

# Duets with My Daughter

Lessons in Hope, Heartbreak  
and the Human Spirit

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Lessons in Hope, Heartbreak and the Human Spirit  
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For Kalena,  
that you might understand  
the family you were born into  
and  
the gift that was and is your  
Auntie Rachael.





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# Prologue

LOVING OUR EXTRAORDINARY Rachael and then losing her at age twenty-four made me desperate to find ways to keep her close. My first thought was to chronicle her life, especially during that profound time of illness, hope and yet ultimately, death. I understand now that writing to keep my connection to her meant bearing witness to the human spirit—hers and all of those who loved her and were touched by her life. I so wanted to be perfect for Rachael. I wanted to ask all the right questions of her doctors, to take her to exactly the right centers for treatment, to anticipate every symptom and have solutions. More importantly, I wanted to be that place of solace and renewal where she could turn to in every moment of need. It was a lesson in humility to realize that no one can measure up to such a standard and as much as I wanted to, neither did I.

What I did learn is that each of us who were close to Rachael and loved her had a special role to play, and our own gifts to bring to the table. Her sweet boyfriend Cheyne, dad Michael, myself, sister Keana, brother-in-law Brandon, grandmothers, aunties and uncles, cousins, family, friends, neighbors and coworkers—we all brought our unique version of love and support to Rachael. In the end there is an understanding of what an absolutely profound blessing it is to love and be loved so dearly that souls will share a heartbreaking path without hesitation, will look for hope with you, and then carry your sorrow as if it was their own.

I half jokingly said to Rachael one day, “Hey! I want to be the

favorite parent!” And I meant it. How come those first phone calls went to her dad? Now I understand. She knew her dad needed her more than anyone on the planet and she was taking care of him. Rach shared a special bond with her dad in their love of the ocean, their unique sense of humor, and her ability to call him out on nonsense. They surfed and snowboarded, took salsa dancing together, and were known to have lightsaber duels on the Breckenridge porch. Rachael’s insight, empathy, and respect for human nature were without fanfare or discussion . . . and she knew and loved her dad. Michael’s energy and enthusiasm for life were like surfing for her: full of joy and strength.

As Rachael’s older sister, Keana brought a lifetime of sharing the same family, the inside jokes, and the simultaneous eye rolling that only doddering parental behavior can inspire. Keana was four years older and (unbeknownst to her parents) would share her ID with underaged Rach so she could get into the Breckenridge nightlife and dance. The kid loved to dance. Brandon was the gentle, loving soul who didn’t always understand the urgency of his wife’s decisions but accepted selling their home in Colorado and moving to Hawai’i to be there during Rachael’s chemotherapy. His love and support were true, his heart as broken as all of ours at the end.

Aunties Madelyn, Anna Mae, and Allie brought a connection to Hawaiian spirituality and a closeness of ‘ohana that transcended genetic ties. Wennes, Northey, Sanders, Horner, Fern, Lee, Andrade, Noa, Bate, Taitano all created our family safety net. Beloved friends, extended family, neighbors, and coworkers at the Sheraton Waikiki and Mayo Clinic in Arizona each brought a unique version of strength and love that will never be forgotten. Grandpa Kaleo and Uncle Eddie had already passed away but chose to visit Rachael often in her dreams. Their presence increased toward the end of Rachael’s life and I am comforted in hoping and believing they were there to be her guides.

The relationship that requires my deepest reverence is the friendship and love between Rachael and her sweetheart, Cheyne. Cheyne

was the one who shared those private moments in the quiet of the night—moments of pain, sadness, and closeness with my daughter. I have told everyone who will listen of my gratitude for this young man who was never afraid to walk the cancer walk with Rachael. You are ours now, Cheyne. We will keep you as a son and a brother and someday we will celebrate the family of your future with you.

And what of me, Rachael's mom? I was given two amazing daughters, and I have learned that despite Rachael's death, I am still the mother of two amazing daughters. Rachael used to say, "Geez Ma, not everything has to have a deep meaning." I can't help it. I think it does. I am a seeker, a caregiver, a grateful, yet often flawed human. I seek to understand what I can and am open to life as it comes. I accept the mystery of it all.

We often feel like we are singing solos in life that no one else can possibly hear, but as we come to understand the true meaning of love, the duets begin to flow with harmonies that not only surprise us but lead us to understand that behind our single voices exists a choir of souls who bring beauty, strength, and courage to our voice—a symphony of human connection. We were all Rachael's backup singers.

This is a dedication, then, to Rachael and to all of us, who will not only love her forever, but because of her also understand how to better love each other.



