

Commentary

Dream new dreams

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I am the founder and President of the American Epilepsy Outreach Foundation. This was not a dream I had - ever. I didn't grow up wanting to be the president of a foundation dedicated to epilepsy. But there you go, a new dream. I have a son with epilepsy and it is my commitment and mission to raise the public's awareness of epilepsy through advocacy and education, and to provide support for those facing the daily challenges of living with epilepsy including patients, their families and their friends.

It has been almost 4 yr since epilepsy came into our lives. We had no idea of the devastation it would create and the toll it would take. There were so many questions and unknowns, which made it difficult for us to hide our heads in the sand. The creation of Epilepsy Outreach allowed us to help others get through what we knew would be a very difficult and trying time in their lives. We didn't want others to feel alone.

Pope John the 23rd said "Consult not your fears but your hopes and your dreams. Think not about your frustrations, but about your unfulfilled potential. Concern yourself not with what you tried and failed in, but with what it is still possible for you to do." A dream is defined as "a visionary creation of the imagination" and a "strongly desired goal or purpose, something that fully satisfies a wish". An expectation is an attitude of eager anticipation, something looked forward to - whether feared or hoped for. Synonyms for expectation are assumption or requirement but also a want or wish! Listening to these definitions therefore,

a dream is also an expectation. There is a fine line between the two.

Think back to when you were a kid, as far back as you can remember. Do you remember the dreams you had as a kid? Those dreams were basically fairy tales or fantasies. As a kid you were taught to dream. Dream Big! As little girls maybe you dreamt of being a princess, as a boy of being a famous sports figure. Hopefully, your parents encouraged these dreams. Mom made you a wand out of tin foil and a wooden spoon; you wore her high heels and put on make-up. Boys - you joined all the teams you could find time for. Your parents decorated your bedroom with your favorite team's logo and bought you the jersey of your favorite player.

Bring your memories forward in time a few years. As a teenager maybe you doodled on your book covers: "Mrs. Rob Lowe" or "Mrs. Shaun Cassidy" or "Mrs. Brad Pitt"! Like me, you probably dreamed the perfect fairy tale wedding: the most gorgeous dress, the cathedral train and the horse drawn carriage. (I had ALL of these of course!) During basketball practice, some of you dreamt of signing a contract with the Chicago Bulls, buying your first Ferrari and the mansion with a gate on the beach in Malibu.

Your parents would encourage you and say "That's nice - Dream Big! But only after you get that college degree". The dreams became less grand and the expectations have taken their place. What do I want to be when I grow up? I need to get into that top tier University. Do I have to get my degree in 4 yr? Can I pay my student loans? Just because these are expectations they are still dreams, maybe not so warm and fuzzy but attainable dreams or goals.

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Fast forward again. You succeeded in achieving some of your dreams and expectations you have had since kindergarten or before. Many of us have gotten that degree. Hopefully, you had your dream wedding or at least married your prince charming (like me!). And dreaming really big here I hope you have your student loans paid off!

When you found out you were having a baby, you began to dream as a parent and now your dreams are for your child. You were dreaming of the day you would send your child off to kindergarten, high school and then college. You dreamt of taking your kids to their first ballgame, of picking out that first car, of walking your daughter down the aisle at her dream wedding or dancing at your son's wedding. Of hearing the words grandma and grandpa for the first time.

This is where I was with my family 3 yr ago when my son, then 2.5-year-old was diagnosed with a rare form of epilepsy called Doose syndrome. That day marked a whole new life for my family and me and we quit dreaming. But was this day going to mark an ending or a beginning? That was for us to decide.

We didn't know about epilepsy, Doose syndrome or even seizures. Our days of living the "dream" were over. Our life as we knew it with two beautiful kids and another on the way, two dogs, two cars and a beautiful home, our dreams and our future was gone or so we thought. Our life became a day to day nightmare, every day exhausting and challenging, the life being sucked out of us. Doctor's visits, medicine trials, prescription changes, hospital stays, and the ketogenic diet: all daunting. Every day life became a revolving door of family members coming in shifts to just hold my son upright or to get him to eat from the ketogenic diet, letting me nap, do the dishes or look at all the medical bills piling up.

