McMaster Children's Hospital

Cystic Fibrosis:

An introduction for parents

Information from the Pediatric Cystic Fibrosis team

Cystic Fibrosis: An introduction for parents

Learning that your child has cystic fibrosis can be overwhelming. You will have many questions. This is normal.

The Pediatric Cystic Fibrosis Team wants you to know that you are not alone. We are here to help you, your child and your family.

This binder has basic information about cystic fibrosis and your child's care. It supports what we will teach you in the clinic. Please feel free to ask us questions at any time.

Inside this binder

Learning about Cystic Fibrosis

Cystic Fibrosis (CF) is condition that mainly affects the lungs and digestive system. The effects of CF are a result of changes in mucus and sweat.

CF makes mucus thick and sticky

- Mucus is normally a thin, slippery fluid. It lines the inside of body parts like the nose, mouth and lungs and keeps them moist.
- With CF, sticky mucus can build up in the lungs and block the airways. This causes breathing problems and infections that can damage the lungs.
- Sticky mucus can also build up and block parts of the digestive system. A blockage in the tube (duct) leading from the pancreas to the intestines prevents enzymes made in the pancreas from reaching the intestines where they are needed to break down and absorb food. Without enzymes, the body can't take in enough fats and protein. This can lead to poor weight gain and problems such as gas, bulky or greasy bowel movements and constipation.

CF makes sweat very salty

- With CF, the body loses a lot of salt with sweating. This can upset the balance of minerals in the body and cause health problems.

CF is:	Inherited	→	It is passed from parents to children through genes.
	Chronic	→	It is a condition that needs lifelong treatment.

What are the symptoms of cystic fibrosis?

The symptoms of CF include:

- a persistent cough
- difficulty breathing
- wheezing
- lung infections (pneumonia)
- very salty tasting skin
- poor weight gain

Each child's symptoms may be different.

Symptoms can range from mild to severe.

Symptoms can change over time.

How is CF treated?

The goals of treatment are to maintain good health, ease symptoms and slow the progress of the condition.

The CF Team will plan treatment to meet your child's needs. This will include treatment to clear the lungs, improve nutrition and add daily physical activity.

Treatment cannot cure CF, but it will help your child grow and stay as healthy as possible.

Clearing the lungs

Chest physiotherapy, medications and physical activity help to clear the lungs of thick, sticky mucus. This will:

- help your child breathe easier and take in more oxygen
- protect your child's lungs and prevent infections

Chest physiotherapy includes:

- clapping and/or vibrating techniques to the chest to loosen mucus
- different positioning to drain mucus
- various deep breathing and coughing exercises to get mucus out

Medications can be used to:

- thin mucus
- open airways
- reduce swelling in airways
- prevent or treat lung infections

Physical activity helps to:

- clear mucus from the lungs
- help air enter the lungs
- help the lungs hold more air
- keep lungs working as well as possible

Improving nutrition

The CF Dietitian will help you plan a diet with enough calories, fat, vitamins, calcium and salt to help your child grow normally and fight off infections.

To replace enzymes made in the pancreas, your child may need to take enzymes with meals and snacks. Your child may also need vitamin supplements.

For more treatment information:

- **Nutrition and CF – page 13**
- **Physiotherapy and CF – page 16**
- **Medications and CF – page 19**

What is the outcome of treatment?

CF is a chronic or lifelong condition. It is most helpful to start treatment as soon as possible. Your child's treatment will continue throughout his or her life. This will include daily therapy and regular visits to the CF clinic.

Most people with cystic fibrosis lead normal, active lives for many years.

Nearly 60% of all people with cystic fibrosis in Canada are adults.

For more Canadian facts and figures go to www.cysticfibrosiscanada.ca

Symptoms of CF can get worse over time. The CF team will keep you informed about your child's condition and answer any questions that you may have.

Hearing the diagnosis

Learning that your child has CF can be devastating. When you first hear the diagnosis you may be in shock and may even deny what is happening. You will have mixed emotions. Sometimes you may feel afraid, angry or guilty. Other times you may feel sad, depressed or numb.

All of these feelings are normal.
They are part of grieving. You are dealing with the loss of the “perfectly healthy” child that you had expected.

Another common response is relief.
You have finally found the reason for your child’s health problems. It is not unusual to feel guilty about this reaction.

Acknowledging your feelings is an important step in accepting your child’s diagnosis.

Coping with the diagnosis

Everyone copes in a different way. You and your spouse or partner may react differently to the diagnosis. You may find it hard to listen, talk and support your partner when you are hurting badly. Each of you needs someone to confide in. Sometimes this may be each other. At other times, it may be helpful to talk with another person that you trust.

At the time of diagnosis, you may feel overwhelmed with information. In the clinic, please ask us to repeat or explain information as often as needed. We are here to help you and your child.

How can the Social Worker help?

