

Neonatal Follow-Up Program

An information package for parents and families



November 2017

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Letter to Parents

Every child is amazing. Watching a child grow and develop is wonderful. For parents who have spent time with their child in a hospital, there can also be worry mixed with wonder.

Children who start life in a Neonatal Intensive Care Unit (NICU) have different experiences than those who do not. Often, these experiences can be stressful and affect how the brain develops and grows, particularly during their time in the NICU.

The purpose of the Neonatal Follow-Up Program (NFUP) is to give parents early support and help them learn more about their child. Ontario's NFUP consists of 25 clinics. At the clinics, staff will teach you exercises and activities that can help your child develop and thrive.

Visiting a NFUP clinic can be stressful. Please know that the follow-up team is there to help you and your child. We will play with your child and learn about his/her strengths and challenges. We will talk to you about what we see and hear your concerns. We will work together and make the best plan for your child. The best plan is one that is achievable for you and that gives your child the best chance of a happy and healthy future.

This information package provides resources to help you meet your child's needs. If you ever have any questions or concerns, please contact your primary care provider or follow-up team for guidance.



Frequently Asked Questions

Q: Why is it important for my child to visit the NFUP?

We want to learn about all the great things your baby is doing. We also want to see if there are any areas of concern. Neonatal Follow-Up team members have skills to help babies with their development. The sooner families and team members start working together, the better. By doing so early, we can help to teach you and your baby ways to work around any difficulties.

Q: What does “corrected age” mean?

Corrected age is when we look at a baby’s age in relation to his or her due date and not birth date. For example, let’s look at a baby who was born on May 1st but was due on August 1st. On September 1st this baby’s real age would be 4 months, but corrected age would be 1 month.

Q: Why is my baby’s corrected age important?

When a baby is born early, he/she really has 2 birthdays: the day of birth and the original due date. When measuring development, it is important to think about both dates.

Knowing your baby’s corrected age will help you know when to expect your baby to reach certain milestones. For example, most babies are expected to be able to roll over by 4 to 6 months. If your baby’s real or chronological age is 4 months, but her/his corrected age is only 2 months, then you would not expect your baby to do that yet.

Q: What if I have concerns or what if my baby needs more help?

We will discuss any concerns you or the clinic staff may have about your baby’s development. If your baby needs help, you will be referred to specialized services; for example, an infant development program, physiotherapy, occupational therapy, or speech therapy. Also, be sure to talk to your primary care provider, like your family doctor or paediatrician, about any concerns you might have.

Q: If I have concerns about my baby should I call my baby’s doctor or the NFUP clinic?

If you have any questions about your baby’s health or development, your first call should always be to your primary care doctor or care provider. The team at your NFUP clinic works in partnership with your baby’s primary care providers. We will send a letter to your child’s family doctor or paediatrician after every visit.

Q: What types of assessments are done during appointments?

Some of the visits will use standardized screening tools to identify any potential issues. We will ask children to play or do certain tasks and we will observe them. Babies do not get needles at follow-up visits.



Visiting a Neonatal Follow-Up Program Clinic

At program visits, you will have an opportunity to ask questions, bring up any concerns you might have about your baby's development, and get help for your baby and your family. It is common for babies who were born preterm or who spent time in the NICU to experience weakness and some delays. It is best to find this out as soon as possible so that your baby can get the right help at the right time.

Children are usually seen at a NFUP at the following ages or corrected ages:

- 4-8 weeks post-discharge
- 4 months
- 8 months
- 12 months
- 18 months
- 36 months

If your baby is not yet reaching specific milestones, the team will help you and your baby work toward these goals. If your baby is making good progress, we will coach you on what to expect next and how to help your baby achieve the next steps.

What to expect at your visit

Appointments usually take between 30-60 minutes. While some appointments involve screening or assessments, others are more open-ended.

In the clinic, your child's development will be looked at. There are several ways development is evaluated. One of the best ways for us to learn about your child's development is from you! Your input and insight is very important. In addition to that, the team at your Follow Up clinic may choose to do a screening assessment, which identifies the possibility of challenge. The team may also decide to do an assessment which is a more specific evaluation that can identify concern or a specific delay as well as strengths that your child has. From this information, we can work with you to make a plan to help you and your child!

