

the self-care project

goals, challenges, and inspiration to be your best you

self-care: project you

“Self-care” is more than just a buzzword. It’s key to living your best life. But what does that really mean for you? Let’s talk.

We’re here to get real. We’re here to talk about how self-care relates to your cystinosis care and overall health.

Self-care is about setting goals, carving out time for things you enjoy, and prioritizing yourself—physically, mentally, and emotionally. Now more than ever, it’s important to pause, take a deep breath, and remember—*self-care is the best care*.

self-care is different for everyone

This resource will help you jump-start your self-care project in 8 different areas of life by:

- Setting goals
- Improving your health and well-being
- Finding inspiration and motivation
- Challenging yourself to be the best that you can be

table of contents

4–5

physical: stretches to start your day

6–7

emotional: mindfulness to calm your thoughts

8–9

healthcare: one team, one goal

10–11

social: maintaining connections and using resources

12–13

personal: hobbies and passions

14–15

space: diy projects to liven things up

16–17

work: make your workspace work for you

self-reflection: a little goes a long way

Before we begin, let’s start with a little reflection.

Boast a little: I am proud of myself for...

Write your worries away: Here are my worries; here’s how I’ll address them...

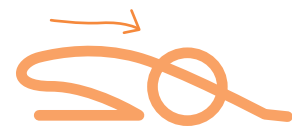
Grow a little: 3 things I want to improve in my life are...

Be grateful: I’m most grateful for...

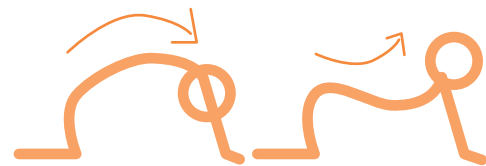
stretches from head to toe

With over 600 muscles in your body, it's important that you take the right steps to maintain your muscles and keep them healthy and strong. Wake up each day and give your muscles the TLC they deserve with these simple stretches.*

m o v e m e n t
can work wonders for your mood.
Try to make regular, light
movements part of your day.



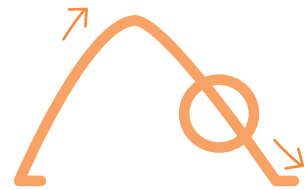
child's pose



cat-cow



neck stretches



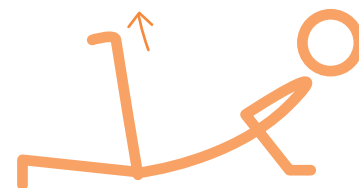
down dog



hamstring stretch



cobra



quad stretch



calf stretch

I spoke to my healthcare team about exercise and they said I can:

Stretches I can do in the morning:

Stretches I can do in the evening:

My fitness goals are:

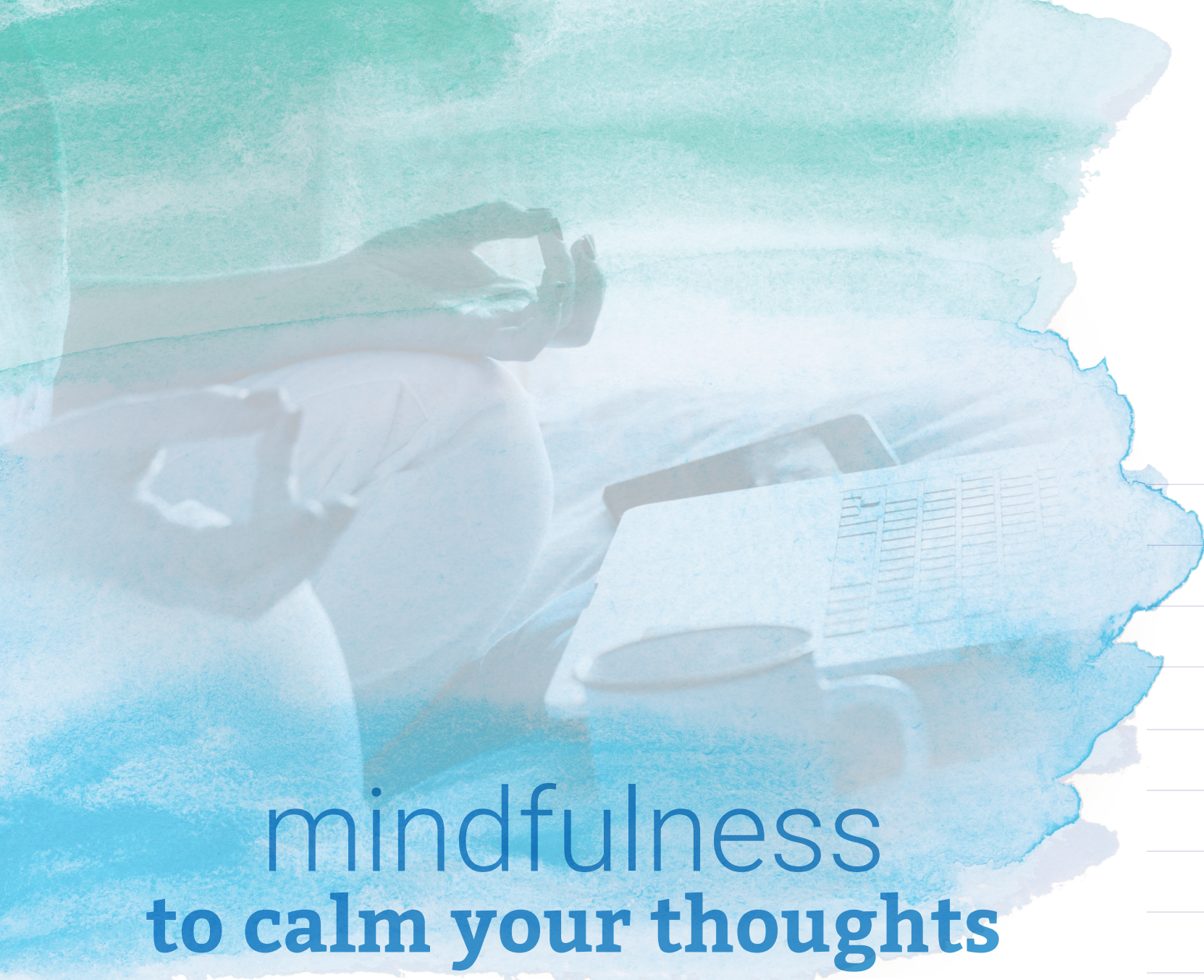
3 exercises I can work into my day to achieve my goals:
(Be specific about where, when, and for how long.)

