Babies Born at 25 Weeks Gestational Age

Information for Families and Caregivers

(Further resources at: www.sdmforepi.com)

Introduction

This information is for parents facing the potential birth of an extremely premature baby.

We have been looking after extremely premature babies and their families for many years. We understand that it can be stressful and frightening for the parents of a baby or babies who need intensive or special care.

The information in this booklet is to help you understand the kind of challenges your baby might face in the short and long term should he/she be born prematurely. The healthcare team will support you as you make decisions that are appropriate for your baby and family. Members of the team are available to discuss your baby's care and any concerns you may have at any time.

This Booklet

The information given in this booklet relate to the babies who are born at 25 weeks.

These data only provide a rough estimate, but we have used the best possible information to help you understand the chances of certain things happening to your baby (e.g. what is the chance she/he will survive?). Your neonatologist will have discussed your own specific situation with you and how that may change your baby's chances.

Unfortunately, we cannot be 100% certain of what will happen as every baby, family and situation is different. The best decisions for your family may not be the same as the best decisions for a different family.

Shared Decision Making

There are many things to consider when making decisions for an extremely premature baby. The first main decision to make before your baby is born is whether you think it is best for him/her to receive intensive care or palliative comfort care. **At 25 weeks gestation, our NICU team's recommended care option is usually intensive care**; the reason for this recommendation will be discussed during your consultation with an NICU team member

In this stressful situation, we want to support you in making the decision that is best for your baby and you and your family. We want to work with you to make a decision that is right for you and your family. That is why we encourage you to engage in shared decision making with our healthcare team. Each situation and family are unique; this results in different final decisions for different babies.

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 information (and possibly a recommendation), it is equally important for you to consider and speak about your own values and preferences.

We hope the information in this booklet will be useful in making decisions for your son or daughter. For more information and support, please speak to members of your healthcare team, friends, family or other people important to you.

Your Options

INTENSIVE CARE**

****(this is often our NICU team's recommendation at 25 weeks)**

The NICU (Neonatal Intensive Care Unit) team will be present in the delivery room to provide medical support to your baby. Even with this support, she/he may not 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 if he/she survives.

PALLIATIVE COMFORT CARE

The healthcare team will be present in the delivery room to provide comfort to your baby. They will 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 (rarely, if ever, longer than 24 hours).

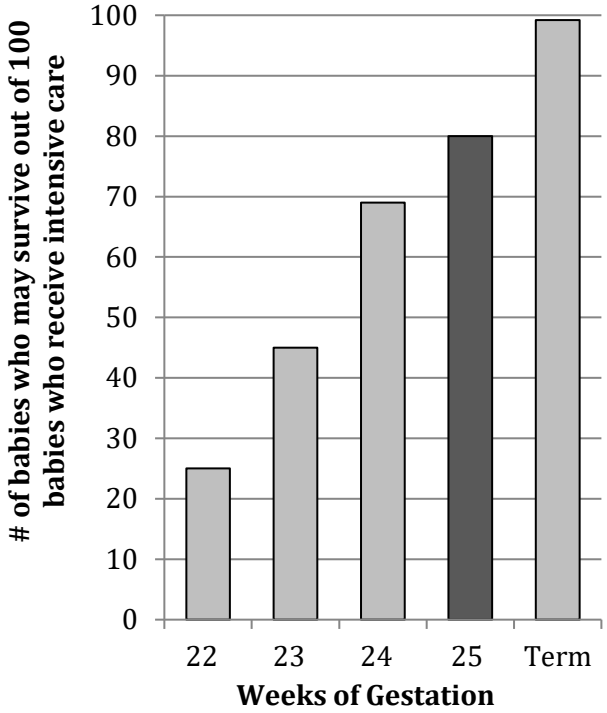
1. **Resuscitation:** NO
   Your baby will receive warm blankets, and be placed with you in a comfortable room. She/he can be skin-to-skin with you or in a warm blanket. Sugar water and other pain-relieving medications will be given if necessary.
2. **Painful procedures:** NO
3. **Duration of care for the baby:** Minutes to hours

Remember, we are here to support you so that together we make the right decision for your baby and you and your family. Support is available to you, regardless of your choice.

