

Everyday



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SUMMER, YOUR WAY

YOUR GUIDE TO SELF-CARE AND SEASONAL FUN



**INSIDE
VOLUME 5**

**RECIPES TO
SWITCH UP
YOUR COOKOUT**

**FOR THE
LOVE OF
CAREGIVERS**

**TIPS
FOR DAY
TRIPS**

IT'S TIME TO SUMMER

The weather is changing, and so is your routine.

With longer days, vacations to plan, and maybe a more free-spirited state of mind, it's time to check in and make sure that you can stay on track while allowing yourself to let loose a little.

In this edition, focus on your wellbeing, inside and out. From self-care tips and a new way to look at your diet to fun-filled ways to stay active wherever you may be, get ready to make this a summer to savor.



Uncommon Lungs

A Podcast by **EverydayCF**



DID YOU KNOW THERE IS AN EVERYDAY CF PODCAST?

UNCOMMON LUNGS: PERSPECTIVES FROM THE CF COMMUNITY

Listen to real stories from people in the cystic fibrosis (CF) community. In the first 3 episodes of *Uncommon Lungs*, Julia Rae (the multi-talented and charismatic host of the podcast) has in-depth conversations with a few of her friends about their experiences with CF. Hear them speak candidly about:

COLLEGE ROUTINES

"I was putting more pressure on myself probably [to] get the perfect grades and do everything that I possibly could to keep my GPA up and be successful."

– Grace, *Living with CF*

CAREGIVER TRANSITIONS

"Teaching your children [at a young age] is really important to give them the life skills they need as adults to manage this illness."

– Jen, *CF Caregiver*

& LOVE STORIES

"So my husband attended my first ever fundraising event for CF and we have been married almost nine years now."

– Tara, *Living with CF*

COMING UP...

New episodes are in the works and will introduce a variety of perspectives on some really interesting topics. Stay tuned by following the *Uncommon Lungs* profile on the streaming service of your choosing!

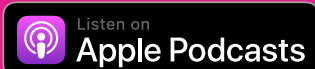


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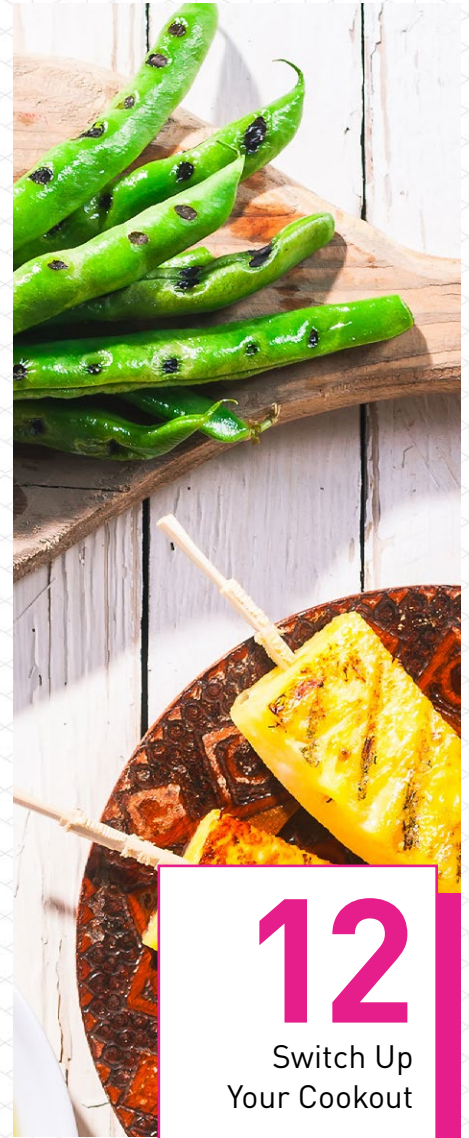
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FOR THE *love* OF CAREGIVERS

SUMMER MAY BE A BREAK FOR KIDS, BUT THIS SEASON OFTEN HAS CF CAREGIVERS BREAKING A SWEAT.

