

# States of Grace discussion guide

### INTRODUCTION

A successful film screening invites viewers to watch the film deeply and purposefully, and to reflect upon what they've seen with their peers, family members or colleagues. We have designed these questions to provide viewers with the opportunity to share their personal and professional views, feelings and experiences. Additionally, we hope the conversation will lead viewers to consider how care giving and care receiving might be enhanced for themselves, for patients and family members, and through the efforts of a variety of healthcare providers and service organizations.

Audiences may range widely from physicians, nurses, and allied healthcare providers to medical and social work school faculty and students, Buddhist and other faith-based groups, meditation practitioners, disability and LGBT organizations, as well as families and caregivers who are dealing with the many dimensions of trauma, illness, aging and disability.

Feel free to pick and choose the questions that are best suited to your particular audience, format, and the amount of time you have for discussion.

### GENERAL QUESTIONS

- 1. What were some of your thoughts and feelings while watching the film?
- 2. What moments in the film affected you the most? Why?
- 3. Whose story did you find the most compelling? Why?
- 4. Did you identify with any of the subjects in any way?
- 5. What questions, fears or concerns did the film raise for you, both personally and professionally?
- 6. Did something inspire you in this film? If so, how might it have an impact on your own life?

### KEY THEMES & ISSUES

#### THE EXPERIENCE OF CAREGIVER AND CARE RECEIVER

The film portrays many dimensions of caregiving and care receiving, an intimate exchange that challenges and changes the lives of individuals, professionals, and the healing process.

1. What are some tasks and stresses Fu faces as a caregiver? How does she manage them?

"Am I actually up for being the primary caregiver of a severely disabled person? That was a big soul searching time for me."

—Fu

- 2. What kinds of challenges does Grace face as a care receiver? How does she handle these challenges?
- 3. What are some things you learned from each woman's experience? How might these lessons inform how professionals provide care to their patients? How might they inform patients and families as they navigate their own healing process?

#### THE IMPACT OF TRAUMA ON FAMILY DYNAMICS

The film shows the experience of an entire family adapting in the aftermath of a life-changing accident. While their journeys through change are inextricably linked, their tasks, challenges and dilemmas are quite different.

 Grace had been the primary parent and breadwinner winner prior to the accident, and had also been a physician and care provider her whole life. How does she cope with her new role and position in the family?

"It was devastating to miss a whole year of Sabrina's life.... Fu and Sabrina formed a strong bond and there were many times I felt left out." —Grace

- 2. Fu describes herself as a person who "had not really taken on the mantle of adult responsibilities" prior to Grace's accident. How does she change in the years following the accident? How do you think she feels about these changes?
- 3. How is Sabrina's relationship to Fu and Grace affected? What impact does this have on Sabrina's life as a teenager?



#### LOSS, RESILIENCE, AND RENEWAL

The film shows multiple types of loss by individuals and families. How loss is experienced is greatly influenced by how one understands and navigates it, and how effectively loved ones and caregivers provide emotional support.

- 1. In what ways do Grace, Fu, and Sabrina exhibit flexibility and resilience? What lessons might there be here for other patients, families, and healthcare providers?
- 2. Prior to the accident, Grace was an honored physician, a partner, a mother, a Zen practitioner, and a longtime member of a Buddhist community. In what ways might these roles have affected how she experienced, and responded to, her circumstances after the accident?
  - "I think I would have died early on if it weren't for my Zen practice. I learned that nothing lasts forever... including great pain, great sorrow, great loss, great sickness, and great helplessness." —Grace
- 3. Grace expresses grief and despair about her many losses on several occasions, including her loss of independence and the burden she feels her dependency places on Fu and Sabrina. How does Grace face her losses? What does the film show about the relationship between hope and despair?

- "I am realizing how much I don't like being disabled.... Mostly I am worried about being such a burden on you and Sabrina, and I have nothing to give you...."

