

Babies Born at 22 Weeks Gestational Age



*Information for
Families and Caregivers*

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Shared Decision Making

There are many things to consider when making decisions for an extremely premature baby. Sometimes, the first main decision to make (if possible) for your baby before he/she is born is whether you think it is best for him/her to receive early intensive care or palliative care should he/she be born extremely prematurely.

In this stressful situation, we want to help you make the decision that is best for you. There is no 'right' or 'wrong' decision, only the one that is right for you and your family. That is why we encourage you to engage in shared decision making with our healthcare team.

Shared decision making is a process where you and the healthcare team will work together to make this decision. While the healthcare team will provide you with medical knowledge that may be useful in your decision, it is equally important for you to consider your own values and preferences.

We hope the information in this booklet will be useful in making this first main decision, and possibly for other future decisions regarding your son or daughter. For more information and support, you are encouraged to speak to members of your healthcare team, friends, family or other people important to you.

SPIRITUAL CARE

Spiritual Care Services supports and guides families as they process their thoughts and feelings regarding moral, spiritual and/or religious beliefs. A family's choice and its outcome is established with an accepting and open-minded approach, assisting them to find comfort, hope and healing throughout the decision making process. A chaplain will also be able to facilitate and provide meaningful rituals, blessings, dedications or baptisms wherever possible.

Spiritual care services contact: 613-737-8899 x.78126
spiritualcare@ottawahospital.on.ca

ETHICS CONSULTATION SERVICE

Making decisions for your baby can be very challenging and result in you experiencing confusing emotions and thoughts about what is right or wrong. The Ottawa Hospital's Ethics Consultation Service is available to support you during this time. This service can help you and your family make decisions by providing information, clarifying values, and identifying ways of considering the difficult decisions. Please ask one of your healthcare team members if you would like to speak with the Ethics Consultation Service, or contact us directly by email.

Ethics service contact: ethics@toh.on.ca

OTHER RESOURCES

NICU main desk: 613-737-8899 x. 78651

Canadian Premature Babies Foundation:
<http://cpbf-fbpc.org/>

Préma-Québec: <http://premaquebec.ca/>

Support Available

We understand that this is a difficult situation for you and your family. We offer a variety of resources and supports to help your family with any difficulties you may encounter and answer any questions you may have.

On this and the following page are a few of the services that are available to you. If you require support, please speak with your healthcare team for more information.

The healthcare team includes the people caring for you and your family and includes: physicians, nurses, social workers, spiritual care specialists or other healthcare team members.

SOCIAL WORK

Social Work recognizes that being at risk for a preterm delivery can be very difficult and add emotional distress in your life. We are here for you, to listen and provide support. Whether it is emotional or practical concerns we can offer guidance and resource information. From financial issues to managing transportation, living arrangements, counselling, management of stress and difficult personal and family situations, Social Work can help parents in various ways to facilitate their journey through a complex pregnancy and NICU admission. Please ask your TOH healthcare provider if you would like to be referred to social work.

Social work services contact: 613-737-8976

Your Options

EARLY INTENSIVE CARE

Healthcare professionals will be present in the delivery room and provide medical support to your baby. It may or may not help him/her survive.

1. Resuscitation: YES

Will include one or more of: bag and mask ventilation, continuous positive airway pressure (CPAP), intubation, mechanical ventilation, intravenous access, chest compressions and epinephrine

2. Painful procedures: YES

3. Duration of care for the baby: Months in the NICU (neonatal intensive care unit) if he/she survives.

PALLIATIVE CARE

Healthcare professionals will be present in the delivery room to provide comfort to the baby and avoid interventions that may cause pain or suffering.

You will be able to hold your baby right away. Your baby will have a natural death within minutes to hours.

1. Resuscitation: NO

Your baby will receive warm blankets, and be placed with you in a comfortable room. Sugar water and other pain-relieving medications will be given if necessary.