Survival or Death

Babies born at 25 weeks can live outside the womb. Your baby will have a chance to survive with intensive care, but will definitely die with palliative comfort care.

The following graph shows that 80 out of 100 (80%) of babies born at 25 weeks who receive intensive care will survive, while 20 out of 100 (20%) will die. These numbers are based on babies born at 25 weeks across **Canada** from 2010-2018.



In **Ottawa**, from 2015-2019, we have had 51 attempts at intensive care for babies born at 25 weeks. **Of these attempts, 36 of the babies survived and 15 died**.

Neurodevelopment (things like thinking and walking)

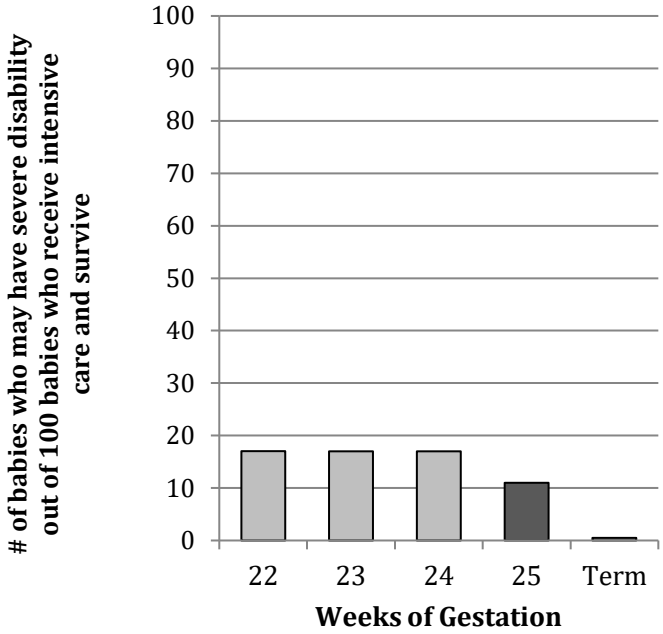
It is often impossible to accurately predict what will happen to a premature baby in the long term, as there are many different factors involved. Babies born extremely prematurely are much more likely than babies born at term to have major, long-term disabilities. They also may have no disability. Regardless of whether they do or do not have disability, they may bring love and joy to a family.

The table below provides information to help you better understand some of the types of disabilities that may be a concern in extremely premature babies. These disabilities affect about 4 in 100 (4%) of babies born at term.

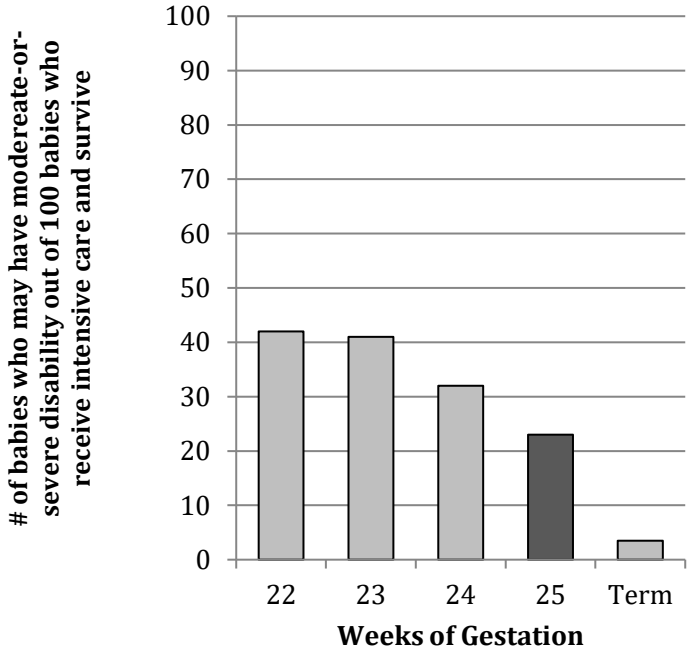
	Most common	Less common	Least common	
Disability	**Cognitive Function**	**Movement or Motor**	**Hearing**	**Vision**
Mild	Learning difficulties	Clumsy, difficulties with paper and pencil	Mild hearing loss	Needs glasses
Moderate	Slower than average; learns with support	Cerebral palsy; expected to walk with help	Hearing loss; corrected with hearing aids	Poor eyesight, even with glasses
Severe	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 severe and moderate-or-severe disability for babies born at 22 to 25 weeks of gestation who are alive at school age (4-10 years old). Note that the darkened bar refers to the babies born at 25 weeks.