# Searching for Answers

HAWAI‘I AND ARIZONA  
JANUARY–MARCH, 2006

WE HAD BECOME a fragmented family by the year 2000. After our divorce in Colorado, Michael headed off to Texas to work and I found my way to Arizona to help with my aging father. Keana had gotten her business degree at Colorado State University, married Brandon, and settled in Denver. Rachael had gotten her degree in Asian Studies and Japanese at the University of Colorado in Boulder, then moved home to her beloved beach in Kailua, Hawai‘i, in 2004.

I was at work that Thursday in January of 2006 in the endoscopy department of Mayo Clinic in Arizona, when Keana reached me by phone. Some people have memories that allow them to recall details with precision. My recall has always been a muffled sort of recollection with minutia lost, yet with the essence intact. I remember hearing that Rachael had been to the doctor because of pain in her left upper back and that an X-ray had revealed a “spot.” I remember thanking Keana for calling and trying to make as many phone calls as possible on my lunch hour to get an understanding of what was truly happening. There was not one moment in that day that I thought that Rachael had cancer. This incredibly healthy, active, joyful twenty-three year old might have a strange infection but never, ever cancer. As a nurse, I had spent years working with cancer patients, and it never crossed my mind that she could possibly be one.

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Rachael had already had a CT scan done of her chest and had seen a pulmonologist by the time the dust was clearing on that day. I took my cues from Rachael, talking matter-of-factly about the possibilities. The doctor had told her it could be a fungal infection or “some kind of mass” and he would do a bronchoscopy first thing on Monday morning. Rach’s dad Michael immediately left Texas to return to Hawai‘i on Friday and I flew in on Sunday night before the procedure. My siblings rearranged their schedules to be available to help with our dad. My boss at Mayo Clinic said simply, “Go, call us for anything, and we’ll see you when you get back.” It was to be my last day of work at Mayo, although that never occurred to me either.

I can’t tell you much about that Monday but I can remember Cheyne talking quietly with Rachael after the procedure was done. I can’t remember who I called first to say yes, it is a mass. Our doctor had tried to get enough tissue sample for an accurate pathology report but as the mass wasn’t easily accessible through a scope, the next step would be to schedule a fine needle biopsy. OK . . . just tell us what it is and how to fix it.

After completing the fine needle biopsy a couple of long days later, the pathology report was still inconclusive so our doctor said that he needed to send the sample out to a second lab for another opinion. I can tell you right now that the moments waiting for return phone calls from doctors and test results to be completed are some of the most wrenching moments of life. So much hangs in the balance: fear of the unknown, the word cancer, the possible new life trajectory that is now out of one’s hands.

Rachael thought I was being pushy, but I finally called her doctor after waiting politely for several days only to be told that the second opinion was also inconclusive and that we needed to be referred to another medical center on the mainland. On one of our doctor visits we had asked if we were jeopardizing Rachael’s health with each day that went by without treatment. The answer was no, and maybe that was true, but psychologically and emotionally those days of inaction were brutal.

We had a compassionate, efficient liaison to work with as we navigated through Rachael's health insurance, and Mayo Clinic was offered as a referral site. As soon as approval was obtained, I contacted my coworkers, explained the situation, and asked for assistance in getting the quickest appointment possible. Within hours we had an appointment with a pulmonologist, tickets to Arizona, and finally, the beginning of a plan.

What went on in our heads in those interim days? Rachael worked, went surfing, rode her bike, and lived her usual joyful life. I walked, drank coffee, and at night would sink to my knees beside the bed in prayer and tears. Please, dear God, don't let this be cancer . . . please, dear God, let me be sick instead . . . please, dear God. What did Rachael think each night, in her own heart? I think she spared me some of her pain just as I spared her mine. I do know she never felt bitter, understanding how random life can be and actually saying, "Why not me?" She told me that in some ways she was glad it was her because at least she had friends and family to support her and insurance to cover expenses. The graciousness of this child was humbling.

Our trip to the mainland became the first of many. We had an appointment with the pulmonologist on a Thursday, and the doctor felt our first step should be to repeat the fine needle aspiration. The soonest that it could be completed would be "next week";—more waiting, yet at least we felt that we would be closer to answers, a plan, and a cure.

