

A black and white illustration of a boat on a dark sea under a stormy sky with lightning. The boat is a small, simple vessel with a single mast and sail, positioned in the center of the frame. The sea is dark and turbulent, with white, jagged lines representing waves and the boat's wake. The sky is dark and filled with white, jagged lines representing lightning bolts. The overall mood is dramatic and intense.

CROSSING THE DEEP, DARK SEA

A CYSTINOSIS VOYAGE

Kevin Patrick McCalla

Cystinosis is a rare, genetic metabolic disease that causes the amino acid cystine to accumulate in various organs of the body. Without specific treatment, children with Cystinosis develop end stage kidney failure at approximately age nine. The availability of cysteamine medical therapy has dramatically improved the natural history of cystinosis, so that well-treated cystinosis patients can live well into adulthood.

This book is an allegorical story about my own experiences living with Cystinosis, especially as an adult.

Thanks to the following organizations for making this comic a possibility:



Making lives better starts here.
The Cystinosis Research Network's vision is the acceleration of the discovery of a cure, development of improved treatments and enhancement of quality of life for those with Cystinosis.



Thank you to everyone else who made this book happen - my family, friends, the Cystinosis community, and kind strangers who helped me on my way. Thank you especially to my wife, my guiding star, who keeps me steady no matter how furious the storm.

This comic book was funded by a grant from Horizon Pharma and Leadiant Biosciences, however, all opinions and statements expressed are of the author and Horizon and Leadiant were not involved in the creation or content of this comic book. Drawings, words, and concept ©Kevin Patrick McCalla. Logos ©their respective owners. Fonts provided by Blambot.com.

IN THE DEPTHS OF WINTER
I FINALLY LEARNED
THAT WITHIN ME
THERE LAY AN
INVINCIBLE SUMMER

ALBERT CAMUS



It feels like...

I am sailing rough waters
on the open seas
in a small boat.



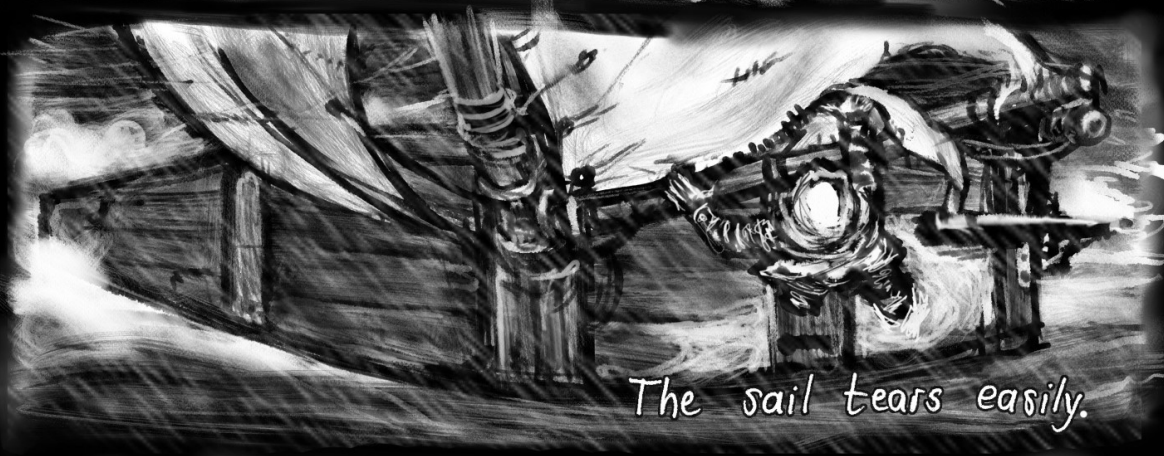
Every day I struggle to keep it afloat.



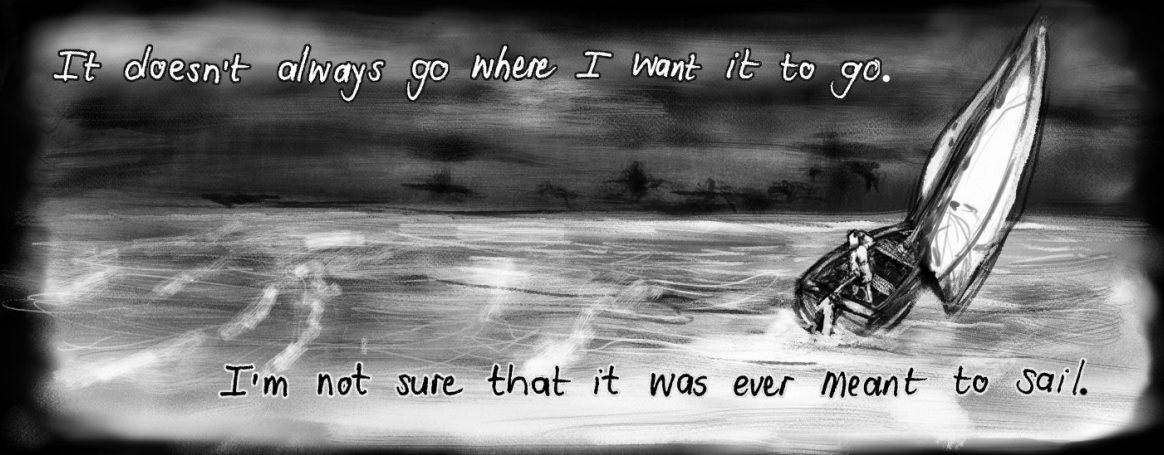
It leaks constantly.