Between balancing work, childcare, summer vacation planning, and daily routines, caregivers sometimes have more responsibilities during the summer months. Taking all that on can be a challenge, but reaching out for support and practicing self-care when possible can go a long way. The following tips may help caregivers navigate a few seasonal scenarios.

TRANSITIONING TO A SUMMER ROUTINE

Finding the right summer routine may take some trial and error, and that's okay. You may need to switch it up here and there to figure out what actually works for you. If you have little ones, a fun way to establish more structure and build trust with your loved one is by making a game out of certain responsibilities and giving points, rewards, or positive reinforcement when your child completes them. There are some pretty cool phone apps out there that can gamify tasks and help keep the whole family motivated, engaged, and productive throughout the week.



Breaking up the day into predictable blocks can help everyone feel a sense of routine. Maybe your mornings are for chores and getting active (see pages 8-9 for ideas on how to stay active inside or outside) while the afternoons are for quiet time and crafts. Setting expectations around screen time can also help keep everyone on the same page.

JUGGLING WORK & CHILDCARE

Caregivers wear many hats. If you are working and need to be with your child while school's out, try asking your employer for flexibility around where and when you work. Remote work seems to be here to stay, and could be a great option for caregivers who can take advantage of it long term—but remember, working from home doesn't mean you don't need outside support for caregiving! If extended time off from your job is needed to care for a child that has significant needs due to their CF, it's important to know your rights under the Family and Medical Leave Act.



PLANNING FAMILY VACATIONS

Checklists are every caregiver's best friend. Planning ahead and making a list of things to pack can help the whole trip go more smoothly. You can find a handy travel checklist at www.everyday-cf.com/cf-resources.



SELF CARE FOR CAREGIVERS

CAREGIVER SPOTLIGHT

“ My biggest advice...to other caregivers and parents out there, or folks, you know, helping support those with cystic fibrosis, is just breathe. And I know that sounds cliché because we’re talking about a lung disease here, but it’s really important. **Take a deep breath, understand that everything is going to be okay.** You know, focus day to day. But I think another thing is to make sure you’re doing self care. I used to think when Michael was younger, if I were to go out with my girlfriends or go get my nails done or anything like that, that that was selfish of me. And I’ve learned through the years that it’s so important to take care of myself, so that I’m stronger, both physically and mentally to be able to be [a] better caregiver for him. So I think self care is another really big, important thing that people have to realize. It’s not selfish. It’s needed and it’s actually better for you and the person you’re taking care of when you take those moments. ”

–Jen, CF Caregiver



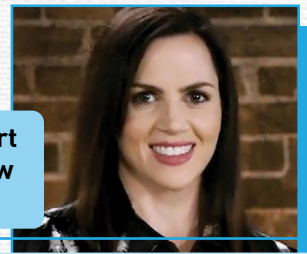
REFLECT ON SELF RESPECT

Admittedly, it is easier said than done to introduce self care into a routine. Managing daily stress and making time for yourself can feel like work on top of what might already be a full plate. But it’s important to understand how these things translate to your loved one. If you feel guilty doing something for yourself, remember that a healthier you can only lead to more positive experiences for those around you. Reflect on the following questions when you’re having trouble giving yourself the care and respect you deserve.

- Have I communicated my boundaries to the people around me?
- How do I feel in my body today?
- What do I have control over right now and are there any worries I can let go of?
- Is there something I can ask someone to help me with today?
- How am I demonstrating the importance of taking care of oneself through my actions?

GET EDUCATED ON INTUITIVE EATING

An expert
interview
with



Molly Bigford, MS,
Registered Dietitian Level 3



You may have heard the buzz about intuitive eating, but what is it really?

And how does it fit into a healthy eating plan for adults with CF? Always work with your CF care team before making any changes to your diet.

Q: WHAT IS INTUITIVE EATING?