On Friday night, Rachael had just gotten out of the shower and started to cry. She said that she was having severe pain in her back and chest but thought it might get better if she could just rest. I persuaded her to go to the emergency room and she said, "What if it's nothing?" I told her fine, then we could just turn around and come straight home. As we were en route, I got a phone call from my sister Anne, who was taking care of our dad in my absence. She asked if I could come over right away as dad had fallen and was being taken by ambulance to another local hospital. I told her that she wasn't going to believe it but Rachael and I were also heading to the emergency

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room and that I knew she could manage all the details just fine. I have looked back on that night in absolute wonder . . . both my daughter and my dad in trouble, heading for their respective hospitals.

Dad was admitted with a broken arm and pelvis. Rachael had a CT of her chest done in the ER and she called me back to look at it, asking “Doesn’t that look a lot bigger than before?” I don’t know if it did or not . . . it was always huge to me. I’ll never forget the ER doc saying to me, “It looks like it’s eroding into the pulmonary artery.” Eroding into a major vessel? I had visions of her bleeding to death at any moment. I don’t know how my own heart kept beating, how I kept standing. I kissed that sweet forehead of Rach’s as she dozed off for a minute and stepped outside to make some phone calls. It was somewhere around 4:00 a.m., the stars were out, the sky was clear, and I was alone. I had to sink to my knees first and cry, then collect my thoughts enough to call the family. Michael was first on the list: “Come as soon as you can.” Keana: “Come as soon as you can.” Family in Spokane: “This is what’s going on.”

Rachael was admitted to the hospital and the workup began. The doctors first advised another bronchoscopy but I said that the original one had yielded virtually no information so please, couldn’t we go straight to the fine needle biopsy? I am a polite, accommodating person, so for me to question this initial decision taught me something basic. I am Rachael’s mother and through this illness I needed to be the very best advocate for her that I could be, and that I was capable of going into Mother Lion mode if required. When it comes to children, I believe that we step into the epicenter of disaster willingly. Our medical team felt that urgency too . . . maybe they saw their own daughters in Rachael. We never felt faceless or anonymous in their presence. The concern in their eyes and the respect in their voices was clearly present.

The admitting diagnosis resulting from that emergency room visit was post-obstructive pneumonia. That meant that the mass itself was blocking part of the large airway on the left side, allowing a pneumonia to develop. That “little” comment about the mass eroding into the

pulmonary artery was later revised to say that it was compressing the artery. What a huge difference that made in my mind! What a great reminder to choose one's words carefully. We got settled into a room at the Mayo Clinic Hospital in Phoenix. The family started arriving, and there was a deep, true belief that it would just be a matter of time before we'd have an accurate diagnosis, a game plan, and the cure every one of us believed was inevitable.

My sister Nancy and her daughters had come to visit from Spokane and brought with them a Hello Kitty pink fleece robe for Rach. Although Rach was a lovely, twenty-three year old woman, who could resist the innocence of that favorite childhood character? She wore it often as she walked in the halls and on the grounds of the hospital, and with her long, sun-streaked hair and soft brown skin she looked beautiful. The contrast of her youthful presence with the predominantly elderly set of patients was further emphasized by this sweet robe. I could always sense an alertness as we passed people in the halls, a curiosity as to what could possibly account for her admission to the hospital. Do you silently pray for children who are ill? Do you send them love, strength, and healing with those prayers? I think that energy followed us on those excursions out of her hospital room.

The staff at the hospital was so accommodating of all of us, as we usually had at least two or three people staying overnight with Rach. Mike would be in a sleeping bag on the floor, Keana and I on fold-out chairs. Once, when we were moved to a slightly larger room, we were even allowed to have a folding bed that Cheyne used for the several nights he was able to be there. I later heard that it was not easy for our nurses to care for Rachael because this was a young person like themselves, with a diagnosis of cancer. It hit too close to home in their own lives, but we never sensed any hesitancy on their part; all we ever felt from them was compassion.

Not surprisingly, the fine needle aspiration was inconclusive so the next step was a referral to the thoracic surgeon for an open lung biopsy. This would entail a trip to the operating room, and an incision into her chest and the mass itself in order to obtain a tissue sample

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that would finally allow our doctors to name this cancer. As I had worked in the operating room setting, I had friends in that department and immediately went to see them, asking what surgeon, what anesthesiologist, what next? The referral was immediate and by that afternoon we were meeting with the surgeon who would perform the procedure the next day.

Dr. L, a busy, eminent physician, walked into Rachael's room with his team that afternoon to review the plan. His eye contact with Rachael was honest and true, his jokes were for her, and their connection was immediate. There can be no minimizing how vital first impressions are—we immediately trusted this man, felt respect and compassion from him, and were reassured beyond words.

