

Everyday



@everydaycf

Embrace Your Summer State of Mind

SOAK UP THE SUNNY
SEASON WITHOUT
SACRIFICING YOUR
HEALTH NEEDS

INSIDE VOLUME 7

Take the summer
date night quiz

Meet our ECF Fast 5
community member

Take a step back
from caregiver duties
with confidence

Noor, an advocate with
cystic fibrosis (CF)





Catch Those Summer Vibes

The sun is out, the weather's warm, and the time has come to celebrate summer without sacrificing your cystic fibrosis (CF) needs.

In this issue, find tools and resources to help manage the season for you or your loved one. From learning about locally sourced, nutrient-packed ingredients to navigating conversations about sick days at work—and everything in between—**Everyday CF has you covered.**

Hear from our community

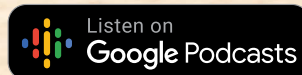
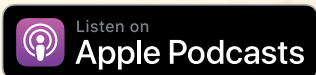
Everyday CF is all about compiling real resources for real life with CF, and every magazine issue includes interviews with members of this community. Don't miss out on what they have to say, and check out page 4 for a chance to join the conversation.



Uncommon Lungs
A Podcast by Everyday **CF**

Are you caught up?

Whether you've got a road trip on the books, or just need something to listen to while you soak up the sun, catch up on candid conversations about self-acceptance, daily mindfulness techniques, and life lessons for caregivers in the latest episodes of the Uncommon Lungs podcast.



What's inside?



The ECF Fast 5

Every issue, get acquainted with a member of the CF community by taking a peek into their world through every sense.

Summer of Love

Navigating your love life can feel daunting, and throwing CF into the mix means figuring out how dating fits into your care routine.



Navigating Your Nutritional Needs

A healthy CF diet isn't only about eating ingredients high in fat and protein.

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The ECF Fast 5

Every issue, get acquainted with a member of the CF community by taking a peek into their world through every sense

Meet Noor

Kindergarten teaching assistant and arts and crafts lover!

The summer months will be all about family, friends, and the multiple new babies coming into our lives. I plan to spend time outdoors enjoying sunsets on the beach, strolls on the boardwalk, barbecues and fire pits on the patio, and the list goes on.

I always have to find a fine balance with taking care of myself, my responsibilities, and then my hobbies and interests. I prepare my daily medications for 3 weeks at a time to have a head start to my day. I also schedule exercise classes to make sure I am getting enough strengthening into my routine. I prepare my snack ideas per week and switch them out so that I will continue to enjoy them. Most importantly, my iced water never goes anywhere without me, not the other way around!



When you need a pick-me-up song to de-stress, what tune is at the top of your ultimate summer playlist?

An upbeat tune is always a mood changer for me! On the top of my ultimate summer playlist, I will always get positive energy from “Higher Love” by Kygo and Whitney Houston. I have too many to choose from, but this is one of my favorites!



What cool treat or refreshing meal is a must-have this season, and how do you make sure your nutrient needs are being met with it?

I always enjoy putting together a refreshing salad, including fresh fruits, cheeses, nuts, grilled chicken, and a raspberry vinaigrette dressing. I make sure I have balanced out caloric intake, protein, and hydration with the ingredients I choose while keeping it light and filling. To top off the caloric intake with something a little extra, I can never go wrong with fresh pistachio ice cream from the local farm as a cool treat!*

* Talk to your healthcare provider about what's right for you.



As an avid walker, what's your favorite local destination for sightseeing and can you give readers one hot tip for managing your CF on-the-go?

My favorite destination for sightseeing is over at the Boston Seaport. I love getting my exercise in as well as taking in the sun's rays as they bounce off of the waterfront. One hot tip for managing my CF on the go is always taking an on-the-go grab bag which includes basics as needed: medications, hydration, sunscreen, and a few snacks!



