PARENTING WHEN YOU HAVE CYSTIC FIBROSIS

A resource to help you succeed while being a parent and living with cystic fibrosis.

TABLE OF CONTENTS

INTRODUCTION AND ACKNOWLEDGEMENTS

The fact that adults with cystic fibrosis (CF) are living longer and having children of their own is a huge testament to how far CF care in Canada has come. Being a parent is challenging enough, let alone being a parent while managing a complex medical condition. The hope is that this resource can help address some of the unique challenges that parents with CF can face.

This resource was the vision of Cystic Fibrosis Canada's Adult Cystic Fibrosis Advisory Committee (ACFAC). It is a component of a project with the goal of providing more resources and support for adults with cystic fibrosis who are parents and for their children. This resource is the complement to the activity book "Keepin' It Rosy – When Your Parent has Cystic Fibrosis: An Activity Book".

Before making this resource, a lot of background work happened:

- It became known that there are many similar struggles for parents with CF, ranging from how to explain CF to your children, to how to manage a demanding CF medication routine when you are the primary caregiver to young kids, as well as how to navigate a hospitalization as a parent
- A comprehensive literature and resource review was done to locate resources that already existed for parents with CF or for their kids
- A list of topics that would be helpful to have more information or support on from the perspective of a parent with CF was written and was used as a starting point
- A survey was conducted among parents with CF in Canada to make sure that the list of topics was complete and useful for the spectrum of parents with CF
- Healthcare providers from CF care teams across Canada were asked to contribute and validate information within this guide, to ensure that it is up-to-date, accurate and based on best care practices and recommendations

IMPORTANT NOTES:

You should always reach out to your own CF team for questions or specifics about your own care. While healthcare professionals were consulted in the development of this guide, your own care team knows your personal circumstances and is best equipped to provide you with personalized recommendations.

We also understand that not all parenting styles are the same. We have tried to keep the information as generic as possible to not favour one style of parenting over another.

This resource is not meant to be read cover to cover. It has been designed for you to be able to find the information you need at the times that you need it.

ACKNOWLEDGEMENTS

A special thank you to Megan Parker (Chair of the ACFAC) and Kim Wood (member of the ACFAC), two mothers living with Cystic Fibrosis, and Eunice Mamic, Associate, Community Relations and Resources with Cystic Fibrosis Canada, for all their work to compile and write most of the sections within this guide.

Thank you to Kim Steele and other members of Cystic Fibrosis Canada for their time and effort to finalize and publish this guide.

Thank you to the healthcare providers that authored several sections. Their names have been credited in the respective sections they authored.

Another huge thank you to the following people, for their contributions and/or reviewing the content within this guide. This guide would not be possible without your assistance:

- Julian Tam, Respirologist, Saskatoon, and Medical Advisor with the ACFAC
- Kate Gent, Nurse Practitioner, Toronto, and Medical Advisor with the ACFAC
- Rob Burtch, parent with CF and previous member of the ACFAC
- Clare Smith, BSc.PT, Calgary Adult CF Clinic
- Jeanette Leong, BSP, ACPR, Calgary Adult CF Clinic
- Pat MacDiarmid, MSW RSW, Social Worker, Adult CF Clinic, St. Paul's Hospital
- Kathleen Lee, RD, Clinical Dietitian, Adult CF Clinic, St. Paul's Hospital
- Heather Switzer, PhD, RD, Psych, Regina General Hospital
- Hilary Power, Clinical Psychology Doctoral Student
- Meghan Walker, M.Ed
- Krista Jensen, B.Ed, B.A., M.Ed.
- Janna Parker, R. SLP, MSc-SLP, CCC-SLP
- Ulrike Eccher, MSW
- Joelle Berlet, for her illustrations and CF-parent themed colouring pages

Finally, thank you to the following parents living with CF for sharing parts of their story:

- Megan, mother to 7-year-old twins, Alberta
- Kim, mother to a 3-year-old, British Columbia
- Emily, mother to a 3-year-old, Saskatchewan
- Jeremy, father to a 12-year-old, Manitoba
- Kalyn, mother to children aged 1 and 4, Alberta
- Anna, mother to 3 adult children, Manitoba
- Haley, mother to a 3-year-old, Ontario
- Melissa, mother to a 9-year-old, Ontario
- Two other parents with CF who wished to remain anonymous

TALKING TO YOUR CHILDREN ABOUT CF

Heather Switzer (PhD, RD Psych), Meghan Walker (MEd), Hilary Power (MA)

Please note that this section contains sensitive topics and may bring up some uncomfortable feelings. Please reach out to your CF Clinic team for more guidance and support in this area.

Living with CF can be complex, challenging and scary at times. It can also be difficult for your family members. Many parents with CF have concerns about communicating with their child about their illness (Hailey et al., 2018). Your instinct may be to protect your children and limit discussions about CF with them to prevent them from worrying. However, *discussing CF with your child may help them to cope better*. Children are impacted by their parent's illness and often already understand that something is going on in their family (McCue & Bonn, 2003). Often a child can imagine things far worse than the truth, and dishonesty or lack of information may lead to mistrust (McCue & Bonn, 2003).

Researchers have found that children appreciate receiving accurate information and updates about their parent's illness to help them prepare for what to expect (Grabiak, Bender, & Puskar, 2007). A lack of information and lack of coping skills in children are related to feelings of uncertainty and distress (Anton-Paduraru, Ciubara, & Miftode, 2015). An important step to relieve distress is to provide CF-related information, as well as information on effective coping strategies. Educating your children about chronic illness can also be beneficial for their well-being and development. Children of parents with a chronic illness are more likely to be tolerant of differences, hold positive attitudes towards people with chronic illness and disabilities, have greater compassion and help others (Duvdevany, Buchbinder, & Yaacov, 2008; Grue & Laerum, 2002; Thorne, 1990).

> Remember that you are the best parent your child could ask for, and that your illness will create a unique perspective for them going forward in life that could lead to a great many positive things.
>
> Emily,
> Saskatchewan,
> child age 3

As a parent with CF you may be questioning what to tell your children about your illness. Before talking with your child about your CF consider what information you want to share with your child. Ensure that you and other family members, such as your partner, are on the same page. When and how *you choose to approach discussions about CF within your family is ultimately your decision.*

GENERAL STRATEGIES FOR DISCUSSING CF WITH YOUR CHILDREN

Discuss your CF at a developmentally appropriate level for your child.

Openly discuss and educate your child about CF at a level that is developmentally appropriate. *You know your child best.* Discuss your illness at a level that you feel your child is able to understand and cope with. When you discuss CF, check-in with your child to ensure they've understood, and clarify any misunderstandings. For all children, this requires a tailored approach, which enables you as a parent to *focus on concerns and needs from your perspective* (Fulbrook, Leisfield, & Wiggins, 2012). Researchers have found the more that children are prepared and informed, as appropriate for their age and developmental level, the more they are better able to cope with a parent's illness (Forrest et al., 2006). Discussing CF with your child will help to diminish their stress and anxiety about your illness.

> I found being straightforward with age appropriate language the best way to explain CF to my daughter. When she was very young I explained that my meds and therapies made me feel better because sometimes I difficulty breathing. When she got a bit older I gave her the specifics as to what each medication or therapy did and why they were important.
>
> Jeremy, Manitoba, 12 year old child

Please refer to "Strategies for discussing CF based on your child's developmental stage" on page 12 for more specific information and strategies for different developmental stages.

Try to remain positive when discussing CF with your child.

> Although he knows I have CF, knows that it is life threatening, we have found that living for each day, focusing on all the positive we have so that when things get negative we are able to keep our spirits up
>
> Melissa, Ontario, son aged 9

Consider including notions of humour, hope and resilience (Jessup et al., 2018). Taking a positive approach to discussing CF may enable your child to view a stressful event from an alternative perspective and reappraise it as less threatening or scary. For example, you can discuss how CF treatments are continuing to progress. You may also discuss how you are adhering to your treatments and ways you are coping with CF effectively. Having a positive discussion about your own resilience may lessen associated feelings of anxiety, fear, anger or frustration (Dowling, 2002).

Normalize your CF regime.

You can also *normalize CF treatments* as part of your family routine, such as completing chest physio treatments and taking medications in front of your child. Get them involved in simple ways such as turning on/off your nebulizer machine or passing you a medication vial. For younger children, you can create a *CF Doctor's Kit* which might include items such as a stethoscope, an old/cleaned nebulizer, and an empty medicine bottle (please refer to the Activity Book for more details). Other ways to normalize your CF would be to bring your kids to the pharmacy to pick up your medications or attend medical appointments with you (just give your CF clinic team a heads up first!).

> Children living with a mom with CF really get to learn what wait a minute really means as they are told that very often. They also see you struggle and cough and would do anything to help make you better. When we take care of ourselves we can take care of you. My kids sat with me all the time while I did my treatment or face mask. They would play right beside me. Then we would go do something together either outside or go for a ride and visit friends.
>
> Anna, Manitoba, 3 adult

Use additional communication tools with younger children.

Social Stories can be a helpful tool to help young children understand what to expect and can help normalize and validate certain feelings and emotions. Social stories are personalized stories about any scenario your child may experience, written from your child's perspective. Pictures (illustrations, clipart, or photos) and words are used to help your child know what to expect and how they can act or react. Some examples of situations where social stories might help support the understanding of CF for young children are:

- When explaining your medication routine
- When visiting you in the hospital
- When you have a pulmonary exacerbation

Please refer to "Create Your Own Social Story" in the Activity Book for more details about how to make your own social story.

Visual Schedules, or schedules in general, can help children feel more comfortable and safe by helping them know what to expect. Some example situations where visual schedules might help young children are:

- When helping your children understand the amount of time/effort that is needed to dedicate to your medications
- When planning the daily routine when you are in the hospital or away for a day at CF Clinic

Please refer to “Create Your Own Visual Schedule” in the Activity Book for more details about how to make your own social story.

Provide your child with the opportunity to express and discuss their emotions.

Acknowledge and validate any emotions your child is feeling about your CF. Share with your child how you are feeling too. Talk with your child on a regular basis regarding how they are coping with your illness (Zahlis, 2001).

Individual and family counselling can play a valuable role in helping families to address feelings about illness, as well as to help parents understand their child’s reactions within their developmental level (Golby, 2013).

Please refer to the Activity Book for more ideas on ways to support your children to express their emotions.

Model positive coping and self-care strategies.

Researchers have found that parents with CF are a remarkably resilient group who cope well with parental stress (Ullrich, Bobis & Bewig, 2015). As a parent with a chronic disease, it is important to practice positive coping and self-care strategies. Taking care of your physical and mental health will help you to be a better parent to your child. Modelling positive coping and self-care strategies in front of your children will also help them to develop their own strategies for dealing with life stress.

There are several ways you may prioritize your health and engage in positive coping and self-care strategies. This may include asking for assistance from family and friends when you are feeling overwhelmed or unwell, such as help with meals, buying groceries, and doing laundry. You can also ask family and friends for help to support your children when you are feeling unwell. Provide adults with specific tasks and instructions for how to support your children during these times, such as picking them up from school or spending special one-on-one time with them. Additionally, practicing relaxation techniques, such as deep breathing and progressive muscle relaxation, can be helpful to reduce anxiety and physical tension that may be associated with anxiety.

If you are having difficulties coping make sure to seek out additional supports, such as psychological services, to help manage feelings of anxiety or fear about the future.

Ask your child if they have any questions or concerns about CF.

Encourage your children to continually communicate their thoughts, questions and concerns about CF with you (Zahlis, 2001). Common concerns children have about their parent's illness include worrying:

- That something bad will happen
- About their family and others
- Their parent will change
- About talking to others about the illness
- That they will get sick too
- That their parent is going to die

If your child asks you a question that you're not sure how to answer, you can tell them you need some time to think and seek assistance to help you answer their question. You can discuss with your CF Clinic Team if your child can ask them questions too and at what age this might be helpful.