  —Grace to Fu
- 4. While Grace experiences profound losses in the aftermath of her accident, Fu and Sabrina suffer reciprocal losses as a direct consequence of Grace's losses. What are those losses, and what helps Fu and Sabrina face them? What are lessons here for patients, families, and healthcare providers?
  - "If I learned anything it is that you cannot do it alone.

    None of us can...only by hard work and risk...and
    not quite knowing what you're doing." —Sabrina
- 5. What one or two key factors stand out most for you as supporting Grace, Fu and Sabrina to stay the course toward healing? How might these inform your own role as patient, family member, caregiver, advocate, or healthcare provider?



#### CONCERNS/QUESTIONS/OPPORTUNITIES FOR HEALTHCARE PROVIDERS

Providers' presence, engagement, and responsiveness with patients are key ingredients of healthcare delivery. The film offers insights into the strengths and limitations of current practices.

1. What did you learn from Grace as she navigated her role as a patient? What are some things you learned from her experience that might affect or enhance the way you practice, or plan to practice, as a healthcare provider?

"I was a caregiver all my life. As a physician, it's a real eye opener to be on the other side of the caretakercaregiver divide." —Grace

2. Fu is not a formally trained healthcare provider, yet she provides significant home care for Grace following the accident. What are some things you learned from her experience that might affect or enhance the way you practice, or plan to practice, as a healthcare provider?

"She needed an ICU, then she needed a rehab hospital, and then they sent her home. And where's the doctor, where's the nursing staff...well, actually, vou're it. Fu!"

—Fu

3. What did you learn from seeing what happens to a patient after she is discharged from a care facility and has to manage in her home environment?

"Regarding the anxiety of going home...! think the only way you're going to get through that is when you actually get home and muddle through it, and find your own routine." —Hospital social worker

- 4. What sort of special considerations, if any, does one need to think about when delivering healthcare services to LGBT families?
- 5. What did you learn from seeing Grace return to work as a physician? In what ways did her experience as a patient influence her work as a doctor?

"People have been offered lots of pain medications... and various pain interventions. But what they really need is a community of people who support them in the process of working through their pain."

—Daniel Rybold, MD, co-worker in pain clinic



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Funding generously provided by The Thoracic Foundation and Marin Community Foundation

Design: PINK TOP Design

Special thanks to Daniel Nevers, Eileen Spillane, RN, Steve Weisner, MD





# States of Grace

### FREQUENTLY ASKED QUESTIONS (FAQs)

- FAQs FOR GRACE DAMMANN, MD
- FAQs FOR NANCY (FU) SCHROEDER
- FAOs FOR SABRINA SCHROFDER-DAMMANN
- FAQs FOR HELEN S. COHEN AND MARK LIPMAN, DIRECTORS

#### FAQs FOR GRACE DAMMANN, MD

### 1. What do you remember about the accident and the immediate aftermath?

I don't remember a whole lot, but I do remember saying to a state policeman, "Do not let me pass out before I get to the emergency room." I knew that I would be able to get information about Sabrina once I was in the hospital. I remember saying something to Sabrina like: "You are going to be okay, sweetie." And then I was out. 46 days later when I regained consciousness and was asked if I knew what had happened and where I'd been, I had no memory of the accident but replied, "I've been in the Bardo" (referring to the realm of consciousness that hovers between life and death).

#### 2. What do you know about the person who crashed into your car or the cause of the accident? Did he survive? Was he severely injured?

I know a great deal about the cause of the accident and the person who hit me. His name is Brian Clark. He was driving into the city after having seen his father's oncologist in Greenbrae, California, where he learned that his father had terminal prostate cancer. While diving across the Golden Gate Bridge, Brian had an episode of atrial fibrillation and lost

consciousness—a result of a previously undiagnosed heart condition. He crossed over into oncoming traffic and hit my car right at the driver's side door where I was sitting. Brian was taken to San Francisco General Hospital where he was treated for symptomatic atrial fibrillation and a dislocated shoulder. He spent a couple of days in the hospital and then went home.