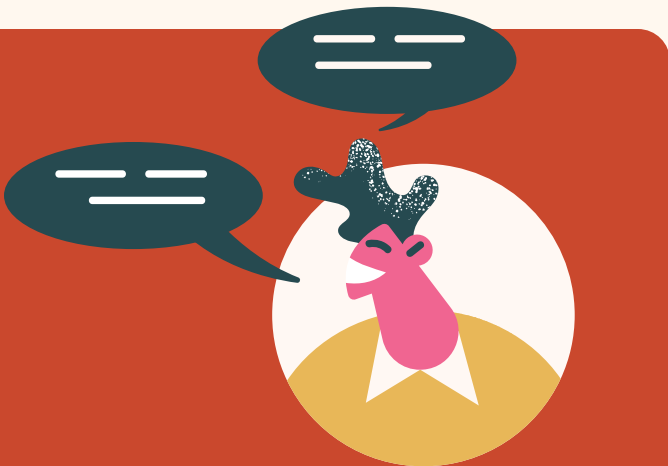
Which scent do you associate with summer, and how does it help ground you in the moment?

I associate the scent of salt water with the days of summer immediately. It reminds me to be mindful of taking in slower, deeper breaths, which in return will really ground me in the very moment, as well as give me the benefit of taking in the fresh salty air.



What kinds of arts and crafts do you do to keep your hands busy on days when your CF keeps you inside?

On those days where my CF keeps me indoors, I enjoy working on my crocheting projects, putting together stationery and cards, as well as working on projects with my goddaughter and little friends. I am able to feel productive, have a sense of joy, as well as stay in a lower energy burning environment.



We want to hear from you!

Share your favourite article from Vol. 7 and tag us on Facebook or Instagram [@everydaycf](https://www.instagram.com/everydaycf) for a chance to be included in the next ECF Fast 5.



Feel confident letting your loved one fly free

**You've prepared them for their independence.
Embrace this new time for yourself.**

As a caregiver, you're probably used to a never-ending to-do list of constant care needs for your loved one with CF. But then one day, you may wake up and realize that they've grown up to become an independent, self-sufficient adult right in front of your eyes! How did this happen? Are you ready for it?

Over the years, your caregiving tasks may have become second nature, and it can be hard to let go of old habits. Empty nest syndrome is real and can be an especially difficult transition for parents whose child is living with a chronic illness.

But fear not. Being a caregiver will always be a part of your identity. Your loved one leaving home doesn't change that. You've prepared them well, and now it's time for you to focus on caring for someone else—yourself.

Here are some ways to keep your mind occupied and embrace your summer once your caregiver duties aren't at the center of your life anymore:



MASTER A NEW HOBBY

The options here are endless. You could try picking up an instrument you've always wanted to play. Or keep your hands busy by learning to crochet, knit, or embroider. Maybe you've always had a flair for creative baking and you want to hone your abilities. Hiking could be a great activity to pick up to clear your mind and get in touch with nature. Feeling extra nostalgic? Put your organizational skills to use and create beautiful scrapbooks out of your old photos.

GET INVOLVED IN THE COMMUNITY

Joining a group may help you connect with others now that your caregiver duties are taking a back seat. It can be comforting to have a network close by. There are plenty of ways to stay involved and be an advocate. Share your stories on online forums, attend conferences, volunteer at charity events, or even consider being a guest on a CF podcast like Uncommon Lungs.

CROSS OFF A BUCKET-LIST DESTINATION

Take a vacation somewhere you never thought you'd be able to go. It doesn't need to be expensive or far from home. Maybe it's with friends to a city in the next state over or a solo trip overseas that you booked when you found a flight deal you just couldn't pass up. Choose your own adventure!

REKINDLE AN OLD FRIENDSHIP

Having companionship when your child leaves home is key. If you're feeling lonely, this may be a good time to reconnect with an old friend and get caught up on each other's lives.

KEEP IN TOUCH

Remember, your loved one is just a phone call, text, video chat, or visit away!



Temporary toodle-ooos to your tots and teens

Even if it's only for a few weeks, days, or hours, it may be nerve-wracking to send your loved one off on their own for the very first time. Whether they are attending summer camp, working a summer job, or taking a trip with friends, it's important to let them take steps to empower their independence. Feel confident knowing you've prepared them well for their time away.

