

your best
self here



be
you

live your best life

Next steps in life

READY. SET. GO!



Juggling life, school, friends, AND cystinosis is no small task. We want you to know this: **We see you. And, you've got this.**

Just remember, wherever you are, your best tools are a positive attitude and being a fierce advocate for yourself.

have that
independent
WAKE UP

and make it happen
type vibe

THE GOODS

What's Inside?

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Paving Your Way
Emojis and Your Journey

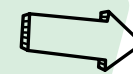


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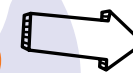


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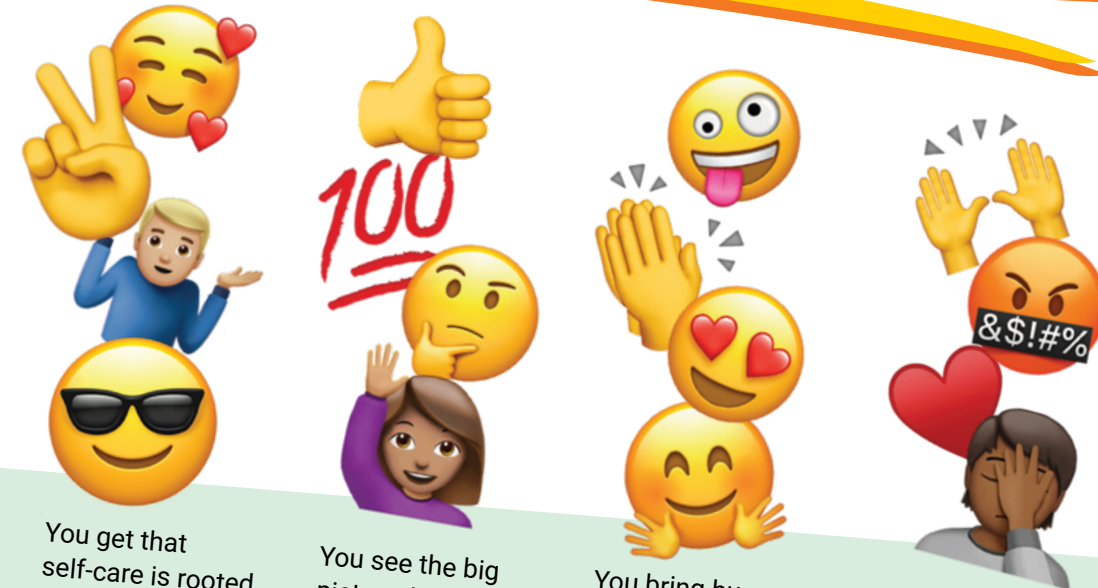
**Resources to
Check Out**



PAVING YOUR WAY

Emojis & Your Journey

The 🚶 to independence is often filled with 👍 and 👎. Some are a 🍰 and you feel like a 👑, but others make you want to 😭 and feel 😡. Let's see how your progress measures up in emojis. Open up your 📱 to see what your frequently used emojis say about you!



You get that self-care is rooted in peace, love, and understanding. You give off that chill vibe. You go with the flow and handle your parents and anything that comes your way with grace.

You see the big picture, but know that focusing on the details will help you reach your goals. You think through consequences and are open to making plans to help you reach your short- and long-term goals.

You bring humour and a positive attitude to everything you do, including taking more responsibility in your cystinosis care. That trait smooths over the bumps when your fierce independence makes it difficult for your family to get through to you.

You work hard and are willing to try new things and learn from mistakes. You wear your heart on your sleeve and are comfortable expressing your emotions. You're open and honest about the ups and downs of your cystinosis care.

WHAT'S IN YOUR BAG?

Step one to a good day out:
Pack the right stuff



- Sunglasses
- Cell phone (Duh!)
- Headphones
- Lip balm
- Wallet and health insurance cards
- Required medicines
- Salt packets and salty snacks
- Vitamins and supplements
- Hand sanitizer
- Water bottle
- Gum or mints
- Keys

Check out the top to-go items that teens shared with us and add your own below.



Oversized, cat-eye, aviators, or round?