1.

2.

3.

* These are all suggestions. Please talk to your doctor before beginning an exercise routine.



mindfulness to calm your thoughts

Just like your muscles need attention, your mind does too. Carving out time for positivity and mindfulness can help calm your thoughts, relax your nerves, and improve your outlook.

We've got great news: It's easier than you think.

Start with the 4-7-8 breathing technique

- inhale for **4** seconds
- hold your breath for **7** seconds
- exhale slowly for **8** seconds
- {repeat 3x}

mindfulness
is about so much more than
breathing. Here are a few ways to
start a mindfulness practice:

List 3 songs that always make you smile. Put in your earbuds and dance to those tunes.

- 1.
- 2.
- 3.

Find an inspirational quote and make it your phone's wallpaper. Write the quote below.

Write down the name of someone important to you and list some reasons why you appreciate them.

Go for a walk and listen to the sounds around you. Return here and list all that you heard that you usually ignore.





healthcare: one team, one goal

Everyone has a unique cystinosis journey, but one shared goal is to delay or limit damage to the body from cystine crystal formation.

At times, it may be difficult to stay motivated to take your medications.
But missing a dose can have negative impacts on your health.

The kidneys are often the first organs affected by uncontrolled cystine levels.
But it's important to remember that even a kidney transplant does not cure cystinosis. *In fact, medications are still needed to prevent cystine buildup in your body even after a transplant.*

make every conversation count

Questions I want to ask my healthcare team:

1. _____
2. _____
3. _____

know your goal

There's so much more than knowing if you're in or out of your cystine level range. Talk to your doctor to help you understand what your number means for you.

My cystine target level is:

achieve your goals

Steps I need to take to reach my health goals:

1. _____
2. _____
3. _____



indulge your hobbies and passions

There are plenty of benefits to having a hobby. It makes you happy and can be a stress-reliever.

But finding the time or even the hobby? That's another story.

Try to take a little bit of time and think about something you're passionate about. Or, something you simply enjoy.

For some, that may be writing a fantasy story, teaming up with online gamers, or simply piecing together a puzzle.

There's no right or wrong hobby. You do you!

Ask friends and family how they found their hobbies and when they find time for them.

self-care

means prioritizing what's important to you. Let's figure out how to rekindle your old passions or find new ones.

If I could spend all my time doing one activity, it would be this:

Why? What does it mean to you and what do you get out of it?

My plan for carving out more time for my passions and hobbies:



liven up your space

Making your space something special to you is a serious mood booster.
Try to spruce up areas of your home with some fun DIY projects.

- Get your cleaning, tidying, or organizing on
- Upcycle old stuff around the house
- Get crafty and spread the love

take stock of your room and home

List some ways to improve your surroundings that complement your personality and make you happy (from decluttering to adding a plant):

Draw the elements of your ideal room or environment:

let the creativity flow

What's lying around that you can turn into a DIY project to move closer to your ideal space?



make your workspace work for you

One way to make work more enjoyable is to make sure your work environment is optimized not only for productivity, but also to help you achieve your health goals.

Here are a few things to keep in mind when setting up your workspace:

Centre your computer monitor directly in front of you, 20 to 30 inches from your eyes.

Use a chair that offers lower back support. If it doesn't, use a pillow or a rolled up towel.

Stand for periods of time and stretch, including your hands and wrists.

Stock a workstation with your necessities: eyedrops, sunglasses or blue light-blocking glasses, stress ball to squeeze for hand stretching or exercise, and a water bottle.

Live by the 20/20/20 rule: For every 20 minutes you look at a screen, look at something 20 feet away for 20 seconds to rest your eyes.

Jot down 3 little hacks that will improve your workspace:

- 1.
- 2.
- 3.

Reflect on what would make you more productive. Are there boundaries you can set or ways to work more efficiently?

time to dream

Map out your ideal workstation. It can be big or small, gadget-crazy or crazy-minimalist.
Just make it yours.



inspiration
for your self-care project



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