Dr. L met with Mike and myself after the surgery to say that all had gone well and that we would now wait for that final pathology report. Life becomes a series of urgent moments like those experienced in crisis, and then long stretches of waiting. All we cared about in this immediate moment was that Rachael was doing fine after surgery, and I hugged Dr. L in gratitude for his part in our daughter's care.

That afternoon Rachael's internist thought we should begin the general workup required in the diagnosis and staging of all cancers and suggested that we begin with a CT of her abdomen. Compared to much of what Rachael had already been through, this was an easy step. Little did we know that this CT would provide us with the most important information to date. Her doctor called me out of the room that evening after reading the results to tell me that the scan had revealed a large pelvic mass.

I remember feeling matter of fact about that information—not shocked or overwhelmed, just a sense of OK, what do we do next to fix this? It was my sense that this was also how Rachael received the news. None of us cried; we were not afraid. We just wanted to name our adversary and get to the part of treatment that included the words “cure” and “recovery.”

Rachael had said from the beginning, and never stopped saying, that she had no intention of dying from cancer. She always knew that

she would be a survivor and over the course of the months ahead, as she faced each new hurdle, she would say, "This is what the cure of cancer looks like," and we would again focus on hope and not despair. This is how she faced the news of a mass in her pelvis.

Our next referral would become Dr. M, the gynecological surgeon who would remove the mass. We knew that Rachael was in the best of hands with Dr. M; his reputation for meticulous attention to detail and his proficiency in surgery using robotic techniques were world renowned. It felt like divine intervention to be under his care.

I can still see that morning of surgery as we were in the preoperative area, kissing Rachael goodbye as she headed into the operating room. She was so small in that bed, so beautiful, so at peace, so unafraid. The nurse who would be with her during surgery said, "We will take good care of her." It is a stock phrase, said over and over every day to family members whose loved ones are going into surgery, and it means the world to those who hear it and need to believe it with all their hearts. A few of my friends who were working in the operating room that day also came into the pre-op area to lend moral support; after the joking and words of reassurance, after Rach's bed had been rolled away, we looked at each other with such incredible pain in our eyes, with tears rolling down our faces, knowing in the truest sense that Rachael belonged to us all.

Hours of sitting, mindless magazine reading, endless coffee, restless walks . . . this describes how one waits for those in surgery. The world is on hold until you hear the words "surgery is over and Rachael is doing fine." Dr. M said he had hoped to save one of her ovaries; however, both were diseased and needed to be removed along with the orange-sized pelvic mass. The loss of both ovaries would put her into instant menopause, requiring lifelong hormonal replacement. He focused on the good news of saving her uterus, and the fact that there were no other areas of disease in the abdomen, no spread to nearby organs. His parting words were that he looked forward to hearing about her back in the water, and surfing again in the future. And that is what it means to focus on hope: you face the facts, sort them out,

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accept the challenges, yet never forget to look for that sweet moment where you visualize the healing.

The first few days of recovery were typical of many surgical patients: waiting for the nausea to subside, the appetite to return, managing pain, finding that comfortable position that would allow sleep. The truly important news, however, was courtesy of those new biopsies taken during surgery. Rachael's cancer now had a name. It was a yolk sac tumor, a type of germ cell cancer affecting young adults. In males, it manifests as a testicular cancer; in women, as a type of ovarian cancer. Our oncologist said that of all the cancers to get, this is the one you should vote for; the cure rate was very high, even with distant spread. The golden child of this type of cancer is Lance Armstrong, having not only survived his stage IV germ cell tumor but triumphed in a way that dazzled the world. Our hope for a cure was not unfounded, and with the example of Lance in every conversation, we felt ready to do what was necessary to reach that moment of wholeness again.

Part of the workup of any cancer includes looking for distant spread in order to stage the disease and decide on the most appropriate protocol and treatment regimen. Rachael had a CT of her head as part of the staging process; Lance's cancer had included metastasis to his brain. On the afternoon of the scan we paced in the hospital, waiting for the results. Her doctor walked in shortly after dinner and said, "Good news! There is nothing in her brain!" Hooray! That comment led to lots of good-natured joking, but the relief was deep. Rachael said afterward that she didn't realize how important that little piece of information was in determining the treatment that lay ahead. I am glad she did not.

Mayo Clinic Hospital has a peaceful little chapel in the main lobby; the door is discreet, the sanctuary private. I found myself heading for that door several times every day to pray, to cry, to give thanks, and to rest my heart. There were times when a flutist might be playing in the lobby, late in the evening, and I would wonder if those lovely notes were a gift sent to ease my soul. There were times in that chapel

where a thought would arise at just the right moment to bring me needed comfort. What I truly learned, each and every day, was not to look further than that precise moment. The surgery was successful; let us give thanks. There is genuine hope for a cure; let us give thanks.