Sunglasses come in all sorts of styles. So do faces. Cystine crystals in the cornea can make bright light painful. Sunglasses may help. So, you might as well look good wearing them, right?!

the right sunglasses for your face shape

heart-shaped face

Look for frames that are wider at the top; avoid bottom-heavy frames

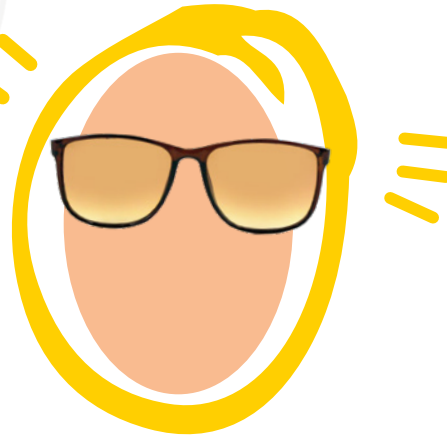
Best choice: cat-eye



oval face

Easy to pull off round or square frames, bold colors too; avoid going too big or too small

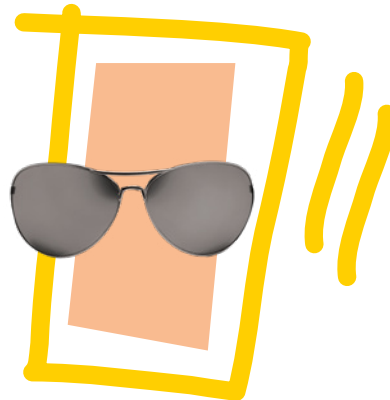
Best choice: retro square



rectangular face

Go big with rounded edges; avoid small and narrow frames

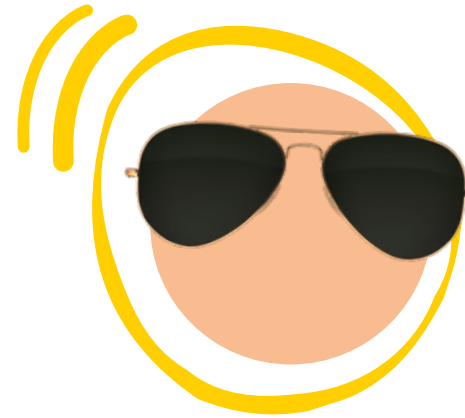
Best choice: large aviators



round face

Go for sharp-angled frames; avoid small and round frames

Best choice: aviators



square face

Round frames complement your features; avoid sharp angles

Best choice: round



Upgrade your shades!

Make your sunglasses fun and get creative with a little hot glue and some beads, flowers, or fabric. You can even use sharpies or markers to create your one-of-a-kind pair!

Getting enough H₂O is an important part of life with cystinosis.

Improves kidney function

Maintains the balance of body fluids

Prevents dehydration headaches

Drink some **WATER!**

Improves skin complexion

Helps keep eyes lubricated

Making hydration fun isn't always so simple. Here are a couple of ways to spice it up.

WATER WORKS

MAKE A SPLASH WITH YOUR H₂O

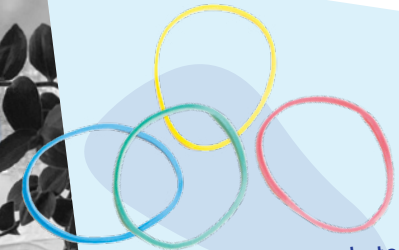
DIY Water Bottle Trackers

Get creative! Check out these fun and easy DIY water bottle projects to track your H₂O intake.

Use markers and puffy paint



Rubber band method



Move the rubber bands to the top or bottom every time you finish the bottle.

Stickers!

Get a water bottle you love. Use stickers to trick it out to match your style.



Stickers can be secret mental cues to remind you about healthy habits.

Muscle MATTERS

Cystine buildup in muscles may lead to muscle-wasting. Fortunately, an individualized treatment plan helps keep muscles intact. Here are a few simple exercises you can do at home. Try each for 3-5 sets.

ARMS

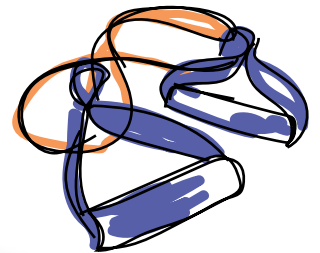
Tricep dips on the floor...