Please refer to "Common questions that children may ask about CF" below on page 10 for a list of questions that you can probably anticipate needing to answer.

Have an emergency plan in place.

Children may worry about who will take care of them if you become unwell or need to be admitted to the hospital. Assure your child that they will continue to be taken care of. It can be helpful to have an "emergency plan" established for occasions where you need to be hospitalized. Having a plan in place will help decrease the impact of your absence on your child and other family members. Share the plans you have in place with your child to help them feel secure. Attempting to protect your child by not keeping them informed or offering them an opportunity to be involved in decisions that affect them can leave them feeling excluded and alone (Golby, 2013).

If you are hospitalized, try to maintain daily contact with your child as much as possible through phone calls, video calls, hospital visits, texts and/or e-mails. Please refer to the Activity Book for more ideas for ways to support your children during a hospital stay.

Please refer to page 50 for more on emergency plans.

COMMON QUESTIONS THAT CHILDREN MAY ASK ABOUT CF

Your children will likely have many questions about your CF and it can be helpful to prepare and begin to think about how you may answer these questions. It is important to answer their questions and to check in with their understanding of the answers you provide.

Why is it harder for you to breathe with your CF?

You could explain that your lungs don't work as well so it makes it harder to breathe. Depending on your child's age, you could use the example of breathing through a straw to help them understand what it sometimes feels like for you.

How did you get CF and will I get it too?

Children may fear that they will catch your CF, especially since CF symptoms may appear similar to having a cough or cold. With younger children, you can explain that you cannot catch CF like you can catch a cold, and you were born with CF and they were not. For older children, you could discuss how CF is inherited genetically. You may also want to discuss with older adolescents that they may be carriers of CF. It is also important to tell your child that they have no power to make CF go away or get worse (McCue & Bonn, 2003).

Why do you get to eat more than me?

Children may be curious about why their nutritional needs may be different than yours. You can explain that everyone needs to eat different amounts to stay healthy. For you, eating more is a part of taking care of your CF, and because they do not have CF they do not have to eat as much. You can explain that their pancreas works better than yours, so you have to eat more to be strong like them. Explain that you need to do some things differently to take care of yourself. (Also refer to the "Nutrition" section on page 26 of this guide for more information on balancing different nutritional needs and promoting a healthy relationship with foods in your children).

Did I make you sick?

Your children may worry that they are to blame for your CF. You can assure them that having children did not make you sick.

Can you die from CF? Children may worry about their parent dying. It is important to acknowledge their concerns and validate their feelings. *Every family is different and may answer this question differently.* Answering this question will also depend on the developmental level of your child. Although answering this question is not easy, by answering it openly and honestly, children learn that difficult conversations can happen safely, they are a valued member of the family, and they can talk about difficult experiences with you.

When discussing death, while there is no “right time” that works for every family, children of all ages benefit from being prepared in advance for the death of someone close to them. It can be helpful to have this discussion in a safe and quiet place where your time cannot be interrupted. You may explain CF, its progression, and the possibility of dying. When explaining death, you may want to discuss your treatments and that although your treatments will not cure CF, they can help you “feel” better rather than “get” better. It is comforting to know that their parent will be cared for even though CF cannot be cured. Children may also worry about what will happen to them if you die. Providing them assurance that an adult will care for them may be important.

SIGNS YOUR CHILD MAY NEED SOME ADDITIONAL SUPPORT

Some children may require additional supports to cope with their feelings and emotions surrounding having a parent with CF. Some signs that your child requires additional supports may include:

- Your child is withdrawing or isolating themselves from yourself or others
- Your child is becoming more resentful towards CF or you for having CF
- Your child is displaying physical symptoms, such as irritability, tiredness, muscle pains, headaches, or stomach aches
- Your child has excessive feelings of anxiety or worry, sadness, anger, frustration or guilt
- Your child shows increased tantrum behaviours, difficulties falling or staying asleep, reassurance seeking, or school refusal

- Your child has a change in behaviour or disinterest in regular activities that they enjoy

STRATEGIES FOR DISCUSSING CF BASED ON YOUR CHILD’S DEVELOPMENTAL STAGE

The following are general guidelines and strategies for discussing your CF based on your child’s age. Remember that every child is different in their development and your child may not fit into a single category.

Ages 0 – 6

Children at this age are impacted by concrete changes that directly impact them. Try to use simple and direct language when explaining your physical symptoms and how they impact your child. For example, “Mommy needs medicine to help her breathe good. We can go to the playground after I’m done doing my breathing medicine”.

> I told them that Mama's lungs need a little extra help to work or to breathe.
>
> Megan,
> Alberta, kids 7 & 7

> My boys are still quite young, but I try as hard as I can to take all the negative verbiage out of why I have to spend time doing treatments or hospital stays rather than play time or outings with them, because I don't want them to [however subconsciously] resent my CF for "stealing Mom's time"
>
> Kayln, Alberta, kids ages 1 and 4

Your child may worry that if they have a cold they may end up being hospitalized. Distinguish between minor illness (i.e., a cold) and major illness (i.e., being hospitalized with a pulmonary exacerbation). You can use words such as “sick” and “very sick”.

Kids in this age group may worry that they caused the illness. Ensure your child they did not cause your illness by telling them you were born with CF.

Separation from parents may be a big concern for children this age. Children’s fears can be alleviated by giving your child verbal reassurance and physical touch, such as hugs and kisses. Tell them who will take care of them if you are unwell.

Children this age may be sensitive to changes in routine, which can come about through parent illness or hospitalization. As much as possible, maintain already established routines for your child.

> I told them that mommies lung don't work right. As they got olde we explained more.
>
> Anonymous parent with CF

Children may also revert back to previous behaviours during times of stress, such as thumb sucking or wetting the bed. Be patient with your child if you notice a regression in their behaviours.

> I try to relate what I am feeling into concepts that my son (who is 3 years old) can understand. Talking about how mommy feels tired sometimes like he does when it's close to bedtime, or talking about how I feel dizzy like when he spins around and around in circles.
>
> He doesn't get the big CF concepts yet, but I'm trying to be open and honest so that it's not too scary for him.
>
> Emily, Saskatchewan, child age 3

Ages 6 – 12

Children this age may be more curious about their bodies as well as other people's bodies. They may ask more questions or feel embarrassed around their peers. They may ask specific questions like, "why do you cough so much?" or "what are all those pills for?".

You can begin to give your child more detailed explanations about CF, such as telling them, "I was born with CF because of my genes, which are like special instructions for how to build your body. You do not have the CF genes and so your special instructions make your body without CF".

Children may begin to understand that CF has numerous effects on your life. They may realize that all families operate differently and other parents do not dedicate so much time to health maintenance. Try to maintain regular family rules, expectations and responsibilities. For example, continue to eat dinner at the table as a family when you are feeling unwell. Children this age can begin to take on more home responsibilities to help out. They may need encouragement to keep up with extra-curricular activities when there is a health crisis.

> My sons are only 2 and 6 so I have not yet explained to them what CF is. I have mentioned it to my 6 year old. I have told him it is a disease. I tried to tell him like it was just a normal thing. The biggest challenge I think I will face when explaining more about CF to my boys is not scaring them into thinking I will die soon.
>
> Anonymous parent with CF

Your child may begin experiencing new emotions and feelings, such as guilt, depression, sadness, fear, anger, longing and confusion. These feelings can be overwhelming and their instinct may be to ignore or bury these feelings. Help your child to navigate any new or overwhelming emotions. Try to normalize and validate their feelings. It can be helpful to talk about your own feelings and emotions about CF.

Older children may become aware that death is something permanent. They may be afraid that death may occur in people they are close with. You can discuss your personal beliefs about death with your child, and how you've dealt with grief in the past.

Ages 12 – 17:

Adolescents undergo puberty, physical changes, increases in self-consciousness, and new emotions. Try to normalize and validate their emotions. It can be helpful to talk about your own experience going through puberty. Your child may begin to develop their personal identity and feel an increasing need to fit in with their peers. They may distance themselves from their parents, which can lead to guilt if they feel obliged to be at home to help out. Promote your child's independence by giving them permission to go out and enjoy themselves with their peers.

Adolescents may start to learn about CF from outside sources, such as the internet, friends, and teachers. Check-in with them about what they've learned about CF and discuss if they have any new questions or concerns.

SUMMARY

Talking to your child about CF will be a continual discussion that will evolve over time as your children grow and mature. Checking in with your child regularly to ask if they have more questions and to see how they are coping is important. Some key points to remember:

- Discussing CF with your child may help them to cope better
- Discuss your CF at a developmentally appropriate level for your child
- Try to remain positive when discussing your CF with your child
- Try to normalize your CF treatments as part of your family routine
- Communication tools, such as social stories or visual schedules, can be helpful when discussing CF with younger children
- Provide your child with the opportunity to express and discuss their emotions
- Model positive coping and self-care strategies
- Ask your child if they have any questions or concerns about CF
- Have an emergency plan in place
- Family counseling can be helpful for you and your children to best manage/navigate having a parent with CF

There are many helpful books and online resources that may further assist you (please refer to the resource section on page 76). Additionally, please do not hesitate to reach out to your CF team for further guidance.

REFERENCES:

Anton-Paduraru, D. T., Ciubara, A., & Miftode, E. (2015). Psychosocial aspects in children with cystic fibrosis. *Journal of Cystic Fibrosis, 14*, S130-S130. doi:10.1016/S1569-1993(15)30457-4

Duvdevany, I., Buchbinder, E. & Yaacov, I. (2008). Accepting disability: The parenting experience of fathers with a spinal cord injury (SCI). *Qualitative Health Research*, *18*(8), 1021- 1033. doi:10.1177/1049732308318825

Forrest, G., Plumb, C., Ziebland, S. & Stein, A. (2006). Breast cancer in the family – Children's perceptions of their mother's cancer and its initial treatment: A qualitative study. *BMJ, 332*, 998-1003. doi:10.1136/bmj.38793.567801.AE

Fulbrook, P., Leisfield, T., & Wiggns, K. (2012). Children's conceptions of their parent's lung transplant. *Journal of Child Health Care, 17*, 6-16. doi:10.1177/1367493512450625

Grabiak, B.R., Bender, C. M., & Puskar, K.R. (2007). The impact of parental cancer on the adolescent: An analysis of the literature. *Psycho-Oncology, 16*, 127-137. doi:10.1002/pon.1083

Grue, L. & Laerum, K. T. (2002). Doing Motherhood: Some experiences of mothers with disabilities. *Disability & Society, 17*(6) 671-683. doi:10.1080/0968759022000010443

Golby, B. J. (2013). Parenting with chronic cancer: A relational perspective. *Social Work in Health Care, 53*(1), 48-58. doi:10.1080/00981389.2013.832468

Hailey, C., Tan, J., Potts Dellon, E., & Park, E. (2018). Parenting with Cystic Fibrosis: Balancing roles as parent and patient with a life-limiting illness. *Journal of Pain and Symptom Management, 55*(2), 649. doi:10.1016/j.jpainsymman.2017.12.195

Jessup, M., Li, A., Fulbrook, P., & Bell, S. C. (2018). The experience of men and women with cystic fibrosis who have become a parent: A qualitative study. *Journal of Clinical Nursing, 27*(7-8), 1702-1712. doi:10.111/jocn.14229

McCue, K., & Bonn, R. (2003). Helping children through an adult's serious illness: Roles of the pediatric nurse. *Pediatric Nursing, 29*(1), 47-51. Retrieved from: https://www.ncbi.nlm.nih.gov/pubmed/12630506

Thorne, S. E. (1990). Mothers with a chronic illness: A predicament of social construction. *Health Care for Women International, 11,* 209-221. doi:10.1080/07399339009515889

Ullrich, G., Bobis, I., & Bewig, B. (2016). Parenting stress in mothers with Cystic Fibrosis. *Disability and Rehabilitation*, *38*(2), 174-179.doi:10.3109/09638288.2015.1031290

Zahlis, E. H. (2001). The child's worries about the mother's breast cancer. *Oncology Nursing Forum, 28*, 1019-1025. Retrieved from: http://europepmc.org/article/MED/11475875

THOUGHTS, COMMENTS AND THINGS TO REFLECT ON

THINGS I WANT TO DISCUSS WITH MY FAMILY

THINGS I WANT TO DISCUSS WITH MY CF CLINIC

MANAGING MEDICATIONS AND MEDICAL EQUIPMENT WITH CHILDREN

CHEST PHYSIOTHERAPY AND INHALED MEDICATIONS

Taking care of yourself is the first step in taking care of your children. When you have CF, this means spending a lot of time doing inhaled medications and chest physiotherapy. This can be very challenging when you have children, especially when you're trying to do your medications and chest physio properly.