It can be very stressful to face a lifelong illness, learn new skills to care for your child and make big changes to your daily life.

It is normal to feel many emotions such as sadness, fear, anger, disbelief, frustration and guilt. These feelings may come and go. They may also appear because of other stressful situations in your life, such as a family conflict or losing a loved one.

Sometimes the stress from CF and life in general becomes overwhelming. It can interfere with your daily life and affect your ability to manage your child's condition and treatments. If this happens, it is important to talk about it and get help.

If you, your child or family need help or support, please speak with the CF Social worker. She can help you develop healthy coping skills, improve communication and connect with helpful resources in your community.

How can the Child Life Specialist help?

The CF Child Life Specialist can help your child and family by:

- explaining cystic fibrosis in a way your child can understand
- helping your child find ways to safely express his or her feelings
- using medical play to help your child learn about his/her treatment
- preparing your child for treatment or medical procedures such as blood tests
- helping your child overcome challenges such as swallowing pills
- helping your child learn healthy ways of coping with difficult experiences related to health care and the hospital
- helping your other children learn and express their feelings through play
- explaining your child's needs to the other members of the health care team

Learning to live with CF

- ✓ Learn as much as can about CF so you will be better able to keep your child healthy.
- ✓ Be ready and willing to explain CF to anyone who wants to learn.
- ✓ Enjoy your child. Do not let CF define your child.
- ✓ Try not to be overprotective. Like all children, your child needs to explore his or her world.

- ✓ Be consistent. If you can't be consistent, be close. When you aren't close, make adjustments.
- ✓ Be prepared and plan ahead.
- ✓ Acknowledge and express your feelings.
- ✓ Work on having a positive attitude. This will help your entire family.
- ✓ Don't be afraid to get help. If you, your child or family are struggling, ask for help. You are going through this together.
- ✓ Join your local chapter of Cystic Fibrosis Canada to meet other families dealing with the same concerns.
- ✓ Over time, teach your child to take responsibility for his or her own health, to honestly deal with the realities of CF and to foster a positive attitude toward life.

Your Pediatric Cystic Fibrosis Team

Val Carroll **Nurse Coordinator**	Val is the first person to call when you have a question about cystic fibrosis. She provides your child's nursing care. She is the main contact between clinic visits for CF issues and concerns.
Jane Nash **Clinic Nurse**	Jane also provides your child's nursing care. She can answer questions you may have about cystic fibrosis.
Dr. Linda Pedder **Medical Director of Pediatric CF Clinic**	Dr. Pedder is responsible for your child's medical care. Your child will see Dr. Pedder at each clinic visit. She will check your child's health and refer your child to other services, if needed.
Rachel Freeman **Registered Dietitian**	Rachel will help you make sure your child grows and gains weight appropriately. She provides nutritional care, including advice about breastfeeding, foods, enzymes and supplements.
Julie Ball **Physiotherapist**	Julie will teach you how to clear your child's airways. She checks how well your child's lungs are working and changes therapy to meet your child's needs.
Jennifer Thomas **Social Worker**	Jennifer's role is to help you and your family cope with the diagnosis of CF and managing this chronic condition. She will give you lots of support, including help to find community resources and financial assistance, if needed.
Heather McKean **Child Life Specialist**	Heather can explain cystic fibrosis to your child and his or her siblings, in a way each one can understand. She can help your child express his or her feelings and learn ways to cope with difficult experiences relating to CF care.
Family Doctor	Clinic visit information is shared with your child's family doctor. The family doctor will follow your

child for routine medical care, including immunizations.

How to reach us

McMaster Children's Hospital: 905-521-2100

2G Pediatric Cystic Fibrosis Clinic appointments – call ext 78515

- At each clinic visit, please take time to book your next appointment. We reserve 1pm appointments for babies.
- Call us if you need to cancel or change an appointment.

Outpatient Pharmacy – call ext 75019

- To reorder medications that your child takes regularly (such as enzymes, vitamins, Ventolin), please call at least 1 week before your clinic visit. This gives the pharmacy time to prepare the medications and have them ready for you at your clinic visit.

Dr Linda Pedder – call ext 73508 (secretary)

- Your child's other doctors (family doctor, pediatrician, or specialist) may want to discuss your child's care with Dr. Pedder. They can reach Dr. Pedder through hospital Paging at 905-521-5030.

Nurse Coordinator – call Val Carroll ext 73086

- On clinic days or for urgent issues, call hospital Paging at 905-521-5030 and ask for Pager 1127.

Clinic Nurse: Jane Nash – call ext 72401

Dietitian: Rachel Freeman – call ext 72591

Physiotherapist: Julie Ball – call ext 76457

Social Work: Jennifer Thomas – call ext 76559

Child Life Specialist: Heather McKean – call ext 76661

The Dietitian, Physiotherapist, Social Worker and Child Life Specialist work part-time at the clinic. If they are not working when you call, please leave a message. They will call you back as soon as possible.

