

Subj: Two Eulogies
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To Dani Harder, A Hero -- My Apology
by Judith Snow
on the occasion of Dani's funeral
Oct. 16, 2002

Last Friday I got a phone call from a friend to tell me that Dani Harder had died of pneumonia. I was stunned. As my emotions tumbled through me I began to wonder why I was having such a strong reaction. I was not close to Dani. I had been with her perhaps five times in our lives. Yet I felt as if I had been personally stricken. I felt for Dani, I felt for her mother Karen who would be devastated, I felt for her friends and family -- but I was and am feeling much more than this empathy.

Dani was a young woman, not yet thirty. I knew her as a person who used an augmentative communication device -- one of those boxes with a funny computer voice. I never heard Dani's box say anything that made any sense, so for me Dani was someone with a silent or silenced voice. I figured that either she had very little to say, or she hadn't yet found or been given the way to articulate her own words. I blamed the box.

I knew Dani as someone who was represented by someone else. Her mother, Karen, would speak and write frequently, glowingly and intensely about Dani's dreams for her own home, her own assistants, an education, her own life. Dani's story and opinions were shared with me by a variety of people from a variety of groups and services aiming to help people who use augmentative communication. Once or twice I heard her personal assistants express Dani's preferences on her behalf. I understand this "speaking for" or "advocating" conversation very well and I participate in it fully and often. I never spoke, woman to woman, with Dani, yet I felt I had a good

idea of who she was.

Karen told me often that I had made a big difference in Dani's life. She and Dani had come to my kitchen once and I had encouraged them to not wait to get into university, but to find a way to get her into a course on the spot -- that day if possible! Dani had gone on to take a course at Ryerson. Dani also showed up at some events I was running -- workshops on rights, on support circles and on community participation. She didn't show up pretty

often as well -- held back by Wheeltrans inflexibility or hospital indifference.

I thought I knew Dani. I knew that Dani was trapped in a children's chronic care facility. For years the Harder family and their support circles had massaged and pummeled at our intransigent provincial health system. The simple idea that if enough money were put in Dani's hands she could be a fully contributing citizen seemed never to penetrate the minds and policies of politicians and bureaucrats. Never mind that the required sum of money would be less than what is spent mindlessly on the chronic care prison. I participated at arms length in Dani's struggle. I never visited Dani. Since I left chronic care myself in 1979 I find it difficult to go into those places.

Last weekend I thought my deep sadness and upset were mainly related to my own fear and frustration. I fear that I will lose my own home and personal assistance to this pigheaded, self-serving government. I fear my own life will be snatched away mid-flight by a relentless virus. I fear that my own voice, articulate as I am, will be lost in the ever so impersonal disability/advocacy conversation that floods our corner of the world. I am continually frustrated by the seemingly endless journey toward building a world where everyone's abilities and gifts will be welcomed for the contributions that they are. I asked again and again, why couldn't we open Dani's cage?

Yet I knew somehow that my sorrow, anger and fear really came from another place. This morning I found that place. And throughout Dani's memorial celebration I became even more aware of the source of my distress.

I'm ashamed that I never let myself know Dani. I never said "Thank you!" for the gift she was to me -- and to so many others.

I imagined that Dani's life was very different from what it truly was. While I imagined that Dani was in a prison, Dani had let herself out of her cage. While I imagined that Dani was struggling for a voice, she was speaking, teaching and reaching out everywhere. While I imagined that Dani's gifts

were buried by hospital and bureaucracy, she was making a big difference in hundreds of people's lives. The appearance of Don Herron, a great Canadian author and celebrity, says it simply. He came to give a heartfelt tribute and a farewell blessing to the young woman who had touched him deeply. Dani lived freely and completely, and the evidence is everywhere.

Dani Harder is a hero. She conquered circumstances where others would be defeated. She created a pathway for her life where none existed. She loved where others would give into fear, hate and self-pity. She didn't wait for a revolution, she didn't just fight for a revolution -- she was a revolution.

