

## Babies Born at 22 Weeks of Pregnancy (Extremely Preterm)

You have been given this information because it is possible your baby may be born very early at 22 weeks of pregnancy.



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Extremely premature babies are only a little longer than an adult's hand.

We have been looking after extremely premature babies and their families for many years. We know that this is a stressful, frightening time. We are here to help you make the best decision for you and your baby. A team of doctors, nurses and other health professionals are available to discuss your baby's care and to support you as you make decisions.

During your prenatal consult, the doctor will go over the challenges your baby may have. The NICU journey can be hard, and it is challenging. Please ask as many questions as you have and if you have questions after the consult, make notes and we can arrange a follow-up visit to talk about them.

**The information in this pamphlet is to help you understand the kind of challenges your baby might face. Unfortunately, we cannot be 100% certain of what will happen as every baby, family and situation is different.**

### Questions families may ask

#### Question #1

#### Will my baby survive?

When babies are born at 22 weeks, their heart, lungs, brain and other organs are very immature (not well grown) and not ready to support life outside the womb. Many babies born this early do not survive labour and birth. Babies born alive will need a lot of medical care in a newborn (neonatal) intensive care unit (NICU) and will spend many months in hospital if they survive the first days and weeks in NICU. In Canada, and based on a small number of babies, about 2 or 3 out of 10 babies born at 22 weeks survive when they receive intensive care.

In Manitoba, between 2017-2020 we had 4 babies born at 22 weeks and 2 babies die.

#### **SURVIVAL IN CANADA 22 weeks**

(~500g ~1 pound, 1 ounce)

**2 or 3 out of 10 will live**



#### Question #2

#### What are my options?

The first decision to make before your baby is born is whether you think it is best for your baby to receive intensive care or palliative comfort care. In this stressful situation, we want to support you in making the decision that is best for your baby and you and your family. Each situation and family are unique; this results in different final decisions for different babies. Support is available to you, regardless of your choice.

## PALLIATIVE CARE

A palliative care approach to care aims to improve the quality of living and dying for infants with life-threatening issues. It acknowledges the uncertainty that exists with premature babies who are very fragile. It can be provided at the same time as care focused on interventions or care focused on comfort.

## CARE FOCUSING ON COMFORT

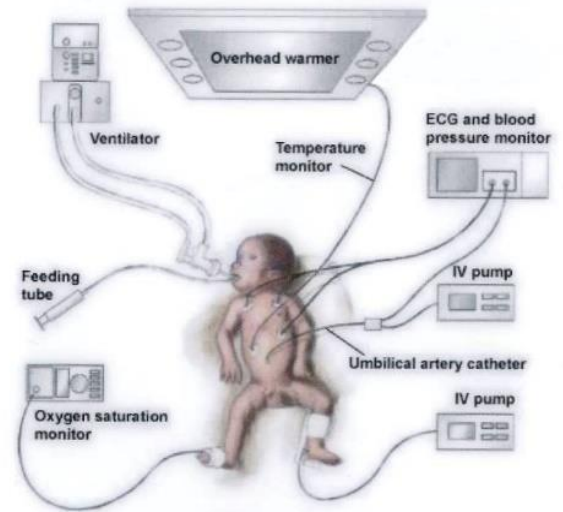
Sometimes parents choose to not start treatments and interventions. Or they choose to stop treatment and interventions that are not working for their baby. This allows parents to provide care focused on comfort for the duration of their baby's short life without interruption from medical tests and procedures. It prioritises keeping your baby pain-free while allowing you time to spend with your baby before your baby dies. When a comfort-focused approach is desired in the delivery room, the healthcare team will be present and will discuss with you what you would like to do after your baby is born. This may include whether you wish to hold your baby, bathe and dress your baby, have any extended family visit to meet your baby, and any other specific wishes you have. Many families will spend this time creating memories. 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). Your baby will receive warm blankets and be placed with you in a comfortable room. Your baby can be skin-to-skin with you or in a warm blanket. Sugar water and other medications may be given if needed. Your baby can stay with you as long as you wish.

