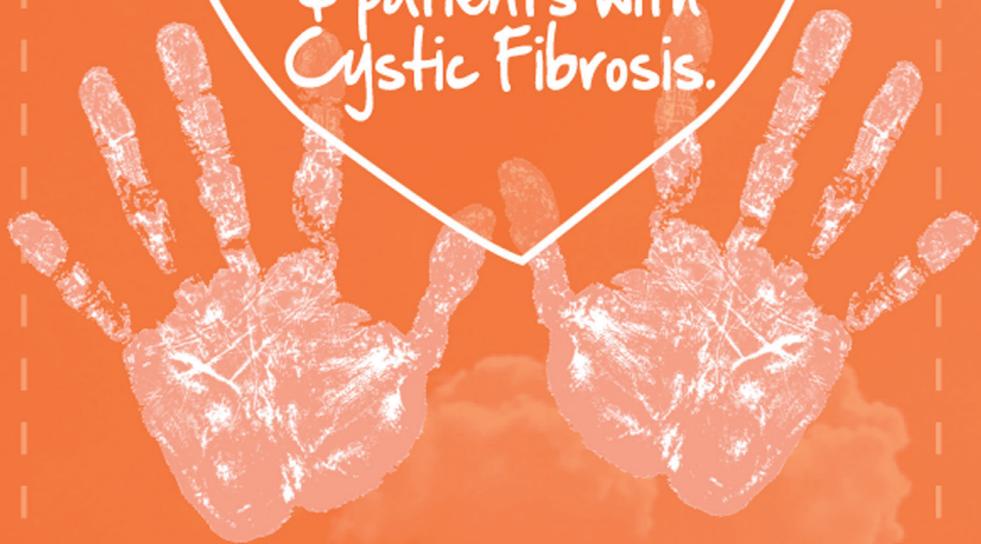




"A gift of stories
from parents
& patients with
Cystic Fibrosis."



EMP^{owered} 
by kids.com

Welcome!

If you are reading this, then you, like all of the contributors to this booklet, love someone with Cystic Fibrosis. This booklet has been created by parents who are ‘Empowered by Kids’, as a reminder that we are not alone.

Each letter or story in this booklet is written by a person with CF or their parents. While each letter comes from an individual with their own experiences, beliefs, opinions and backgrounds, all share a common thread – *we are not alone*.

Some of us are fairly new to the world of CF – a world that is filled with new symptoms, medications, tests, doctor’s appointments and whole new vocabulary. Others have been on this journey for quite some time. We each bring a personal and unique story to the table, but we all share a common need to hear the words “me too”.

As parents, we all understand how important it is to see our kids feeling well and living a normal life, in spite of CF. Yet we can easily become consumed with worry about our child’s diagnosis and feel trapped without the ability to help. We encourage you to work together with your care team collaboratively. You know more than you think you know and you are truly the expert on the care of your children. Your voice can be a powerful advocacy tool, and by working together we can accomplish great things. We are all in this together, and together we will make life the very best it can be for our CF kids and the CF kids of the future. Together we are going to make a difference for everyone living with Cystic Fibrosis.

Best wishes to you and your family



COLLABORATIVE CHRONIC CARE NETWORK

Reach the parents who contributed to this booklet at: info@empoweredbykids.com





When I was a little over a year old, I was diagnosed with Cystic Fibrosis. My parents knew nothing about CF, so hearing that their daughter was born with a life threatening disease changed their mindset completely. My mom told me the first year was the hardest because they were just starting to learn what Cystic Fibrosis was and how this disease would affect my family's lifestyle. My parents told me they had to stay positive and have always kept that mindset. My parents' attitudes have rubbed off on me, and I do not have the mindset that Cystic Fibrosis is going to control me, but instead, I am going to control Cystic Fibrosis. Throughout my life, I have always used Cystic Fibrosis as a motivator in everything I do from playing sports to academics and community projects. I have wanted

to show people that this disease is not going to affect who I am and what I do in life. I can do just as much if not more sometimes as an average healthy individual. I was able to maintain playing varsity sports with a 4.0 grade point average all while juggling daily breathing treatments and medications during high school. The key is multitasking. Do not be afraid to have your child do breathing treatments and work on homework at the same time. From a personal standpoint, it saves a lot of time. I continue to juggle treatments and medications along with furthering my education as a current junior in college while maintaining a part time job. I feel I was born with CF for a reason with one of them being to educate people about it and to spread awareness. CF is my part of my life, but CF is not my life, and I encourage any child or parent of a child with Cystic Fibrosis to have this mindset. What I mean is that CF does not define me as an individual, but instead Cystic Fibrosis has made me the strong, positive person I am today.

