



Nurturing Resilience: An Advocacy Journey

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About Me

- Associates Degree in Elementary Education


- Family of nurses and child care providers

- Early Childhood Educator


- Former Preschool Director

- Child Life On Call

- Parent of a Deaf child with Cochlear Implants and child who was on dialysis and recently had a kidney transplant



If you can't fly then run, if you
can't run then walk, if you can't
walk then crawl, but whatever
you do you have to keep
moving forward." – Martin
Luther King Jr.



Medically complex parenting is a lot like running a marathon.

It's not about the speed or your ability, it's about accomplishing a challenging goal that requires daily work that can sometimes cause physical and emotional pain.

Physical- Daily requirements of lifting and carrying, even moving medical supplies or checking a line to a feeding tube or IV, lots of repetitive movements

Mental-There are so many things to check off the to do list on top of the care you give your child(ren) each day. From calling your DME company, arranging an IEP meeting or getting a second opinion, your mind can feel quite busy at times.

Adapting to the weather -This is your environment whether your child is at home with you, at school, in the hospital or therapy center we are in a state of adaptation to the environment around us all the time.

Staying the course

How am I going to keep going? You probably have thought this at some point in your journey of being parent and/or caregiver. Most of us are not prepared for this as much as we may or may not know before finding about our child's diagnosis.

You may have experienced a shift in your mindset.

A change in perspective and beliefs about the world and about you.

You may experience changes in your relationships (spouse, friends, family etc)

Ever changing environment, learning new things about your child and yourself every day

Think about the day that you got discharged from the NICU or hospital after receiving your child's diagnosis. What advice would you give yourself?

Extensive Training

As caregivers we undergo extensive training to care for our children and their needs. We become knowledgeable about medical terms, treatments and the healthcare system.

In addition to us becoming experts on children, we teach other people how to best care for our child.

We have to spend time educating ourselves on the latest research on things pertaining to your child's medical condition.

We learn what rights are available to our children from healthcare laws, disability laws and education laws.

You deserve support.

Marathon races have huge crowds of loved ones cheering on the runners as they pass through the hardest parts of the journey. Who is cheering us on and giving us that support we need?

Family and Friends

Sometimes our family and friends don't always know the right words to say or how they can help in times of need or struggle, however focus on the love they give and support that they are willing to give you. Not everyone along this journey can meet all of our needs

Spouse/ Significant other

Lean on each other every day as much as you can. Share fears with one another, ask for help if you feel overwhelmed.

You deserve support.

Child Life Specialists

Child Life Specialists are experts in child development and know how to support your child in the hospital. They can also be vital resource for helping you advocate for needs in the hospital. They help develop coping plans to help your child cope with medical procedures among many other things.

Social Workers

Social workers can help you with your financial and socio-economic needs in and out of the hospital. They can also help you apply for state based insurance and any grants that may be available to your family.

Case workers

Case workers can help with so many things. From being double billed by the provider, arranging equipment to bring home after discharge, arranging for travel if you need to travel for medical care. Your insurance plan may have a nurse case manager. They are also vital in helping you get discharged to go home. Ask for checklist or expectations to be discharged in advance.

You deserve support.

-Support Spot App- Created by Child Life Specialists, helps me know what to advocate for and what questions to ask and tons of resources for all of my children.

Connect with other parents who truly understand what you are going through

-Facebook Groups by diagnosis

-Podcasts are such a great way to feel connected in busy seasons

-Child Life On Call Podcast

-The Rare Life Podcast

-Special Needs Mom Podcast

-Virtual and In Person Meet Ups as well as Retreats

-We are Brave Together

Effectively Communicating with your care team

- Be clear and concise with communicating with the care team
- Write down what you want to say and any questions you may have
- Practice saying it outloud to yourself
- Document the main parts of your conversation if possible. If you know it is going to be a hard appointment, admission etc if possible have your partner or another family member there to be a listening ear and take notes
- Talk it out with your significant other, friend or confidant.
- After the conversation reflect on what went well and what didn't go well

Develop strong partnerships

-Work to communicate with your care team to help get everyone on the same page to develop a plan of care that will work best for your child, family and the care team.

-Get involved with your child's educators at school. Many schools have opportunities to be apart of Parent Advisory boards for Special Education. If you don't feel qualified, it's ok to still go and listen and speak up when you felt lead to. This is a great way to get to know leaders in your school district and other parents as well.

-Utilize Child Life Specialists and Social workers to help you collaborate if you feel stuck whether in patient or outpatient.

Be persistent

-Advocate for resources. Whether it is new equipment, therapies or financial aid ask your social worker or case manager about what is available to your family. It never hurts to ask!

-Stay on top of any referrals, appointments and evaluations that may need to be completed to ensure there is no gap in services which can sometimes happen in the therapy world with authorizations as well as prescriptions for medications your child needs.

-Speak up when you feel the plan of care or a decision is being made that doesn't align with what is best for your child. This can be very hard as a lot of us have probably experienced this a a few times or many.

Taking care of you

The term self care can seem very light hearted at times. Being in a constant state of caring for your child and family, it can be so hard to have time for yourself. Everyone who is a caregiver struggles with 'self-care'

- Seek counseling or therapy
- Advocate for activities for your child to improve their quality of life
 - Seeing our children do things that bring them joy is priceless
- Listen to your favorite music or audiobook while setting up medical equipment
- Text another medical mom friend late at night that is going through it too.
- Listen to a calming prayer or meditation on youtube
- Go on a walk or sit outside, even if it is short lived or a short youtube exercise
- Invite a friend over for a cup of coffee

Plan for the future

- When your child gets closer to the age of being transitioned over to adult care, ask your care team on how to best make this transition and if they have any resources available to help with this transition.
- Begin to think about long term care options, legal guardianship or special need trusts to help secure your child's future. This is something you can ask your social worker about.
- Begin involving your child in discussions about their care if and when it is appropriate for their age and development.. This will help them begin to develop self advocacy skills.

Celebrations

- Celebrate Inchstones! An Inchstone is a tiny triumph that is worth celebrating.
- What is an inchstone that made you the most proud in recent months?
- What is an inchstone or few that you have made personally in the recent months?
- Focusing on inchstones will put our perspective in a positive light and give you stamina to continue on.

Closing

-You are not alone in alone this, there are so many people that want to help and understand what you are going through. We are better when we are in this together.

-One day at a time, it a whole day is hard then work on getting through the next hour or 15 minutes. Be patient and kind to yourself. Always.

-Always have the mindset of wanting to improve, change and grow. It will not only help just you but your children along this journey of advocating and staying resilient through it all.

Contact Information

Please reach out to me if you want to connect or have questions about today's presentation. It was an honor to share with you today.

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