*"At 22 weeks pregnant my water broke, and I was put on bedrest, hoping I could keep my baby safe in my belly for weeks, if not months. But after a series of complications, he was born 9 days later when I was 23 weeks and 5 days pregnant. He was one pound, two ounces and twelve inches long. Impossibly small and impossibly perfect. Beckett died, enveloped in his parent's arms, surrounded by love. We spent about 7 hours as a family of 3, soaking every inch of our boy in. Those seven hours contained a lifetime of love. And a lifetime of heartbreak."* Kieran Powers – [www.becoln.com](http://www.becoln.com)

## CARE FOCUSING ON INTERVENTIONS

The Neonatal Intensive Care Unit (NICU) team will be present in the delivery room to provide medical support to your baby. Your premature baby will need various machines and devices to monitor them and help them to breath, maintain their temperature, feed and grow.

Your baby will be taken to the NICU very quickly after delivery. Even with this support, your baby may not survive. There may come a time when a decision to stop supports and interventions may need to be considered. This may happen if despite all support, your baby is not improving. These are called goals of care discussions, which often occur with parents when the healthcare team is looking for guidance on how to proceed in providing care to your baby.



*"There were very difficult conversations, but we took everything hour by hour and celebrated every milestone. Although he has challenges, no one ever mentioned how much joy this happy and curious little boy would bring to our lives."*  
Heather-Parent of a baby born at 22 weeks

Question #3

If NICU care is an option and my baby survived this journey, what are the health issues my baby can have?

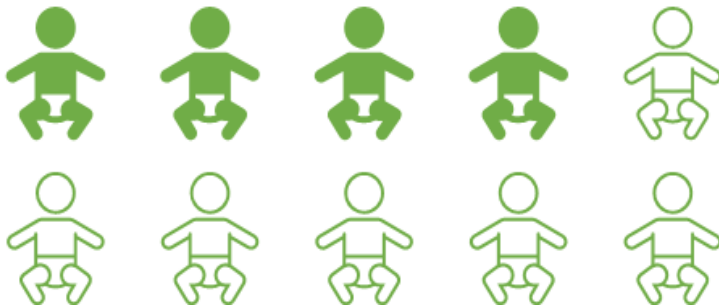
The earlier your baby is born the higher the risk of having these types of problems:

- Challenges with movements causing activity limitations (cerebral palsy).
- Challenges in solving problems of everyday life, and with learning.
- Behaviour issues.
- Ability to hear and see.
- Lung disease and the need to go home on oxygen.

Predicting the chance that an individual baby will or will not have a disability is difficult. There are many different factors involved. Babies born extremely prematurely are much more likely to have major, long-term problems or neurodevelopmental impairment (NDI). Regardless of whether they do or do not have impairments, they may bring love and joy to a family. These impairments can be mild, moderate or severe.

**About 34% (between 3 and 4 in every 10 babies born at 22 weeks) who survive have a significant impairment, that affects movements, problem solving, vision or hearing problems.**

(CNFUN report 2009-2018)



Question #4

What will my baby's life be like?

Life for 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. From long term follow up studies, we do know that adolescents who are born extremely premature rate their life to be very similar to adolescents who were born at term.

Question #5

Where can I go for more information and support?

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. If you require support, please speak with your healthcare team for more information. Your healthcare team cares for you and your baby and includes physicians (residents, fellows, obstetricians and neonatologists), nurses, social workers, spiritual care specialists or other healthcare team members.

**CANADIAN PREMATURE BABIES FOUNDATION**

Includes a lot of great information – can be found online by visiting: <http://cpbf-fbpc.org/>

**NICU**

(we can arrange a tour if you are interested)

Phone #: \_\_\_\_\_

**NICU PARENT SUPPORT**

NICU has a team of volunteer veteran parents to support you in your NICU journey. They understand your journey because they have been through it too. They are available on the unit to talk to you and help you through your NICU experience.

## SOCIAL WORK

The Social Work Department recognizes that being at risk for a preterm delivery can be very difficult and add emotional distress in your life. Social workers are here for you, to listen and provide support. They can help with financial issues, transportation needs, living arrangements, counselling, stress management and difficult personal or family situations.

## SPIRITUAL CARE

They support and guide families as they process their thoughts and feelings regarding moral, spiritual and/or religious beliefs assisting them to find comfort, hope and healing.

## WOMEN'S HEALTH PSYCHOLOGY

This service is available to women who would like to speak with a psychologist about adapting to new life circumstances or who are grieving. A referral from a health care team member is required to access the service – more information can be found online:

<https://wrha.mb.ca/psychology/services/womens-health/>

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