...or with a chair for an extra challenge.



Arm curls with cans or exercise bands



HANDS

Word to the wise: Check with your doctor before starting any exercise regimen.

These are only suggestions. You should always consult your physician or other healthcare provider before starting an exercise program.



Hold a pan and rotate your wrist around as if you're dumping what's in the pan onto a dish



Pinch a book between your thumb and first 2 fingers. Dangle it for 30 seconds.

Roll up a towel and wring it out for 30 seconds.



Crush a stress ball in your hand and squeeze it for 20 seconds.

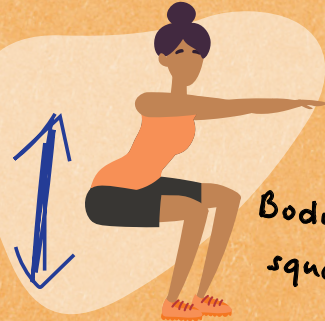


EASY AT-HOME WORKOUTS

step up on a chair, then switch legs.



LEGS



Bodyweight squats



Lunges

Pro tip: Rest is key. Give your muscles a day or two to recover before working them again.

Extra challenge: Use exercise bands or light weights if you have them. Or, hold cans or water bottles for more resistance.

TALKING IT OUT!

Tips for Breaking the Ice When Talking About Cystinosis

Talking to a friend about cystinosis takes some skill. It requires patience and clarity. When you want to fill in a friend, keep these **4 tips** in mind.

1. You don't have to tell anybody about cystinosis if you don't want to.
2. If you do, explain the basics and keep it simple.
3. Let others know you don't want to be treated differently—if that's true.
4. Don't be offended if someone doesn't respond right away.

not ready to talk about it

Science project is due in 2 weeks. When do you want to work on it?

This weekend?

Cool

So, I noticed you taking some meds. All ok fam?

All good. Just something I need to do

What's it for?

Well...you can ask, but...TBH it's not something I want to talk about now

Kk. Sorry

Np

showing appreciation

Whoa! How'd you get it?

Born with it. It's genetic

I can do pretty much anything

gotcha

Thanks for asking. 🙌

No prob

I know it's awkward.

It's nothing. Glad to know you got the meds you need

Let me know if you want to know more

I'll send you some links. They've got better info than I do

Cool thx. HMU!

HOW IT LOOKS IN TEXTS

ready to share

New console arrived. Video games in hand

Heck yeah! 🎮👍⚡

Let's play after science project is finished

Definitely!

It's on. Still want to know about those meds?

Sure. If you want to tell me about it

I've got a rare disease called cystinosis

I need to take medicine or these crystals build up in my body and they can damage my organs

Questions

to get you thinking & prepared

Positive Talk

Positivity is a powerful tool. Write down 3 lines or quotes that speak to you.

1

2

3

Life throws a lot at you. But, you're likely to handle the challenges smoothly with a bit of preparation. Pick a parent or your bestie to figure out how to stay chill in an awkward situation. **Use these prompts** or create your own. It's a tricky balance, but, for best results, make it fun while taking it seriously.

Social situations

- What if someone is interested in me, but doesn't know about my cystinosis?
- What if I like someone, but don't know how or when to tell them about my cystinosis?
- What if I find out my friends are making fun of me?
- What if I'm out with my friends and you hear someone say, "What's that smell?"

General awkwardness while out

- What if I'm suddenly feeling weaker or having trouble holding things?
- What if I'm out and I lose my phone?
- What if I'm out and I start to feel unwell?
- What if I'm feeling pressured to do something that I know isn't healthy for me?
- What if I'm suddenly feeling anxious, but nobody understands why?

Medicine-related scenarios

- What if I lose my medicine?
- What if my medicine doesn't arrive in time?
- What if I miss a dose?
- What if I'm out with friends and have to take medicine?

What if?

every day is a gift.
open it. celebrate it.
enjoy it.

good vibes only

Positivity to keep you going on your journey.

Add your fave
"good vibes"
quote here.

You are allowed to
make a big deal about
things that are important to you.

Hello

100

be you

BELIEVE IN YOURSELF.