> My wife and I have always believed our individual wellbeing is important and we make sure that wellbeing is taken care of. How we're we supposed to care for a baby if we didn't care for ourselves first? My therapy was always a high priority.
>
> Jeremy, Manitoba, child 12 years

As your children grow up, you will face different obstacles for completing your inhaled medications and chest physiotherapy. Your children's understanding and acceptance will also certainly change over time as they grow up. Being open and honest can help them to learn that it is important. Here are some ways in which you can help your children understand:

- Do your medicines in front of your children to help them know it is a normal part of your routine.
- Include your children in your medication routine. For example, have your child pass you a medication vial or your chest physio device.
- Get a book that can help explain and normalize a parent doing their medications and chest physio – see list references on page 76, the Seb and Oli books are fantastic.
- Refer to section on "Talking to Your Children About CF" on page 5 for how to talk to your children about your medical routine at different ages.

> I let my three year old hold his own unplugged neb up to his mouth and copy me. It was a short phase, and made doing medicine alongside me somewhat fun. Sometimes I'd ask him to help press the power button - this was also a favourite for him as he loved to participate.
>
> I let myself offer TV time to the kids when I do treatments and I don't feel bad about it. 1 hour of TV each day wouldn't kill them, and this way it became part of the day's routine. After the treatments were over, they knew the TV was being turned off and we'd start a new activity or go outside.
>
> Kayln, Alberta, kids ages 4 and

- Kids may get frustrated or mad with you having to spend so much time doing your medications. It’s important to name their emotions or feelings and let them know that it is ok to feel that way. Help them find ways to cope with these emotions and feelings and help them find things that they can do during medication/physio time.
- Have fun and new activities for your children to do when it’s time for you to do your medications → keep these put away for all other times (to keep them exciting and engaging).

After having my son, my ability to multitask became essential, especially when trying to fit everything in. Shortly after bringing my son home, I spoke with my physiotherapist about ways I could potentially break up my routine so I could chose more opportune times to get it done (so I could pair it better with my sons routine), but I also streamlined my physio routine as much as possible. Instead of doing hypertonic saline, then PEP, I combined them and did them at the same time with the guidance from my physiotherapist. I also found there were many activities that could still be done with my son, while doing physio at the same time such as feeding or playing with him while he was in his high chair, puzzles, building a train set or lego, audio books etc. I also started to bring out a box of toys that I only bring out during physio time. Fitting everything in is challenging but kids are so adaptive. My son has really learned that it’s ok when Mom does physio. He’s learning skills too like patience and flexibility. There are definitely days when he is just not willing to wait while I get my routine done, and on those days, I pull out some special activities that I’ve put aside, or if I’ve got nothing, I take a break from physio at that moment and play with my son. I often find that if I play with him for a short while, he’s ok to carry on himself while I finish up.

- Create a social story by using photos or clip art. Please refer to the Activity Book for more details on how to create your own social story. Example below (Illustrations by Joelle Berlet):

Every morning my mom needs to do her medicine to help her breathe better.

Mom needs to breathe in her medicine and then blow into something that makes a funny noise. She coughs a lot when she does this. She calls it her “good cough”.

Sometimes it can feel like Mom’s medicine takes forever, and I can get frustrated and mad. But I know that it is important for Mom to do her medicine.

Mom can’t read to me when she is doing her medicine so I need to do a good job and play by myself. Some of my favourite things to do during her medicine are: colouring, playdough, or playing with my stuffed animals.

When Mom finishes her medicine, she needs to clean everything that she used….

…and then we get to do fun things together like go to the playground!

- Create a visual schedule. Please refer to the Activity Book for more details on how to create your own visual schedule. Example:

FIRST	THEN
 **Medicine**	 **Playground**

SPECIAL CONSIDERATIONS WHEN YOUR CHILDREN ARE YOUNGER

You might need to be a little more creative when it comes to completing your medication routine when your children are younger. With a little thought, creativity, and planning, there are so many ways that you can set yourself up for success.

> I try to stick with routine the best I can. I'll sit down and we can snuggle while they watch a show and I do my nebs. They know it is important for me like brushing their teeth is for them.
>
> Anonymous parent with CF

Here are some questions you can ask yourself. The answers can help guide you towards small changes you can make in order to set yourself up for success when it comes to doing all your medications while being a parent. There are no right or wrong answers, these questions are just meant to help you reflect.

What time of day am I doing my medications and am I doing them at the best time (best time for my benefit or best time for my family's routine)?

1) If my child naps, do I need to use nap time to catch up on sleep or can I use nap time to do my medications?
2) Am I able to wake up before the kids and finish my medications before our day starts?
3) Am I waiting to do my medications after my children go to bed and do I need to do them earlier in the day because my lungs need it earlier?
4) Am I doing my medications during a time of day that my kids can usually entertain themselves? Ideas:
    i) During tummy time
    ii) Baby in jolly jumper or exersaucer
    iii) Baby in high chair (eating a snack or doing a game or activity on their tray)
    iv) During tv time
5) Are my kids signed up for any drop-off classes or preschool? Can I use that time without kids to do my medications?

> I would wake up an hour before them and do my inhaled meds so when they woke up I was able to get breakfast going then get them dressed and start our day.
>
> Anna, Manitoba, 3 adult children

> To be completely honest, I cannot get inhaled medications done with my two year old around! I cannot stand being crawled over and having him grab at my mask while I do it. I find it very frustrating. Typically, I wait until they are in bed at night and in the morning, I only do my mask if my husband is around to keep the two year old occupied.

Where am I doing my medications?

1) Can I get a second or third nebulizer device so that I can more easily do my medications in different rooms or floors of my home?
2) What is there for my kids to keep busy with in the room where I do my medications?
3) Is the space baby-proof or will I need to stop my medications to remove something from my baby/child?
4) Is there a baby bouncer or baby chair to safely put my baby into during medications?
5) Are there times when I ride in the car (not driving) that I can do my medications?
6) Do I have everything I need to complete my entire medication routine (for example, all nebulizers, medication vials, chest physio device)?

> We watch shows together and I let my daughter feel like she is helping me stay healthy.
>
> Haley, Ontario, 3 year old daughter

What is my posture/positioning like while doing my medications?

1) Am I in a good upright position to make my inhaled medications or chest physio the most effective?

What am I (and my child) doing during medications?

> I have a vivid memory of loading my kids into the stroller and pushing them around the dog park while our dog burned off some steam. The kids had little cups of cheerios and I popped my battery-powered air compressor into a fanny pack and did a few laps while doing my inhaled medications. In other words... creativity and multitasking were essential to make sure everyone's needs were taken care of!!

1) For inhaled medications, the two biggest things to think about are:
    i) Keep your posture in an upright position, and
    ii) Keep talking to a minimum (to make sure you are breathing in the full intended doses of medications) → you can still join in most games or activities if you keep these two things in mind!
2) For chest physiotherapy, you might need to have your kids do something that they can do on their own so that you can put your full attention and energy into properly completing chest physio
3) Make a special “physio box” that’s filled with toys/craft activities that only comes out during physio time.
4) Young kids often mimic their parents. If your child keeps taking your physio device to “do” their own chest physio, you might find it helpful to get a second physio device or pretend one of their toys is their physio device. This will cut down on the number of germs that are transferred to your physio device. Ensure no small pieces can detach as they can be choking hazards.
5) Refer to Activities page 73 for a list of different activity ideas for your kids to do

Other considerations:

- Babies can be interested in tubing and nebulizers. Make sure you are aware of choking hazards (during and between treatments).
- Do your inhaled medications or chest physio in the car if you are not driving.

- Do inhaled meds during housework chores or while prepping your dinners → Get a nebulizer device that operates with batteries and you can pop it in a fanny pack to be hands free.
- Look into childcare, even on a part-time casual basis (even if you are a stay-at-home parent).
- If you are comfortable doing your medications in front of others, look into community options (example: indoor playground) where you can take your child and sit on the side to complete your meds
- Look into daily activities or classes where you can drop your children off. Use the time to complete your medications and chest physio.

> My daily physio routines and medications definitely took a hit having a newborn, it's tough to make your health a priority during that phase so make sure you organize all the help you can get.
>
> Trying to support independent play options for my son at a young age was key for me, and also allowing him to participate to an extent by letting him hold parts of my Pep and bring me tissues etc. Some days are tougher than others!
>
> Emily Saskatchewan child age 3

"SECOND-HAND INHALATION" OF MEDICATIONS AND YOUR CHILD

There is not much research about "second hand inhalation" of aerosolized/nebulized medications for people that might be in the same room as you when you are doing your inhaled medications. Please speak directly to your own CF Physician or Pharmacist to ask whether you need to take any special precautions when you are completing some or all of your nebulized medications right next to your children.

SAFETY CONSIDERATIONS WITH MEDICATIONS AND DEVICES

It is important to make sure that your medications and equipment are kept out of your child's reach to help keep them safe. Also teach your children about how to stay safe with your medications.

General safety considerations to reflect on:

- Pills can sometimes look like candy to kids.
- Babies explore and learn about the world by putting things in their mouths - make sure you quickly pick up any dropped pills.
- Many of our medications or medication containers can be choking hazards (example: pulmozyme vial caps) - throw them in the garbage and don't leave them lying around where your kids can reach them.
- Use a sharps container to dispose of needles. These are free from most pharmacies.
- Make sure your pill bottles have child-safety-lids and that the lids are fully on.
- Think about where you store your medications (examples: on a high shelf out of reach, or in a locked cabinet).

Special safety considerations with tubing (IV/oxygen/feeding tubing):

Tubing can be a strangulation hazard for babies or young children. Babies and young children also love pulling on tubing. Here are some strategies to consider with tubing:

- Keep tubing covered as much as possible. Some ways are:
    - Keep IV lines tucked under clothing
    - Wear ¾ sleeves or a PICC-guard with PICC lines
    - Secure IV lines with tape
- If you have a port and when your port is accessed on your upper chest, have your kids snuggle on your other side, or use a pillow to cushion your accessed port site
- Give something for your baby/young child to hold to keep their hands busy and less focused on your tubing.
- Be aware of any oxygen tubing at the top of stair cases (to prevent a trip and fall down the stairs)

THOUGHTS, COMMENTS, AND THINGS TO REFLECT ON

____

____

____

____

____

____

THINGS I WANT TO DISCUSS WITH MY FAMILY

____

____

____

____

____

____

THINGS I WANT TO DISCUSS WITH MY CF CLINIC

____

____

____

____

____

____

Take care of yourself first. Make it a priority. If you aren't healthy you can't take care of anyone else. Kids don't judge. Make your CF normal a family normal.

Anonymous parent with CF

TAKING CARE OF YOURSELF

NUTRITION

Tiffany LaFleur, Registered Dietitian

Staying Well-Nourished

Good nutrition is an incredibly important part of caring for your body when you have CF. However, when you are a parent with CF and you balance many roles and responsibilities, it can sometimes feel overwhelming to keep on top of grocery shopping, meal preparation, and cooking.