The sail tears easily.



It doesn't always go where I want it to go.



I'm not sure that it was ever meant to sail.

But when I look around,
it seems like

I'm surrounded by large,
sea-worthy ships.

Some fly by in speedboats, bumping over
waves that would topple my small ship.

Others cruise through the dark waters in
great ships of war, ready to face any challenge,

seemingly protected from the dark depths,

ignorant of the shadows below.

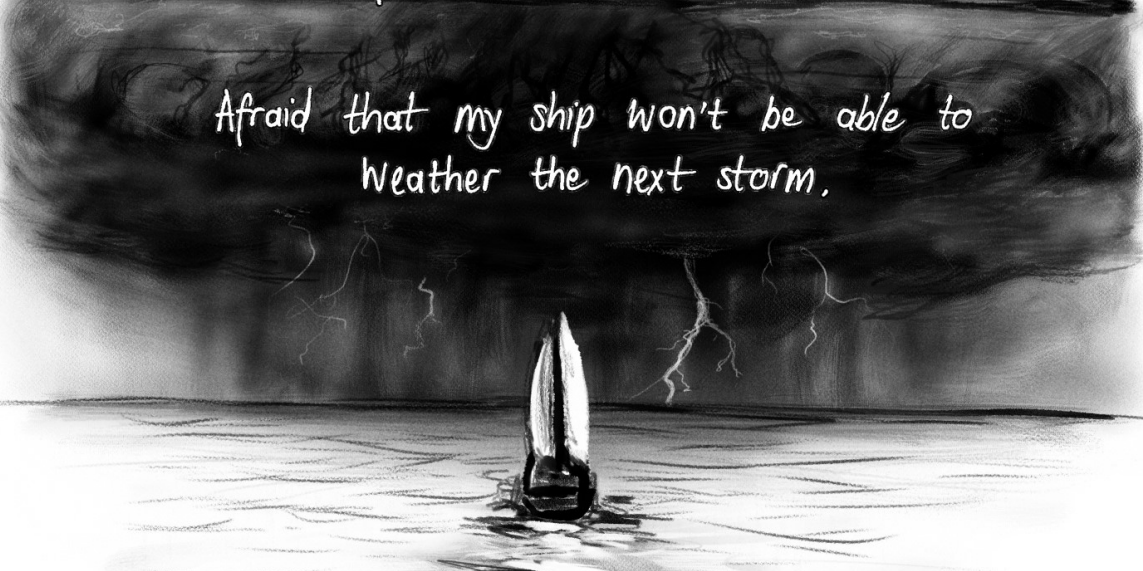


So, I'm afraid.



Afraid that I'll be lost in their wake.

Afraid that my ship won't be able to
weather the next storm.



Afraid that I just don't have the skill to keep my boat righted,

...and afraid that anyone who offers to help



will drown, too.

So I refuse rescue.



This ship is my burden
not theirs!



But I grow weary, tired from the constant struggle.

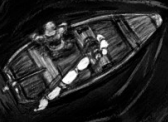
I do my best to patch my boat, but there are always new leaks.



I can never rest.

This is my burden.

And so the deep, calm, dark



seems somehow comforting.



The shadows tempt me.

They see my weakness.

The abyss seems peaceful,

a reprieve from struggle.

But ...





And through my struggles,

I am strengthened.



I become a better sailor.



my vessel is not perfect,

but it is MY vessel.



I now see it as my truest friend.



We struggle, we grow, and together we are made stronger.

Yet... the horizon seems so far away...



and the sky darkens once again.



Even our new strength seems futile.



The abyss appears inevitable.



The shadows mock me.



Great waves threaten to overtake us.



I fight harder!



But I am still afraid.

For the first time in a long time,

I call for help.



I don't expect an answer.



