



Information for Families and Caregivers Babies Born at 22 Weeks of Pregnancy (Extremely Premature)

You have been given this information because it is possible your baby may be born very early.



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

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

During the consult, the doctor will go over the difficulties your baby may have. The NICU journey can be hard. 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.

This pamphlet will help you to understand the kind of difficulties your baby might face. 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 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 intensive care unit (NICU) and will spend many months in the hospital.

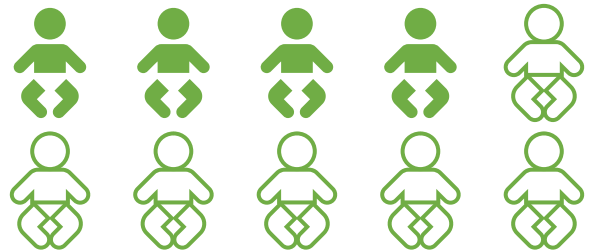
In Canada, and based on a small number of babies, about 2 or 3 out of 10 babies born at 22 weeks survive when they receive intensive care.

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)

4 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 care in NICU or palliative comfort care. Each baby and family are unique, and we are here to support your choice.

PALLIATIVE CARE

This type of care aims to improve the quality of living and dying for infants with serious issues like very premature babies who are very fragile. It can be provided at the same time as care in NICU or care focused on comfort.

CARE FOCUSING ON COMFORT

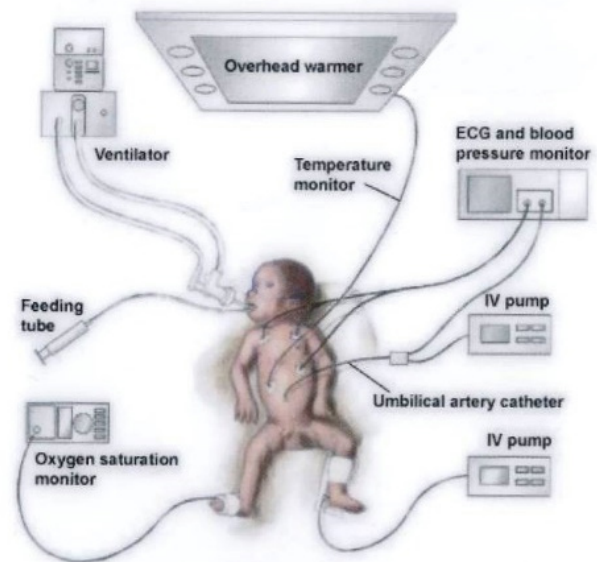
Sometimes parents choose to not start treatments. Or they choose to stop treatment that are not working for their baby. This allows parents to provide care focused on comfort for the duration of their baby's life and avoid medical tests and procedures. The main goal is to keep your baby pain-free while 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 other family member 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 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. Your baby will have a natural death within minutes to hours (rarely, if ever, longer than 24 hours).

"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

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 baby will be taken to the NICU very quickly after delivery. Babies in NICU will need various machines to help them to breath, keep them warm, feed and grow.

Even with this support, your baby may not survive. There may come a time when a discussion to stop NICU care is needed. This may happen if despite all support, your baby is not improving. These are called goals of care, 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

What are the health issues my baby can have later, after NICU?

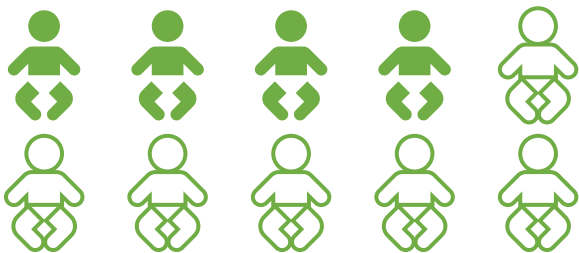
The earlier your baby is born the higher the risk of having these types of problems:

- Can affect their movements including walking (cerebral palsy).
- Challenges in solving problems of everyday life, and with learning.
- Problems at school or home.
- Hearing and seeing.
- Lung disease and the need to go home on oxygen.

Knowing the chance that your baby will or will not have any of these problems is difficult. There are many different factors involved. Babies born very early 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 23 weeks) who survive have a severe 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 very premature and their parents tend to vary. 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 very early.

Whether these changes affect you will depend on how you deal with these changes. Each family is unique. From long term follow up studies, we do know that teenagers who are born premature rate their life to be very similar to those who were born at term.

Question #5

Where can I go for more information and support?

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. Please let us know if you have any questions or you would like more information.

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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