match your values and preferences.
- *(Discuss follow up appointment/meeting as required; provide parent handout(s))*

Extra Information for Parents Leaning Towards/Choosing Early Intensive Care: (to be provided by neonatal team at the appropriate time based on family's needs and wants)

- As we have discussed, during early intensive care, there will be doctors and nurses present in the delivery room to provide medical support for your baby.
- You will probably see about 3-6 people in the delivery room helping your baby.
- There are usually 2 physicians. The physicians are there to oversee the care of your baby and perform any necessary procedures
- There are also usually 1 or 2 nurses as well. The nurses are there to perform or assist with procedures/interventions and to give any necessary medications or fluids
- There will probably also be 1 or 2 RTs or respiratory therapists. The job of the respiratory therapists is to assist with managing the breathing support required for your baby.
- You might see a lot of people in the delivery room, but more people does not mean bad news. Our hospital is also a teaching hospital, so you may see trainees who are sometimes present as well.
- Your baby will be taken to the NICU or ‘resuscitation room’ right away to allow us to best care for your baby; your partner is welcome to come.
- After early intensive care, your baby will need further intensive care in the Neonatal Intensive Care Unit or “NICU”. On average, babies born extremely prematurely stay in the NICU until their expected full term delivery date.
- In the NICU, complications due to extreme prematurity may arise. Some of these postnatal complications can increase the risk of disability or cause a baby to die. We can discuss some or all of these complications now, if you’d like? Or we can do so at another time?
- Three particular complications that can impact the risk of death or disability are: bronchopulmonary dysplasia, retinopathy of prematurity and intraventricular hemorrhage/periventricular leukomalacia.
- Bronchopulmonary dysplasia, or BPD, is the word we use to describe premature lungs that are sick.
- When babies are born early (prematurely), their lungs are not fully developed. The lung tissue that is present is very fragile and can be easily damaged.
- The baby may need to be on a breathing machine to help him/her get oxygen.
- Unfortunately, since the lungs are so fragile they become injured, and injury leads to scarring.
- When babies have a hard time getting oxygen into the lungs, they have a hard time getting oxygen to the brain. This will affect how the brain develops and can lead to long term problems.
- Retinopathy of prematurity, or ROP, is the word we use to describe abnormal development of blood vessel in a premature baby’s eye.
- When a baby is born prematurely the blood vessels that are forming in the eye may not grow properly.
- These abnormal blood vessels can spread across the retina – the part of the eye that “sees”.

- Just like the other parts of the baby's body that are fragile, these abnormal blood vessels are fragile and can leak. This causes scars in the retina and can cause blindness.
- Intraventricular hemorrhage, or IVH, is the word we use to describe bleeding in the spaces (the ventricles) in the brain.
- Just like the other parts of the baby's body that are fragile, there are tiny blood vessels in the baby's brain that are fragile, and they can break easily.
- These tiny blood vessels are around a part of the brain called the ventricle – which is a fluid filled space. There is a ventricle on the left side of the brain and one on the right side of the brain.
- When the tiny blood vessels break, blood gets into these ventricles. We use the terms: Grade 1, 2, 3, and 4 to describe how much blood is in the ventricle. Grade 1 means there is a small amount of blood. Grade 2 means there is a moderate amount of blood. Grade 3 means there is a moderate amount of blood and it's causing there to be pressure in the ventricle, making it bigger. Grade 4 means there is a moderate amount of blood, the ventricle is bigger, and the blood has extended into the brain tissue around the ventricle.
- When the brain around the ventricles is damaged, it can lead to a type of brain injury called periventricular leukomalacia or PVL.
- Babies who are born prematurely and never have IVH are still at risk for long term problems. However, the chances of having serious long term problems go up if there is IVH.