

Transformation

Over four weeks have passed and there's been no bleeding. Inflammation is subsiding. Bruising is fading. Suture sites are healing. Everyone said it was just a matter of time. Yet, I never imagined a day would pass when it wasn't all I thought about. Managing the tasks associated with Kenny's medical condition had become my job.

A new year has begun and, miraculously, my days unfold without the anxieties associated with the middle of my child's face.

I am raising three boys. I realized early on that each of my three sons would be different. I respect those differences. Kenny's difference, however, is not specific to personality, intellect, physical stature or strength. Kenny's difference concerns his face.



Kenny's nose, a "blush" pink at birth, had become, over the past five years, deep red and very bulbous. Kenny has a rare vascular disease called an arteriovenous malformation (AVM). Although AVMs are typically found in the brain, Kenny's disease affects his nose, cheek and lip. An AVM is a tangle of abnormally connected arteries and veins.

His nose has given rise to staring, questioning, teasing and cruelty. Scores of medical procedures, intended to control his condition and improve his appearance, were not as successful as we'd hoped.

Life presents us with challenges to make us stronger, or so I've been told. Advocating for Kenny and his face has been a challenge. Standing by him during countless surgical procedures and hospitalizations has been a challenge. Observing the curious behavior of strangers as they wonder 'what in the world is wrong with this child's nose?' has been a challenge.

As tough as the challenges have been, I've grown accustomed to them. They are a part of my life and I accept them as such.

Four months ago, Kenny had a severe, uncontrollable arterial bleed. Blood spurted from an ulcer that had developed spontaneously on his nasal tip. Twelve minutes of holding pressure at the nasal tip was required to get us safely into a car and into the capable hands of his surgeon.

All existing methods to keep his arteriovenous malformation under control had been exhausted. It was time to intervene more aggressively by surgically resecting his AVM. In other words, it was time to remove a major portion of his nose.

The surgical resection was an extremely invasive and difficult procedure and required extensive skill and commitment. 'Good hands and good judgment' were what we needed to get through this ordeal. Fortunately, our surgeon was blessed with both.

To decrease the chance of excessive blood loss during surgery, Kenny's endovascular surgeon performed a pre-operative embolization. This is done by threading a tiny catheter into an artery in Kenny's groin and advancing it to the arteries that supply the AVM. Once the catheter is in place, glue or alcohol is injected into the diseased vessels to seal them off; temporarily diverting blood from the AVM. As a devoted surgeon, his long-standing relationship with Kenny had forged a trusting bond. He provided simple explanation and moral support concerning what was to follow.



In the operation, a large portion of Kenny's nose was resected. Following surgery, Kenny looked as though he did not have a midface. What was left was covered with a large gauze bandage. It was better that way - for him - for us.

Our fear about all that was happening was immense. Would there be significant bleeding? Was the chance of infection high? Would the skin graft take or would he need a nasal prosthesis? Would the residual AVM regress or would it return with a vengeance?

How would Kenny react to his bulbous nose being removed? How would his brothers react? His friends? Extended family? These were questions without answers. His prognosis, good or bad, was beyond our control.

What was within our control was how to explain to Kenny what had happened. With his faith in our love for him, he could take his cue from us; we would pave his path toward self-acceptance.



The post-resection hospital stay was briefer than expected. We were told that kids heal quickly and recover better at home. The skin grafting took place the following week. Skin from Kenny's groin was taken to "make a temporary nose". There were sutures at the groin site, nasal tip and around the periphery of what was once Kenny's nose.

After the skin grafting, it was determined that Kenny would recuperate at home. We arranged for home schooling. He had limited visitors. The bandage covering his nose served as protection ~ from infection, from bleeding, from the reaction of others, and from his reaction to himself.

The recuperative process was slow. Although I followed all post-operative instructions diligently, check-ups with his surgeon were frequent. Minor, in-office procedures were necessary to control bleeding.

Each bandage change required care and sensitivity -- care so as not to disturb the healing process -- sensitivity toward his altered appearance. I was tentative and awe-struck by what I saw each day. He was still Kenny, but his appearance had changed dramatically.

Days went by and Kenny had no interest in looking at himself. He would pause, as if frozen, before entering a room or new situation with others. Slowly, his brief glances in the mirror evolved into a conscious examination of his new face. As time passed, he began to express openness to "new possibilities".



He regained his strength. He regained his sense of humor. He regained his interest in the activities of daily living. Prior to Kenny's return to school, we decided to do a "test-run". We met briefly with the school principal and his kindergarten teacher. We arranged to see a few close friends to 'preview' Kenny's nose. Positive reinforcement from those he trusted was key. The transition to a normal routine was becoming a reality.

It has taken time for Kenny to become accustomed to his new nose. As tired as he'd become of the nosebleeds and unkind comments, his big, red nose was a part of him. He was afraid that it would be difficult for his friends to get used to his new nose.

We openly discuss the process of emotional healing. In a strange sense, we are grieving the loss of the old nose. He will become accepting of the new.

I am still responsible for raising three boys. I am a wife, mother, daughter, and friend. As far as the management of Kenny's nose -- at least for now, I'm off duty. Kenny is moving forward.

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