—Olivia, age 21



Just Breathe. That means you too, Mom and Dad.

My child with CF is now 10yrs old and she continues to inspire me with her inquisitive mind and beautiful soul. She is smart, athletic, competitive, and empathetic in a way she might not have been if not for the challenges of CF. Every family has a story, and yours will include Cystic Fibrosis, but it doesn't have to be your whole story, just a subplot that will weave its way through. At times it will be in the forefront commanding all of your attention, while at other times it will lay low as a subtle background.

So while a cough will never be just a cough again and daily treatments will become routine, don't let the time fly by without enjoying your kid being just a kid; silly, fun, dramatic, and loud!

Heather (parent)

~ Believe that you will come to terms with this overwhelming diagnosis;

~ Know that you will find humor is CF's Daily life.

~ Believe that you will find your own voice and fight for your child;

~ Know that your child is amazingly strong and special.



Gavin was diagnosed with CF at 2 1/2 years old after an exhausting 2 year search to figure out what was causing him so much stomach pain. That



relief quickly turned to panic after reading that CF was a genetic disease, because I happened to be 6 months pregnant at the time. Three weeks later, through amniocentesis, my unborn son, Jake, was also diagnosed with CF. Those were some very dark days...months actually. I remember feeling my heart breaking while watching the neighborhood children outside playing and wondering how I could ever survive emotionally. I also remember watching those same children running around, playing ball, laughing and wondering if my

boys would be robbed of that same luxury. Looking back, I wish that I had someone in that moment who would have been able to wholeheartedly tell me that YES!! My boys would definitely be able to do all of those things - and more! Twelve years later, Gavin has competed on a National level in wake boarding and came in third in the country at the age of 9. He has also played on the select lacrosse team for several years and will play for our high school as he enters the 9th grade this fall. Did I mention that he can run a mile in under 6 minutes?!?! Not bad for a boy with a lung disease!

Jake has tried all kinds of sports, but fell in love with tennis 3 years ago. He practices several times a week and plays team tennis several times a month throughout the school year.

Jake loves tennis so much that he wants to play professionally! I can honestly say that in those early days I would never have imagined that Gavin and Jake could be as successful in sports as they are today and I can honestly say that I am so grateful that they proved me wrong!

Pam, CF MOM



Grateful. Why am I grateful? Because I am 33 years old with CF and it's 2014. I am grateful and have witnessed many advances in research, technology, and the ever growing compassion of CF Teams and the internet support of bloggers with CF. You will witness many advances of CF care too and be amazed. I live in a time I can maintain my CF. We have cutting edge treatments that cut the duration of treatments and increase effectiveness of not getting sick as often. We have our families who really want us to feel as good as we can and will contribute to that goal. We have the world wide web of CFers around the world blogging about their life and about their good days and bad days. I have learned over the years that no one may be able to fully understand a bad day with CF more than another person with CF. But that is OK! We still have the love of our family, friends, and even strangers without CF. I know your bad days will lift and you will be able to breathe better another day and be grateful for that day. I know this because my bad days lift and I live and breathe for the many good days. So embrace all you have and take care of yourself! And don't let CF stop you from living your dreams. I live my dreams everyday.

XOXO Mell



Hi. My name is Justin. I am 9 ½ years old and I have Cystic Fibrosis. Cystic Fibrosis is a genetic disease that effects the lungs and the digestive system with a build-up of sticky mucus. I was 7 years old when I was finally diagnosed. I had many digestive problems and several pneumonias. It was a scary time for both me and my family, but now I am doing much better. I take 25 enzyme pills a day to digest my food, do 2 "vest" treatments, 4 nebulizers and a whole lot of other meds. It is a lot to do, but it keeps my body healthy.



