

DAD'S PERSPECTIVE – TWELVE GIFTS

This page is for parents of all children. Our family has been on a difficult journey and I hope that some of what I am sharing will give strength to others in their lives. These gifts are lessons that I learned when our family was touched by cancer and in many cases I have shared a “real life cancer story”. I hope you never have to experience what we did, but if you do, find peace in sharing your gifts with others.

The 1st gift: Truth.

I think I am like any ordinary dad that will go to battle for my kids and do as much as possible to shield them from harm. What do I say when at the bedside of my son that is diagnosed with a rare cancer in his skull and he asks: “Am I going to die?” I could only hold back the pain and the sadness, be strong, reassure and cry. That is a tough question to answer but especially when your child is close to heaven: “No one really knows when people die. That is in the hands of God.”

Real Life Cancer Story.

When Nick was going in for radiation treatment for 28 days, on the first day, it was easy to be re-assuring and tell him that everything will be okay. When he was a week into it, and he knew he would be behind six inches of lead walls all alone, with his head strapped to a table, with a gigantic machine that moved around him like a robot, nauseous from the chemotherapy and radiation, smelling his face getting burned, what could I say to comfort him? This is a moment in your child's life when things are really bad and there is nothing you can do to soften it. This is a moment of truth. As parents, while it is important to protect our children, it is equally important to tell them exactly what is happening in their world. You can't hide the things that affect your children. You may think it is a good idea because you are trying to protect them, but when your child finally figures out the truth their hurt will be worse. I think parents have an obligation to tell their children the whole truth about little things and big things and not keep any secrets. You may discover that your children are stronger than you think. On our journey, Nick walked farther than all of us!

“In the most difficult moment, you can't protect your children or take away the pain. All you can do is to hold your child's hand and walk along side them.”

The 2nd gift: Time.

I think our family keeps very busy doing all kinds of things: family, school, sports, friends, hobbies, vacations, etc. As a result, some times we put off doing things for a time when “life is easier” and not as hectic.

Real Life Cancer Story.

When Nick was diagnosed with retinoblastoma in 1996, the time period from discovery of the tumor that engulfed his left eye, to removal of his eye was 5 days. When Nick was diagnosed with rhabdomyosarcoma, the first thing we did was take Nick, Nick's brother Joey, Nick's cousin Ryan and Nick's best friend Joe P. to Disneyland for 4 days. We had a great time on our trip but the feeling I had was that we were running out of time. No one likes to think about or dwell on death but this was a time when I thought we might lose our son forever.

"Look into the hourglass and hold on to one of the grains of sand and treat it like it was the last one. Take a small moment to do something that you have put off for a long time. Time is precious. Make the time for what is important to you in your life."

The 3rd gift: Knowledge.

Communicating with our children is hard. I am not sure there are any set rules about how to communicate with your children because every situation is different. I think that the foundation for healthy communication is to tell them everything that you know and in a form that they will understand it.

Real Life Cancer Story.

When Nick got cancer a second time, we found out everything we possibly could about rhabdomyosarcoma. We looked into the treatment protocols and we researched every nook and cranny that was possible. We sat down with the doctors and asked them all the questions imaginable. We had no idea what the storm would really be like.

We didn't expect 70 days in the hospital, 106 doctors office visits with long days and long nights. I think that we were able to get through it because we would talk about every little thing that was happening. There were moments when Nick was asleep and he was going to have blood drawn or his temperature checked and we would wake him to tell him what was going on.

"The road one takes to fight cancer is like the rest of our lives, one never knows what can happen. The best thing you can do is to communicate what you understand is happening along the road and make sure your children know that the road may change. The more our children know about their lives, the easier they can prepare for the challenges they face regardless of how big or how small.

The 4th gift: Advocacy.

As parents, we are advocates for our children whether old or young, whether in sickness or in health. In the world we live in today, I wouldn't send my kids to the

park or to a birthday party unless I had all the details. When your kid has cancer, you don't hand your child over to the medical community and "trust" in the system to care for your child, and expect to "hear back" when your child is healthy and cured!

Real Life Cancer Story.

In March 2003 we discovered Nick's second cancer. Tammy had noticed that Nick's prosthetic eye was protruding from his face more so than normal. We asked our physicians for an MRI and had a difficult time getting it "scheduled". In addition, our insurance company did not "authorize" such a preventive procedure. On March 23, we had the MRI done without the blessings of the doctors and without the blessings of the insurance company. On the evening of March 23 they discovered the large mass in Nick's head: Rhabdomyosarcoma. The tumor was within a few millimeters of his brain and growing.

"Our situation is no different from any situation a parent might encounter on an ordinary day. We know our kids better than anyone and so whether it is directing treatment for cancer, making sure they get the best education or have the right friends, I think parents should always act as advocates for our children and we shouldn't be shy about it, especially when it comes to your child's health!

The 5th gift: History.

If you entered a drawing and were one of 250 people out of sixty million that were chosen to go on a once-in-a-lifetime travel experience, would you take your camera? I would. The travel experience I just described is the journey that we embarked upon with Nick. In the very beginning, the last thing I thought about doing was taking pictures or shooting a video because the journey started off bad and I didn't think the odds of getting through it were great. Do you really feel like taking pictures of your child, especially if there is a chance that they might die?

Real Life Cancer Story

When Nick was 2 1/2 years old and had his eye removed because of his first cancer (retinoblastoma), we have a very special moment captured on video. When he returned from the hospital following surgery, his face was so swollen that he could not see at all – he was blind. We have a video of Nick standing at a kiddy table, holding on to a small cup of Jell-O and feeling his way around the table to find the chair to sit on. He sits down and he slowly brings his spoon up to his face to eat his Jell-O like it was the way things were going to be. It is one of the saddest moments in our lives but it captures the strength of our little boy.

"If you happen to be close to someone that is going on a special journey, a nice gift to bring along to visit might be a disposable camera. In the middle of the most difficult moments of our lives there is always a moment worthy of a memory!"

The 6th gift: Faith.

Faith is an incredible thing. It is hard to believe in something that you cannot see. We are Catholic and we believe in God. The truth however, is that going to church is hard and living a faith-filled life is an ongoing struggle and a lifelong challenge. When something happens in your life that you have no control over, you turn into yourself and ask for help. When Nick got cancer a second time there was a lot of praying.

Real Life Cancer Story

On December 28th Nick had a horrible nose bleed while he was in the hospital. His nose had been bleeding for over two hours, he was vomiting blood, and the doctors were doing everything possible to stop the bleeding. There was complete chaos at Nick's bedside with IV fluids, medications, basins, flashlights, blood, surgical tools, and a lot of desperation in a critical situation. In the middle of this "hurricane" there was a moment when Nick held his hands together, with his eyes shut and was silently praying. It was as if everything in the room didn't matter and there was warmth and it was calm. This was a moment of faith and answered prayers.

"Our life experience has been very difficult but we very much believe that it would not have been manageable without our faith. We should take a moment in our lives to give thanks and know that our faith will always bring us light."

The 7th gift: Family.

When your little boy has cancer, this is a good time to "phone home". The one thing you can be sure of is that your family will always be your family for the rest of your life. We have an incredible family that has supported us throughout this journey in every possible way. We had many long days and many long nights and in every circumstance, when everyone else went home, there was always a family member nearby.

Real Life Cancer Story

We spent a lot of time in the oncology ward of a pediatric hospital. This is a place where all the kids are very sick. On most occasions you share a room with someone else. Nick had one roommate, a teenager who was getting chemotherapy, always by himself, who never got any visitors. Nick had another roommate that was about 6 years old and had his mom with him for as long as she could be there because she had a job during the day – there were no other visitors. I watched this little kid walk up and down the halls pulling his IV on wheels along with him. One day on the way out of the room his IV fell over, and I helped him pick it up and he was on his way again.

“When you are on a difficult journey, it is a gift to have your family with you. The most important thing is not to wait until you need your family to appreciate them.”

The 8th gift: Patience.

I think patience is definitely a virtue. I also think that kids definitely test your patience. I laugh at some of the “how to” books on parenting. The first time you see Johnny write on the wall with a crayon, encourage him to use a piece of paper. The second time you see Johnny writing on a wall, encourage him to do some other activity. The books never talk about the tenth time! When Nick got cancer, we were under a lot of stress and patience was hard to manage by the book.

Real Life Cancer Story

I remember driving to the hospital one morning to visit Nick and Tammy after they had been there for 5 days. I was driving down a busy street when a car cut in front of me. I am not big on road rage but I remember thinking: “My son is fighting for his life and this person is probably late for work and driving like a jerk!” I really wanted to pull the person over and give them more than a piece of my mind!

I can’t think of another time in our lives when things could be more stressful. And yet most of the time, the things that stress you out the most may be little things that involve other people, and guess what? They don’t know that your kid has cancer! We are all required to be patient in our everyday life and just because something bad happens to you, it shouldn’t mean that you are entitled to lose your patience. It doesn’t mean that you shouldn’t feel that way, but losing your temper or hurting those around you will not make anything better.

The 9th gift: Cleaning

I can’t think of anything that I like less than cleaning house. Unfortunately, everyone has to do it at one time or another and if you are part of a family, everyone has to do their share. When someone in the family has cancer and is treated with chemotherapy and/or radiation treatment, their immune system is compromised and they can very easily get sick.

Real Life Cancer Story

Nick had a central line in his chest that was probably touched by human hands at least 1,000 times. He had the line in his chest for 9 months and it never got infected. Our family also managed to not get sick during the entire time that Nick was treated.

During Nick's treatment, whenever he was admitted, before Nick touched anything, we would put on rubber gloves and wipe everything down using antibacterial wipes. I mean everything: light switches, TV controls, chairs, bed handles, toilets, counter tops, doors, and anything that the hands might touch. If you think the hospital is clean, think again. There are super germs living in the hospital that are waiting to get people sick. At home, we would also wipe everything down after normal house cleaning. Hand washing became a matter of survival.

I think people get sick too often because hand washing and cleaning are not taken as seriously as they should. But when your kid has cancer and has less than 100 white cells per micro liter and normal is over 4,500, one infection and he is in the hospital. This makes cleaning and germ control very important. If this awareness of infection control existed in every household, we would all be healthier!

The 10th gift: Technology.

We are blessed to live in the 21st century and in a great age of technology. I read in a book once that if you are stuck in the middle of the ocean, you should pray to God and in case there is a chance that doesn't work, start rowing for shore. I would add to that, take your cell phone and your computer!

This is not a time when you can afford to be without technology for it has become the medium of the world. I use technology to update the web site, for hours of invaluable research, for e-mail and the list goes on and on. If you haven't stepped into the 21st century, now is the time to do it because one day you will really need it!

The 11th gift: Darkness.

I think that there are always moments in our lives that are dark moments and we do as much as possible to set them aside. We don't forget about them, we just put them in a special place. I can remember being at the bedside of both of my parents, holding their hand when they died. They each died at the age of 57. I also remember numerous days and nights worrying about Nick and what our lives would be like without Nick and why this was happening to us. This was a very dark time in our lives.

Real Life Cancer Story

When your kid has cancer, people treat you differently. I remember having conversations with people where I would tell them about Nick and then ask them about how they were doing and they would just say: "great". After all, how could they possibly tell me about their kid staying home from school with a cold? I remember standing next to Nick's 4th grade teacher and a little girl coming up to

her to show her a cut on her finger that was bleeding. For this little girl, a painful bleeding finger was a very dark place. And at that moment that is the only thing she knew.

For me, the gift of darkness is about perspective. You have to believe that there is some light in the darkness and that in the middle of all the pain and heartache, things could be worse. There are children and families whose journeys have been ten times as hard as ours. There are children and families that have never seen the inside of a hospital. In the midst of all the suffering, you have to find the light if you want to survive.

The 12th gift: Blessings.

I don't think that there are enough words to describe how thankful we are for all that we have been blessed with. When I was writing about "darkness" and finding the light, the light came in the form of many blessings.

Real Life Cancer Story

I think it was a blessing that we found both of Nick's cancers at the time that we did. I also think that it was a blessing that Tammy is a nurse and was able to care for a Nick with the love and devotion of a mother and the care and dedication of a nurse. I think it was a blessing to have as great as a family embracing us during these difficult time. It was blessing to have friends and a community putting their arms around us and not letting go. It was a blessing to live 20 minutes away from one of the best facilities to treat this kind of cancer in the country. Finally, it is a blessing to have two sons, Nick and Joe, that have endured this battle together, as brothers and as friends, like two warriors with big shields, sharp swords and hearts of gold.