One night, before any of the surgeries had occurred, Keana and I decided we would actually go back to my apartment, twenty miles away, get showered, sleep, and be back in the morning. It was a contrived decision. It seemed important to give Rach the message that of course she would be fine, and her dad would be staying by her side in our absence. We had been in the apartment for an hour or so and had taken a couple of random phone calls from a very nervous Michael, who was calling to be reassured over a few issues. Keana and I both thought the decision to take a short break was reasonable, but I will never forget standing in my kitchen, Keana crying with a look of such grief on her face and saying to me, "I am so scared." There was so much unknown in front of us. We looked at each other for a moment and knew we had to go back to the hospital. We both took a quick shower, pulled a few odds and ends together, and immediately headed back.

We parked in the Mayo parking lot in my little Honda Civic and got as comfortable as we could. We slept in the car that night, took bathroom breaks in the lobby, and kept this secret to ourselves, not wanting Rachael to think we were overly worried. It was February and even though it was Arizona, it definitely got cold during those hours after midnight. We turned on the car for a few minutes to let the heater warm us up, then settled back in for another hour or so before the cold woke us up again and we repeated the cycle.

Leaving Rachael's side, even briefly, was never easy. It seemed so important to know firsthand each and every detail of her day—to never to miss a doctor visit, a symptom, or just the opportunity to spread some imagined layer of protection over my daughter. Is that the definition of hovering? I did it. Whenever we did pull ourselves away, we did so in shifts and spent the time away from her distracted and anxious, thinking only of needing to be back, to be of help. I am

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quite sure we drove Rachael crazy on more than one occasion. There were times, albeit rare, that we could see the look of exasperation cross her face because of our continual presence. I can remember several times when my feelings were hurt, thinking to myself, are there no smiles for me today? Why do you have that tone of annoyance in your voice, Rach? I know my child loved and needed me, but there were times when I simply did not know how to read her. Did she need a break or did she need me to be close?

Keana brought some clarity on this issue by reminding me that I was the face of cancer for Rachie. My presence in every minute of her daily life, although necessary and loving, also meant that she was ill. I have also come to realize that so much physical and emotional energy was being drained from our sweet girl as she dealt with cancer. Keana and I were her safe haven, where she did not always need to feel brave or strong and we would understand. We always did, eventually, but occasionally our feelings got bruised along the way.

Things were beginning to move quickly at this point; we had the name of her cancer, the staging was complete, and a referral had been made to the Mayo oncology department. She would begin chemotherapy in a few days once she was sufficiently recovered from her surgery. It was also decided that she would have several days of radiation therapy to the chest mass, considered “bridge therapy,” to help shrink the size and minimize compromise to her pulmonary artery. It felt so wonderful to have a plan and to be taking action that none of this news was anything but good. We all wanted to do whatever was required to get rid of Rach’s cancer and focus on being her cheering section through recovery.

The radiation was stopped as soon as it was deemed safe to start chemo. She ended up with only three sessions. In retrospect, they may not have had any significant impact on the chest tumor itself, but one thing for sure: we knew we were in the hands of a medical team who felt the urgency to treat this cancer as aggressively as possible to give Rachael every chance of surviving.

Prior to starting chemo, Rach’s oncologist ordered the placement

of a PICC line. This is a venous access device that is placed into a large vein in the upper arm and threaded into a central vein in the chest, allowing for medications to be administered, lab work to be drawn, and to generally minimize all the needle sticks required for treatment. It is generally a simple procedure; however, access to her veins was difficult and it took several painstaking attempts to finally place the line. Over the months to come we would realize that the nature of Rachael's cancer treatment would never be predictable or smooth. Her response to challenges, minor or overwhelming, would invariably be: what do I need to do . . . let's do it . . . thank you for helping me.

Rachael and I were both staying in near-daily contact with friends and family via e-mail, each of us with our own list of people who had asked to be kept in the circle of information, support, and love we needed. Although some of our contacts overlapped, I wasn't on her list, nor she on mine, and in retrospect, I think that was a good thing. We could be open about our feelings without having to guard our words or tiptoe around issues. It's hard to overstate how important these daily connections were for both of us. I did most of my writing in the evening, when I could wrap the day's details into some kind of positive light, wanting to share clinical details, acknowledge the enormity of the task in front of her, and yet offer true hope. Each morning I would find my e-mail inbox full of replies bringing words of encouragement, kindness, and humor, and a willingness to carry heartache with me.