2. Painful procedures: NO

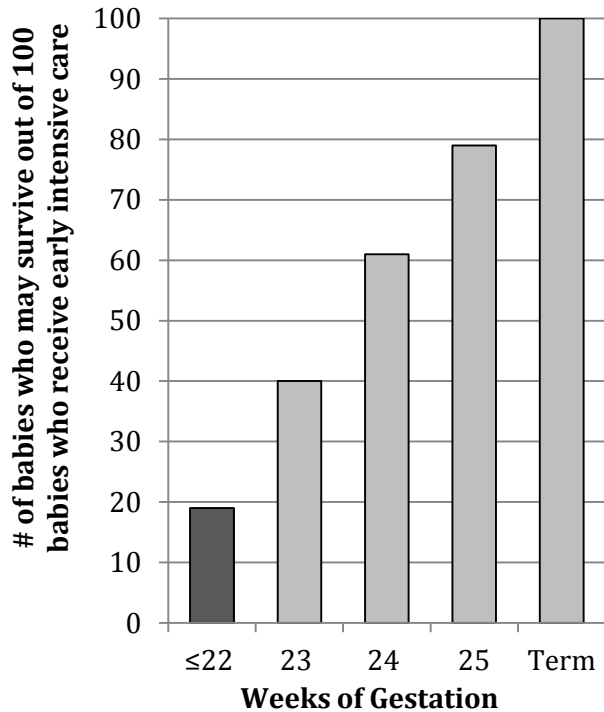
3. Duration of care for the baby: Minutes to hours

Remember there is no 'wrong' decision, only the right one for you and your family. Support is available to you, regardless of your choice.

Survival

Babies born at 22 weeks can live outside the womb. Your baby will have a chance to survive with early intensive care, but will definitely die with palliative care.

The following graph is the number of babies born at 22 weeks who survive after receiving early intensive care. These numbers are based on **13 out of 70** (or 19%) babies born at 22 weeks receiving early intensive care in **Canada** from 2010-2013. See the darkened bar in figure below.



In **Ottawa**, from 2010-2014, we have had very few attempts at early intensive care for babies born at 22 weeks. **Of these attempts, no babies have survived.**

Maternal Impact

In any pregnancy, the chance of the mother dying is very rare. Maternal health risks are largely related to maternal health condition. Keep in mind that your choice, be it early intensive or palliative care, does not generally have an impact on maternal health.

The medical problems leading to extremely premature births may have an impact on maternal health. Delaying delivery in these situations could negatively affect the mother's health and may even lead to death. In these cases, delivery is strongly recommended.

The mode of delivery can also impact maternal health. The best method of routine delivery for extremely premature infants is unclear; studies do not support C-sections as routinely being better for survival or the risk of long-term disability in children who were born extremely prematurely.

The maternal-fetal medicine team will discuss with you the potential advantages and risks of each option in your situation. We urge you discuss your concerns further with the healthcare team.

NOTES (based on your discussion with maternal-fetal medicine)

Benefits of vaginal birth:

Risks of vaginal birth:

Benefits of C-section:

Risks of C-section:

Quality of Life

The quality of life of both the babies born extremely 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.

The following is a short list of factors for you to consider. This list is not comprehensive.

PREMATURE INFANTS

- Ongoing medical problems from being born very premature can happen
- Limits in ability to perform everyday tasks may be present
- When asked to rate their quality of life, adolescents who were born extremely premature rate their quality of life very similarly to adolescents who were born at term
- Young adults also report resilience and good quality of life

PARENTS/CAREGIVERS

One can expect to see different types of impact on:

- Emotional health
- Stress
- Family and marital bonds
- Confidence in parenting ability