We went into survival mode. Instead of dreams of taking all the kids to Disney again, of the boys playing baseball, football or soccer, we hoped and prayed there would be fewer seizures marked on the calendar for that day. We worked on the basics: Sleeping through the night, getting our older son to school on time or reading him a story and adjusting to the birth of our newborn baby girl. We were always behind, just trying to keep up was impossible. There was no time to adjust, research, or grieve. As we all know, being a parent changes your lifestyle dramatically. However, being the parent of a child with special needs - NOT a special needs child - changes everything. That is when we realized that those fairy tale dreams were not what were important in the real, normal world. It was time to stop

and smell the roses and take joy in the little things. We got joy from seeing a smile on our son's face, hearing him giggle, feeling him relax when he needed comforting, and sitting at the table (either with or without his special chair) - it didn't matter as long as we were together as a family.

How, you ask, could we even begin to dream when we are caught up in a nightmare? Dr. Moses says "As disability bluntly shatters the dreams, parents face a complicated, draining, challenging, frightening, and consuming task. They must raise the child they have, while letting go of the child they dreamed of. They must go on with their lives, cope with their child as he or she is now, let go of the lost dreams, and generate new dreams. To do all this, the parent must experience the process of grieving."

Yes, grieve. You need to grieve. Dr. John Brantner, a professor of psychiatry said "Only those who avoid love can avoid grief." That is not you. You love your child, you can't avoid grief. Grief is a spontaneous and protective process, a natural defense mechanism of the brain and the heart. The definition of grief is a deep and poignant distress. Synonyms for grief are sorrow, heartache, anguish, angst, pain, misery and woe. These are probably all words that described your feelings at some point since you learned of your child's diagnosis. You are grieving a loss, a death of sorts - a loss of dreams.

Doctors, generally, try to comfort, reassure, minimize concerns, give hope, or sometimes even avoid the subject altogether. A story I read:" a doctor with a cheerful manner and bright smile, who picked up a newborn baby girl missing her left forearm and hand, examined her, straightened out the awkward swaddling performed by her inexperienced parents, and said, "How are you feeling about Emma's arm?" She went on, "It's okay to grieve, you know. Parents need to grieve the lost image of a perfect child." When the parents worried about the child's losses, the doctor confidently observed that the child would find a way to tie her shoes, to play the piano, and so on. She concluded with the statement, "The only thing this girl won't be able to do is to wear her wedding ring on her left hand!" Hopefully, you have a doctor that understands your grief, doesn't give you false hope, and doesn't avoid the "disease" altogether. If you do not have a doctor that meets your needs, now is the time to find a new one. Your doctor should have compassion, should take all the time that you need to answer all your questions and not just pat you on the leg and say "It'll be ok". That is not what you need or deserve.

Elizabeth Kübler-Ross, author of “On Grief and Grieving” [1] says: “The stages of grief were never meant to tuck messy emotions into neat packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss.” There are stages of grief and they apply to our loss, a child’s disability. You may have experienced some or all of these stages when you learned that your beautiful child, your dream, has a disability. It is a natural response. You are experiencing a loss of dreams for your child. In her book, Kübler-Ross and Kessler [1] note that there are typically seven stages of grief. There are many variants of these stages but these are the basic, most commonly accepted.