Then, in the blinding maelstrom,

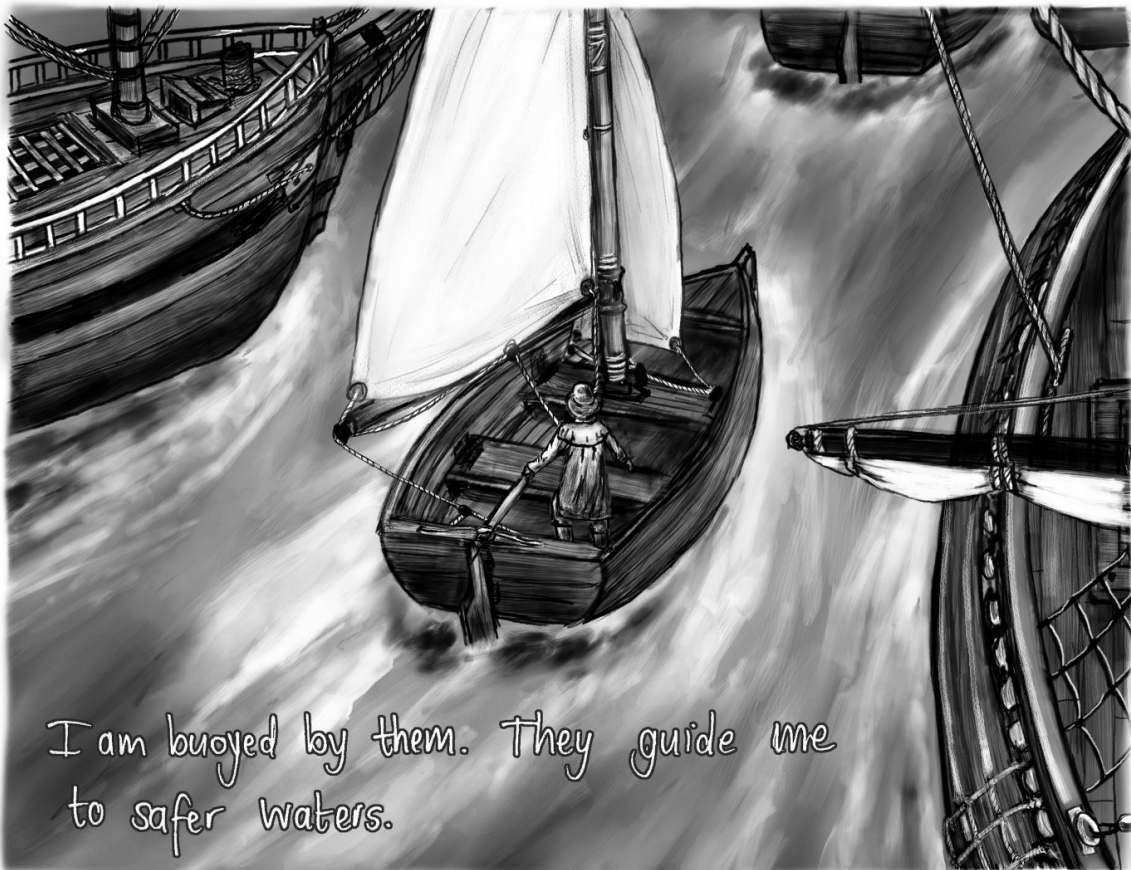


I feel a soft, friendly touch.





The waters calm around us, and I see
the boats and caravels I had been
so afraid of are alongside me.



I am buoyed by them. They guide me
to safer waters.

The horizon is bright

And beautiful

And hopeful



The End

Kevin Patrick McCalla



I'VE ALWAYS BEEN INTERESTED IN ART, ESPECIALLY AS A MEANS TO TELL A COMPELLING STORY. PAINTINGS ON HOSPITAL WALLS AND VISITS TO GALLERIES AND MUSEUMS AROUND WASHINGTON D.C. WERE HIGHLIGHTS OF MY YEARLY TRIPS TO THE NATIONAL INSTITUTES OF HEALTH. I WAS DIAGNOSED WITH CYSTINOSIS AT 13 MONTHS, AND WAS EXTREMELY FORTUNATE TO ALMOST IMMEDIATELY BEGIN CYSTEAMINE TREATMENT.

LIKE MOST OF MY FRIENDS IN ELEMENTARY SCHOOL, MY LOVE FOR STORYTELLING AND ART EVENTUALLY RESULTED IN A FASCINATION WITH COMIC BOOKS THAT'S LASTED THROUGH TO ADULTHOOD. COMICS ARE A WHOLLY UNIQUE MEDIUM IN HOW THEY ENGAGE THE AUDIENCE, COMBINING ART AND WRITING IN A WAY THAT IS BOTH INFINITELY COMPLEX AND INSTANTLY ACCESSIBLE TO ALL AUDIENCES.

WITH THESE SHORT COMICS I HOPE TO UTILIZE THE UNIQUE STRENGTHS OF COMICS TO ENGAGE THE CYSTINOSIS COMMUNITY - PATIENTS OF ALL AGES, DOCTORS, CAREGIVERS, SOCIAL WORKERS, AND ANYONE WHO IS INTERESTED. I CAN ONLY HOPE THAT MY OWN EXPERIENCES LIVING WITH CYSTINOSIS HELP ME PRODUCE INTERESTING, MAYBE EVEN COMPELLING STORIES THAT OTHERS FIND HELPFUL, RELATABLE, AND ULTIMATELY ENJOYABLE.

