

## BECOMING DIFFERENT

Many of us have wakened one day realizing that we have become different. Becoming different can come from having an injury, illness, disease, getting older or a life choice requiring change. This story hopefully will help individuals gain a better understanding of what it has been like for me and the changes that occurred when I was going blind due to having Retinitis Pigmentosa. My story will cover my experience. Others may have experienced something different with their life challenge or change. Developing a better understanding of who lives in our communities should be considered a great opportunity not something to fear.

Here is a brief explanation of my situation. I was told at age 23 that I had 24 months to see. Now 33 years later, I am still not totally blind. My vision is limited to shadows, light, and dark. What a blessing it was to have time to prepare. From another standpoint, the slow progression caused me to make changes every year for 33 years. I do not want you to think that I am not thankful for the slow progression. I definitely am, but making and adapting every month and year took a toll on me as my vision changed. Imagine what you see today suddenly changing every time you went to do a task or activity. Would you have the strength to do this?

Throughout the entire progression, I had to call upon God and my faith. My family, friends, and my faith helped me or I would never have made it this far. After I was diagnosed, I chose to tell myself that the doctor was wrong and this would not happen to me. I was raised in a strong Christian family. I was sure that God was going to heal me. My choice was to not tell anyone except my immediate family and a few close friends. This phase or time period is what I would call a period of denial. You see I did not want to be different than anyone else.

Maybe you are asking why would I keep this in and not tell anyone. My beautiful younger sister was born mentally challenged. As she grew up, I saw how children and adults treated her. Even though she was a very loving young child, individuals would tend to avoid her. For seeing this, I knew that I would have to face this as well. For fourteen years, I never told my work, other employees, or friends that I was going blind. You see I wanted to give God a chance to heal me. I wanted to move up with my company, take all the educational courses I could, and have time to prepare if the healing did not come. The time was good for me in many ways but holding this in worked on my confidence and strength. I started to withdraw as I approached the time that I would have to tell others that I was going blind.

Then the time came, I could no longer hide the fact that I was going blind. I then entered the second phase of fighting this disease. This time or phase was extremely rough on me. I was ashamed in many ways because I felt that my faith was not strong enough. I became very depressed inside but would still not admit how I was feeling to others. I just did not want others to treat me different. I was remembering what my sister had and still has to face every day of her life. Neither she nor I ever wanted to be a person that someone might avoid.

Many of my feelings I know were created in my mind because I became focused on the actions of others. I was watching how my friends and family treated me after telling them about my disease. Some of them ran to help or encourage me. Others seem to start distancing themselves from me. It is human nature to avoid things that might make us feel a little uncomfortable. The major difference was that everyone thought I would not be able to continue working or do the things that I loved. The conversations with me changed to questions on what I was going to do when I go totally blind. The company that I loved changed how they looked at me for future promotions. The focus was on that I could keep my job, as long as I could do the essential duties of the position.

The focus of how I was viewed by others started changing how I saw myself. I became very hesitant and unsure of my abilities. This was different for me; I had always had strong motivation to succeed and would never give up before. The questions came up like, "So now how long are you going to be able to work? What do you see?" I had to start asking for more assistance from others by grabbing their elbow or asking them to help me read something. Imagine how you would feel if you needed help but were afraid if you ask, it could cause you to lose your job. I do not think that this ever crossed the minds of those that worked with me. I felt the pressure to find ways to continue on my own. I would run and pray for hours. The good Lord helped me find a way to continue even when I was unsure of what to do. Even though this was extremely hard, thinking and learning new ways to continue helped me overcome the thought of giving up. I started doing things that I use do. I was so encouraged that I could still do them, just a different way.

Then the major blow occurred. On my way to work a truck ran a stop sign and totaled my car. I knew it was time to stop driving. This was the time to make the transition. Truthfully I should have stopped driving before this. This was the hardest thing I ever had to face. This was the loss of my independence to come and go as I wanted. Remember, if you have a family member who has to give up driving, it is extremely difficult. The question you have to ask yourself is, could you give it up?

It took me a while to accept not driving. My fellow employees knew how hard this was for me to overcome. They got together and saw that I had a ride to work every day. Imagine for 14 years of never missing a day of work due to not having a ride. This touched my heart. I knew that I could overcome this as well. I asked the Lord to give me the strength to continue working, running, and give me a creative mind to find a way. He did and continues to help me find new ways even today.

Now I am in the third and final phase of fighting this eye disease. I openly share that I am vision impaired. The Lord healed my mind, heart, and spirit to find creative ways to continue. This is truly a blessing. I was praying for physical healing for my vision but he gave me something even better. I see things differently than I ever did. He restored my confidence, strength, and motivation never to give up.

I would like to share what it is like for me every day and some of the major hurdles that I have to overcome. The only way that you will be able to understand my world is for you to think about waking up one day not being able to see. All of you know what it is like to get up in the middle of the night with no lights and half awake. How many things have you ran into? Did you get lost for a moment and not know where you were? This is my daily world to face.

Every day I have to see that I have a ride, make sure someone helps me match my clothes, go for a run hoping that there are not parked cars, trash cans, or construction equipment along my course, and then face the tasks at work that were unexpected. If you like constant change and challenges, then you would be perfect in the non seeing world. Then the person you had planned to ride home with has to leave early. Now how do I get home? Maybe this doesn't seem that bad to you. Well, then how do you get to the board meeting that you serve on that night? Now you need a ride to and from this board meeting. How do you get your groceries, buy your clothes, do home repairs, and what do you do with all the time you are home alone and cannot go anywhere? Does this sound easy or desirable?

Please understand I am not bitter with all the daily tasks that I must do every day. I welcome the opportunity to continue and am thankful to God, my family, and friends for all their assistance. I could not do this daily without all of you.

As I have mentioned before, finding transportation to and from work, taking care of personal needs, and attending state and local board meetings can be challenging at times. I want to make sure that any individual that would give me a ride feels no pressure from me to do this. I am aware that some people would be hesitant to tell me, no. Most individuals take for granted the ability to just jump in a car and go. Asking for a ride is what I must do to continue to live my life and be part of the community and state where I live.

I try to ask an individual enough questions before riding with them the first time. I let them know that I will need to grab their elbow when I walk around. Are they going to be okay if their friends or family members see them helping me? I ask, "Is this going to be embarrassing for you?"

Sometimes no matter how careful I am or the steps I take the individuals helping are judged by others. Individuals that may or may not know that I am blind, tend to talk about the person that helps me. Unfortunately, gossip and rumors are part of our world today. Comments are made like, "Are they a couple?" I just wish our world would see the kindness that the man or woman helping me is demonstrating. I have had individuals come to me and say I will be unable to help or give you a ride any more. The reasons are that they do not want others to talk about them. Truthfully, I respect the individuals that just come tell me. I do not want any person that helps me being hurt because of what others say and think. Please just tell me if helping me is embarrassing you or other co-workers or friends are talking. Its okay and I understand. Just remember, I am thankful for what you have done for me. Having others being judged because of helping me bothers me a lot. I am just trying to survive in a seeing world.

Our world has become a place of a lot of free advice. I welcome ideas since I am focused on continuing to live independently. These comments are made frequently. The first is, why not take the bus, taxi, or other transportation other than relying on friends and family for rides? That is a great question. Transportation is one of the major hurdles for individuals with disabilities. The cost can be overwhelming or may not exist. For example, there is no transportation system that could take me directly to work in St. Louis other than a taxi or a friend from St. Charles. We need everyone to support a better public transportation system.

Another frequent question is why do you not get a Seeing Eye dog? Wouldn't this give you more freedom? This is another great question. Some vision impaired individuals want and use a dog very effectively. My choice is to continue like I have for years. I like the opportunity to have individuals come up to me without knowing I am blind. This gives me an opportunity to talk with the person and they become comfortable with me before I tell them I'm blind. This is to help others realize that we are not different, just do things a different way. I love it when someone stops me when I am running and asks, "Do you know how to get here?" Believe it or not, I can tell them. They drive away not knowing they took directions from a blind man. Now, that makes me smile. Is this not demonstrating independence?

Many have asked why I haven't gone out on disability. The Social Security Disability programs are greatly needed for individuals who can no longer work. Consideration should be given to continue, if not expand these programs for those in need. By me continuing to work, I am doing my part to contribute, so these benefits will be available in the future. For me, I need to be working and enjoy the relationships with my co-workers on a daily basis. I love the chance to serve on the state and local boards that assist and help people with disabilities. I am the happiest when I am busy. I do not want to stay home. I plan to be working for a company, organization, or volunteering for the rest of my life.

You see I have become different. Your thoughts probably in the beginning were those of feeling sorry for me. I am fine today. I have overcome one of the largest life challenges. I have gone blind but I am surviving and succeeding in a seeing world! I do not have any time to think about giving up. I have to encourage, motivate, and help others find a way as well. You see the third phase of fighting this disease is, accepting I am going blind but finding a way to live a normal life.

I lost my job to company reorganization. This hurt but I am overcoming this as well. I cannot wait to go to work for another company or organization. This company will choose me knowing that I am vision impaired. They will see my talent, abilities, and potential by looking at everything that the good Lord has allowed me to accomplish. I want to serve as a role model for individuals with disabilities. I would love for companies and organizations to actively seek us out for employment. We have had to overcome major challenges in our personal lives. Who better to employ in a constantly changing environment than the ones that are used to making changes? We adjust and find a way.

I hope you have been encouraged and realize that you can overcome your life challenges as well. I have a lot of work to do in making a difference with my life. Will you join me? All of my fears in the early years of being different have faded now. I am definitely different. I am more determined, stronger, focused, and happy. What more could anyone want? I do not want to go back. I like who I have become! Who do you want to become? It's time for us all to live our dreams.

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