- 1 Shock - a disturbance in the equilibrium or permanence of something; a sudden or violent mental or emotional disturbance. When you receive devastating news of a disability, your body’s protection mechanism kicks in to protect you from being completely overwhelmed. Up until this point, our family, both sides of the family, didn’t have anyone with a disability or illness, or at least never recognized it as such. My first response to the epileptologist after he gave us the news was “So, it’s not because of his 2 yr molars?” That was one doctor visit I will never forget. After he left the room, I was crying and hugging my husband, and he came back in and said, “Oh sorry I forgot my pen”, and left the room when instead he should have comforted us in some way, given us a sense of hope, or at least a number to go for support instead of nothing.
- 2 Denial - refusal to admit the truth or reality; refusal to acknowledge an occurrence. Denial is a natural defense mechanism as you are forced to absorb the unthinkable. This can’t be happening to me. Denial steps in to avoid the pain of the news and shock provides emotional protection. I think I was in denial for a month or two. I was determined to do this all on my own, I was Super Mom! I can do this: clean wrinkle free clothes, a visit to the zoo or the children’s museum, a nice healthy snack and dinner on the table, kids to bed by 8, bathed and teeth brushed, two bedtime stories, a run through the ABC’s and a little bit of monkeys jumping on the bed, and finally the Eskimo kisses and tickles before lights out. I didn’t want to ask for help mainly because I thought okay, he’ll take a drug and he’ll be fine. It is epilepsy, not cancer. We can deal with this. So he started the drug and
- I remember counting the days of seizure freedom. On the tenth day, I took a picture of him finger painting and I gave it to his nurse at the pediatric subspecialties clinic, and the caption read “10 days seizure free”. She smiled and said “Oh I pray it continues”, and the first thing I thought was, “Huh, why wouldn’t it?” He is taking his medicine, he is fine. Just 2 days later, everything broke loose. The seizures were back and worse than ever. The nurse knew something I did not. That is when the sleepless nights of endless research began.
- 3 Anger - strong feeling of displeasure, rage. Rage and resentment replace denial. Again, another natural feeling because life is not going according to your plans and your dreams are crushed. You may direct anger toward God, your partner, and/or yourself. Anger is probably the most detrimental of all of the feelings. It can manifest itself as rage, which can cause serious mental, emotional or even physical harm. This is one stage that you may need to seek professional help for, and you should not feel embarrassed by it. I don’t think I ever felt the anger in a physical violent way, but more in an emotional way. I was fed up with the side effects, the unknowns. Was he drooling because of the intense seizures and his brain is now damaged? Or is it the medications? Why does my doctor seem clueless on what to do next? I wasn’t going to sit there anymore and listen to these doctors actually say out loud “Maybe we should start over. Take him off all drugs, and start over, what do you think?”
- 4 Guilt and bargaining - The guilt, a feeling of responsibility. What did I do to cause this disability? How did I fail? I should have been able to prevent this. I didn’t drink, I ate right, I rested, and I didn’t smoke. Irrational thinking. From the guilt you may try to bargain with a higher power: I’ll do anything to take away the disability of my child. I’m certain this happened because of the endless McDonald’s I ate during my pregnancy with my son. For his older brother and his attention-deficit/hyperactivity disorder, it was the Doctor Peppers and the brown sugar cinnamon pop tarts. And for my baby daughter and her mood swings it had to be my addiction to Tootsie Rolls. All irrational thoughts, but like anything I live and learn. I can’t dwell on it. But this guilt is one thing I think will never go away. For me I always feel guilty about something, “I should have been more patient today”,

“I should never have said that to my husband” or, “I shouldn’t have eaten that last slice of pizza”. But now I don’t dwell on it, instead I ask how I can make it better tomorrow.