SEVERE DISABILITY



MODERATE-OR-SEVERE 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 or risk of disability, compared to the expected 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.

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. Each family is unique.

The following is a short list of factors for you to consider.

PREMATURE INFANTS

- Potential to have (or not have) ongoing medical problems from being born extremely premature
- Potential to have (or not have) limitations in the child's ability to perform everyday tasks
- Potential to have (or not have) a life they enjoy
- In research studies, adolescents who were born extremely premature rate their quality of life very similarly to adolescents who were born at term
- Young adults who were born extremely preterm also report resilience and good quality of life

PARENTS/CAREGIVERS

Compared to having a baby born at full term, one can expect to see different types of impact on:

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

The different types of impact may be positive or negative.

Maternal Impact

Keep in mind that your choice, be it intensive care or palliative comfort care, does not generally have a direct impact on maternal physical health.

The medical problems leading to extremely premature births, such as pregnancy-induced high blood pressure, 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 method of delivery can also impact maternal health. Studies do not support routine C-sections as being better or worse for survival or the risk of long-term disability in babies born extremely prematurely.

The obstetrics team will discuss with you the potential benefits and risks of a C-section or vaginal birth in your situation. We urge you discuss your concerns further with your healthcare team.

NOTES

Benefits of vaginal birth:

Risks of vaginal birth:

Benefits of C-section:

Risks of C-section:

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.

Your healthcare team includes the people caring for you and your family, such as: physicians (includes residents, fellows, obstetricians and neonatologists), 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. Social Work can help with: financial issues, transportation needs, living arrangements, counselling, stress management and difficult personal or family situations. We support parents in various ways to facilitate their journey through a complex pregnancy and NICU admission. Please ask your healthcare provider if you would like to be referred to Social Work.

Social work services contact: 613-737-8976

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: 613-737-8651

Prematurity information and decision tools:
www.sdmforepi.com

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

Préma-Québec: http://premaquebec.ca/

Acronyms

- **AOP** – apnea of prematurity
- **Anemia** – anemia of prematurity
- **BPD** – bronchopulmonary dysplasia
- **CLD** – chronic lung disease
- **EBM** – expressed breast milk
- **EOS/LOS** – early or late onset sepsis
- **IVH** – intraventricular hemorrhage
- **NEC** – necrotizing enterocolitis
- **PDA** – patent ductus arteriosus
- **RDS** – respiratory distress syndrome
- **ROP** – retinopathy of prematurity
- **TPN** – total parenteral nutrition
- **UVC** – umbilical venous catheter

Definitions

Neonatologist: a Pediatrician who completed additional training to specialize in Neonatology (that is, the care of premature or sick full-term babies

Fellow: a doctor or Pediatrician who is completing additional training to become a Neonatologist

Resident in Pediatrics: a doctor who is completing training to become a Pediatrician

Notes

Feel free to use this space to jot down questions for the healthcare team, thoughts/concerns or anything else that may come to mind.

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