For concerns or questions not related to CF, call your family doctor or pediatrician, go to a walk-in clinic, or take your child to the emergency department.

What to expect at the clinic

McMaster Children's Hospital CF Clinic:

- Monday afternoons and Tuesdays
- In the 2G area, beside the main entrance on the 2nd floor

Clinic visits

When CF is first diagnosed, your child will have many clinic visits. Later on, you won't need to visit as often. Our goal is to see your child at least every 3 months and more often if he or she is unwell.

Your child will see Dr.Pedder at every visit. You will see other team members as often as needed. You can ask to see any team member at a clinic visit if you have questions or concerns.

We make every effort to see your child at the scheduled appointment time. If there is a delay we will try to make your waiting time as short as possible.

It is best to be prepared for clinic visits to last several hours. Please bring snacks, medications and activities for your child.

Tests

We will swab your child's throat or take a sample of sputum (spit) at each visit. These tests help us check for infection and decide the best treatment.

Once a year, your child will need:

- blood tests to assess overall health status, measure vitamin levels and check how well the liver is working
- a chest x-ray

When your child is around 6 years old, he or she will have a breathing test (Pulmonary Function Test) before each appointment. The results of this test help us monitor the health of your child's lungs.

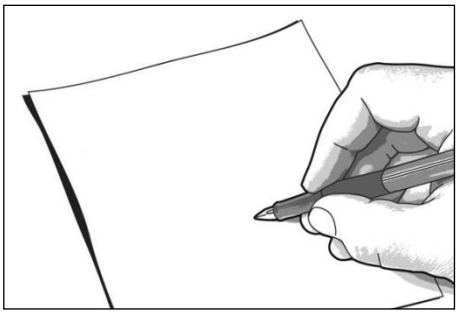
Every 2 years, your child will have an abdominal ultrasound to look for any changes in his or her liver.

Starting at age 10, your child will have more tests:

- Oral Glucose Tolerance Test – to check how your child's body responds to sugar. This helps us check for diabetes related to CF.
- Exercise testing – will be done approximately every 6 months.

How to get the most from your clinic visits

Before your visits



- ✓ Write down questions and concerns
- ✓ Write down your child's symptoms
- ✓ Bring the records you keep about your child, such as food records

During your visit

- ✓ Take time to ask questions
- ✓ Write down the answers
- ✓ Repeat the answers in your own words to check your understanding
- ✓ Tell us if there is something that may prevent you from following the treatment plan
- ✓ Make specific plans
- ✓ Ask about books or community resources

After your visit

- ✓ List the recommendations
- ✓ Decide to follow recommendations
- ✓ Tell others your plan
- ✓ Keep a journal or diary
- ✓ Seek out supports as needed
- ✓ Review your questions list

Nutrition and CF

Breastmilk or formula gives babies all the nutrition they need until 6 months of age. Good nutrition helps babies with CF to grow, develop normally and fight off infections in the lungs.

For more help growing:

- Breastfed babies can be given a small amount of formula after nursing to add some extra calories.
- Formula fed babies may be given a formula that is higher in calories or easier to digest.

Just as with other babies, solids like cereals, strained meats, vegetables and fruits should be added to the diet at 6 months of age. Your CF team dietitian can help you make sure that your baby gets enough iron, fat and calories from these first foods.

- ✓ **A well balanced, high calorie diet with plenty of salt, fat and extra vitamins can help to keep your child healthy.**
- ✓ **A healthy body weight is linked to good lung function.**

Why does my child need more calories?

Your child may need 10 to 50% more calories than children without CF.

Extra calories are needed because:

- foods are not fully absorbed
- breathing and coughing is hard work that takes a lot of energy
- fighting infections in the lungs takes extra energy

Fat has the most calories (more than carbohydrate or protein), so the CF Dietitian may recommend a high-fat diet for your child.

Why are enzymes sometimes needed?

- If the tube between your child's pancreas and intestine gets blocked with sticky mucous, enzymes made in the pancreas cannot get to the intestine where they are needed to digest food.
- Your child can take capsules containing enzymes with meals and snacks. The enzymes help to break down and absorb food. This helps your child gain weight, grow properly and stay healthy.

Why are vitamins needed?

- Vitamins help keep your child healthy and strong, and prevent infections.
- Some vitamins (A, D, E, and K) must be absorbed along with fat. If your child has difficulty absorbing fat, he or she may not get enough of these vitamins from foods. Your child can take vitamin supplements that are made for children with CF. (At this time, the CF specific vitamin, MVW Vitamins, is **not** covered under the CF formulary).

Why is calcium important?

- Calcium is important at every stage of life to keeps bones strong and growing properly.
- If your child has digestive problems, he or she may not absorb enough calcium. Your child can eat calcium-rich foods or take a calcium supplement.