Here are a few strategies that can help keep your well-nourished:

- Meal plan! It can help you become more efficient with both grocery shopping and cooking. If you do not currently meal plan, start small by planning 2-3 suppers/week and build up from there.
- Make quick and easy meals. Keep a list of fast meals that you and your family enjoy. Some ideas are: eggs and toast, quesadillas (even easier with pre-shredded cheese!), grilled cheese, pasta, tuna melts, wraps, pita pizzas, french toast or pancakes and fruit salad.
- Use convenience foods to simplify putting together a meal. Some examples are: Rotisserie chicken, frozen veggies and fruit, bagged salads, canned fish, liquid eggs, frozen pizzas as a base for other ingredients, frozen meatballs, jarred pasta sauce (Alfredo for higher calorie!), pre-cut veggies in the produce section, canned beans, shredded cheese.
- Batch cook! Double or triple your recipe and freeze portions of leftovers for a quick meal.

How to Balance Different Nutritional Needs

It can sometimes be a challenge to balance your CF nutritional needs and those of the rest of your family if you need to consume more calories. Reach out to your CF Dietitian for individual strategies and ideas to make sure you are meeting your own nutritional needs.

Here are some general strategies that can help you to get your required calories:

- Bump up your calories by adding in snacks that you can eat when your children may not be around.
- Smoothies can be an easy way to increase calories and protein. Ingredients to consider adding to your smoothies: nuts & seeds and their butters, oats, 1 tsp of oil, canned coconut milk, dessert tofu, pasteurized liquid eggs, cottage cheese, full fat Greek yogurt, avocado, cocoa powder, maple syrup, jam, canned fruit in syrup, milk powder.
- To increase your calorie content, take a larger portion of protein and add sauces/butter/oil to your vegetables.
- Consider using beans or lentils for your starchy food to further increase calories and protein.
- Purchase two different types of milk.

Promoting a positive relationship with food for your children

You might have foods that are unique to you to help ensure you are meeting your calorie and overall nutritional requirements. This might include whole milk, saltier foods, foods that contain more sugar and nutritional supplements. It can be helpful to explain to your children that you have to eat a little differently to take care of your body because CF changes what you need for fuel. You may want to treat these foods like part of your "medicine" regime for CF when explaining their role in your health.

Many of the high calorie foods you eat will be perfectly fine for your children to eat in reasonable quantities: nuts & seeds and their butters, dried fruit, full fat yogurt, cheese, cottage cheese, avocado, hard boiled eggs, canned fish mixed with mayo. Remember that infants/toddlers require a high fat diet (including full fat dairy) until at least 2 years of age.

Here are some extra tips that can help build a positive relationship with food for your family:

- Avoid naming foods "bad" or "good". Try using "sometimes" or "always" foods.
- Encourage your children to identify hunger and fullness and listen to these physical cues for eating.
- Avoid distractions such as TV and phones at meal times (unless it's movie night of course!).
- Eat meals together as a family whenever you can. Try to have consistent meal and snack times. Involve your children in meal planning.

- Try to avoid using food as a reward or bribe.
- Avoid withholding food as a punishment.
- Eat a variety of foods and experiment with new things together as a family.
- Aim for balanced meals that include vegetables, a grain/starch and a protein.

MENTAL HEALTH

> Being a Mom with CF has been the most challenging thing I've ever faced. It's made me realize so many things about growing up with CF and the person I've become because of CF. Taking time to reflect, learn (and unlearn) and grow through my ups and downs has been helpful as well as connecting with my CF Psychiatrist and local counsellors. I've also realized how important self-care is, beyond CF care. Paying attention to and taking care of my emotional and psychological health as well as my physical health has been incredibly important.
>
> Kim, BC, child age 3

Being a parent is hard and challenging and can sometimes lead to struggles with mood and mental health, regardless of physical health. When you have CF, parenting can be even more challenging at times. Furthermore, having CF has been shown to make you more susceptible to anxiety and depression, which means that when you are parenting with CF, it is even more important to focus on your own mental health.

> Don't beat yourself up after having a hard day. Every parent feels this way sometime - and most of them don't have a chronic illness to contend with as well. Also, remind yourself that your kids, especially young ones, won't remember most of the bad days you though were so tough.
>
> Kalyn, Alberta, kids ages 1 and 4

Pay attention to signs of depression or anxiety and reach out to your CF Team for more support if you notice any of these:

- Sadness or irritability
- Changes in weight or appetite
- Feelings of guilt, hopelessness or worthlessness
- Fatigue or lack of energy
- Sleep disturbances
- Decreased activity
- Restlessness or feeling on edge
- Physical aches and pains with no medical cause
- Feelings of suicide

- Inability to concentrate, remember things or make decisions
- Loss of interest in activities you once enjoyed

Untreated anxiety and/or depression can impact your ability to care for both yourself and your child. In people with CF, it's also shown that people who have untreated depression and/or anxiety can:

- Have lower lung function
- Have lower body mass index (BMI)
- Are less likely to manage their treatment plans effectively
- Experience more hospitalizations
- Have more absences from school or work
- Experience a lower quality of life

> Emotional & Mental health are so important as a wife and mom. If you don't have a good support system I highly advise finding one.
>
> Whether you are feeling discouraged about your health, parenting, kids or just balancing it all, I guarantee someone else can relate and would love to talk with another person about it. Be brave enough to think outside the box and not to rely just on family or friends.
>
> Kalyn, Alberta, kids ages 1 and 4

Post-partum depression is also a serious illness that can occur within the first few months after a baby is born. There are many resources available that can help manage postpartum depression. Please connect with your medical team, family physician or Community Health Nurse in your area for local resources and supports.

If you are having thoughts of suicide or if you think you can't keep from hurting yourself, your baby or someone else, call 911 or see your doctor right away.

Please see additional resources for mental health on page 78.

My depression was at its worst when I was hospitalized for two weeks when my kids were just toddlers. This hospital stay followed a very challenging year for my CF and it seemed like I could never get ahead. Even with an incredible amount of support and grandparents that moved in to look after them, it was incredibly hard on the kids, which made it incredibly hard on me. I remember getting a video call at around 11:30pm one night, and one of my kids had a bloody nose (his first of many, but it was his first, and it wouldn't stop). He was screaming and was inconsolable and there was nothing I could do. It felt so crushingly defeating. I was thankfully quickly connected to my CF Clinic Psychiatrist and she supported me to be better able to manage my mood.

Megan, Alberta, kids 7 & 7

Sometimes it helps to just let myself have a bad or hopeless feeling day, and know that it's just a day. It always gets better if I just keep going, and if I reach out to friends, my spouse or family, or get outside or out of my house. In my worst moments I have also reached out to my clinic to ask them for additional support.

My son has also been a big factor in keeping me going, it's hard to be too depressed when he is being such a character! He helps me to live more in the moment.

Emily, Saskatchewan, child age 3

I talk about my feelings or stressors with those close to me and I release through exercise.

Jeremy, Manitoba, child aged 12

The support groups online have been a good place to talk about my emotions and mental health.

Haley, Ontario, 3 year old daughter

EXERCISE

The current guidelines for exercise in adults with CF is as follows:

- 150 minutes per week or more
  - 30-60 minutes of aerobic activity, 3 times per week
  - 2-3 times per week resistance training

> I have always been active and exercised my while life. It's part of my lifestyle just like eating and sleeping.
>
> Jeremy, Manitoba, child aged 12

While exercise certainly is an important aspect of CF care and is important for lung health, it can often feel like too much when you are also a parent and manage demanding medication routines. It is important to balance exercise and rest, especially with young kids (because let's face it, young kids are exhausting).

SPECIAL CONSIDERATIONS WITH EXERCISE WHEN YOUR CHILDREN ARE YOUNGER

You might need to be a little more creative when it comes to exercising when your children are younger. With a little thought, creativity, and planning, there are so many ways that you can set yourself up for success.

Here are some questions you may consider asking yourself. The answers can help guide you towards small changes you can make in order to set yourself up for success when it comes to completing your medication regime while being a parent. There are no right or wrong answers, these questions are simply meant to be a helpful reflection tool.

What am I doing for exercise?

1) What kind of exercise do I enjoy?
    i) Examples: walking, yoga, biking, public gym, swimming
    ii) It is easier to stay engaged with exercise when you enjoy it.
2) How active is play time with my kids?
    i) You might already be doing a lot more exercise than you give yourself credit for!
3) Are there any physically active activities that we enjoy as a family?
    i) Examples: going for a bike ride together, hiking, playing

> Always make it fun. Exercise is important for everyone. My kids think it is just a regular part of life.
>
> Anonymous
> parent with CF

> I found a gym that provided childcare during classes which was perfect because it gave me a chance to get my workout in, but it also gave me a bit of a break.
>
> Kim, BC, child age 3

soccer, getting on playground equipment together

   ii) Are there any shared parent/child classes that I can sign up for?
   iii) Examples: baby and me fitness classes, yoga and baby, baby and me dance classes, moms and strollers running clubs, etc

> Include them in these exercises.
>
> Anna, Manitoba, 3 adult children

> Doing mommy and baby exercise classes was a great way to get in exercise, but I found I had to make sure they were not a high impact class as I just didn't have the energy to spare at that point of my sons life.
>
> More successful for me was having exercise equipment in my home so that I could do short work outs and build my energy levels, and also signing up for evening classes on my own once a week was a great "me time" activity.
>
> Emily, Saskatchewan, child age 3

What supports do I have for me or my child while I am exercising?

1) What options do I have for paid child care?
   i) Day home or daycare (full time, part time, casual/drop-in)
   ii) Gym childcare service
   iii) Babysitter (hire for just your child or else jointly hire a babysitter with a group of friends or community members)
   iv) Preschool
   v) Un-parented class for your child
2) What options do I have for unpaid child care? (Take advantage of the offers you have received for help from others!)
   i) Friend
   ii) Family member
   iii) Neighbour
   iv) Co-worker

Exercise was an area that I struggled with at times when my kids were babies. It felt like I had endless barriers like the kids having short naps or being fussy or not being able to do their own thing for even short stretches, or I'd be exhausted, or my blood sugar would go low when I was finally able to exercise. I realized that I needed to carve out the time and ask for help from family to watch the kids so I could exercise at the right time and in the right way for my needs.

Megan, Alberta, kids 7 & 7

Where am I exercising?

1) Am I working out at home?
    i) Workout videos (ie, DVDs, YouTube, Social media sites)
    ii) Home exercise equipment (examples: elliptical, spin bike)
    iii) Bodyweight exercises (examples: squats, push-ups)
2) Do I exercise at a gym or community program or recreational centre?
    i) Some gyms offer complimentary child care with gym membership (up to a certain age). Some recreational or community centres have volunteers to help watch your children.
    ii) Can you sign your kids up for a class/sport while you can simultaneously do your own workout or class?

For exercise right now I horseback ride and walk the treadmill. Horseback riding with my six year old has been great this summer as he likes to come with me and spend time with the horse while I get him ready. Then my son will play trucks in the dirt while I ride. It's a great bonding experience while still getting exercise. The treadmill is very useful as well as I can start/stop very easily as necessary and it is also in the downstairs play room so I can be walking while the boys play. They like to play with toy cars and trucks on the treadmill while I walk (I walk at a slow pace right now)

Anonymous parent with CF

When am I exercising?

1) Is there a specific time of day that is better for me to exercise?
    i) Is this a good time of day when my child is able to entertain themselves?
    ii) During preschool or school time?
    iii) During nap time?
    iv) Before the kids wake up or after they go to bed?
2) Is the time that I'm able to exercise good for my energy levels or routine?
    i) Is there a better time of day?
    ii) Are there better days of the week?
3) Am I more likely to follow-through with my exercise if I sign up for a scheduled class?