I dance for Pennsylvania Regional Ballet to keep my lungs clear. It is my passion. My studio has been a second family for me. They even hosted a "Dance for a Cure" benefit for me this summer, where I was a featured soloist. It made me feel so special. My suggestion to kids with Cystic Fibrosis is find a passion to keep you healthy. It makes all of the things we have to do worthwhile.



Bigger Than CF

Yesterday, my son Ryder and I visited Children's Hospital Colorado for his 3-month check-up. I love these monthly appointments. Everyone from the receptionist to the respiratory therapist dotes on Ryder; telling him how big he's getting and how cute he is. And I always end up having a good CF discussion with someone while we're there. Yesterday, it was with the hospital social worker. She's usually one of the first people to stop in after we've completed our initial check-in with the nurses. The social worker comes to get a feel for how we're doing, to take our emotional temperature, so to speak.

When she popped in yesterday, our discussion eventually led to the fact that I haven't told my extended family that Ryder has cystic fibrosis. Two months ago, when we got his diagnosis, my husband sent an email to all of his friends and family.

He bulleted the positives- the things Ryder has in his favor which will help him live a healthy life. It was a good way for him to process the diagnosis. And in turn, we received supportive emails from everyone; emails he printed and I tucked away for the future, for difficult days when we might need to reread them. As much as I appreciated everyone's support,

I knew I wouldn't be telling my friends and family about Ryder's CF anytime soon. I still won't be. And here's why:

Ryder is bigger than his cystic fibrosis.

Ryder is bigger than his cystic fibrosis.

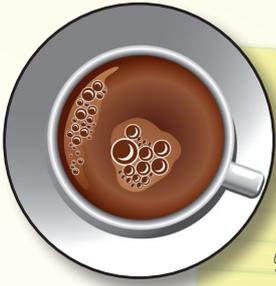
I send my friends and family photos of him. I send texts with the funny things he does, just as I do for my other children. I call my friends and family and we chat about how he's sleeping, how breastfeeding is going, what makes him smile, where he is on the growth charts... Collectively, these things make Ryder. These are the things I think about when I'm falling asleep at night. And when I wake in the morning, I'm looking for what will make him smile. Or I'm looking for a shirt that will fit him because he's growing so fast, I can hardly keep up. When he's fussy, I'm listening to his cry to figure out if he's tired or hungry or wet or uncomfortable. And I'm looking for a song, or chant, or bounce that will bring him back to calm. These things make Ryder.

Along with these things, we have the funny way he works his tongue to spit out the enzymes he eats before each meal. We have his wide, full of pride smile when I tell him he's doing a good job taking his antacid. That wide, full of pride smile that dribbles that antacid right out the sides of his mouth to pool on his too small shirt! We have the multiple ways I've tried to get him to like the pounding of his chest therapy, which include pounding to the beat of classical music and pounding while singing "Head, Shoulders, Knees, and Toes." I've even tried to massage and pound at the same time (which is a lot like patting your head and rubbing your belly). Not easy!

What might be hard for people to understand is that these things aren't very different than helping our older son learn to fall asleep in his big kid bed last week or helping our daughter throw a curve ball last summer. In all these experiences, we see the kid first. The kid is bigger than the trouble he's having falling asleep, bigger than the number of times it takes to perfect the curve ball, and bigger than the hereditary disorder he happened to inherit.

Eventually, my friends and extended family will know that Ryder has cystic fibrosis. It will be when they are able to see CF for what it is: part of a collection of things that make him Ryder. It will be this way because Ryder is bigger than his cystic fibrosis.





One thing that I would have liked someone to say was "it's going to be okay" and that my son was going to be happy, play sports, go to school and be just like everyone else. He might have bad days but they won't last and he'll have more good than bad. To let him be little and enjoy his time and not be afraid of what he could catch that would make him sick, but to just take extra precautions, not to miss out completely. Live life as normal as possible and just adapt when needed. Get to know your CF center and staff so when the time comes that you need to talk, you won't be afraid. Because they are your life line!
I hope this helps! Thank you,
Jamie, Mother of 10 yr old boy with CF

What we wish we had known about Cystic Fibrosis when Reagan was diagnosed is this: it is harder for the parents to accept than the child. Our daughter Reagan was diagnosed at her newborn screening and has never known life without CF and all the things that go with it. My husband and I were the ones who had visions of how her and our life would be and what she would do. We had our ideas about what a "normal" childhood was and grieved the lose of that for Reagan. (Which is okay to do!)