Why is more salt needed?

- Children with CF lose more salt in their sweat than other children.
- To replace this salt, your child can add salt to foods and choose salty foods and snack.

How can the CF Dietitian help?

The CF Dietitian can:

- Measure and weigh your child at each visit to make sure he or she is growing properly.
- Teach you and your child about good nutrition and how to make sure your child gets enough calories, fat, vitamins, calcium, and salt to grow normally and fight off infections.
- Suggest ways to give your child extra calories when needed.
- Make sure your child's enzymes are working properly.
- Give you specific information about nutrition and answer any questions that you may have.

Good nutrition is vital for children with CF.

The Dietitian can help you learn how foods, enzymes and supplements help your child grow and stay healthy.

Physiotherapy and CF

How do lungs work?

The main job of the lungs is to bring the oxygen we need into our bodies and remove the waste gases our bodies don't need.

When we breathe in, air enters the trachea (wind pipe). The trachea divides into two 'branches' that take the air into each lung. The air continues to flow through smaller and smaller branches until it reaches tiny air sacs (alveoli).

In the alveoli:

- Oxygen is moved from the air into the blood. The blood carries the oxygen to all parts of our body.
- Carbon dioxide and other waste gases are moved from the blood into the air. This air leaves our bodies when we exhale.

How does CF affect the lungs?

The thick sticky mucus from CF can build up in the alveoli, making the transfer of oxygen and gases slow and difficult.

When the small airways fill with this mucus, the lungs are more likely to become swollen, inflamed and infected. The airways react by creating more thick sticky mucus, which makes it even harder to clear the lungs.

Why is it important to clear the lungs?

Clearing the lungs helps to keep your child as healthy as possible.

Daily chest physiotherapy and physical activity can:

- Prevent mucus from building up in the small airways
- Loosen and clear mucus from the lungs

When mucus is cleared from your child's lungs:

- ✓ The lungs work better
- ✓ There is less chance of a chest infection

What is chest physiotherapy?

Chest physiotherapy may include:

- Clapping (percussions) and/or vibrating techniques to loosen mucus. Family and caregivers do clapping with a cupped hand or manual cups to target specific areas of the lungs.
- Positioning to drain the loosened mucus from all areas of the lungs.
- Deep breathing and coughing exercises and games to move the mucus out of the lungs (starting at toddler age).
- Using devices to clear the airways (starting at early school age).

Each child's treatment plan varies, depending on his or her age and health needs.
The CF Physiotherapist will work with you to determine the routine and techniques that work best for you, your child and family.

How often will chest physiotherapy need to be done?

Chest physiotherapy is usually done two times a day. The timing of your child's chest physiotherapy will depend on his or her needs. If your child becomes ill, the CF team will decide if he or she needs more frequent or longer sessions.

Why is daily activity and exercise important?

Daily physical activity and exercise can:

- ✓ Open clogged or collapsed airways
- ✓ Loosen mucus so it can be cleared
- ✓ Help lungs and muscles work well
- ✓ Improve physical fitness
- ✓ Promote healthy development
- ✓ Improve quality of life

Regular physical activity and exercise is an important part of your child's CF care plan!

Daily physical activity and exercise includes:

- Moving large muscles to raise the heart rate. Examples are jogging, swimming and cycling.
- Strengthening muscles. Examples are lifting weights and body weight.
- Stretching to lengthen muscles and improve posture.

For older babies and toddlers, tumble play, jumping, walking and running are important ways to strengthen, stretch and clear their lungs **and have fun!**

Medications and CF

Your child may take a number of medications to treat CF. Many of the medications are covered under a special government medication plan, but some are not. Some medications may also be covered through the OHIP+ program. If your family does not have insurance coverage for prescription medications, speak with the Social Worker for help.

Antibiotics are used to prevent or treat infections. As lung infections are common with CF, antibiotics are an important part of your child's CF care.

Antibiotics come in three forms:

- **Oral:** liquid or tablets that are swallowed.
- **Inhaled:** an aerosol or mist that can be nebulized — turned into a fine mist which can be more easily breathed into the airway
- **Intravenous (IV):** liquid medications that go through the IV into the blood. Your child may need to stay in the hospital to have IV antibiotics.

Anti-inflammatory medications reduce swelling in the airways.

Bronchodilators help to open the airways by relaxing the muscles around them.

Mucus-thinning medications make mucus less sticky, so that it is easier to clear from the lungs.

Growth and development with CF

With improved nutrition, daily physical activity and CF treatments, your child's physical development (weight gain and growth) will be the same as his or her peers.

CF does not affect brain development. Children with CF learn and develop on track with their peers.