Your Summer *of love* is about to begin

Navigating your love life can feel daunting, and throwing CF into the mix means figuring out how dating fits into your care routine. Whether you're new to finding love or looking to add a little romance to a thriving relationship, it's important to identify activities that meet your needs. Whether you plan for social distancing, the level of physical activity, or even budget, knowing these details can help reduce the dating jitters and set you up for having an honest and enjoyable time.

Take the quiz!

Need help planning an outing? Answer these 8 questions and discover which date idea is right for you.

What do you most look forward to during the summer months?

- a Relaxing with a book or catching up on the latest blockbuster hit
- b Enjoying the great outdoors
- c Meals with friends under the patio lights

What is your social distancing comfort level?

- a Screen-to-screen
- b In-person but masked-up or at a distance
- c Face-to-face

Where are you on your dating journey?

- a Just getting started and feeling a little nervous
- b I've done some dating and am always up for the next adventure
- c Ready, steady, and looking to settle down

Is including an active lifestyle in your dating life important to you?

- a No, doing what I can is important, but too much physical exertion can be tough on me
- b Absolutely, staying fit is a big part of my life
- c While not a deal breaker, I try to stay active but some days are easier than others

What kind of atmosphere are you looking for in a date activity?

- a Casual and comfy
- b Fun and free
- c Intimate and romantic

How important is sticking close to home?

- a Some aspects of my CF and routine make it uncomfortable to stray too far
- b I'm gone! I've got my on-the-go routine down to a science
- c With time to prepare, I feel confident in a day away

When are you most comfortable with having the CF talk with your partner?

- a CF can be unpredictable and I'm an open book, so I'll let them know right away
- b I'll take my time getting to know them before sharing the nitty gritty of my CF needs
- c It's a big part of who I am but not the only part, so I'll find a time that feels natural, whether it's on the first date or the fifth

There can be a lot of costs when it comes to managing CF, are you looking to date on a budget?

- a I prefer to find fun ways to connect that are easy on our wallets
- b Dating can be expensive, so let's split the bill
- c I don't mind spending a little money to make the most of our date



Answer key

Calculate your score to start planning your next date!

a = 1 point

b = 2 points

c = 3 points

Your total:

What's your ideal date?

8-13 points

Watch Party Movie Night

Sometimes managing CF can make it impractical to connect in person, but never fear! Carefully curated virtual romance is possible in three easy steps:

1. Choose a movie to stream together from the comforts of your own couches (or a series if you want an easy excuse for date number 2)
2. Plan your home theatre snacks ahead of time and each buy the other's favorites to try
3. Make a game to play along (e.g. How many actors can you name before the movie ends? Winner gets to pick the next flick!)



BONUS: Leave plenty of time after to get to know one another a little better.

14-19 points

Summer Sightseeing

For something that gets you both outdoors, take advantage of your local area and play tourist.

Make a list of 2-3 local destinations each and take turns choosing places to explore. Whether you're taking in nature, discovering new corners of your city, or introducing each other to favorite haunts, being on the move (no matter your pace) is a great way to combine dating and staying active.

You can make a day of it or just the afternoon depending on how you're feeling. The important part is sharing an adventure with your date.

BONUS: Don't forget to snap a few selfies to remember your day out.



20-24 points

Delectable Dinner Date

Nothing says romance like a meal by candlelight.

A reservation at a fancy restaurant is always a fun treat, but don't underestimate the romantic power of a home-cooked meal. That, and the ability to add in a few high-fat or nutrient-dense ingredients.

For a restaurant substitute, find a how-to recipe video online and try your hands at learning to make dinner together.

Preparing and sharing a meal will give you plenty of time for connection and conversation.



BONUS: Share your favorite dessert to top off the evening.

Navigating your nutritional needs

A healthy CF diet isn't only about eating ingredients high in fat and protein. It also includes plenty of nutrient-dense fruits, veggies, and whole grains. Look for ingredients that are rich in nutrients like iron, salt, zinc, and calcium to name a few.*

* Talk to your healthcare provider about what's right for you.

