

After I got her snuggled into cozy pjs and nestled in bed, I found myself staring at my daughter's fleshy fingertip pads. Isn't that what the doctor had called them, as she scrutinized every inch of my sweet girl, searching for a diagnosis?

For a moment, I saw her differently.

Yesterday, those hands had made my heart skip a beat when they reached for mine. They had stirred contentment deep within me when I watched her stroke the hair of her itty-bitty brother. And those hands had made me laugh when they worked hard to try and reach the cookies cooling on the counter.

But today those fingertips meant our world had turned upside down. Today they meant life was going to be harder than I expected. Today they meant my girl was different.

Because the blood test results are in, and a new word is etched into my daughter's life. And into my life story.

Coffin-Siris Syndrome. And it can't be erased. Ever.

And so I stared at those hands. And I didn't know if I could do it. Mostly because I was just so very tired. I didn't know how I was going to make it for the long haul. Because tomorrow itself seemed like too much.

But I did make it.

And you will, too. Tomorrow you will wake up and you will do all the things. And the next day as well. And pretty soon, most of the things don't feel like things anymore, they are just life. And there will be joy again. With some heartbreak sprinkled in, but definitely joy.

It's ok to let yourself stand in that place of staring at those fingertips and being sad. Or wondering why. Or being relieved. Or angry, or scared. Because one day soon those fingertips will turn back into the cutest little fingertips you've ever seen.

And when you feel like you're not enough, I wish you could see all the things others can see when they look at you. Beauty and grace and strength. Your love for your child is written all over you in your choices, in your movements. It's written on your face in wrinkles and in your encouraging smile and even in your tears. In the middle of the what-ifs, when you let yourself face the worst of it all, love will persuade you to suck all you can out of life each day and that, dear friend, is a gift worth far more than most.

And you will rise. Because you will. Because love is bigger than big. Because love can do amazing things. For your child. But also for you.

And life will be good. Your kiddo is going to make you smile. And probably belly laugh. And you will find small moments that feel so big you won't think your heart can contain that kind of joy. Life will be normal. Except when it's not. And on the days when you feel like you can't keep going, we're here. Walking alongside you on this unexpected but beautiful journey that will make you hurt and cry and dance and giggle.

You will find your way.

And you are not alone. We've got this with you.

We'll rise together.