For more information

1. If you have questions about your child's development, talk with:
   - the members of the CF team
   - your family doctor, nurse practitioner or pediatrician

2. If your child is under 6 years of age, you can talk with professionals at one of the **Check it out** drop-ins that are held in different locations across Hamilton. For the schedule go to: www.hamilton.ca/HealthandSocialServices/PublicHealth/Nutrition/ChildDevelopmentScreeningClinic.htm

3. Read '**Let's Grow'** a series of newsletters about children's development from newborn to pre-school age. Let's Grow is available at: www.hamilton.ca/HealthandSocialServices/PublicHealth/Parenting/infant.htm

4. Family Resource Center and Growing Together (A Community Education Guide for Parents, Youth and Children) available at: www.mcmasterchildrensfamilyresourcecentre.ca

Common milestones for children in the first year

Milestones are tasks that most children can do at a certain age range. As all children develop differently, your child will develop in his or her own way. This chart is just a guide to what you can expect in the months ahead.

	From birth to 6 months	From 6 months to 1 year
Socializing	• Starting to smile • Imitate facial expressions • Mimic sounds • Babble, coo, gurgle	• Understands simple commands • Uses gestures to show needs • Says ‘mama’ ‘dada’ • Imitate others’ actions • Plays beside another child
Feelings and emotions	• Learning to soothe self after crying • Able to express feelings such as happiness, anger or sadness • Developing a sense of love and trust with caregivers	• Very curious about surroundings • Starting to have mood swings and temper tantrums • Upset when cannot have their own way • Loving but tends to focus on self • Gets anxious when separated from caregiver
Moving hands	• Puts toys in their mouth • Reaches for objects • Holds toys • Bats at toys or objects • Bangs toys together • Throws toys	• Learning to eat with fingers • Drink from a cup • Grasps objects with thumb and first finger • Holds two objects at the same time • Drops and picks up objects • Can push, pull and throw objects
Moving body	• Lifts head • Kicks legs • Rolls over • Sits with help • Begins to crawl • Like to bounce with support	• Sits without help • Pulls up to stand • Walks holding onto furniture • Moves from lying to sitting • Crawls well
Using senses	• Likes to feel different toys and textures • Likes to hear music, voices and different sounds • Likes to see faces, pictures and bright colours • Likes to be touched and cuddled	

Checklist for daycare or school

This checklist has helpful information for people who care for your child such as:

- daycare providers
- homeroom teachers
- school secretary
- principal
- lunchroom helpers
- babysitters

For more information see Cystic Fibrosis Canada's brochure:

"Education and Cystic Fibrosis: Information for Teachers and professors" at www.cysticfibrosis.ca

Arrange a meeting

- Phone the daycare or school and ask for a meeting to discuss your child's needs related to CF.
- Fill out the medical forms required by the daycare or school and take them to the meeting.

What your child's caregivers need to know

- ✓ Your child has Cystic Fibrosis. Give a simple explanation of what CF is and how it affects your child. If it is appropriate for you and the school, consider having a photo of your child and the diagnosis of CF posted in the staff room and office.
- ✓ Your child needs to take enzymes. Let them know your child carries a day's supply of enzymes and will take them with meals and snacks. The CF team can give you a letter explaining this to caregivers.
- ✓ Your child needs to drink fluids. Your child must always be allowed to get a drink of water and go the bathroom.
- ✓ You must be told of any changes in school routines, for example field trips and special events.
- ✓ All caregivers must know when, where and how to contact you (parents or guardians).
- ✓ All caregivers must know what to do in an emergency.

Helpful resources

Cystic Fibrosis Canada

A Canadian charity with 50 volunteer chapters. Your local chapter can connect you with other parents, families and people with CF. They have e-mail newsletters and support group meetings on topics related to CF.

Chapter	Address	Contact Person
Hamilton and Area Chapter	1300 Garth St. PO Box 79005 Hamilton, ON L9C 5V0	Chapter President Katie Schulz E-mail: mrskatieschulz@gmail.com
Kitchener-Waterloo Chapter	69 Sydney Street Kitchener, ON N2G 3V1	Chapter President Jamie Ruth E-mail: kwdcfc@golden.net
Niagara Chapter	c/o 7051 Dolphin Street Niagara Falls, ON L2E 6Y3	Chapter President Cherie Willis E-mail: cfniagara@hotmail.com

Publications from www.cysticfibrosis.ca

- Cystic Fibrosis in Canada
- Your Child and Cystic Fibrosis
- Education and Cystic Fibrosis: Information for teachers and professors
- Carrier Testing and Cystic Fibrosis
- Cystic Fibrosis and Lung Transplantation
- Disability Tax Credit and Cystic Fibrosis
- Infection Control and Cystic Fibrosis
- Newborn Screening and Cystic Fibrosis
- Sexuality and Cystic Fibrosis: Information for Adolescents
- Sexuality, Fertility and Cystic Fibrosis: Information for Adults
- When a Parent has CF: Explaining your illness to your child
- Summer Tips for CF Care
- Registered Disability Savings Plan and Cystic Fibrosis
- Travelling with CF
- Clinical trials: Information and Options for People with Cystic Fibrosis
- **The Guide: Resources for the CF Community**

To order printed copies, call 1-800–378–CCFF or email info@cysticfibrosis.ca

Community resources

If you are struggling with parenting or behavior issues, community resources can be helpful. The Social Worker may be able to give you more specific community resources, as needed.