Ask your team more questions about how they are evaluating your child's development and always speak up about your thoughts, they are most important!

Things to Remember

- You will receive a lot of information at your appointment so come with another person if you can, or take notes.
- Write down your questions ahead of time so you do not forget any; the team will address as many as they can.
- Do not be surprised if you get "homework" at the visit (such as exercises to do at home). It is not a sign that you are not doing a great job. It is just a way for you to give your baby some guidance for skills he or she is working toward.

- While we are here to help your baby, we are also here to help you. We may ask questions about how you are feeling and coping, and we hope you will share your thoughts and feelings about your own well-being with us.
- Do not be afraid to speak up. If you have questions or we do not talk about something important to you, please let us know. We are here to help and support you.



Neonatal Follow-Up System

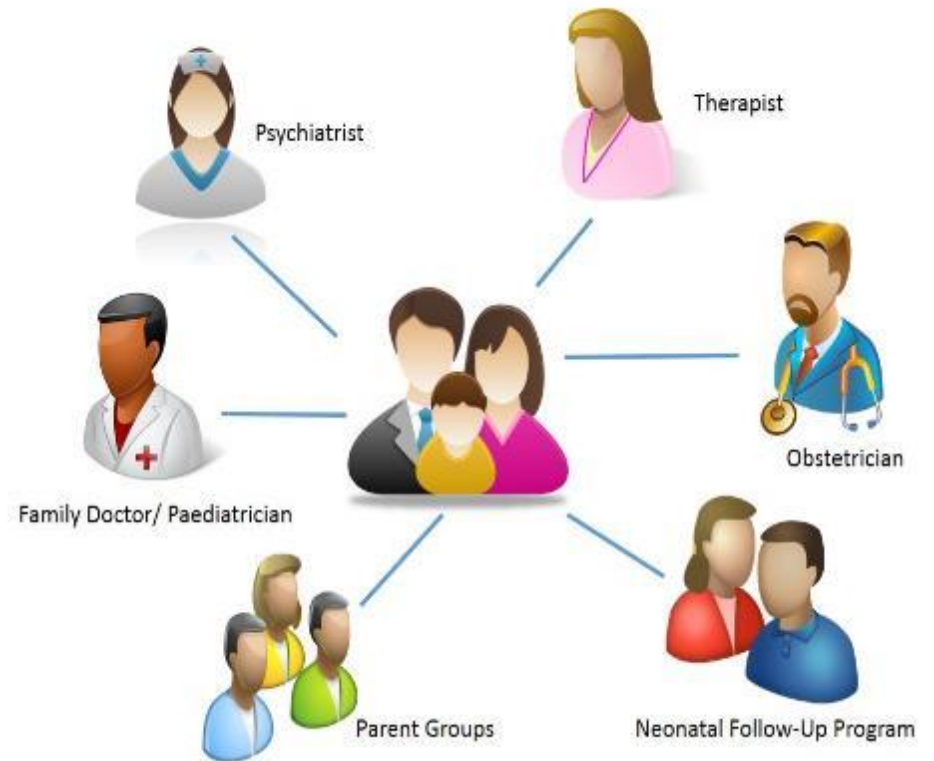
Neonatal follow-up care focuses on you and your baby!

Follow up is an important opportunity

- To check on how you are doing emotionally
- For you to learn about your baby
- Learn about how to help your baby recover from the NICU

We focus on your baby’s developmental needs but do not deal with medical needs such as vaccinations or if your baby is not feeling well. It is important to understand the other providers, people and resources available to help you and your family in the journey to care for your baby.

You can ask questions about the care you think your child needs. Feel free to ask for more information or about resources you can access to learn more and get support for your baby.



Physical Development

Your baby will go through a lot of physical changes in a short period of time, from rolling in both directions, to crawling, standing and walking. It is important to know how you can help with your child's development. The team at the NFUP will examine your baby's activity and provide important tips and input to help. It is also important to identify challenges for your child early, to allow for more specific exercises and interventions.

Your primary care provider should regularly measure your baby's weight, length and head size to assess their growth and determine if there are any concerns as soon as possible.

If you are concerned at any point about your child's development, seek help. Contact your paediatrician, family doctor, or primary care provider. You can also contact your local NFUP clinic to get more information.