A: Intuitive eating is not a diet—it's an approach to eating that is centered on **listening to your hunger and fullness cues and trusting that your body will tell you what it needs**. Even though the idea of eating when you're hungry and stopping when you're full might sound simple, it's not as easy as it sounds. A hunger-satiety scale like the one on the next page can help you to understand what your body is telling you.

TOP 3 TIPS for Intuitive Eating

1. Spend time learning about your own personal hunger and fullness cues. Use the "What is your hunger telling you?" scale on the next page to help you get in touch with those feelings.
2. Avoid distractions while eating and focus on how the food makes you feel.
3. Remember that intuitive eating is a journey that takes time and practice.

Q: WHAT SHOULD ADULTS WITH CF KEEP IN MIND IF THEY'RE STARTING AN INTUITIVE EATING JOURNEY?

A: Although people with CF may need to spend a lot of time thinking about food and eating, the mind and body can sometimes be disconnected when it comes to food. From an early age, people with CF learn the importance of food and maintaining their weight in order to stay healthy and help their bodies function. In time, many people with CF learn to ignore their natural feelings of hunger and fullness.

While working to repair the mind-body connection to get in touch with your own personal hunger cues can be useful for adults with CF, it's important to note that everyone with CF is different. Intuitive eating may not be appropriate for those who are struggling to gain or maintain weight.

Q: HOW CAN INTUITIVE EATING AFFECT BODY IMAGE?

A: Learning to understand and acknowledge your personal hunger and fullness cues may help you accomplish your long-term health goals, such as fueling your workouts or making meals a more joyful experience. And, learning to trust your own feelings may enhance positive thoughts about yourself.

Q: HOW MIGHT SOMEONE KNOW IF INTUITIVE EATING IS RIGHT FOR THEM?

A: Things like managing blood sugar levels or the medications you take may affect your personal dietary needs. Always work with your CF care team before making any changes to your diet.



WHAT IS YOUR HUNGER TELLING YOU?

Empty. Feeling faint or sick because you are so hungry, as if you haven't eaten for days.

1

Ravenous. Your stomach is growling and you are easily irritated and edgy.

2

Hungry. You feel a little low on energy and are slightly uncomfortable.

3

Peckish. Hunger signs and symptoms are manageable.

4

Neutral. Hunger is on the horizon.

5

Comfortable. You can eat with control.

6

Full. Feeling satisfied.

7

Too full. You've had a few too many bites.

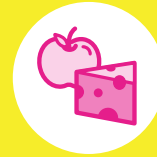
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Stuffed. Feeling bloated.

9

Thanksgiving Day full. You never want to look at food again.

10



IT'S EASY TO OVEREAT WHEN YOU'RE THIS HUNGRY.

Try to carry snacks and plan ahead so you don't feel this way very often.



IT'S TIME TO EAT!

Your body is sending hunger signals and food sounds great. Because you have more self-control at these hunger levels, you can practice mindful eating.



PROCEED WITH CAUTION!

Eating past the point of fullness can lead to negative self-talk and may exacerbate body image concerns. Stay mindful of your fullness level and remember that it can take 20 minutes for your stomach to tell your brain that you are full.



Hungry for more?

Check out these books for a more in-depth guide to intuitive eating.

Intuitive Eating by Evelyn Tribole and Elyse Resch

Mindful Eating by Jan Chozen Bay



Are you #ECFTeamInside or #ECFTeamOutside?

No matter the weather, summertime is all about fun. Whether you love soaking up the rays outdoors, or prefer to relax in cool, climate-controlled indoor spaces, here are some fun ways to add a bit of activity to your day, whether on your own, with friends and family, or with the kids.

Always talk to your CF care team before starting any new exercises.

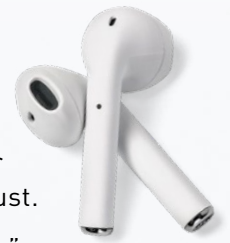
Indoor Fun

- In a rut with your workout routine? Check out YouTube for inspiration, whether your style is more “dance cardio” or “high intensity interval training.”
- Try your hand at rock climbing at an indoor gym.