Hamilton and area	
Inform Hamilton	http://inform.hamilton.ca/ A website to search for community resources.
Contact Hamilton	905-570-8888 Provides information and referrals for children/youth with emotional or behavioral issues.
Catholic Family Services	905-527-3823, ext 279 Provides individual and family counseling.
Ontario March of Dimes	905-528-9432
City of Hamilton Social and Public Health Services	905-546-3057
Ontario Ministry of Children and Social Services	905-521-7280 or 1-800-561-0568
Niagara and area	
Family Counseling Centre	905-937-7731, ext 3345
Regional Municipality of Niagara	www.niagararegion.ca A website to search for community resources.
Information Niagara	http://niagara.cioc.ca A website to search for community resources.
Ontario Ministry of Children and Community Services	1- 800-561-0568
Kitchener-Waterloo area	
Community Information Centre of Waterloo Region	www.waterlooregion.org A website to search for community resources.
Ontario Ministry of Children and Social Services	Waterloo office: 519-883-2100 Cambridge office: 519-740-5700

Resources for financial and lifestyle support

Assistance for Children with Severe Disabilities (ACSD)

Financial help for families with low or moderate incomes to help with extraordinary costs related to their child's disability.

http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/disabilities/index.aspx

Disability Tax Credit (DTC)

Your child with CF may qualify for the DTC if a medical doctor certifies that he or she needs, and dedicates time for, life-sustaining therapy (such as chest physiotherapy) at least three times a week, for an average of 14 hours a week.

http://www.cra-arc.gc.ca/disability/

Please note: Benefits received from either ACSD or DTC can be used to purchase MVW Vitamins or nebulizer supplies.

Child Disability Benefit

A tax-free benefit for families who care for a child under age 18 who is eligible for the disability tax credit. The benefit is based on family net income and provides a specific amount of money per eligible child each month.

http://www.cra-arc.gc.ca/bnfts/dsblty-eng.html

Make-A-Wish

Grants wishes of children with life-threatening illness. Anyone can refer a child for a wish. The child's age, health and safety are considered before a wish can be granted.

http://makeawish.ca/

Ministry of Children and Youth Services

This Ministry has a website listing of programs available for children with special needs.

http://www.children.gov.on.ca/

Jennifer Ashleigh Foundation

A children's charity that considers requests for emergency financial relief, medical treatment not covered by OHIP, parental relief, educational supports and some recreational programs.

http://www.jenash.org/

Starlight Children's Foundation Canada

This foundation provides wish-granting and entertainment to seriously ill children and their families. The Starlight Foundation runs online programs that are available across the country including Starbright World, an online networking service for teens.

http://www.starlightcanada.org/

Registered Disability Savings Plan (RDSP)

This is a savings plan operated by the Government of Canada to provide for the long term financial security of a beneficiary who has a prolonged physical or mental impairment. The beneficiary named under an RDSP must be eligible to receive the disability tax credit.

http://www.mcss.gov.on.ca/en/mcss/programs/social/what/rdsp.aspx

Canadian Cystic Fibrosis Foundation

This foundation has an online guide which outlines a number of provincial and federal resources available to CF patients and their families.

www.cysticfibrosis.ca/assets/files/pdf/TheGuide_Resources_CF_2009_E.pdf

CF words to know

Word	Meaning
ACBT	• Active Cycle of Breathing Technique. • A form of chest physiotherapy that uses controlled breathing and coughing to move mucus out of the lungs.
Acute	• An illness that lasts a short time, such as an infection.
Alveoli	• Tiny air sacs at the ends of the airways, deep in the lungs where the body gets its fresh oxygen supply.
Aerosol	• Tiny particles of liquid or solid forming a mist in the air. • In breathing treatments, a device can put medications into a mist so they can be inhaled directly into the lungs.
Antibiotics	• Medications that fight infections caused by bacteria. They may kill or prevent bacteria from growing. • Antibiotics may by given by mouth, by injection, by intravenous (IV) or inhaled during breathing treatments.
Bacteria	• Tiny germs that live and grow in the body. Some types of bacteria cause infections, but not all cause harm.
Blockage	• With CF, thick mucus may cause a blockage in the lungs (preventing air from moving freely in and out) or in the digestive system (preventing food from being digested and absorbed).
Bronchitis	• An inflammation of the lining of the bronchi (airways). Usually the result of infection caused by bacteria or viruses. • Bronchitis is a common complication in CF.
Bronchodilator	• A type of medication that relaxes the airway muscles. This allows the airways to open wider. • Bronchodilators help children with CF breathe more easily.