> When my daughter was younger I would exercise while she napped, now we do the exercises together.
>
> Haley, Ontario, 3 year old daughter

Other strategies to help set you up for success with exercise:

- Baby carriers or jogging strollers can be a helpful way to more easily go out walking or running or hiking
- Sneak little bits of exercise in throughout your day vs. committing to a full 30 minutes (or longer)
- Track your activity when first starting out – this will allow you to track your progress
- The intensity or resistance level of your exercise is important. By exercising at a moderate-intensity level you will be able to avoid overdoing it and limit excessive aggravation of your symptoms or fatigue. Exercising at this level supports an endurance-training model which will hopefully allow you to do more and feel better overall.

SLEEP

***Please reach out to your CF team for individual support and advice regarding any concerns about your sleep, as impaired sleep can be the result of medical problems that may need to be more fully assessed and treated.*

Optimizing Your Sleep

Getting enough good-quality sleep is an incredibly important part of taking care of your body when you have CF. However, with CF, sleep can become impaired for different reasons, such as:

- Frequent night-time awakenings (from chronic cough, sinus congestion, GERD, or frequent need to use the bathroom from GI issues)
- Discomfort from tubing (oxygen, feeding tubing, IV lines)
- Muscle-skeletal pain from excessive coughing
- GI pain
- Anxiety or changes in mood

In addition, sleep can become impaired from non-CF factors such as being unable to stop thoughts, increased stress, use of screens leading up to bed, eating/exercising too close to bed, etc. Not to mention night-time interruptions from your children (to feed them or help with nightmares/etc).

A good place to start is to reflect on all the factors that may be contributing to your impaired sleep.

1) Are there things that you need further support from your CF Team?
2) Are there things that you can change on your own?

A helpful article on sleep hygiene strategies "**37 Science-Backed Tips for Better Sleep**" by Sarah Klein can be found here:

https://www.huffingtonpost.ca/entry/better-sleep-tips-best_n_4958036

> We explained to the kids that sometimes mommy needed extra rest. We made it normal and our kids don't know any different.
>
> Anonymous parent with CF

When you have babies and younger children, some extra things to reflect on:

1) What are you doing while your kids are napping or sleeping?
    i) Do you need that time to catch up on sleep yourself?
    ii) Do you need to consider changing your bedtime and go to bed earlier?
2) Ideas for ways to minimize the impact of night-time awakenings:
    i) If possible, have you and your spouse alternate who gets up to help your baby/child in the night so you can each get a longer stretch of uninterrupted sleep
    ii) Formula or pumped breast milk can be a way to alternate night-time feedings for babies
    iii) When your children are a little older, come up with strategies that they can use themselves if they are waking up with scary dreams (example: having favourite picture books next to their bed to look at to distract)

> When my babies were waking up every 3 hours to eat, my husband and I would trade off night feeds so that we could each get a stretch of 5 hours every night. I'd pump breastmilk around 2am that he could use to feed them around 5am before he'd start his morning routine before work.
>
> Megan Alberta kids 7 8

Optimizing Your Children's Sleep

Just as all kids have different sleep styles and sleep patterns, all parents will approach sleep with their children differently. There are many different opinions about kids and sleep and many resources to support all approaches.

If you are struggling with your child's sleep, you might find it helpful to hire a sleep consultant in your area that can help support you and provide specific strategies for you and your child's needs.

PROTECTING YOURSELF FROM VIRUSES

Germs are unavoidable, especially when you have children in the house. However, there are some things you can do to minimize your risk of getting sick.

Wash your hands!!

Handwashing is the best way to stop the spread of infections. Make sure you are diligent with hand washing and teach your children why it is important and how to do it correctly.

1) Washing your hands follows these steps:
    i) Wet your hands
    ii) Scrub your hands using soap (front/back of hands, between fingers, tips of fingers/fingernails) → you should do this for at least 15 - 20 seconds
    iii) Rinse hands off with water
    iv) Dry hands using a clean dry towel
2) Wash your hands before:
    i) Handling food in any way
    ii) Eating
    iii) Doing your CF treatments (oral/inhaled/injectable medications or chest physiotherapy devices)
3) Wash your hands after:
    i) Coughing or sneezing
    ii) Going to the bathroom
    iii) Preparing food
    iv) Handling garbage
    v) Cleaning the house
    vi) Petting animals
    vii) Touching shared surfaces in public (example: door handles, shopping carts, etc) → assume everything you touch in public has viruses
4) Other points for children to wash hands:
    i) Immediately upon arriving at home from school or daycare
    ii) After playing outside

Cover your cough and sneeze.

Teach your children to cough or sneeze into their elbow.

Don’t share personal items with your children.

Examples:

- Straws
- Cups
- Utensils
- Toothbrushes/toothpaste tube
- Hand towels

When your children are sick, attempt to keep your distance as much as possible.

Obviously this is hard as your children will need you the most when they are feeling unwell. Here are some examples of things you can do:

- Avoid kissing your children on their faces
- Do laundry frequently (example: sheets, your clothes and your children’s clothes)
- Wash your hands more frequently
- Clean toys

Some additional practical tips:

- Keep hand sanitizer bottles in various locations
    - In your vehicle
    - On each level of the house
    - In your purse/bag
- Be prepared to deal with more viruses once your children start daycare or school, have plans in place
- Be diligent with sterilizing your medical devices and washing your hands before handling them (example: nebulizers, chest physiotherapy devices)

THOUGHTS, COMMENTS, AND THINGS TO REFLECT ON

THINGS I WANT TO DISCUSS WITH MY FAMILY

THINGS I WANT TO DISCUSS WITH MY CF CLINIC

SURGERY AND CHILDREN

There are many reasons that you may need to have surgery when you have CF. Some common surgeries people with CF may have include:

- Sinus surgery
- Port placement
- Feeding tube placement
- Lung transplant

Each surgery will have its own specific restrictions that your doctor will review with you. It is important to brainstorm as a family *before* the surgery in order to best manage as a family. Some general things to reflect about when you are taking into consideration surgery as a parent.

> The only surgery I recovered from with my son there was my C-Section, and I probably learned more from what I did wrong than what I did right :)
>
> Ask for help, ask for help, ask for help.
>
> Emily, Saskatchewan,
> child age 3

Surgery

- Is it a scheduled surgery or an unpredictable surgery time (i.e. transplant)?
- Is it a day procedure or does my surgery require time in the hospital for recovery?
- Does the surgery happen in my city or do I or my entire family need to relocate temporarily for the surgery?
- What are the implications for:
    - School
    - Sports/activities
    - Friends
    - Childcare
    - Informal supports (friends/family)

My kids were in their teens when I had my transplant so they were pretty independent. Many phone calls were done. While in hospital my husband did school trips with them as I never wanted them to miss out. This also got their minds off of me as they were very worried.

One day at a time and don't think too far ahead. Do what you can and the rest can wait. Enjoy your time with everyone.

Anna, Manitoba, 3 adult children

Recovery

- What is the anticipated recovery time?
  - Do I need extra child care or support to keep up on household tasks or errands?
  - Some areas you might need assistance with:
    - Grocery shopping
    - Meal preparation and cooking
    - Cleaning
    - Laundry
    - Transporting your children to/from school, child care, or sports/activities
    - Child care
- Are there lifting restrictions (especially important when you have babies or young kids)
  - Will I be able to lift my kids in/out of their cribs or in/out of their car seats?

Additional Appointments

- Pre surgery?
- Post surgery?
- Do I need to have child care set up for these appointments?

There is a fantastic resource specifically for lung transplant and families: https://www.uhn.ca/Transplant/Lung_Transplant_Program/Documents/Lung_Transplant_Guide_Support_People.pdf

THOUGHTS, COMMENTS, AND THINGS TO REFLECT ON

THINGS I WANT TO DISCUSS WITH MY FAMILY

THINGS I WANT TO DISCUSS WITH MY CF CLINIC

How to Manage When You Feel Unwell

Feeling unwell can mean anything from having a cold, being on home IVs, or just having an "off" day with increased fatigue/pain/coughing/etc. Preparing in advance to manage on these days can be extremely helpful. Here are a few things you can do ahead of time in order to make things easier when you're not feeling your best:

> When I'm on home IVs I focus on myself and my health first. If I don't get better then everything else is pointless
>
> Jeremy, Manitoba, child aged 12

- Stock up your freezer with ready-made meals that just need to be reheated (whole meals or just parts of a meal)
- Have some ready-made snacks on hand
- Create a special box of favourite toys and activities you know your child will love and that will keep him or her occupied. Depending on your child's age, something new to play with or that they haven't seen in a while tends to keep their attention for longer periods versus toys they see and play with every day. The key is to only pull this out when you're unwell so the novelty doesn't wear off.
- Have a plan already in place with friends and family, reach out to them with specific asks when you need it. Some things you might want to ask for include:
    - Assistance with errands or grocery shopping
    - Assistance with meals (homemade or gift cards for takeout/delivery)
    - Assistance with household chores, laundry, etc
    - Dropping off or picking up your kids from school, daycare, or activities

> I also had help from mom, friends, and husband to get through. Quickly found out I couldn't do it alone. I also had trouble with losing control of my household.
>
> Anna, Manitoba, 3 adult children

My first set of Home IV's occurred when my son was 9 months old. When he was a baby and toddler, I found it was impossible to care for him and myself on home IV's, so we always got support from friends or family so that I could assist with his care but also not be responsible for him entirely on my own. That way when he got too handsy with tubing, or I was suffering too much from the side effects, I could tag team someone and he got the care and love that he needed, and mom was there with him as much as possible.

Emily, Saskatchewan, child age 3

Home IV was very difficult when they were young. We tried to get friends and family to help support us. My kids are now 10 and 12 and could do the whole thing for me. They know what supplies we need and how to give it. They have been pushing flushes into my line since toddlers. Again it’s just part of our life. They don't know any different.

CF-RELATED DIABETES: HYPOGLYCEMIA

Having kids can sometimes make managing blood sugar levels more challenging. To name just a few of the reasons why:

- Being more active than you planned or expected
- Being late to a meal or snack because you have a fussy baby or tantruming toddler
- Sports or activities that change your usual eating routine/times

Some things that can help you:

- Check your blood sugar levels more frequently, or consider getting a continuous glucose monitor (talk to your Endocrinologist about different options)
- Keep candy or sugar items to treat a low blood sugar in different places
    - Each level of the house
    - Your vehicle
    - Your purse
- Talk to your kids about diabetes, low blood sugar, and why they can’t help themselves to your low-blood-sugar candy stashes

My kids know my low-blood-sugar candy is off limits for them. I tell them: “I know it might seem funny and not fair, but this candy is medicine to me when my blood sugar is low”

Megan, Alberta, kids 7 & 7

- Teach your kids about calling 911 if you pass out
- Talk to your CF Team or Endocrinologist if your CF related diabetes becomes more challenging to manage

HOSPITALIZATION

If you are hospitalized, you may be worried about how it will impact your children. Remember to refer back to page 5 for guidance on how to explain hospitalization and illness to your children, as well as different ideas for how to explain hospitalization to your children.