- In the mood to binge watch and chill? Mix it up by adding a quick activity break. How many squats can you do before the next episode starts playing?
- It's time for a kitchen dance party! Crank up the tunes, move your body, and let your mind relax.

- Ever heard of balloon volleyball? Make a net by stretching a piece of string between two chairs, and serve, volley, and bump a balloon back and forth.
- Stop by an indoor pool for laps, dives, and water slides.
- Time to clean! Listen to *Uncommon Lungs*, the Everyday CF podcast on Apple Podcasts, Spotify, Google Podcasts, or Stitcher while you tidy, sweep, and dust.
- Walk the mall and play “I Spy” in store windows. “I Spy three shirts with dinosaurs on the front.”, “I Spy five people wearing hats.”, “I Spy a delicious treat that we can get for a snack!”



Outdoor Adventures

- Challenge each other at the playground. Who can cross the monkey bars the fastest? Who can swing the highest? Who can make the funniest face at the bottom of the slide?
- Beach day! Jump in the waves, try boogie boarding, or build a beautiful sand castle.
- Time to drill! Line up some obstacles on the yard and try to dribble a soccer ball around them.
- It's time for a shaving cream showdown! Grab one can of shaving cream per person, and have fun chasing and spraying each other from the neck down. Clean up by running through the sprinkler afterwards.
- Go for a "heads or tails" stroll. Every time you come to a corner, flip a coin. Heads means turn left, tails means turn right!
- Play flashlight hide-and-seek.
- Set up a car wash. With a bucket of soapy water and a few sponges, everyone can clean up their own ride: cars, bikes, or even toy vehicles.
- Plan a bike race. Find a stretch of path, mark start and finish lines, and get ready to race! Who can go the fastest? Who can go the slowest?



- Turn a hike into an obstacle course. Use fallen logs as balance beams, leap over small creeks, and hop up onto tree stumps.



Tag us at [@everydaycf](https://www.instagram.com/everydaycf) and tell us how you add activity every day with [#ECFTeamInside](https://www.facebook.com/everydaycf) or [#ECFTeamOutside](https://www.facebook.com/everydaycf)



TIPS FOR DAY TRIPS

Invite some more excitement to your summer by planning a day trip! An excursion doesn't have to be complicated to create memorable moments, but there are a few extra things to consider when CF is involved. As long as you're prepared, day trips are a great way to seize the moment and open your mind to possibilities.

HOW TO PREPARE

PLAN YOUR ITINERARY AHEAD

Make sure you know the best route to take to your destination, and if you're driving far, identify CF Centers along the way and in the area. It's also good to account for breaks throughout the day to eat snacks and meals, do treatments, take bathroom breaks, and stay hydrated.

INVITE FRIENDS OR FAMILY

Having a support system to enjoy the day with can make a big difference. Make sure they know your plans, and ask them to check in on you throughout the day if needed.

CHECK WITH YOUR HEALTHCARE TEAM

Discussing plans with your doctor is always a good idea. Find out if there is anything important to keep in mind while planning your trip.

WHAT TO PACK

No matter how big or small your trip is, there are a few essentials that should be by your side when you're away from home for more than an hour or two.

- Snacks, snacks, and more snacks
- Medicine (plus a cooler for storage if needed)
- Plenty of water and drinks with electrolytes
- Sunscreen
- Hand sanitizer and masks
- Your phone (set reminder alarms if needed and make sure your emergency contacts are programmed just in case)
- Something fun! Bring along a frisbee, speaker, camera, or your latest leisure read to keep things interesting
- A bag or backpack to keep everything in

EVERYONE
— IS —
DIFFERENT

So it's important to take the extra steps necessary beyond what's mentioned here to feel prepared— whatever that means to you.