Resources

Centre of Excellence for Early Childhood Development

http://www.excellence-earlychildhood.ca/documents/Parenting_2011-04.pdf

About Kids Health

<http://www.aboutkidshealth.ca/En/ResourceCentres/PregnancyBabies/Babies/PhysicalDevelopmentofBabies/Pages/default.aspx>

Caring for Kids

http://www.caringforkids.cps.ca/handouts/your_childs_development

Healthy Families BC

<https://www.healthyfamiliesbc.ca/home/articles/babies-physical-development-0-6-months>

Tip: Play time is not only a great bonding experience for you and your child but also a great way to support healthy physical and mental development.

Tip: Avoid toys such as 'jolly jumpers' or exersaucers. The best place for your baby to play is on the floor with you!

Nutrition

Good nutrition is key to your child's healthy development. Exclusive breastfeeding (or providing breast milk), when possible, is recommended for the first six months of a child's life with breastfeeding continued up to two years and beyond. Some small babies will need extra calories added to some of their feeds to boost their growth. Feeding generally progresses based on your baby's corrected age rather than birth day.

When your child starts eating solid food, it is important to know the safest ways to prepare, use and store food. You also need to know how babies show they are ready for solid food. Most babies will start solid food between 5 to 6 months corrected age.

Resources

Mount Sinai – Breastfeeding your Preterm Baby

<https://www.mountsinai.on.ca/care/nicu/Documents/PDF/Breastfeeding.pdf>

Peel Region – Breastfeeding in the First Few Weeks

<http://www.peelregion.ca/health/family-health/breastfeeding/first-weeks/enoughmilk.htm#howto>

Breastfeeding Resource Ontario

<http://breastfeedingresourcesontario.ca/>

Feeding Matters

<https://www.feedingmatters.org/>

Healthy Canadians: Healthy Eating for Children Under 5

<http://healthycanadians.gc.ca/eating-nutrition/healthy-eating-saine-alimentation/safety-salubrite/vulnerable-populations/children-under-5-moins-enfant-eng.php>

Eat Right Be Active: A Guide for Parents and Caregivers

http://www.beststart.org/resources/nutrition/pdf/erba-eng-3-5_01OC07.pdf

Eat Right Ontario: Child and Toddler Nutrition

<http://www.eatrightontario.ca/en/Articles/Child-Toddler-Nutrition/Help!-My-kids-won-t-eat-enough-vegetables-and-fruits.aspx#.V6JQFvkrKUK>

Tip: Feeding should be fun! Sometimes it is hard to enjoy the time spent feeding your baby, especially if your baby has had a hard time learning to eat. The most important thing to remember is to pay attention to your baby's cues not a set amount. Feeding shouldn't be stressful. If it is not enjoyable for you and your baby, talk to your Neonatal Follow-Up

Sleep

Sleep is essential for healthy development. It is important to make sure that your child gets enough sleep every day. The following resources provide information on how much sleep children need and how to ensure that they have a good night's sleep in a safe environment. Remember – back to sleep and front to play!

Resources

Healthy Families BC: Encouraging a Healthy Sleep Schedule

<https://www.healthyfamiliesbc.ca/home/articles/baby-sleep-schedule>

Best Start Resource Centre: Sleep Tips

http://www.beststart.org/resources/hlthy_chld_dev/sleep_tips/BSRC_Sleep_Well_TIPS.pdf

The MotHERS Program: Safe Sleep and SIDS

<http://www.themothersprogram.ca/after-delivery/sids>

Public Health Agency of Canada: Safe Sleep

http://www.phac-aspc.gc.ca/hp-ps/dca-dea/stages-etapes/childhood-enfance_0-2/sids/index-eng.php



Tip: Sleep is important for babies, and it is also important for parents! If you are sleep deprived, it becomes harder to enjoy time with your baby and be the parent you want to be. Ask your partner or support people to help you get the sleep you need.

Speech and Language

Communication starts before words! Your child will quickly let you know important things with his or her cry, eye contact, body language and voice. Up to age 5, children quickly develop speech and language skills. Encourage speech in whatever language is used at home and learn about what milestones to expect. You will then be able to tell if there are any reasons to be concerned about your child.