I apologize to Dani's spirit, to Dani's friends and family, to myself and to the past. I apologize for missing the opportunity to recognize Dani's great victory until after her death. I apologize for never saying: "Good on you! and Thank you!" to Dani in person. I promise to take notice of the heroes in my life from now on.

Dani, your spirit now brightens all of heaven and the whole world. Thank you for being you.

Remembering Scott Christianson

The circus left town last Wednesday.

Scott Christianson was one of my best teachers. I miss him.

When I say he was my teacher I feel it is important to say what I learned from him. I think this is important because I don't want to forget my lessons. I think this is important because I want to pass his teachings on.

Scott has the largest and most vibrant circle of friends I have ever seen in seven countries. He has moved hundreds of people to committed action. Government officials have set aside entrenched policies in his wake. His name, face and story are known in at least three continents. And he accomplished this in only nineteen years. When I encounter such power I take notice. I want to learn the secret to great success.

Scott was one of those of us who is called "disabled". He was born without eyes. He had to struggle between breathing and swallowing moment by moment.

In all the years I knew him he never topped fifty pounds. His slender body was almost translucent. People say Scott spoke but I never heard him utter a word.

To explain what Scott taught me I need to use an ancient word -- the word epiphany. Epiphany is a word about a magical, timeless moment. It is a word about where two worlds meet. These two worlds are sometimes called "heaven" and "earth".

One world has no time and no place and it is a space of always. It is the world of mystery, of creation, of dream and of Holy Spirit. We really have no words to describe it because it can't be described, but sometimes we call it heaven and we say that God lives there.

The other world is here and now, the world of good and bad, life and death, peace and war, birth and death. We know it very well -- it's our world and we are always asking God to please visit and help out a little.

Epiphany is when a gate opens between earth and heaven and God does indeed

visit, in the form of the Holy Spirit. One wonderful man, William Stringfellow, said once that epiphany is like when the travelling circus comes to town. Men and women can fly through the air and dance in the stars, everything is upside down and magical and beautiful, and miracles happen

before your very eyes right out in the open. When God visits everything ordinary is transformed into more than it could ever be on just a regular day.

Scott Christianson taught me about epiphany. I think it happened this way.

Most people want to be like someone else. Most people want to be taller or shorter, thinner or more beautiful, smarter or richer, or married or married to someone else, or something other than what they are. When someone is disabled, this desire can be even stronger. When I was growing up this desire was very strong in me. It wasn't that I was envious - it was that I wanted to know how to live. I looked around me to see how other people lived. I always tried to be like them and do what they did. Most people try to be like other people and do what other people do.

But you can't be like someone else completely. We all can end up being bad copies of each other and not knowing and being who we really are ourselves.

In the Bible we are told another word that describes being yourself and not trying to be someone else. It is called "obedience". Obedience means you have really listened to what God has designed you to be and you have willingly gone ahead to fulfill your own design.

Scott wasn't designed to see. Instead his vision spread across his community, enlightening people everywhere and it's still spreading. Scott wasn't designed to speak. Instead he communicated love, fun, joy and much, much more -- sometimes his very presence showing up mysteriously kilometres, even countries distant from his body. Scott wasn't designed to walk. Instead he built an intergenerational, interfaith, diverse team of compassionate, intimate, intelligent and vibrant people -- his Mom and Dad, his friends, his school mates, his interveners and many more who were organized by Scott into a marvelous, inspiring international community.

What I learned from Scott is that to be willing to fully be who you are is to invite your life to be an epiphany. You allow the Holy Spirit to dance

with you. You can create the holy within the ordinary. Scott Christianson taught me the value of obedience -- to listening to who God calls me to be and to willingly adopt the plan.

Last Wednesday the circus left town. Scott Christianson died. We are sad because it truly was an awesome circus and we don't want the show to end. But Scott knew that there can always be another circus. He taught me to be my own circus -- to willingly live the life God designed me for. I know he

is in perfect joy and peace now because he lived his life fully. He is calling you and me to be ourselves and to live fully too.

And so I say to my brother, my teacher Scott -- thank you, good-bye and Amen.

Love; Judith

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