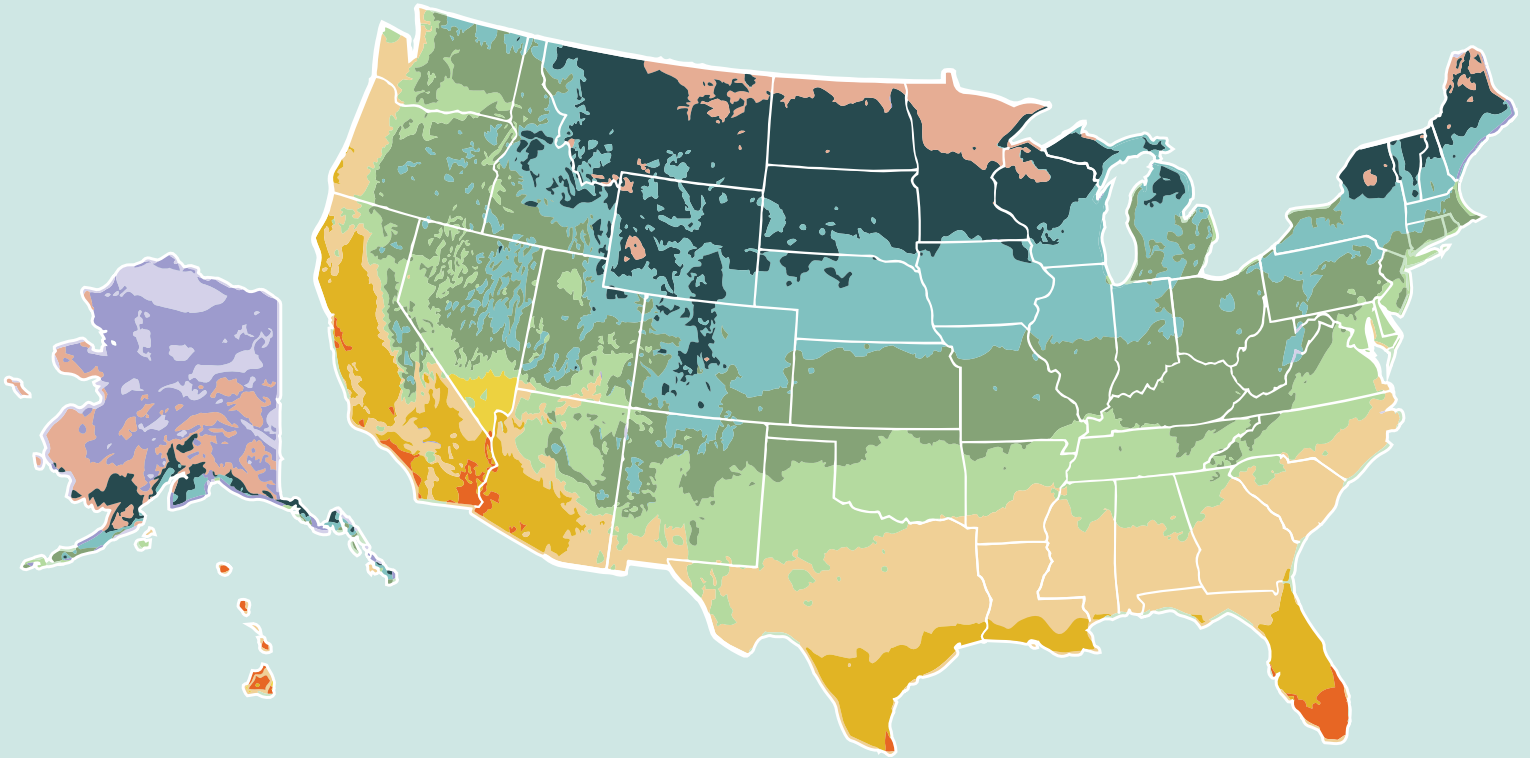
Here are just some of the foods you can eat to pack nutrients into your day:

PROTEIN	IRON	SALT	ZINC	CALCIUM
 meat	 dried fruits	 salty snacks	 eggs	 full-fat dairy products
 eggs	 fortified cereal	 meat	 whole milk	
 soy foods	 meat	 seafood	 pizza	
 fish	 dark green veggies	 sports drinks		
 nuts				
 beans				

Taste the difference fresh can make when you shop at your local farmers market or prioritize in-season produce at the grocery store.



Where does your favorite powerhouse produce call home?



ZONE 1

Beans, broccoli, cabbage, kale, lettuce, radish, spinach, tomatoes

ZONE 2

Mustard greens, Swiss chard

ZONE 3

Winter squash, cherries, apricots

ZONE 4

Pumpkins, melons

ZONE 5

Kale, lettuce, radishes, spinach, winter greens

ZONE 6

Lettuce, tomatoes, winter squash, melons

ZONE 7

Arugula, sweet peppers, turnips, cherries, apricots

ZONE 8

Lettuce, tomatoes, lemon, orange, cantaloupe

ZONE 9

Broccoli, Brussel sprouts, cabbage, cauliflower, spinach, avocado, orange, kiwi

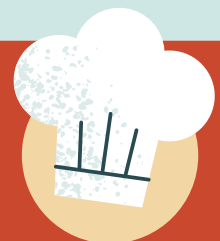
ZONE 10

Peanuts, spinach

Based on the 2023 national growing zones.

Keep your eyes peeled for fresh CF-friendly ingredients

This summer, have a bit of fun with your meal planning and see what you can make with nutrient-rich produce that grows close to home. Need recipe ideas? Visit everyday-cf.com/recipes and get cooking!



Seasonal savings and other grocery solutions

BULK BARGAIN FREEZER FILLERS

Don't be intimidated by buying in bulk to save on long-term costs. All it takes to make the most of your grocery haul is planning ahead and having plenty of freezer bags on hand. Like meat, much of the produce you buy can be frozen to be eaten later. Be on the lookout for bulk deals on seasonal foods, especially crops that have had abundant harvests.

FIELD-FRESH AND CLOSE TO HOME

Joining a community-based agricultural program (CSA) and getting to know your local farmers can be a great resource for weekly farm-fresh food during the summer. While prices and produce may vary, joining a CSA can also open the door to new hobbies like canning and preserving for savings all year.



Amber Dawkins, a mom with CF

SCRAP SAVERS

So you've made dinner and have a bunch of unused odds and ends. What now? For the scrap savvy, the end of a carrot, a leftover wedge of lemon, or the rinds of your citrus can be given a second life.

Save your food scraps for:

- Soup stocks
- Smoothies
- Homemade jams
- Infused olive oils

HOT TIP

Save yourself a trip to the store! Try replanting the root ends of some of your veggies in your home garden. A quick search online can tell you which are best for re-growing.



Calling in sick?



GET AHEAD OF OUT-OF-OFFICE ANXIETY

Hospitalizations happen. As do unexpected CF center visits. For many, it's just part of life with CF. But whether you're spending time in a healthcare facility yourself or looking after a loved one who is being hospitalized, being proactive about expressing your needs to your employer may make these unpredictable events feel a little less stressful.

CF is covered under the Americans with Disabilities Act (ADA), which means that you have the right to ask your manager for accommodations such as flexibility around where you work and the amount of time you can take off for medical care. The exact accommodations you can ask for will depend on the type of job you have, but negotiating these terms up front will help you and your employer manage these moments.

While caregivers are not covered under ADA, they do still have rights under the Family and Medical Leave Act (FMLA). If your child needs to be hospitalized due to their CF or requires transportation to frequent check-ups, check with your employer about FMLA or work with the social worker at your CF center to figure out your options.

Some workplaces offer remote options or even unlimited paid time off (so you don't have to use all your "vacation days" for "sick days" and you can

take the time you need to rest and feel better). If you're new to the workforce or looking for a career change, seek out jobs that understand your condition and will meet your needs. If you're happy in your current role, get familiar with your contract and reach out to your company's human resources (HR) department if you need accommodations based on a change in your health or your loved one's health. Check out our [Workplace Accommodations Template](#) to help you make these kinds of requests.