As Reagan got older, I realized this **IS** her normal and she really didn't mind the treatments and medications. For example, Reagan received her vest at 13 months old and I was a wreck and thought this isn't fair; she'll hate this! Sure enough, Reagan didn't even care or flinch and she actually enjoyed it. We realized that we might have veered down a different road in life but it wasn't all bad. Reagan showed us how great our life and new experiences could be. We decided that we still were going to raise our child like we had always dreamed, but just with treatments, sanitizing and medications added in.

This wasn't how we pictured our child's life or our life to be, but without CF we wouldn't have Reagan and we wouldn't trade her for anything in the world.

~ Kelsey and Andrew (parents of a child with CF)





One of my first despairing cries when the kind young doctor told us our nine month old son certainly had cystic fibrosis was, Oh dear God, my baby's going to die. Indeed, it was all I could think of those first foggy days and weeks (probably even months). My baby's going to die. My baby's going to die. My baby. . .

And then he wasn't a baby anymore. He grew into a toddler like any other toddler. He yelled No, No, No with all his might. He swallowed his medicine-laden applesauce. He watched Little Bear DVDs during his thrice daily pulmonary therapy sessions (patting all over his chest and back to loosen thick mucus for coughing up). He ran from me naked and peed on the floor. He occasionally was hospitalized with IVs. He learned colors, letters, Mama, Daddy. He was cute. He was naughty. He did need extra care to be healthy, but he definitely was not dead.

Over the years, our perspective shifted.

The pulmonary therapy sessions, once such an imposition, have forged a close relationship that remains to this day. The high nutritional standards, once such a stressor, have forced me to research and refine my culinary skills. The existential anxieties, once such a depression, have demanded discussion of the tough topics. Appreciating these silver linings has enlivened our family, from good cooking and stronger bodies to spirited conversations and an easy-going lifestyle. We saved less money and went out for more ice cream.

We are wiser and more understanding. **Thanks to CF.**

Allison, mother of a child with CF



My name is Jacob Greene and I have cystic fibrosis. Having CF is not easy but it doesn't stop me from doing the things I want to do. In fact, it just makes me try harder! I have been in scouting since the age of seven and recently earned my Eagle Scout at age fifteen. Some of my scouting highlights include riding the RSVP Seattle to Vancouver BC bike ride which is 188 miles.

I also went on a 12 day backpacking trek through the high desert at Philmont Scout Ranch in New Mexico and did a presentation for the Seattle Mariners Friends of Scouting where I shared how being in scouts has helped me over the years with having CF.

In addition to scouting, I am an honors student at school. I ended my freshman year with a 4.0 GPA and awards in Math and Track and Field. I have also been very active in sports over the years including basketball, wrestling and track. I also love snow sports. Being active really helps me to stay healthy. Exercise is very important for everyone but especially for people with CF.

I plan to be an engineer someday. I love science, math and technology.

I build and compete robots through FTC Robotics and am learning CAD, a virtual design software, to design robots on the computer. Last year, we made it to the regional competitions and I am hoping we make it to Worlds this year.

I also like to make a difference in my community. Every year I go on a mission trip to Mexico to help build houses for the poor and am planning on joining Auto Angels, a group of people who fix cars for people who can't afford it.

Doing all of this plus having CF is not easy. I have to stay organized and on top of things in order to manage my many pills, breathing treatments and chest physical therapy. Sometimes I have to go into the hospital for a while which is kind of hard. But that's okay, I know it's important to take good care of myself so that I can get better and get back to living my life.





I know you might not believe it right now, but you're going to be okay. I've walked in your shoes before, wondering and worrying and waiting, trying to get use to new

treatments and medications and all of the medical terminology, meeting dozens of new people who will be involved in your care and your life for a long, long time. It is okay to feel tired and overwhelmed. This isn't an easy life. It is tough, there is no doubt about it. But you are very capable and you don't have to do it alone. There are many people like you, and you can find us online, in support groups and wandering the halls of the hospital.