Disabilities

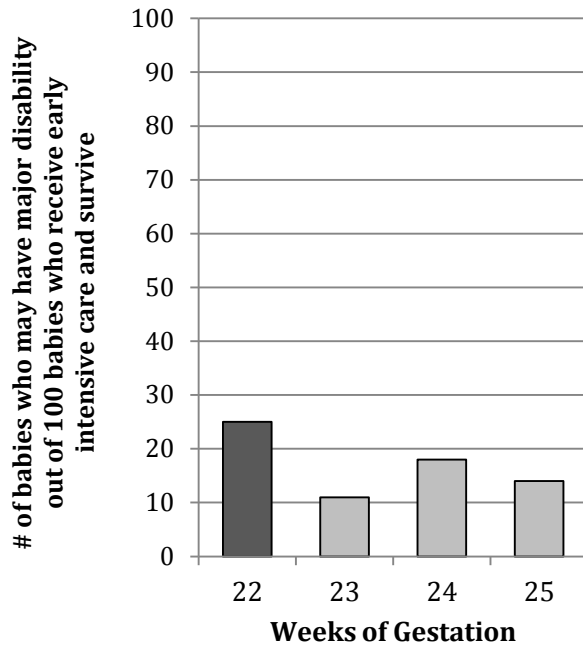
It is difficult to predict what will happen to a premature baby in the long term, as there are many different factors involved. Children born prematurely are more likely than children born at term to have long-term disabilities, including major ones.

The table below provides information to help you better understand some of the major long-term types of disabilities that may be a concern in extremely premature babies. One or more of the following disabilities affect about 4 in 100 (4%) children born at term.

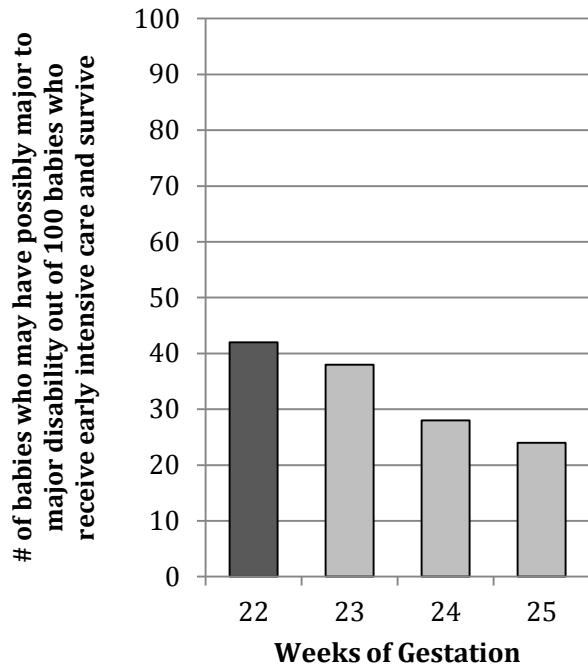
Disability	Most common	Less common	Least common	
	Cognitive Function	Movement or Motor	Hearing	Vision
Mild	Learning difficulties	Clumsy, difficulties with paper and pencil	Mild hearing loss	Needs glasses
Possibly Major	Slower than average; learns with support	Cerebral palsy; expected to walk with help	Hearing loss; corrected with hearing aids	Poor eyesight, even with glasses
Major	Very slow, needs lifelong care	Cerebral palsy; cannot walk without help or cannot walk	Deaf; cannot hear even with hearing aids	Blind

The graphs on the following page illustrate the estimated risk of major and possibly major disability for babies born at 22 to 25 weeks of gestation who are alive at school age (4-8 years old). Note that the darkened bar refers to the babies born at 22 weeks. It must be noted that this information is based on less than 15 babies, so it may be very inaccurate and underestimating (or, less likely, overestimating) the risk of disability.

MAJOR DISABILITY



POSSIBLY MAJOR DISABILITY



Things Affecting Survival and Risk of Disability

There are other factors besides gestational age that may increase or decrease the chance of your baby's survival and/or risk of disability, compared to the expected average survival and disability rates shown in the bar graphs.

Survival or risk of disability, compared to the average:

Worsen	Improve
Lower birth weight	Higher birth weight
Early in week of gestation	Late in week of gestation
No maternal steroids	Maternal steroids
Male	Female
Multiples	Singleton
Some ultrasound findings can also affect survival and/or risk of disability.	

Keep in mind that these are just a few factors to consider. There are other factors not mentioned here that may also have an impact on your baby's survival and risk of disability. Every baby is different.

Your baby (compared to average – less, more, equal?):

- Predicted chance of survival:

- Predicted chance of a major or possibly major disability: