

What If?

Written by Gayle Nobel

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Wow, it's Friday already? How did that happen? My guest blogger this week is Pam Blackburn. Three of Pam's five children have special needs. This is from her blog, Trying2Express.

What if...?

I hear my friends either joyfully or sadly announce, "I'm officially an empty-nester." They question, "What will I do now? How will I handle it? Should I get a new hobby, begin travelling, go back to school?" Perhaps they start taking those cooking or art classes they've always dreamed of or begin a new fitness workout, take up dancing or meditation. Some turn one of the extra rooms in their home into the room they've always envisioned with white furniture and glass items that they always worried before would get broken. I see my friends free to go away for a weekend (or a month) without worrying about who will watch the children or whether they'll be alright on their own. They begin buying "toys" such as boats and motorcycles and recreational vehicles or pick up old hobbies put aside long ago while raising a family. Some struggle a little or have a desire to nurture or help others, and I see them get new puppies to care for, or begin volunteering at a local shelter, food bank or hospital. Some have changed careers or retired and are now pursuing various other dreams.

The Empty Nest; I'd like to try it on for a couple days. I can't quite picture how it would fit or feel. I don't see that vision in my future. I shamefully fantasize about it, picture various ways I might imitate or pretend it exists for short periods of time. I even try to feel what it's like for those who struggle with the empty nest, not quite able to step into their new role, and I feel for them. I dream about care-free vacations, sleeping late on the weekend, leaving my house without a plan or time I have to be home.

I've seen my friends who have children born with special needs or who have acquired physical, intellectual, and emotional disabilities or health challenges go through various stages. I don't know if there are actually stages someone has clearly defined, but as I've seen myself and my friends go through life I've noticed these stages evolve. I would identify them as birth (or time of acquired disability or challenge), school and transition years, adulthood, and then aging of parent and child. Each of these stages carries its own unique set of rewards and challenges as we work through the doctor visits, IEP's, therapies, parenting our other children, socializing, friendships, family time, finances, and so much more. Every person has their own way of dealing with these challenges and finding a way to work through them until they finally come to acceptance. We deal with a full range of emotions from joy and excitement to fear, grief, anger, disbelief, happiness, overwhelm, exhaustion, love and appreciation. Some find themselves questioning why me or why my child? Most of us learn we have gifts we never knew existed

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such as incredible strength, the ability to advocate, patience and more love than we ever thought possible.

As I find myself in this new stage of the aging parent actively parenting adult children with multiple challenges I know I will find the acceptance I found in each of the other stages and that brings me comfort. The burning question at this point though is a little different, not one that can be answered simply, yet one we are all asking when we dare. What happens when we are no longer able to care for our child who is unable to fully care for themselves? We have taught them as much independence as we can and we continue to guide them to reach their highest potential. We know if we don't have a plan someone will decide this for us, or rather for our children.

The question turns into more questions as we watch others face the challenges of caring for their children while trying to care for themselves as well. What if that time comes suddenly and there is no plan? What if we have not yet been able to set up a trust (or don't financially have the means to do so), haven't got a will in place, a plan laid out, or answered that ultimate question of where they will live, with whom and how much time do we have to figure all of this out? Will someone care for, love and advocate for your child's best interest? Will they fully accept, honor and value the person they are? Will they see the abilities rather than the disabilities, the possibilities and potential rather than the unachievable? What if...?

I moved across the country over ten years ago and saw one of my good friends the night before we left. She has a son who has Down syndrome and is a fun-loving, active young man who has a curiosity and love for life but certainly needed loving guidance in all areas. We joked about growing old and keeping up and she laughed and said to me, "I just have to live forever." Unfortunately that did not happen, but she had built a support system and as soon as she was diagnosed she invited those special people to be in her life for the time she had remaining on earth. Together they made plans for her son's future and that plan is being supported. I admire her courage, strength and openness to invite others in to her life, and be with her during her final days to support her and her husband and son. She remains one of my role models and reminds me that we have to be open, and build a support system of people we trust. What if you have unanswered questions but have a support system, will all work out as it should? What if being surrounded by people you trust is the answer to all your questions? What if...?