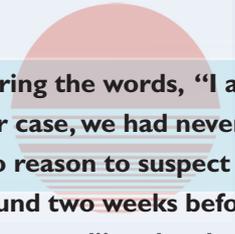
When our journey began 4 years ago, our entire lives flashed before our eyes. We felt scared and hopeless. You have to take some time to mourn the loss of the life that you had expected before you can fully appreciate the life that you have been given.

Our son goes to preschool, takes swimming lessons, plays soccer and t-ball. He takes pills like a champ, sits for breathing treatments several times a day, and hands out smiles and high-fives every time we have to see the doctor. Cystic fibrosis is a part of our life, and often times a big one, but it does not control it. We're here for you, and although you might not believe it right now, you're going to be okay.



xoxo, Erin, CF Mama





There is no way to prepare yourself for hearing the words, “I am sorry but your child has cystic fibrosis.” In our case, we had never heard of CF; no family history, no warning, no reason to suspect anything was wrong. Until we had an ultrasound two weeks before my due date and our ob-gyn saw “something unusual” and ordered an immediate C-section. That “something unusual” was meconium ileus, caused by cystic fibrosis.

The emotional climb uphill from devastated and overwhelmed to handling it generally okay has taken some time. The road to rebuilding shattered dreams is not a straight road. It is filled with hills and valleys, peaceful by-roads, and at times, hairpin turns. U-turns are often necessary. However, through it all, there are many unexpected blessings:

- ~ We value each day, each breath, and each other.**
 - ~ We enjoy life to the fullest. Don't wait for tomorrow to live your dreams.**
 - ~ We appreciate the good times and take advantage of a sunny day.**
 - ~ We have learned coping and resiliency.**
 - ~ We have grown in faith and compassion.**
 - ~ We have an opportunity to help others.**
 - ~ We can make a difference.**
- 

Our two kids, both with CF, are teenagers now. They are doing well and work hard to stay as healthy as possible. They are happy, well-adjusted, do well in school, have lots of friends, and enjoy life. They have many dreams for the future.

It's not easy but they, too, have discovered unexpected blessings like perseverance, empathy, gratitude, courage and hope. Our journey is far from over. It's hard to know where this crazy road will lead but this we do know: we will take it one day, each breath at a time.

Lisa, mom of two teens with CF



Hi my name is Laura and my 3 year old son Jayson has Cystic Fibrosis. Jayson does not let CF slow him down! Most days we forget he even has it!

He does do his treatments twice a day and takes his enzymes with every meal but that's just normal to him since he's been doing it since he was diagnosed at 1 month old.

Stinko (his nickname ;) has been hospitalized a few times for DIOS and RSV but is so brave and tries to look at the positive side like getting to play with the toys from the playroom!

If you are reading this then you probably have CF too or know someone that does and I hope this helps you feel better knowing that there's lots of other kids doing the same thing as you every day!! I know Stinko loves watching videos of other kids shaking in their vests!! Hehe! Keep kicking CF's butt!! Xoxo



Jayson, Laura (mom), Jay (dad) and Rosie (grandma)

My name is Kasey Greene. I have cystic fibrosis but CF does not stop me from enjoying life. I am just extra careful about the choices I make because taking good care of myself and living life are equally important.

I have done many fun things growing up. I was in Brownies and Girl Scouts for many years and earned lots of badges. I went camping, once even at an amusement park. That was really fun until the sprinklers went off by accident in the middle of the night and flooded the whole field where we were camped.

I like horses and ride them when I can, mostly at summer camps or when we are on vacation. I even got to ride a horse through the Gettysburg Civil War Battlefield on a family vacation. I also got to drive a horse-drawn wagon through an Amish animal park as well as feed the animals. Some of them, with horns, wanted to get really close so that was sort of scary but fun at the same time.

I am an honors student at school and especially like reading, math, and science. That is good because I want to be a doctor who works with children someday. I am also good at languages including Spanish and American Sign Language.

Sports are a big part of my life and one way I try to stay healthy. I like taekwondo, played basketball for several years, and now play volleyball and do track and field at school. I also like to help others. I do presentations for families who have children with CF about how they can help their children to stay healthy and happy. I have also been a pen pal for younger girls with CF and had my very own Great Strides fund raising team for the CF Foundation.