Word	Meaning
Calorie	• A measure of the amount of energy the body gets from food. • Children with CF need extra energy and must take in more calories than other children.
CF	• Cystic Fibrosis.
CFRD	• Cystic Fibrosis Related Diabetes. • Starting at age 10, your child will have an Oral Glucose Tolerance Test each year to check for diabetes.
Chest Physical Therapy	• Physical methods used to loosen and help clear mucus from the lungs. • Chest physiotherapy may include postural drainage, percussion, vibration and exercise.
Chronic	• A condition that lasts a long time. • Most chronic conditions such as CF, can't be cured. Treatment can manage the symptoms and effects of the condition.
Clubbing	• A condition is which the ends of the fingers and toes are enlarged or bulb like. The nails may also be rounded. • Clubbed fingers and toes sometimes appear in people who have a chronic lung disease, such as CF. The actual cause of clubbing is unknown.
Crackles	• An abnormal sound heard when listening to the lungs with a stethoscope.
Diabetes	• A disease in which the body loses the ability to make insulin. Insulin is made by the pancreas. It controls how the body uses sugar for energy. Without insulin, people cannot get the energy they need from food. • CF can damage the pancreas, which can cause diabetes.

Word	Meaning
Digest/Digestion	• The process of breaking down food into nutrients that are absorbed into the bloodstream and used by the body. • Digestion begins in the mouth and continues in the stomach and intestines.
Digestive System	• The digestive system includes the mouth, esophagus, stomach, small intestine, liver, pancreas, large intestine, rectum and anus. • These parts work together to take in food, break down food into nutrients that can be absorbed, and remove the wastes.
DIOS	• Distal Intestinal Obstruction Syndrome. A partial or complete blockage of the intestine. • The blockage is made up of partly digested food and mucus. It usually occurs in the large intestine (colon) or last part of the small intestine. It may cause stomach pain or constipation. • The problem becomes more common with age.
Enzymes	• Chemicals the body uses to break down or digest food. Without them, food can't be broken down into nutrients the body can use. • Enzymes are made in the pancreas. In CF, thick mucus can block the tube that carries enzymes from the pancreas to the small intestine. Without enzymes, food passes thorough the intestine without being digested. • Most people with CF must take pancreatic enzymes to digest food.
Esophagus	• The tube that connects the mouth to the stomach.
Gastro-Esophageal Reflux Disease	• Also called GERD for short. • The flow of stomach contents back up into the esophagus, because the muscle where the esophagus and stomach join is weak. This may cause vomiting or heartburn.

Word	Meaning
Genetic Counseling	• A discussion with a medical professional trained in genetics. Genetic counseling may help a couple figure out their risk of passing on an inherited disease.
Hypoxia	• A condition in which the amount of oxygen in the body is lower than normal.
Infection	• An illness that happens when a germ (bacteria or virus) grows in a body tissue and causes harm.
Infertility	• The condition where a person can't conceive a child. • About 97% of men with CF are infertile because the tube that carries sperm (vas deferens) is blocked. • Many women with CF are able to conceive. Abnormal mucus may block the cervix, however and make it difficult for some women with CF to get pregnant.
IV	• An Intravenous or IV catheter is a thin plastic tube placed in a vein. It can be used to give your child fluids and medications, such as antibiotics.
Lower Respiratory Infections	• Infections in the airways or lung tissue. In CF, such an infection is usually bronchitis or pneumonia. • The infections may be caused by bacteria or viruses.
Malabsorption	• A condition in which the body can't absorb nutrients properly from the intestine. • Most people with CF do not have enough digestive or pancreatic enzymes, and this keeps the food they eat from being properly digested. It passes out of the body without being absorbed or digested properly, causing fatty foul-smelling stools and leading to poor growth. • Malabsorption can be controlled by pancreatic enzymes taken along with food. The enzymes help break down food in the small intestine so that it can be absorbed.