> I found doing home IV was too much work for me. I prefer staying in the hospital even though I have to live with the sub-par food (I bought a lot of takeout) and only getting to see the kids on weekly visits.
>
> Anonymous parent with CF

There are many ways to help both you and your children stay connected in special ways during hospitalization. Please refer to the Activity Book for more details, but here are a few ideas:

- Have your kids make you something special to bring to the hospital with you. Examples:
  - Have your child pack you a stuffy to bring with you. You can even take a series of creative pictures of their stuffy's time in hospital and send them to your child (example: doing treatments, getting a coffee from the cafeteria, talking to your doctor, hanging out on your IV pump, etc)
  - A decorated pillow case (it could be decorated with written messages using a sharpee or even hand prints with fabric paint, etc)
  - Special photos
  - A coloured picture for you to hang up in your room
  - "Hugging Hands"

> Hospitalization gets increasingly harder as my son gets older. He becomes more aware of how severe CF can affect our lives, so when I am there we try to keep joy in our life. I never miss a bedtime routine. We read via Facetime, I "tuck him in" and he holds the phone until he falls asleep. We sometimes chat before school too so I can wish him a great day. Now that he is into online games, we play different games like checkers, Uno and Bingo together. He always packs me a stuffy to cuddle at night, and I give him my "Brave" penny. This penny holds all Mommy's bravery, whenever I was scared during appointments or procedures I held it tight, now he uses it to be brave
>
> Melissa, Ontario, son aged 9

- "Pocketful of love": kids often get comfort from tangible things that they can hold and touch that remind them of the people they love and might miss. You could put together a little box for your child(ren) and fill it with special photos of you together, written memories, favourite jokes, objects that trigger happy memories, etc. You could even write special messages such as "I love you because ________" or "I feel proud when you ________"
- Other ideas to support your children while you are hospitalized:
    - A traveling journal to draw or write special messages to each other, transported from you/to your children via visitors
    - Storing kisses around the house
    - Creating matching friendship bracelets you can both wear
    - Make a special trade with your child
    - Create a "countdown to discharge" if your discharge date is known
    - Create social stories to support your children to better understand what their routine will look like with you in hospital and to validate how they might be feeling about you being away in the hospital.

> When I am hospitalized and my kids come to visit for the first time, I always have a gift for each of them. I guess I'm trying to associate the memory of me being in hospital with something positive. My husband will try to bring the kids in on the weekends. We try to different things (public gardens, museum, harbor hopper) when they come to visit. I would talk to them on the phone or FaceTime. I did find that the boys were sometimes resistant to connecting with me at first when talking on the phone or coming to see me. They are too little to express complex emotions and we always worked though it and seemed happy to see or talk to me.
>
> Anonymous parent with CF

SOME OTHER THINGS TO CONSIDER WHEN HOSPITALIZED

Having your children visit you:

- Does your unit have specific policies about visiting hours or about younger kids visiting?

> Hospitalizations are the hardest part. We try to do somewhat normal things like have dinner together in the cafeteria or play games together in my room.
>
> Jeremy, Manitoba, child aged

My son has been quite young for my hospitalizations, so it was tricky trying to determine what would be best for him. In our circumstance, I often felt that out of sight was out of mind for him (being 1 and 2 years old), so we arranged visits once or twice a week and did Facetime maybe once a week as well. That way he could be distracted by fun time with Dad and not spend too much time missing mom. It was hard being away from him, but it was also hard every time we had to say goodbye after a visit. It's all about balance.

Emily, Saskatchewan, child age 3

- What is your hospital routine like and are there ideal times for visitors that won't interfere with your treatment regime?
- Who can bring your children to visit you?
- Are you able to get a day pass and have your family and children pick you up to go out to a playground (or similar) nearby the hospital?
- What do you need to explain to your children in advance before they visit you?

When I would come home for a few hours on pass, I would try my best to speak positively in front of the kids about the hospital.

Instead of responding to their tears by only saying "Mom was sad I couldn't be home last night too" I would try to describe something interesting like. "I had a nice conversation with my doctor, her name is ___. She is giving Mom some really important medicine to make me feel better"

Kalyn, Alberta, kids ages 1 and 4

It is important to maintain daily contact with your children as much as possible. Thankfully, there are now many different ways for you to do this:

- Phone calls
- Video calls
- Emails
- Apps that allow you to play online games together

Other creative ways to stay involved with your children while in hospital:

- Pack some of their favourite books and bring to the hospital with you, read to your child over a video call
- Call your children to be involved in the bedtime routine (listening to or reading stories, saying goodnight, etc)

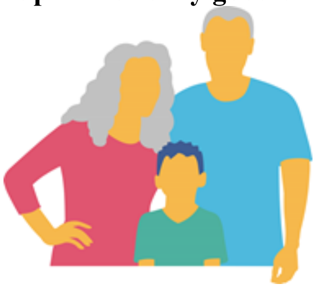
- Listen to music or watch a tv show together over a video call
- Eat meals together over video call
- Play board games together by having your kids roll the dice and move your piece for you

> When my kids 6, we would play board games over video calls together. They would do the rolling. For the game itself, we would either download a PDF of a board game, or else they would move my piece. When I'm going to be admitted, I always ask my kids to draw me a picture that I can take with me while I'm in hospital. It helps them by giving them an important job to do and it helps me because I have incredibly sweet and heart-filled drawings to hang on my hospital room walls.
>
> Megan, Alberta, kids 7 & 7

On the next page is an example social story that you can create to help your child understand hospitalization. Illustrations by Joelle Berlet.

Sometimes because of Mom's Cystic Fibrosis, her lungs can get extra sick. When this happens she needs to go to the hospital to get extra medicine.

I don't need to worry about not being taken care of, because Dad and Grandma and Grandpa take really good care of me!



When Mom goes to the hospital, I really miss her and it can be hard not having her at home all the time. When I miss Mom, there are lots of things that I can do like call her on the phone or draw her special pictures. Dad gives me really good hugs when I'm feeling sad about missing Mom.

Mom still hangs out with me as much as she can, just in different ways. She reads me funny jokes or books on the phone and always tells me she loves me when I'm getting tucked in for bed.

Sometimes I even get to visit her when she has to stay in the hospital! We have lots of snuggles and even watch movies together in her hospital bed. I just have to remember to be quiet and not run in the hallways which can be hard when I'm so excited to see her!

The best part is when Mom comes home from the hospital when she is all done her extra medicine and we always make her favourite food and a special cake to celebrate!

"UNWELL PLAN"

It can be incredibly helpful to have an "unwell plan" built *before* you are unwell and use it when you are feeling very unwell at home or need to be hospitalized. Having this plan in place can help your support people know what needs to be done and who will take over what responsibilities. Having this plan in place will help lessen the impact on your children and other family members. Include your children in the development of this plan.

> Plain and simple, it takes a village, especially when one parent has CF!
>
> Kim, BC, child age 3

**Important:

- Identify support people in your life - people that you can rely on to help if needed (friends, family members, neighbours, community members, etc)
- Do NOT make assumptions about what a support person can and cannot do - make sure you talk to each of your support people and come up with specifics about what they are or are not able to do
- Write this all down
- Make sure you review your plan regularly. Have ongoing conversations with your support people to make sure that you are all on the same page

There are many different ways to keep track of all of these details. Look at pages 51 -56 or templates for keeping track of your Unwell Plan. Some of the things you will want to keep track of include:

- Who you need to inform if you are unwell or need to be hospitalized
    - Write down your email message or phone script ***before*** you are unwell. This will make it quicker and easier for a time when you are already feeling unwell
    - Keep track in a document or spreadsheet, along with contact information. Then you can just copy/paste/send your messages.
- Who are your support people
    - What are they able to help out with?
    - How do you get in touch with them?
    - Do they have any restrictions for when or how they are able to help?
- A list of jobs or tasks that your family would either need support or want support (in other words: what are things that YOU do for the home/family/kids that other people would need to do if you were in hospital).
    - Consider tasks such as dropping off kids at childcare, school, activities, grocery shopping, errands, household management tasks (inside the home and outside the home), homework assistance, bedtime routine, bathing kids, cooking, etc.

Please use the following templates to create your own Unwell Plan.

UNWELL PLAN

TASK THAT PARENT WITH CF NORMALLY COMPLETES	BACKUP PLAN OR PERSON	BACKUP FOR BACKUP

UNWELL PLAN

THINGS OR TASKS THAT WE'LL NEED SUPPORT WITH	SUPPORT PEOPLE WHO CAN HELP	COMMENTS OR RESTRICTIONS

UNWELL PLAN

PEOPLE TO INFORM	CONTACT INFORMATION	MESSAGE

UNWELL PLAN

SUPPORT PERSON	WHAT THEY CAN HELP WITH	ANY RESTRICTIONS WITH WHEN OR WHAT THEY CAN HELP WITH?	CONTACT INFORMATION	LAST TIME SUPPORT AVAILABILITY CONFIRMED?

IN CASE OF EMERGENCY

BASIC INFORMATION

NAME: ....

BIRTHDATE: ....

HEALTHCARE NUMBER: ....

EMERGENCY CONTACT #1

NAME: ....

RELATIONSHIP: ....

CONTACT INFORMATION: ....

EMERGENCY CONTACT #2

NAME: ....

RELATIONSHIP: ....

CONTACT INFORMATION: ....

HEALTH CONDITIONS

....

....

....

MAIN DOCTOR INFORMATION

NAME: ....

HOSPITAL: ....

CONTACT INFORMATION: ....

*****PLEASE SEE ATTACHED FOR MEDICATIONS**

MEDICATIONS

MEDICATION	DOSE	COMMENTS

THOUGHTS, COMMENTS, AND THINGS TO REFLECT ON

____

____

____

____

____

____

THINGS I WANT TO DISCUSS WITH MY FAMILY

____

____

____

____

____

____

THINGS I WANT TO DISCUSS WITH MY CF CLINIC

____

____

____

____

____

____

Strategies for Being Successful as a Parent and Family with CF

Megan Parker, MScOT

***For more guidance on how to adapt these general strategies, please ask to be referred to an Occupational Therapist that specializes in chronic disease management.*

It is hard to fit everything into your day when you are a parent or to find the time and the energy to do all of the things you want or need to do. This is *especially* true when you have hours of inhaled medications and chest physiotherapy to do every day. It can be helpful to use some strategies to organize yourself and use your time wisely and in a meaningful way so that you have time and energy for the important things in your life.

> Trying not to compare yourself to other parents is key. I think parents without this illness struggle with that, but its extra tough when you are comparing yourself to people that don't share the same struggles as you.
>
> Emily, Saskatchewan, child age

> I really struggled the most with my CF and my son when he was a toddler. The more active he was and more independent he became at age 2-4, I was more drained. I tried to nap when he did and if he didn't nap I would put on a movie and we would cuddle (I usually fell asleep!) Once he became a bit more independent to the point I didn't have to helicopter over him, it became easier to juggle my health and being a Mom.
>
> Melissa, Ontario, son aged 9

It all comes down to the "3 P's": prioritizing, planning, and pacing.

PRIORITIZING

Don't be afraid to ask for help when you need it.

Haley, Ontario,
daughter 3 years

It can be helpful to change your thinking from "all or nothing" (where you have to "do it all", and "do it all the time") to thinking about how, why, and when you do things. This way, you are not at risk of overdoing it or burning out (not to mention you will have the time and energy to do the things that are the most important to you). How do you do this?

1. Make a list of all the things you do in your life (examples: things you do around the house, things you do for your CF, things you do at work, things you do in your community, etc). It might take you a long time to write this list down. Once your list is done, go through and prioritize all the things you are doing. This can help you think about whether you are spending your time/energy in the right place. Go to page 60 for the worksheet "Writing Down your Life's To-Do List".
2. Think about how often you do some tasks and can you change this? (example: vacuum every other week instead of every week).
3. Delegate some tasks to others (even to your kids!)
4. Get rid of some tasks altogether
5. Remember that it's ok to say no!

WRITING DOWN YOUR LIFE'S TO-DO LIST

Use a different page for each different category of things that you do (things you do at home, in the community, for volunteering, for errands, etc)

Category: ____________________

LIST OF ALL THE THINGS THAT YOU DO	**PRIORITY LEVEL?** 1 = Top priority, absolutely has to be done 2 = medium priority, should be done if I have time or energy 3 = low priority, does not need to be done by me or done at all	**ANY OPPORTUNITY TO MAKE CHANGES?** How often? Who does it? When you do it? Etc

PLANNING

Use daily and weekly schedules to help you plan ahead. Schedules can help you to better pace out the things you need to do in a given day or given week. Check out https://scatteredsquirrel.com/ for free printable sheets to help you better organize your time. Also see page 64 for a blank weekly planning sheet to get you started.