OH DAY TRIP, WHERE ART THOU?

What counts as a day trip? The possibilities are endless!
Here are a few ideas ranging from simple trips to ambitious adventures.



Go on an
arts, culture,
or history
tour



Get an
amusement
park day
pass



Explore
a nearby
city



Take a
beach
day



Admire
animals
at a zoo or
sanctuary

Relax at a
wellness
retreat or
spa



Get
curious at
a museum



Have a
picnic in
the park



Tailgate
at a sports
event

Hike at a
state park



UPGRADE YOUR COOKOUT

Summer and cookouts go together like s'mores and marshmallows. If you're looking to spice up your routine, try these delicious recipes. Ask your guests to bring the side dishes, and you'll be ready to celebrate summer, potluck-style.





Grilled Salmon With Herbs & Honey Mustard

Love eating salmon, but not the smell of fish cooking?
Try this method for grilling instead.

2 Total Servings

239 Calories Per Serving

31 Grams of Protein Per Serving

3 Grams of Carbohydrates Per Serving

11 Grams of Fat Per Serving

3 Grams of Sugars Per Serving

INGREDIENTS

- 10 ounces salmon filets (2 skin-on 5-ounce filets)
- 1 teaspoon honey
- 2 teaspoons Dijon mustard
- 1 teaspoon fresh tarragon
- 1/4 teaspoon dried oregano
- 1/4 teaspoon dried thyme
- 1/8 teaspoon salt
- 1 teaspoon olive oil

INSTRUCTIONS

1. Preheat your grill to medium (about 375° F).
2. Line a baking sheet with a large piece of aluminum foil and place the salmon filets on top, skin-side down.
3. Whisk the other ingredients in a bowl.
4. Spread the mixture evenly over each piece of salmon.
5. Fold the sides of the foil up and over the salmon, making a sealed packet. Leave a bit of room inside the foil so that air can circulate.
6. Carefully slide the packet onto the grill. Close the lid of the grill and cook for 14-18 minutes, until almost completely cooked through at the thickest part.
7. Being careful of hot steam, open the foil so that the top of the salmon is uncovered. Close the lid of the grill and cook for a few more minutes until the salmon flakes easily with a fork.

KEEP IT SIMPLE

No grill in sight?
Try slow cooking or baking your salmon.

Strawberry Icebox Cake

Keep things simple for dessert with this make-ahead, no-bake cake full of fresh seasonal fruit. The whipped cream-covered graham crackers soften in the fridge into a delicious cakey consistency.

6 Total Servings

429 Calories Per Serving

5 Grams of Protein Per Serving

50 Grams of Carbohydrates Per Serving

25 Grams of Fat Per Serving

20 Grams of Sugars Per Serving

INGREDIENTS

- 1 pound fresh strawberries, washed and patted dry
- 2 3/4 cups heavy whipping cream
- 3 tablespoons powdered sugar
- 1/2 teaspoon vanilla
- 2 sleeves graham crackers (about 10 ounces)

Not in the mood for strawberries? Try making this cake with any other kind of fruit, like raspberries, blueberries, peaches, or whatever is in season near you. Frozen fruit works too!



INSTRUCTIONS

1. Hull the strawberries and slice them thinly.
2. With a hand or stand mixer, whip the heavy cream until it holds stiff peaks. This means the whipped cream should stand straight up when you lift the beaters out of it. Mix in the powdered sugar and vanilla.
3. Spread a small spoonful of whipped cream in the bottom of an 8- or 9-inch pan. Cover the whipped cream with a single layer of graham crackers, breaking them into smaller pieces if needed. Lightly cover the top of the graham crackers with more whipped cream, then cover with a layer of strawberries.
4. Repeat the graham cracker, whipped cream, and strawberry layers 3 more times. Spread the rest of the whipped cream on top.
5. Refrigerate for at least 4 hours, or until the crackers have softened completely.





*What does
SUMMER
have in store?*



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