Having CF is not easy. I take lots of pills, do breathing treatments two or three times a day plus chest physical therapy to shake the mucous loose. Sometimes I go into the hospital for a long time and need to make up my schoolwork and miss out on things that my friends are doing. But I try to keep a good attitude, work hard to get better, and jump right back into my life as soon as I can. Because CF won't stop me!



I was a young adult asked to meet with a newly diagnosed family years ago. I told them how sorry I was about hearing of their child's new diagnosis without telling them I had CF myself. I asked them what hit them the hardest by what the physicians or team is telling them. They looked at me and said, "Well it is terminal." I looked at them (thinking to myself are you calling me terminal or CF) and said, can I share some important info about the terminal. They said, "Sure". I told them that they were terminal too. Months later I saw that family. They sat me down and told me how they have adjusted to the diagnosis, but the gift of life their child has given them, and the perspective shared about their own terminal prognosis has been such a blessing. They told me I need to share that perspective with everyone. I only listened to their fear and shared reality, but thought we all need to hear our myths sometimes to get a reality check.

Adult with CF



"It's nearly eleven years now since we got the diagnosis. Living with CF is no child's game. I remember when we were in the first shock, with our little baby deadly sick in our arms. We thought all was over. Then it was so good to get a diagnosis and see other CF families visiting the CF center. Strong and healthy kids really. Although we all have to do the hard CF-work with its ups and downs or in fact our sons and daughters have to.

And we want to help them will all our hearts, minds and hands. In our family we have this mission statement for life with CF,

expressed by Sonia at age 9: "I have Cystic Fibrosis, CF.

Its a rare diagnosis that forces me to live like a top athlete in order to stay fit and free from injuries. Home treatments take approximately two hours every day, all year round. I must always be careful not to get ill and healthcare is a lifelong partner." The mission statement helps us focus and carry on, and it even inspires my daughter to be proud of both her daily self care training and her six pack abs!

Hälsn. Andreas CF Dad, Sweden

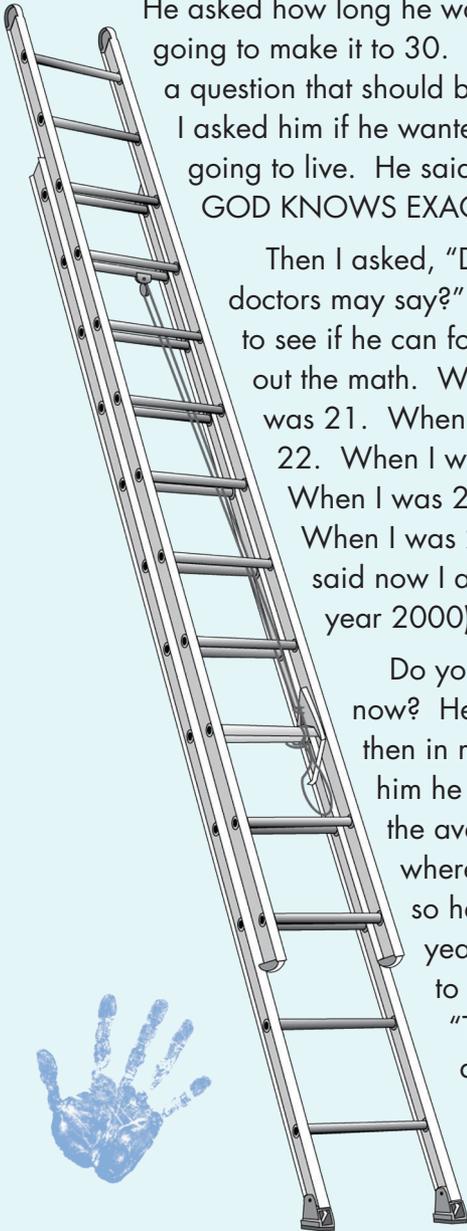


One time I was talking to an eight year old with CF. He asked me if I had CF. I told him that I did. He said aren't you in your 30's or something. I told him that was correct. He asked how long he was going to live and if he was going to make it to 30. I thought to myself, this is not a question that should be asked by an eight year old. I asked him if he wanted to know how long he was going to live. He said yes. I said, "First of all **ONLY GOD KNOWS EXACTLY**".

