

CHRONIC PAIN · PARENTS PERSPECTIVE · UNCATEGORIZED · WRITTEN BY MOM

Advice From My Mom

April 2, 2017 [saneinchronicpain](#)

Just as I asked my dad to write an article, I asked my mom. So thank you mom! I hope you all enjoy this.

"We have to live a new life that would not seem possible. But that's not something you need to be Superman to accomplish"

Christopher Reeve "Nothing is Impossible" 2003

Madeline asked me what is it like to parent a chronically ill child? I told her it feels like a firefighter sometimes. I am ready to tackle new symptoms, run to the ER, the doctor or whatever is needed that day. The first thing chronic illness taught me as a parent was to be flexible. I thought I would write about tips that we have learned that helped our family. I am always asked by friends how do we deal with Madi's illness and how do we do deal with it as a family. Chronic comes from the Latin word chronicus, meaning lingering and pertaining to time. You learn quickly your schedule does not matter. I also learned this takes your time, your most precious gift. Chronic illness becomes the unwanted guest that stays. So what are some of the tips I have learned:

1. Laminate a medication list. You always have to know what your child had taken that day and what time.
2. Let your child rest. Healing is resting. Don't push your child through the pain.
3. Know your child's limits. Frequently on good days, they will want to overdo. They will end up paying for this and it could make them worse.
4. Consider a pet for your child. We have two dogs and they are pure joy to us. They wake up with us when we have bad nights. They are our constant companions.
5. Consider a nutritionist to help maintain the best diet you can afford.
6. Doctor appointments are a fact of life now. They can take an entire day. Try not to overschedule your child. Madi needs two days sometimes to recover from one appointment.
7. Consider making their bedroom an electronic free zone. Have them rest/read in their room only. Have them watch tv/computer in a family room.
8. Listen to your child daily. Sometimes, they just want to talk. Stop and listen.
9. Make time for your friends too. I know it's hard to leave your child but try to make the time.

Your child is fighting everyday but you are too.

10. Laughter is the best medicine. Keep your sense of humor.
11. Take care of yourself. If you run yourself ragged than you are no good to your child.
12. You are your child's best advocate. Fight for them. Ask a lot of questions in the doctor appointments. If the doctor has a terrible bedside manner or does not listen to you or your child, move on. A good doctor is gold.
13. Let people help. Don't always feel like you have to do everything.
14. Forgive yourself. It sounds easy but as parents we want to blame ourselves.
15. Watch positive movies. We try to have family movie night weekly. It gets everyone together and with illness it is one of the few things we can all do together.
16. Stay flexible. It is okay, it does not all have to be done today.
17. Consider Chinese medicine. This has really helped Madeline. I know she will go into more detail later on this subject.
18. The best tip for last, enjoy every minute of a good day! Every spoonie knows a good day makes you want to share it on every social media platform available. It is such a joy to feel good!

We had to learn to live a new life with chronic illness. It is not what we planned and like Christopher Reeve said in the quote at the top, it would not seemed possible. We had to grieve the old life. Our home went from chronic noise of softball girls to silence. We spent every weekend in a different city for softball or hockey. She was going to have her pick of colleges. The first year of illness is a blur trying to find out what happen and fix it. There comes that moment when you realize you have to hand it over to God and let him handle it. My husband and my family are a great support for me. I have several family members I can dump on at any time of day or night. This is invaluable to me. Mr. Reeve is correct, it can be done and you don't have to be superman. I learned a long time ago to retire my cape. I thought I could do it all. In the end, after you burned the candle at both ends, you burn yourself out. Anyone who knows me knows I love Amy Grant. She has been my favorite singer for decades. She has a song "Somewhere down the Road" . They lyrics read:

So much pain and no good reason why

You've cried until the tears run dry

And nothing here can make you understand

The one thing that you held so dear

Is slipping from your hands

And you say

Why, Why , Why

Does it go this way

Why why why

Is all can say is

Somewhere down the road

There'll be answers to the questions

Somewhere down the road

Though we cannot see it now

Somewhere down the road

You will find mighty arms reaching for you

And they will hold the answers at the end of the road

Yesterday I thought I'd seen it all

I thought I'd climbed the highest wall

Now I see that learning never ends

And all I know to do is keep on walking

Walking round the bend saying

Why, why why

Does it go this way

Why, why why

And all I can say is...

It is a great song for loss and the need to begin anew. Sometimes we just don't know why of something. We do not know what our journey will hold. I ask God daily for the strength to keep walking for that "day". I also learned I married a hero. A person that I can trust to be there at any time and any moment I need him. We are in this together, all in 100 percent. It took me a long time to realize to enjoy the moments. I stop and recognize the moments now. I appreciate the times we laugh and the times Madeline is comfortable. We do not have all the answers but we will find them together, somewhere down the road.