In any workplace situation, hopefully as an individual, you have people who care about you, support you, want to see your best development and your best self come to work. Those might be peers. Those might be managers or leaders...

...Those might be executives in an organization. Knowing who those people are, building those relationships, knowing yourself will give you a strong foundation for which to advocate for yourself and to ask for those considerations.”

– Susan, HR Expert



MAKE YOURSELF AT HOME

If you or your loved one are staying at a healthcare facility for an extended period of time, find elements from your home to make the space feel more familiar. Incorporate your personal collection of art, books, toys, trinkets, and blankets throughout the room. If you're up to it, maybe you can even set up a little office space so you're not nervous about falling too behind with work. Do whatever makes you feel the most in your element and gives you the space to recuperate.

Keeping your cool when medical needs interrupt your summer plans

If you do need to undergo a medical procedure or are spending an extended period of time at your CF center during the summer months, try the following tips to make your stay a little more comfortable:



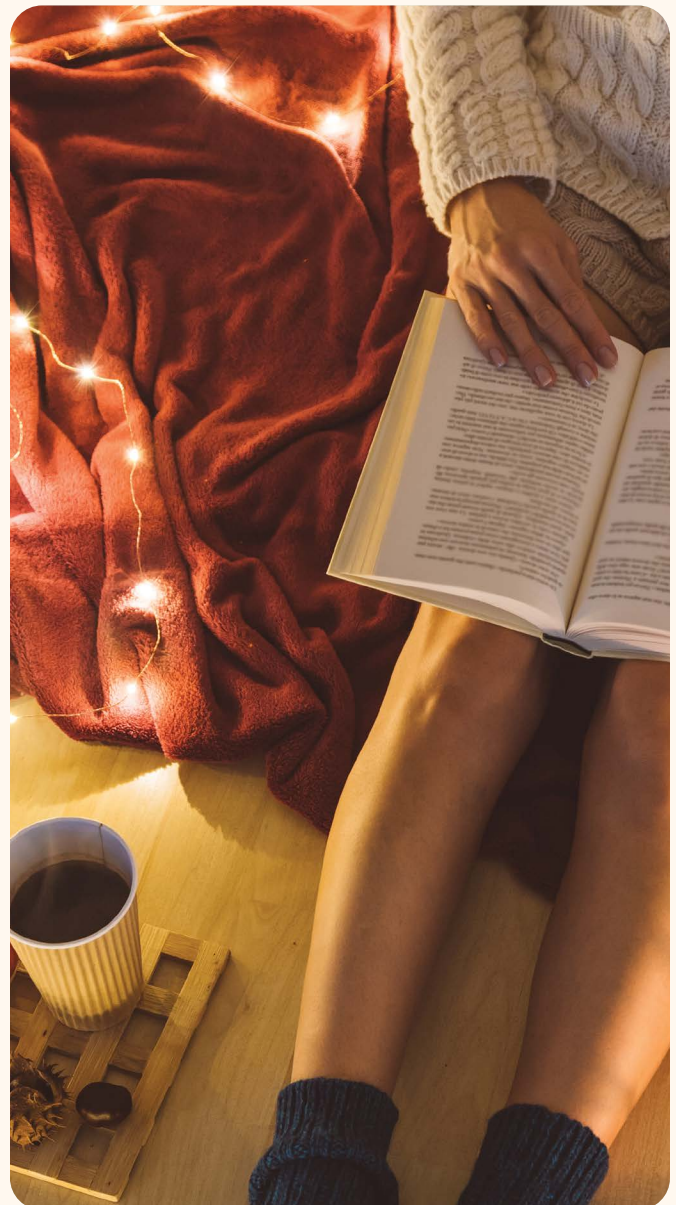
BRING THE BEACH TO YOU

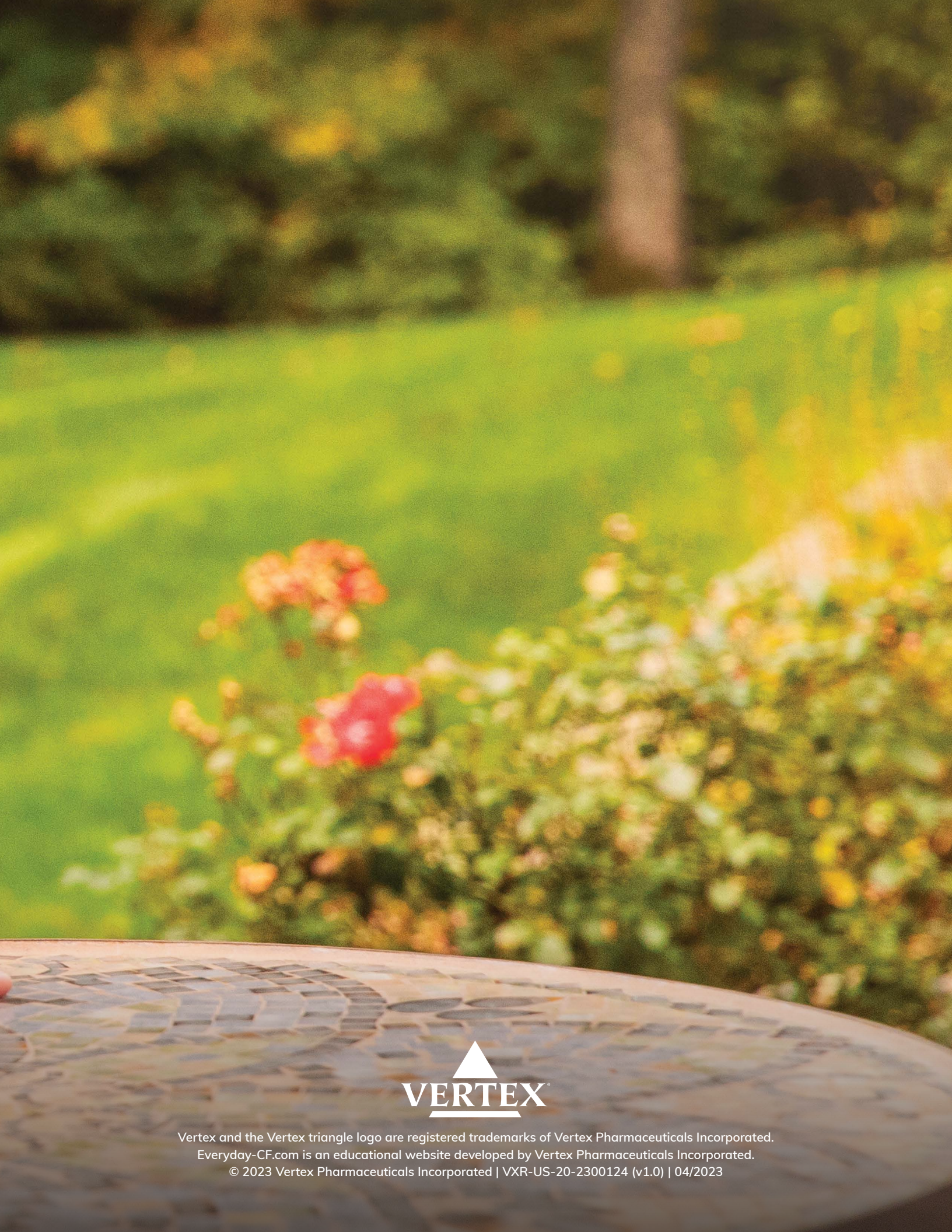
If your hospital or CF center allows it, see if you can have someone bring in a palm tree, some big shells, or a little sand in a bottle. Play some ocean sounds on a speaker or an island-themed movie to catch those summer vibes wherever you are.



STAY ZEN WITH SENSORY ITEMS

A comforting, squeezable stuffed toy, a sand garden, or some fidget items might help you release some stress. Do bright hospital lights overstimulate you? Try bringing a sheer piece of fabric like a silk scarf or a light-filtering curtain to drape over lamps or add some fairy lights for extra ambiance. Don't forget noise-cancelling headphones to help you zone out with some calming music or your favorite podcast.





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