


Resilience and Self-Care for Parents of Medically Complex Children


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A poem to share...

“Welcome to Holland”

by Emily Perl Kingsley



“Welcome to Holland” by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....


When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.



“Welcome to Holland” (cont'd.)


So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.



But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



From a fellow traveller:

By prevailing over all obstacles and distractions, one may unflinchingly arrive at his chosen goal or destination.


-Christopher Columbus

Self-care

Cheesy therapy term or just too hard to pinpoint?

- *Psychological*
- *Physical*
- *Medical*



Psychological - Know where you are

- *Guilt*
- *Relief*
- *Anger*
- *Sadness*
- *Depression*
- *Frustration*
- *Joy*
- *Fear*
- *Stressed*
- *Happy*
- *Confused*
- *Anxious*

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Physical – know what your body needs

Where are your challenges?

Nutrition

Exercise

Sleep

Set goals – small and short-term

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Medical – know the facts about you

- *Doctors may be the worst patients, but parents with chronically ill or medically complex children come a VERY close second.*
- *Sets a good example for your children*
- *You are more at risk, so it is more important to follow through*
- *Try to avoid secondary gains – eg. It is easier to get sympathy for an illness people understand vs a life situation that they cannot*

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Know what you need

- *Stress Management techniques*
- *Outlets – hobbies/enjoyable interests*
- *Vices - you are all coping, so let's make it count*
- *Recognition – words, actions, financial rewards, physical contact*
- *Compare apples to apples*

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NOW you can give

*It may not always go in this order, but grounding yourself first, can make all of the difference in **what** and **how** you give to others.*

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Primary places of impact

- *Family*
- *Peers*
- *Education*

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Roles and Responsibilities

- *Insert your name here*
- *Parent – children/siblings*
- *Spouses/Partners*
- *Roles (family, community, job)*

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Erickson's Stages of Development

Stage	Psychosocial Crisis	Basic Virtue	Age
1	Trust vs. Mistrust	Hope	Infancy (0-1 ½)
2	Autonomy vs. Shame	Will	Early Childhood (1 ½ to 3)
3	Initiative vs. Guilt	Purpose	Play Age (3 to 5)
4	Industry vs. Inferiority	Competency	School Age (5 to 12)
5	Ego Identity s. Role Confusion	Fidelity	Adolescence (12 to 18)

McLeod, S. A. (2013). Erik Erikson. Retrieved from www.simplypsychology.org/Erik-Erikson.html

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Spousal/Partner relationship

- *Quality, quality, quality*
 - *Planning may be the only way you make it happen*
 - *Spontaneous moments are there – use them*
 - *Communicate one way or another*
 - *Avoid competition/one-upping on who has it harder*
- HW: Write down three things your partner has done for you in the past that made you happy*

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Siblings

- *Siblings responses vary*
- *Types of reactions*
 - *Independent*
 - *Negative attention*
 - *Fixers of the problem*
 - *Extra good - stay out of the way*
 - *Angry*
- *Goals - love, understanding and security*

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Siblings - Your responses

- *Speak openly – age appropriately*
- *Positive reinforcement for everyone*
- *Quality/individual time*
- *Give them a role*
- *Take inventory of the positives*
- *Take advantages of the resources around you*
- *Know when to seek professional help*

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Bullying

- *Bullying vs Teasing – neither are socially acceptable*
- *School policies*
- *No federal law applies to bullying*
- *State policies – www.stopbullying.gov*

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Bullying – what you can do

- *Talk about it – some children do not recognize it*
- *Discuss ways to respond*
 - *Speak up, leave the setting, reach out to an adult, use humor*
 - *Practice leads to better preparation*
- *Know your legal rights*
- *Be a good role model*

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Education

- *IEP vs 504 Plan*
504 Plan
- *Increasing positive school experience*
 - *Milson 2006*
- *Your role – stay involved*

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The best advice...



Be kind to yourself.



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Final notes for your continued journey

- *Seek support from other caregivers. You are not alone!*
- *Take care of your own health so that you can be strong enough to take care of your loved one.*
- *Accept offers of help and suggest specific things people can do to help you.*
- *Learn how to communicate effectively with doctors.*
- *Caregiving is hard work so take respite breaks often.*
- *Watch out for signs of depression and don't delay getting professional help when you need it.*
- *Be open to new technologies that can help you care for your loved one.*
- *Organize medical information so it's up to date and easy to find.*
- *Make sure legal documents are in order.*
- *Give yourself credit for doing the best you can in one of the toughest jobs there is!*

-CaregiverAction.org

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Off to the New World

Following the light of the sun, we left the Old World.

-Christopher Columbus



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References

Milsam, A. (2006). *Creating Positive School Experiences for Students with Disabilities. Professional School Counseling Journal*, October 2006, 10(1), 66-72.

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