- 5 Depression (or sorrow) - Hopelessness; a lowering of functional activity. Sorrow and sadness are experienced throughout the process of grieving. But during this state you may realize the magnitude of your loss. You are sad that your child has this disability. You are sad that the dreams you had for your child may not be possible. This may be another stage that you require professional help. Again, do not be ashamed. Depression can be debilitating but it can be managed with the help of a professional. Oh the tears I’ve shed. There were times I thought I was perfectly fine, putting on my happy Super Mom face and the moment I would open my mouth to say something I would start crying, over the simplest things. I was falling apart inside, how long could I carry on this façade? It means a mask, like the façade of a building) It wasn’t right, it wasn’t normal, more importantly it wasn’t healthy. Not for me, not for my family, not for my son. His seizures were killing me inside. However, as I look back now, I ask who was really in pain here? Was it my son or was it me? Of course it wasn’t the life I wanted for him! Of course not! But it wasn’t the life I wanted for me either. I wanted to run and I wanted to run far! I couldn’t deal with the sleepless nights of running back and forth to be with him during another seizure, I didn’t want to deal with the painstaking gram counting for the ketogenic diet, the oil stains on the clothes, the force feeding of the meds, the speech therapy, the occupational therapy, the doctor visits, the blood draws, the medical bills and the expensive specialty equipment. This certainly wasn’t the life that I had dreamed of.
- 6 Loneliness - a feeling of desolation, bleakness, isolation. You may cut yourself off from others at this point because you feel that no one knows how you are feeling. No one knows the magnitude of your sadness, your loss. But you are not alone. You can find others that are feeling what you are. There are so many outlets for you to express yourself, share your feelings and receive comfort and compassion. Once you don’t feel alone any longer you can begin to move on. Epilepsy consumed me! Sucked the life right out of me. I couldn’t talk about anything else,

and friends were now not calling anymore. There was a long period of time when I didn’t laugh. I was one to find the humor in everything, and now there was sadness, loneliness and a sense of despair: All part of the grieving process.

Then out of the darkness comes light:

- 7 Acceptance - engaging in life again - To endure, to regard as normal, to recognize as true. This is now your own personal “normal.” You accept that you need to live again. You begin to be functional again. Your mind becomes calmer and more organized. You begin to think of your new life in a more rational way. You begin to dream new dreams. Barbara Sher, a bestselling author says “As soon as you start to pursue a dream, your life wakes up and everything has meaning.” I will be honest that at that moment of acceptance, I was at the lowest of lows. I remember that I was able to sneak away for a nap, and instead I wept like, I had during most of my “naptimes”. I wept quietly into my pillow, quietly but productively. These were good cries, much needed cries, exhausting cries. I guess I would cry myself to sleep, but this one was different. The phone rang, and it was from a woman that I can now call my very good friend, a mentor through all of this. She was a neighbor to a cousin of mine, whose daughter has epilepsy. Her voice was very comforting, very calming, I don’t remember much of the conversation but I remember her saying, “It’s not going to be easy, but I am standing here watching out my window as my daughter is riding her bike”. I specifically remember that part, “she is riding her bike”, and it was a sign of hope! Hope? There is hope!! Yes! Yes!! I can’t describe it but as I picture her riding her bike there was never any idea of me even thinking about tomorrow let alone the future when my son would be old enough to ride a bike. I was so caught up in the grueling routine of just getting through the day, not daring enough to try new things, and life was passing us by. It stood still, it was ugly and it was dark! It was at that very moment that decided that I wasn’t going to do this anymore. We had to move on. I had three children, and an amazing husband who was dealing with this in his own way but was so supportive of me and so strong. It took nearly 5 mo before I could finally accept and see that this was the hand I was dealt. I was moving forward, dreaming new dreams!

My dreams started out as what many would think to be meaningless or insignificant, but to dream that one

day my son could hold his head up on his own seemed the impossible. After much research on anti-epileptic drugs, we weaned one and added another. Soon muscle tone increased and he was able to hold his head up. Soon, my dreams were to be a family again. We took a big step 6 mo into the ketogenic diet and decided to all go out to dinner as a family, again another day I will never forget. We only went to the mall and ate in the food court, but it was the best dinner we ever had. My older son had his cheeseburger, my husband and I had Subway, the baby ate her baby food, and my son ate two pieces of hot dog, apples cut up like French fries and his cream was in a McDonald's cup mixed with Diet Black Cherry pop. He ate it all up without a fight, and took his medications without a fight. It was though it was all in our heads, as though we were making mountains out of molehills. Of course it is serious but I think it was in our minds that it's bad...it's sooooooo bad. Of course we would do everything to keep him safe and keep him as healthy as possible but we had to let him live, let him explore new things and let him be a kid. We owed it to him and we owed it to our other kids as well.