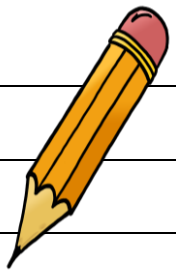
Word	Meaning
Meconium Ileus	• A condition of some newborn babies with CF. • The intestine is blocked with a mixture of meconium and mucus. An operation may be needed to treat the blockage.
Mucus	• A thin, slippery liquid produced by the mucous membranes and the mucous glands. It moistens and protects the membranes. • In CF, the mucus can become very thick and sticky.
Mucus Membranes	• The tissues in the body that produce mucus. They line various passages of the body, such as the nose, mouth, bronchi, esophagus, stomach and intestine.
Nebulizer	• A device used for breathing treatments. • An air compressor forces air through the liquid medicine in the nebulizer, turning it into a fine mist. • The mist is inhaled using a mask or mouthpiece.
Nutrients	• Substances the body uses from digested food. They are needed for energy, growing, and normal functioning. • Nutrients fall into several groups: proteins, carbohydrates, fats, vitamins and minerals.
Oral Glucose Tolerance Test	• A test given yearly to CF patients 10 years of age and older to check for Cystic Fibrosis Related Diabetes. • This test measures blood sugar levels before and 2 hours after drinking a solution containing sugar.
Oximetry	• A test that measures how much oxygen is carried by the red blood cells. • A clip is applied to a finger, toe or ear lobe. It measures how well a beam of light passes through the skin. • The test result is called oxygen saturation. It helps doctors determine whether a person has enough oxygen.

Word	Meaning
Pancreas	• A gland that is part of the digestive system. It is behind the stomach and is connected to the small intestine. • The pancreas makes enzymes which travel into the small intestine to digest food. • In CF, mucus can block the tube from the pancreas to the intestine. Enzymes can't reach the small intestine, so food cannot be properly digested. Poor growth may result. • The pancreas may become scarred. If the damage is severe, the gland cannot produce enough insulin. This results in diabetes.
Polypectomy	• Surgery to remove one or more polyps. This is usually done by an otolaryngologist or ENT (ear, nose and throat) surgeon. The polyps may reappear.
PEP device	• Positive Expiratory Pressure Device. • A small device used as a form of chest physiotherapy. Exhaling into the device increases pressure in the airways. This may stimulate coughing. • The purpose of the PEP device is to force mucus up and out of the lungs.
Percussion	• A form of physiotherapy where a cupped hand is clapped over the rib cage to help loosen mucus in the lungs. • Percussion on different areas of the chest and back helps move mucus up into the airways so that it can be coughed up.
Pulmonary Function Test	• A series of tests that show how well a person can breathe. • The tests measure the flow rate (how fast air moves) and the volume of air moving in and out of the lungs.
Pneumonia	• An inflammation of the lung tissue that leads to increased mucus in the alveoli (air sacs). • The usual cause is an infection of the lung tissue.

Word	Meaning
Polyp	• A small growth of tissue from the mucus membrane. Polyps are usually not cancer (benign). • Some people with CF get polyps in their nose. Although not usually painful, these may block the nasal passages or sinuses. Surgery may be needed to remove a nasal polyp.
Postural Drainage	• A form of physiotherapy where the body is placed in various positions during percussions. • As percussion loosens mucus, the postures allow gravity to help drain it into the large airways. The mucus can then be cleared from the lungs by coughing.
Productive Cough	• A cough that brings up sputum or mucus from the lungs. It is also described as a "wet" or "loose" cough. This is common in people with CF.
Pseudomonas	• A group of bacteria often found in secretions from the lungs. Pseudomonas may cause lung infections in people with CF.
Reactive Airways Disease (RAD)	• A medical condition in which the airways overreact to stimulation. The symptoms may include coughing, wheezing and shortness of breath. • Episodes or attacks of RAD may be triggered by allergens, exercise, infections or smoke. Different people are affected by different triggers. • The airways may react to these triggers in three ways: 1. The airway muscles tighten in what is called a bronchospasm. 2. More mucus is produced. 3. The cells lining the airways swell. • These reactions cause the airways to become narrower, which makes breathing harder. • RAD is treated with medicines that help open the airways.

Word	Meaning
Rectal Prolapse	• The lining of the rectum (last part of the large intestine) comes out through the anus. • In CF, this may be caused by large stools from the poor digestion of food. Rectal prolapse may be the first sign of CF in young children. • Prolapse usually improves when the person takes enough enzymes to digest food better. Surgery is only rarely required to correct this.
RSV	• Respiratory Syncytial Virus. The most common cause of viral respiratory infections in children younger than five. • RSV can cause colds, bronchitis and pneumonia.
Sputum	• Another name for mucus or phlegm coughed up from the lungs.
Staphylococcus Aureus	• A type of bacteria that can cause infections. • In CF, it can cause bronchitis.
Sweat test	• A method of diagnosing CF. • With CF, the sweat glands produce sweat that is saltier than normal. A high salt level usually means the person has CF. The sweat test is not painful.
Trachea	• The windpipe connects the lungs to the nose and mouth.
Upper Respiratory Infections	• Infections of the nasal passages, sinuses and throat. • The infections may be caused by viruses or bacteria.
Vibration	• A form of chest physiotherapy where the hands or an electrical device vibrate the chest wall as the person breathes out. This is usually done after percussion.
Wheezing	• A high pitched whistling sound heard in the lungs. It may be heard with or without a stethoscope. It happens when air moves through narrowed airways and may be a sign of illness.

Notes



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