Then I asked, "Do you want to know what the doctors may say?" He said, "Yep". I asked him to see if he can follow my logic here to figure out the math. When I was 20, the average age was 21. When I was 21, the average age was 22. When I was 22, the average age was 23. When I was 23, the average age was 24. When I was 24, the average age was 25. I said now I am 30 (actually this was in the year 2000).

Do you know what the average is now? He looked up to the ceiling and then in my eyes and said, "31"? I told him he was correct, the doctors say the average age is 31. Who knows where it will be 20 years from now, so he needs to plan to live to be 100 years old. He said, "I don't want to be 100 years old." He said, "They have wrinkly skin and don't do anything, I just want to be 90." I told him to just plan on being 90 years old.

Brett, Adult with CF





Right now, in the throes of your child's recent diagnosis with Cystic Fibrosis, I can only imagine how enormous, terrifying and all encompassing it must feel. Actually, scratch that. Who am I kidding? The truth is I can't even begin to imagine!



As a 29 year old diagnosed at 6 weeks with CF, what I can say with certainty is that life does go on. These crazy medications and treatments become normal, like brushing your teeth or getting dressed in the morning. And while the gravity of living with a progressive and fatal disease never gets lost, not even for a moment, it does eventually fade to the background to make room for everything else -- swim lessons and play dates, birthday parties and scraped knees.

On the cold day in 1985 when my parents received my diagnosis of CF, I bet they never would have guessed that nearly 3 decades later their daughter would be living in center city Philadelphia with a graduate degree in bioethics and a thriving career in digital health research, that she would be a patient advocate speaking around the country or a proud founder of a nonprofit called Emily's Entourage (emilysentourage.org) that has raised over \$650,000 for CF research in just over 2 and a half years. While a life with CF might not be what you planned for, and it certainly is not what I would have picked, I hope my story shows that it can still be magnificent and productive, meaningful and remarkably normal too.

Emily, 29yr old CF Patient

I asked Frank Deford in the late 1990's, What would you tell a family recently diagnosed with CF? He said, "There is never a better time to be diagnosed with CF in all of history. With all of the recent studies of medicines, and technology, children are living into adulthood like never before." I would agree wholeheartedly having asked that question almost two decades ago having CF myself. I have been in over a dozen research experiments myself including gene therapy. The commitment that the CF Foundation has to improving research and managing the disease is amazing! Thank you to those CF directors raising money, doctors, pulmonary staff, and all who are committed to making life better for the patients and families with Cystic Fibrosis! YOU ARE TRULY THE UNSUNG HEROS.

Adult with CF



If you know of a parent who is recently diagnosed with Cystic Fibrosis trying to process the news, let them know this. I am not Cystic Fibrosis, who happens to have _____. I am _____ who happens to have Cystic Fibrosis! Please do not make CF the anxiety or the centerpiece of life. There are dreams to be had, days to be lived, and coughs to be laughed at rather than to be embarrassed about.

EARLY CHILDHOOD: As to the issue of being small or eating, please do not listen to everyone telling you to eat eat eat, as if weight is the only importance. I connected my anxiety to eating while I was young in life and now still eat Mac n Cheese and fatty foods at the age of 44. I am now wishing someone taught me to eat fruits and vegetables at a young age. I did not die by eating fatty foods, but my pallet sure did. EAT smart and enjoy life while having to do therapies to stay healthy. Yes calories are important, but so is planning to eat like this at 50 because bad habits are hard to break.

TEENAGE YEARS: To those cough suppressors in their teen age years, who try to hide their coughs because of on-lookers in public. I demonstrate my peace with CF and my lack of shame by my coughing and hacking.

YOUNG ADULT YEARS: Be sure to dream big in your teen age years. Parents dream for you is to be a doctor so they discount your dreams and try to make you think about responsibility. Who knows responsibility more than you! Don't listen to the DREAM CRUSHERS and live your dreams out. Perhaps you won't be a doctor like they dream of you, but maybe you will still make an impact on the medical community by being a social worker, chaplain or just being a dad one day.

TO ALL PARENTS: Remember children learn more by what they see than what we tell them. Practice emotional and spiritual peace, and your children will live it out and discover their own peace along the way.

Adult with CF





**ANYTHING IS POSSIBLE
FOR A WILLING HEART**



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