Some things to think about when you are making your daily/weekly sheets:

- Get a good understanding of how long it takes you to do things (examples: morning routine, medication routine, getting your kids ready to get out the door). Knowing how long these tasks take will help you to plan what time you need to wake up or when you need to get started.
- Pay attention to patterns.
    - Are there times in your day where you consistently feel your best? This is when you should plan to do your hardest jobs or the jobs that take the most effort/energy.
    - Are there times in your day where you consistently feel your worst? This is when you should plan for some rest time.
    - Do you have any patterns throughout the week?
    - Are there certain times in the day that you would be better for doing your medications?
- Plan for rest time. You are way more likely to actually stop and rest if you plan ahead for it.
- Plan to rest *before* the fatigue becomes overwhelming.

> I got up with the children as my husband worked all day but he took over in the evening and on weekends. If I needed more help my mom would come for a couple of days which gave me time to refresh and start a new week. Day by day.
>
> Anna, Manitoba, 3 adult children

WEEKLY PLANNER

M

MEDS DONE?
☐
☐
☐

DINNER:

T

MEDS DONE?
☐
☐
☐

DINNER:

W

MEDS DONE?
☐
☐
☐

DINNER:

T

MEDS DONE?
☐
☐
☐

DINNER:

F

MEDS DONE?
☐
☐
☐

DINNER:

S

MEDS DONE?
☐
☐
☐

DINNER:

S

MEDS DONE?
☐
☐
☐

DINNER:

TO-DO LIST & REMINDERS

PACING

You spend less energy when you pace yourself, or spread out when you are busy and what you are doing. Some different ways to pace yourself throughout your day or week:

- Alternate between easy and hard jobs (don't just do all your hardest jobs at the same time)
- Alternate between sitting and standing jobs
- Alternate between jobs that need physical effort and jobs that need brain power.
- Spread your chores/errands throughout the week or month
- Break up bigger jobs into a series of smaller jobs and slowly work your way through all the parts. For example: instead of preparing dinner, cooking dinner, eating dinner, and then cleaning up dinner all in one go, you could break it up like this:
  - Do some of the food preparation earlier in the day (chopping vegetables or meat, measuring out ingredients, store in fridge)
  - Cook and eat dinner
  - Soak the dishes in the sink
  - Finish washing the dishes, let them air-dry on a rack
  - Put dishes away later or even the next morning
- Sit whenever possible to save energy. Examples:
  - while preparing ingredients for dinner or if stirring at the stove for a longer period of time
  - getting dressed
  - showering
  - ironing/folding clothes

TIPS FOR HOW TO MAKE SOME JOBS EASIER

Sometimes making small changes to how you do things can make a huge difference. Here are a few things to think about for different jobs you might be doing:

Managing Around the House

- Think about how often you do chores. Can you change how often you do these chores? For example, vacuum every other week instead of every week.
- Hire a cleaner, even for the occasional deep clean.
- Hire somebody to manage the yard work (mowing the grass, gardening, shoveling, etc).
- Write a list of chores/errands that you need done and hang this list somewhere visible. It is possible that you have friends/family/coworkers that have offered to help out. It is also possible that they are waiting for directions from you to know *what* would be helpful. When you have this list, when visitors come over and they have the time or desire to help out, they can simply look at the list and choose something to do without you even needing to ask them.

> We hung a whiteboard on our fridge and wrote down any jobs or errands that needed to be done. When family or friends would come over and had time to help, they just looked at our board and chose something without us needing to ask.
>
> Megan, Alberta, kids 7 & 7

- Give chores to your kids. Even very young kids can help out around the house (example: sweep the floors, dust, put away toys, etc).

> We have always been organized and everyone has always been responsible for themselves. The more my kids could do the easier life was for me when sick. They clean their own rooms and make their lunches for school. I'm there to support them and help them as needed. They are maturing into well rounded kids ready to face their future.
>
> Anonymous parent with CF

> My wife and I manage parenting and my CF together. We work together on a daily basis to do what needs to be done either for my health or our household.
>
> Jeremy, Manitoba, kid aged 12

> I found it easier to not sweat the small stuff. Everyone had a chore so things ran smoothly.
>
> Anna, Manitoba, 3 adult children

Groceries

- Meal planning is a great way to save time and energy at the grocery store and when cooking. After planning out your meals, make a grocery list and buy items for the whole week. See the next page for a template for meal planning and grocery list.
- Map out your trip around the grocery store. When you are making your grocery list, group similar items together (fruits and vegetables, canned goods, bakery items, frozen items, dairy, etc). You can even write out your grocery shopping list to match the layout of the store to save even more time and energy while grocery shopping.
- Think about grocery shopping in different ways. Find out what your local grocery stores offer:
    - Online ordering for pick-up which saves you time/energy instead of walking the aisles and collecting items
    - Home delivery (some have a small fee, others do not if you spend over a certain amount)
- Use a grocery shopping app or a pre-made grocery list to help stay organized. Make one on your computer and print a blank one for every new week.
- Avoid going grocery shopping at busy times.
- Plan to buy groceries when your energy levels are highest.
- Direct grocery baggers:
    - Ask them to not make bags too heavy.
    - Group fridge/freezer groceries together in separate bags – when you get home, just put away the fridge/freezer bags. Come back later to put away the other groceries.
- Get help carrying and loading your groceries into your vehicle. This is usually a free service, take advantage of it!

WEEKLY MEAL PLAN AND GROCERY LIST

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

FRUITS

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

BAKERY

☐
☐
☐
☐
☐
☐
☐
☐
☐

VEGETABLES

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

MEATS AND FISH

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

DAIRY

☐
☐
☐
☐
☐
☐
☐
☐
☐

FROZEN

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

CANNED GOODS

☐
☐
☐
☐
☐
☐
☐
☐
☐

SNACKS

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

BAKING SUPPLIES

☐
☐
☐
☐
☐
☐
☐
☐
☐

MISCELLANEOUS

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

HOUSEHOLD

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

HYGIENE

☐
☐
☐
☐
☐
☐
☐
☐
☐

Meals

- Meal planning is a helpful tool and will save you time and energy when grocery shopping and cooking your meals.
- If you are taking the time to make a meal, double the ingredients so you can either have a planned left-over meal during your week or freeze one dinner for zero-meal preparation on a different week
- One-pot meals can be helpful to reduce time/effort with meal preparation and clean up.
- Set up the kitchen before you start. Bring all the items you will need to a central area in your kitchen to prevent walking back and forth across the kitchen.
- Prepare food/meals in stages if possible. Chop vegetables/meat earlier in the day or week and store in the fridge until it is time to cook the meal.
  - Sit during food preparation (examples: during chopping or peeling)
  - Have a discard bowl next to you for peels/seeds/etc instead of making trips back and forth to the garbage/sink/compost
- Make substitutions to your recipes to simplify preparation:
  - Substitute fresh ingredients for frozen pre-chopped options
  - A lot of vegetables and meats are available for purchase already cut and prepped, which can save you time and effort
- Recruit a sous-chef to help with preparation. This can be a great way to teach children how to cook and also to spend quality time together.
- Get a stool so that you can sit while at the stove or for meal prep at the counter.
- Line your cooking pans with aluminum foil or parchment paper. This will make clean-up easier.
- Websites such as www.mealtrain.com can be incredibly helpful if you have specific days that you need meals. Family/friends simply go to the website you have created and sign up for a meal to make/drop off. There are similar apps and services to organize assistance for things like chores and errands as well

Child care

- Paid child care, even if just every once in a while, can be very helpful in helping give you some time to just rest or complete medications, even if you are not working.
- Un-parented activities are a good time to just rest. If the class or activity is short, bring your medications or a book and just relax in your vehicle to save time driving home and back again.
- A lot of communities have drop in play groups or meetups where you can connect with other parents. This can be an easy way to meet other parents in

your community and build friendships (which then may give you the ability to drop your child off for play dates)

- Other child care options: neighbours (adults or teenagers), babysitters, coworkers
- Connect with your Obstetrician or medical team to see whether there are any services or programs that provide post-partum care.
- Some things to think about for paid child care (especially when your kids are younger):
  - Do they make and serve breakfast and lunch? (this would save you extra time and effort by not needing to either wake up earlier to feed your kids or make a lunch to send with them)
  - What is their stance on naps?
    - If your child needs to nap, is this something that can be offered?
    - If not, will this make it more demanding on you after you pick up your child?
  - Are they open to getting your child dressed in the morning if you bring a change of clothes? (this again will save you time and effort in the morning)
  - What is their sick policy? Do they make other kids stay home when they are symptomatic or will your kids be exposed to a lot more colds?
  - If you are doing child care part-time only, is there the possibility of increasing hours or days if you are sick so that you can have extra resting time?

THOUGHTS, COMMENTS, AND THINGS TO REFLECT ON

THINGS I WANT TO DISCUSS WITH MY FAMILY

THINGS I WANT TO DISCUSS WITH MY CF CLINIC

MAKING CHANGES

Throughout this resource, there are many sections where you have had a chance to reflect about what you might need to change to make life as a parent with CF more manageable. Some examples are changing when/where you do your CF medications, what you do for exercise, how you plan and prepare your meals, and what you do to prepare for a hospital stay, just to name a few.

When making changes, there are many ways that you can set yourself up to succeed.

- Write down your initial thoughts on what changes you are thinking about making.
- Choose just ONE change to work on at a time.
- Be as specific as possible with the change you want to make and how you are going to set yourself up to be successful with the change. Ask yourself:
    - Why do I want to make this change? This will help keep your motivation up to continue to work at making the change stick.
    - When are you going to do it? (time of day, day(s) of week, etc)
    - Where are you going to do it?
    - Do I need support from anyone else to do it? What does that support need to look like?
    - What is the change I want to make? Be as specific as possible.
- Start small and build your way up
- Track your progress and celebrate your success!

Use the worksheets on the next two pages to help set yourself up for success.

GOAL SETTING

BRAINSTORM ALL POTENTIAL CHANGES TO MAKE

CHOOSE ONE GOAL TO WORK ON

Goal:____

Why do I want to make this change? ________________________

HOW YOU WILL SET YOURSELF UP FOR SUCCESS

Where will I do it?______________________________

Do I need any equipment or supplies?______________________

Do I need support from anyone? If yes, what does that support look like? _______

When will I do it?______________________________

Do I need to set anything up different for my kids in order for this to work?_____

How else can I set myself up for success? (alarms, reminders, etc)____________

GOAL TRACKING

WEEK 1

		Things that helped me succeed	Barriers for being successful
Monday	☐ ☐ ☐		
Tuesday	☐ ☐ ☐		
Wednesday	☐ ☐ ☐		
Thursday	☐ ☐ ☐		
Friday	☐ ☐ ☐		
Saturday	☐ ☐ ☐		
Sunday	☐ ☐ ☐		

WEEK 2

		Things that helped me succeed	Barriers for being successful
Monday	☐ ☐ ☐		
Tuesday	☐ ☐ ☐		
Wednesday	☐ ☐ ☐		
Thursday	☐ ☐ ☐		
Friday	☐ ☐ ☐		
Saturday	☐ ☐ ☐		
Sunday	☐ ☐ ☐		

WEEK 3

		Things that helped me succeed	Barriers for being successful
Monday	☐ ☐ ☐		
Tuesday	☐ ☐ ☐		
Wednesday	☐ ☐ ☐		
Thursday	☐ ☐ ☐		
Friday	☐ ☐ ☐		
Saturday	☐ ☐ ☐		
Sunday	☐ ☐ ☐		

ACTIVITY IDEAS

All of the things that you do in a day with your kids can be changed in different ways to make them doable depending on your needs/restrictions and your kids' needs. Here are just some of the reasons why you might need to modify activities or think about choosing activities where your kids can be more active than you:

- You have to put all your effort into doing chest physio properly (and so your kids need to have more independence during this time)
- You have low energy levels
- You have lower lung function, making it harder to keep up physically
- You are feeling sick or unwell (for the entire day or just part of the day)
- You are on home IVs and need to spend more time resting
- Your kids have way more energy than you
- You have CF-related arthritis and your joints can be painful
- You have CF-related diabetes and you need to rest while you recover from low blood sugar

> I really struggled with MOM GUILT. I couldn't always keep up to him, still can't. That pains me to not be able to be physically present 24-7 in his life (ie: play ball, skate)
>
> Melissa, Ontario, son aged 9

LESS PHYSICALLY DEMANDING ACTIVITY IDEAS

Here is a (non-exhaustive) list of activities that are less physically-demanding for *both* you and your kids:

- Books
  - Read to your kids
  - Have your kids read to you
  - Have your kids make up their own story to the pictures
  - Audiobooks (consider getting the "Libby" app, or similar, where you can be connected to free content using your local library card)
  - Picture books without words so your child can make up their own story and tell it to you. A good one is the book "You Choose" by Pippa Goodhart
- Drawing
  - Look at "Keepin' It Rosy – When Your Parent Has Cystic Fibrosis: An Activity Book" for some ideas
  - Search for "step by step" drawing instructions or YouTube videos for instructions your children can easily follow by themselves

- Colouring (books or printable pages)
- Arts and craft projects
- Puzzles
- Playdoh
- Sorting items
- Card games
- Board games
- Tape paper to your dining table and draw roads, buildings, parks, etc for toy cars to drive on

ACTIVITIES THAT ARE LESS DEMANDING FOR YOU, BUT NOT YOUR KIDS

Here are some examples of activities that challenge your kids more physically but don't challenge you physically (at all or less than your kids):

- "Scavenger Hunts" → send your kids to look for 5 things that are blue and touch with their elbow, 3 things that are yellow and sit on them, bring back 3 different objects that are round, etc
- Foam letters/numbers (often sold as bath toys) → put a pile in another room, tell them to bring back a specific letter (great for when toddlers are learning their alphabet or numbers)
- Indoor gross motor equipment, examples:
    - small trampoline
    - small bouncy castle
    - Indoor swing/rope
    - Small indoor play structure
    - DIY indoor climbing wall
- Simon Says
- Ship to Shore
- Dance parties
- Musical "Freeze dance"
- Sign them up for un-parented classes and watch from the side
- With younger kids, look into community-based drop-in play groups. This is a good time to let your child roam with various gym equipment while you can sit on the side and watch or sit on a mat nearby.
- Hire a babysitter to come over (even if you are home) to do some physical activity with your kids
- Play date with similar-aged kids
- Create a road map or paths on the floor with painters tape

- Chores - vacuuming, dusting, sweeping etc.
- Obstacle course
- Dress up parade
- Ribbon wands
- Fill an old playpen with pillows and blankets and jump in
- Pretend to run like monkeys, dinosaurs, tigers etc.
- Sticky spider web game - use painter's tape to make a web-like design in a doorway then scrunch up some old newspapers, balloons or craft pompom balls to throw at it.
- Have a set of special toys that only come out when you're not well.
- Do regular toy swaps with other friends with kids. This is a free way to rotate through toys/books/puzzles to keep your kids engaged.

For more ideas: https://www.babycenter.com/0_40-ways-to-entertain-your-kids-while-lying-down_10350158.bc?scid=mbtw_post20m_3w%3A1259&pe=MlV5blFFQnwyMDExMTEwMw

CF SPECIFIC ACTIVITIES

Kids learn best through play and you will find that they often will mimic the people around them and their routines/roles. Here are a few different ideas for CF-specific activities. For more information, please go to “Keepin’ It Rosy – When Your Parent Has Cystic Fibrosis: An Activity Book”.

- CF doctor kit
- CF stuffy
- Science experiment: how do lungs work?
- Learn CF anatomy – life size
- Special crafts/activities before and during a hospital stay
- Visual schedules and social stories
- CF-themed colouring sheets

RESOURCES

CF THEMED CHILDREN BOOKS

Please note that some of the books are written from the perspective of a parent with CF and others from the perspective of a child with CF:

- Cystic Fibrosis Trust Children's Books:
    - https://www.cysticfibrosis.org.uk/the-work-we-do/information-resources/rosie-and-seb
    - Seb's Best Game
    - The Lost Collar Investigation
- Foundation Care Publications:
    - https://www.foundcare.com/Patients/Educational_Resources.html#57982
    - Email: Email help@foundcare.com to receive a copy
    - The Amazing Story of Huxi: A Panda with Cystic Fibrosis
    - Huxi Goes on Vacation
    - Huxi Meets Her Super Team
- Jasper's Story Living With Cystic Fibrosis by Andy Glynne, Nandita Jain and Salvadore Maldonado (2017)
- Beauty and the Disease by Mallory Hicks (2019)
- Mallory's 65 Roses by Diane Shader Smith (1997)
- Charlie and Me by Kathryn Archambault (2001)
- Sticky Icky Booger Bugs by Sherry Frith (2013)
- Cystic Fibrosis and You by Emilie Sasso (2008)
- Kyle's First Crush by Leah Orr (2006)
- Liam, Strong as a Tree by Meghan Behse and Liam Wilson (2020)
- Cadberry's Letters by Jennifer Racek (2008)
- Go Lungs Go! Cystic Fibrosis and My Mom By Stephanie East (2008)
- My DNA Diary: Cystic Fibrosis by Lisa Mullan (good for 9-12 year olds) (2018)
- How Charlie Mouse Learned About Cystic Fibrosis by Stephanie Bloxham and Teresa Jewell (2011)

CHRONIC ILLNESS THEMED CHILDREN BOOKS

- My Daddy's Sick by D. onisor (2010). Published by Authorhouse.
- The Invisible String by Patrice Karst (2018). Published by Little, Brown Books for Young Readers
- The Invisible String Workbook: Creative Activities to Comfort, Calm, and Connect by Patrice Karst and Dana Wyss (2019). Published by Little, Brown Books for Young Readers.

- The Memory Box: A Book about Grief by Joanna Rowland (2017). Published by 1517 Media.
- I Miss You: A First Look at Death by Pat Thomas (2001). Published by Peterson's.
- The Goodbye Book by Todd Parr (2015). Published by Little, Brown Books for Young Readers.

RESOURCE BOOKS FOR PARENTS WITH A CHRONIC ILLNESS

- How to Help Children through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist by Kathleen McCue and Ron Bonn (2011). Published by St. Martin's Publishing Group.
- When A Parent is Sick: Helping Parents Explain Serious Illness to Children by Joan Hamilton (2007). Published by Pottersfield Press.

CF THEMED COMICS

- Ghosts by Raina Telgemeier https://goraina.com/ghosts/
- Chilman-Blair, K., & deLoache, S. (2011). What's up with beth? Medikidz explain cystic fibrosis. Medikidz: London, UK.
- Chilman-Blair, K., & deLoache, S. (2011). What's up with justin? Medikidz explain nutrition in kids with cystic fibrosis. Medikidz: London, UK.

YOUTUBE VIDEOS

- Getting Nosey About CF with Oli and Nush created by the Cystic Fibrosis Trust https://www.youtube.com/watch?v=WuI72eMrIQI
- What Is Cystic Fibrosis? Created for the San Diego Chapter of the Cystic Fibrosis Foundation https://www.youtube.com/watch?v=FMAOEOmLoUE&feature=youtu.be
- What is Cystic Fibrosis? Created by Cystic Fibrosis Canada https://www.youtube.com/watch?v=DtL-3VIBHTs
- Welcome to Joshland - videos featuring Moganko, a puppet
    - Moganko Tries a Pulmonary Function Test https://www.youtube.com/watch?v=zXiGkbZx_Yg
    - All videos found here: https://www.youtube.com/user/welcometojoshland

WEBSITES

Parenting with CF

- Cystic Fibrosis Foundation: Parenting as an Adult with CF https://www.cff.org/Life-With-CF/Transitions/Family-Planning-and-Parenting-With-CF/Parenting-as-an-Adult-With-CF/

Dealing with depression and anxiety

- Anxiety Canada: www.anxietycanada.com
- Canadian Mental Health Association: www.cmha.ca
- Centre for Clinical Interventions: https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself
- Bounce Back program - there is a referral form if you want to be attached to supportive coaching. https://cmha.bc.ca/programs-services/bounce-back
- Centre for Clinical Intervention - Resources on Depression and Anxiety - good handouts
- https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/Depression
- https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/Anxiety
- Cystic Fibrosis Canada - Depression, Anxiety and CF
    - Go to https://www.cysticfibrosis.ca/our-programs/resources
    - Click on “CF Health”
    - Scroll down to “Mental Health”
- Depression, Anxiety and Cystic Fibrosis – What the Guidelines Mean for You https://www.cff.org/Living-with-CF/Emotional-Wellness/Depression-Anxiety-and-Cystic-Fibrosis-What-the-Guidelines-Mean-for-You/
- Cystic Fibrosis Canada’s Virtual Education program for Patients and Caregivers
    - https://www.cysticfibrosis.ca/about-cf/virtual-education-program-for-patients-and-caregivers/new-international-guidelines-on-mental-health-in-cf
    - https://www.youtube.com/watch?v=VS7WZgwDn-g&feature=youtu.be

Dealing with illness and death

- Canadian Virtual Hospice – When to Tell the Children: Preparing Children for the Death of Someone Close to them: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication/When+to+Tell+the+Children_+Preparing+Children+for+the+Death+of+Someone+Close+to+Them.aspx
- Kids Grief – Talking with Kids and Teens about Dying and Death: www.kidsgrief.ca

- University Health Network - Talking with Young People about Illness and Dying: https://www.uhn.ca/PatientsFamilies/Patient_Services/Documents/TalkingWithYoungPeople.pdf
- Eluna -Talking to Teens and Children About Illness and Death: https://elunanetwork.org/resources/talking-to-teens-and-children-about-illness-and-death/

FACEBOOK GROUPS FOR PARENTS WITH CF

- Cystic Fibrosis Mummies: private page therefore requires admin approval upon request.
- Moms with Cystic Fibrosis #CFamilyLife https://www.facebook.com/groups/2653982721495014

> Become a part of CF Parent groups online, and use that resource when you are in need of CF specific support and ideas.
>
> Emily, Saskatchewan, child age 3

BREASTFEEDING AND MEDICATIONS

Please make sure to talk to your own CF physician, nurse, pharmacist and/or lactation specialist to come up with options and strategies for breastfeeding and CF medications. The following articles can be used to help guide the conversation with your CF team.

1. Edenborough FP, Borgo G, Knoop C, Lannefors L, Mackenzie WE, Madge S, et al. Guidelines for the management of pregnancy in women with cystic fibrosis. J Cyst Fibros 2008: S2-32.

2. Peddlesden J. Drugs in breastmilk. Pharm Prac 2005; 21(8): 15-25.

3. Kroon MAGM, Akkerman-Nijland AM, Rottier BL, Koppelman GH, Akkerman OW, Touw DJ. Drugs during pregnancy and breast feeding in women diagnosed with Cystic Fibrosis – An update. J Cyst Fibros 2018; 17: 17-25.

OTHER

- Education and CF (Guide for Teachers with a CF student).
    - Go to: https://www.cysticfibrosis.ca/our-programs/resources
    - Scroll down to “Education” to find two different resources

- Article - ‘I’ve got to prioritise’: being a parent with CF https://www.tandfonline.com/doi/full/10.1080/13548506.2016.1233345?scroll=top&needAccess=true
- Article - My Mother’s Life Overshadowed CF by Melissa Kandel https://www.cff.org/CF-Community-Blog/Posts/2017/My-Mothers-Life-Overshadowed-CF/
- Blog entries and articles on Parenting as an Adult with CF through the Cystic Fibrosis Foundation https://www.cff.org/Life-With-CF/Transitions/Family-Planning-and-Parenting-With-CF/Parenting-as-an-Adult-With-CF/