We could not put all of our lives on hold. Soon I quickly learned to allow my house, my life, to be an open book. I finally accepted help from others. Many wanted to help and didn't know how. I soon learned to accept their kindness and put aside my pride, and realized it was best for everyone including myself if I was going to survive this. People genuinely want to help.

We went through these stages of grief, my husband and I. And we were probably never on the same step at the same time. We wanted to do it all ourselves. We didn't want to accept the diagnosis. We wondered why, why us, why our son? What did we do? What didn't we do? What could we do to make it go away? We don't need help and we don't want to talk about it - it will make it all the more real.

Then we accepted it. Emmett was going to suffer from seizures and it is what it is. We grieved the loss of our dreams but we learned that we could pursue other dreams. This is how you make your life normal.

Everyone's perception of normal is different. Maybe for you it was the two kids, two cars, and white picket fence life. Dinner every night on the table at 6 pm - meat, potatoes, veggies on real plates. Sunday mass, brunch and a touch football game with your family and no fighting. But life, real normal life, gets in the way. I bet if you pick any house on your block, or the one family from school everyone wants to be most like, or the envy of your neighborhood with the perfect garden and the white picket fence, their life is as chaotic

as yours. The part of their picket fence facing the house, its paint is chipping, the pickets are warping and maybe in some places there is moldy, rotting wood. What you see is not necessarily what you get when it comes to normal. Yes there are two cars in the driveway, but one is 10-year-old and in desperate need of a paint job and new tires. Dinner is on the table but it came out of a box and a can and was cooked in the microwave and those potatoes - they are flakes! And you did see them at church on Sunday morning, but you didn't see the battle to get the kids up, clean and dressed on time. That family brunch after mass, yes everybody was there but not at the same time because of the crazy shift work schedules. That describes normal in my family! And that's the way we like it!

You can get there too!! I challenge you to get involved in something outside your comfort zone. Don't let today's disappointments cast a shadow on tomorrow's dreams. We got involved in the 2007 Epilepsy Foundation's Walk, we gathered a team of at least 100 and called it 2 E'S 2M'S 2T'S - 2 cute, we rented a bus and traveled to the lakefront, we collected \$11,000 and made quite the impression. This is when we decided to create the American Epilepsy Outreach Foundation - quite the dream! We felt we could make a difference. If we could just make it easier for others that have fought their way through a devastating diagnosis, we would feel that there was a purpose behind it all. My nephew created an arm of the Foundation where he purchases seizure-safe toys for kids in hospitals, elfchicago.org. One of the nurses asked him once wouldn't it be great if his cousin had never had the seizures and he said yeah definitely but if he didn't have the seizures we never would have created any of these things to help people with epilepsy and seizures.

My son has taught me so much in life. He has taught many of us. Before epilepsy came into our lives, we were always on the go, keeping up with the Jones'. Looking back, my worries then were more concerns than problems. We had no idea of the challenges so many families faced. I was so ignorant of it all. Having a child with special needs changes a person, and for me as I'm sure for many it made me a better person, a more patient person, a more compassionate person, a more curious person and a more forgiving person. It has taught to me enjoy life, to see life in its fullest, to appreciate the little things and to not to sweat the small stuff. I have come to realize that my mom was right, what doesn't kill us will make us stronger and that God only gives you as much as you can handle. If I had a dollar every time, I heard that one... But it's

true...I truly feel blessed. While preparing this paper, I thought, "How could anyone ever see a light at the end of the tunnel?" But I have also realized it has been just another piece of the healing process bringing me to acceptance so that I can continue to create and aspire to new dreams for myself, my son and my family. I am happy with the person I have become. Never in a million years would I have thought I would be in this position today, but can honestly say I can't think of any other place I would rather be right now. My father-in-law would always say, "A star shines brightest in the dark".

I challenge you to confront your grief. I challenge you to accept your fate. I challenge you to take on your future. I challenge you to see the beauty of every day. I challenge you to dream new dreams. I challenge you to dream new dreams.

Reference

- [1] Kübler-Ross E, Kessler D. On grief and grieving: finding the meaning of grief through the five stages of loss. 1st ed. New York: Scribner; 2005.