Resources

Government of Alberta – Talk Box

<http://www.humanservices.alberta.ca/family-community/talk-box.html>

Ontario Ministry of Children and Youth Services - Preschool Speech and Language

<http://www.children.gov.on.ca/htdocs/English/earlychildhood/speechlanguage/index.aspx>

Children's Treatment Network

<http://www.ctnsy.ca/Online-Resource-Centre/Speech-Language-and-Communication.aspx>

Autism Navigator

<http://www.autismnavigator.com/>

Tip: From the time your child is born, it is important to sing, talk and read age appropriate books to your child. Interacting often with your child will help him/her with their speech and language development. The more they hear different words, the more they

Play Time

Babies need to play and move in order to learn. Time spent practicing skills is important play. Instead of using screens to distract your baby, read books. Take your baby to the library. Remember that you are your baby's best toy.

Put babies to play on their tummies as much as possible when they are awake. This promotes head control and strengthens arms and tummy muscles. Encourage your baby to lift their head by using your face, a mirror, or a favourite toy. If your baby does not enjoy tummy time, you may also need to provide short frequent sessions of tummy time, like with every diaper change.

As your baby gets stronger, you can help by placing your hand on the baby's bottom and pressing gently back and downward to shift baby's weight off his/her face. Also encourage babies to turn their heads from side to side.

Resources

Sunnybrook Hospital: Tummy time exercises for your baby

https://www.youtube.com/watch?v=UEnzqSK-j_s

Therapy BC

<http://www.therapybc.ca/eLibrary/docs/Resources/Tummy%20Time.pdf>

Zero to Three

<https://www.zerotothree.org/early-learning/play>

Child and Family Mental Health

The NICU can be a stressful place. Parents who have spent time in the NICU with their babies can feel depressed or anxious, even after they go home. It is possible that new moms and dads may experience depression, anxiety or post-traumatic stress disorder (PTSD) after spending time in a NICU.

At your NFUP appointment you should be asked about your own mental well-being. We want you to bring your concerns and worries to the team. We will work with you to find help.

Your baby's mental health is connected to your own. To support your baby's mental health, spend time connecting with and responding to your baby. Babies need a strong attachment to their parents or primary caregivers.

Do not forget to spend time caring for yourself. You may want to connect with people who understand your situation, like other NICU parents. Make sure to regularly get enough sleep, good food, and some exercise. If possible, reach out to your support system to help you when possible. For example, ask a family member to hold your baby while you get some sleep. It is easy to forget about yourself when you have a baby. It won't be good for your baby if you forget about your own needs.



Resources

If you are in crisis, call 911 or go to the nearest emergency room

Canadian Premie Parent Support Network

<https://www.facebook.com/groups/CanadianPremieParentSupportNetwork/>

Life with a Baby

<http://www.lifewithababy.com/>

Children's Treatment Network

<http://www.ctnsy.ca/>

Mental Health Helpline

1-866- 531-2600. <http://www.mentalhealthhelpline.ca/>

Infant Mental Health Promotion

<http://www.imhpromotion.ca/>

Reaching IN Reaching OUT

<http://www.reachinginreachingout.com/resources-parents.htm>

More Resources

Parents for Kids – Information for parents from Canadian paediatricians.

<http://www.caringforkids.cps.ca/>

Ministry of Child and Youth Services – Information about government resources available for new parents and families.

<http://www.children.gov.on.ca/htdocs/English/earlychildhood/index.aspx#!>

About Kids Health – A health education resource for children, youth and caregivers that is approved by health-care providers at The Hospital for Sick Children.

<http://www.aboutkidshealth.ca/En/Pages/default.aspx>

Telehealth – A free, private service you can call to get health advice or information.

<https://www.ontario.ca/page/get-medical-advice-telehealth-ontario>

Canadian Premature Babies Foundation – Provides resources, for both parents and those supporting them, about life in the NICU and beyond.

<http://www.cpb-fbpc.org/>

Life with a Baby - Ongoing practical and emotional peer-based support for new and expecting parents, and parents of children up to the age of six.

<http://www.lifewithababy.com/>

OMama – Trusted, evidence-informed healthy pregnancy, birth and early parenting information for Ontario, Canada.

<http://www.omama.com/>



Access the Ontario Neonatal Follow-Up Program
Directory for more information about your local
program.

www.pcmch.on.ca