Our families exchanged letters when we were first in the hospital and while I was in a coma. They were bereft about the accident and the impact on my life; I offered my forgiveness but was not ready to engage with him much for quite awhile. We didn't meet until shortly after I was released from the hospital. He came out to Green Gulch with his whole family and it was an emotional experience. We are bonded at the hip in that we went through a most important experience in both of our lives.

The day after I watched the news report about the Bridge District's vote to fund the median barrier on the Golden Gate Bridge, I called up Brian and I asked him if he would like to write a letter of gratitude thanking the bridge district directors for their willingness, finally, to fund the barrier. I wrote the letter, and my caregiver drove Brian and me across the Golden Gate Bridge. We held hands on the way during the trip. We read the letter out loud at the Board of Directors meeting, an act we were to repeat at the ribbon cutting when the median barrier was finally opened in January 2015.



# 3. How did being a physician influence your experience as a patient? Did working with HIV/AIDS patients prepare you in some way for dealing with your own situation?

Being a physician deeply affected my experiences as a patient. I had an easier time as a patient than many, I think, in large part because I was so comfortable being in the hospital and felt right at home. I love being in hospitals and am fascinated by all things medical. I loved being an intern late at night when everyone was asleep and I would walk the halls.

Initially, when I was in my first rehab hospital, I would call every time the operator announced a code blue saying, "I didn't hear what room you said it was in." The operator would have to say, "Dr. Dammann, you are not a doctor here—you are a patient. We're not expecting you to run the code blue!"

During the AIDS epidemic, I signed over 1,000 death certificates and witnessed a lot of suffering. But I'm not sure my experience as an AIDS physician helped me or prepared me for my own experience as a patient. I had watched other people die and I watched them suffer, but it really had very little to do with what I was experiencing. During my first year as a patient, I wasn't actually suffering very much, despite the pain I had to endure, the surgeries, and so on. I didn't suffer from psychic pain or what the Buddha called the second dart, the second arrow. The second arrow comes when

we say, "Why me? Why now?" I had very little of that. As a matter of fact, I don't think I experienced suffering in the true sense of the word until after I got home from the hospital and had to face the full, ongoing extent of my limitations.

## 4. How did being a patient influence your experience when you returned to medical practice?

I was unprepared for how much I depended on and needed the CNAs (certified nursing assistants) who took care of me when I was a patient. Of all the staff, they were the most important. They were the first people I saw in the morning. They were there whenever I needed them, and they did everything to care for me. I had always respected CNAs for the work they do, but being a patient gave me a whole new perspective and appreciation that I carried back into my work as a doctor.

Being a patient changed what I see as the most important elements in healthcare work. I learned first hand how important it is to be happy working as a healthcare provider and that it profoundly affects how the patient feels and responds to treatment. While in the hospital, I very quickly realized that I could sense the emotional state of everybody coming into my room, and when a cranky healthcare worker came into my room, I would pull the covers over my head,



#### GRACE FAOS

feigning sleep. I was never rude and never unwilling to participate in my own care. I just didn't want to have to interact with anyone in a bad mood who didn't want to be doing the job!

It became glaringly clear that what each person has to give is her own happiness. It doesn't matter whether you are a janitor, a nurse, a physical therapist—your mood is palpable and your attitude about healing work affects the patient's state of mind. Your joy or misery with your job as healing professionals is what makes the difference.

When I went back to work as a doctor in the pain clinic, I realized that my primary job was to have my staff be as happy as they possibly could be. We structure our day so the staff is happy. That way, they are more effective clinicians and can offer genuine healing for our patients. We also meditate several times a day—as a staff and also with the patients, which helps everyone's state of mind.

## 5. What role do you think humor played in your recovery?

Fu is particularly good at getting me to laugh or see the absurdity in pretty much everything. She was indispensable keeping my spirits somewhat up, or keeping me laughing. I think humor was indispensable.

# 6. The film shows the ways in which the accident created losses for you and Sabrina. Are there any ways the experiences have positively affected your parenting and relationship with Sabrina?

I've developed much more empathy for Sabrina in that I now have a sense of what she experienced most of her life, living with a chronic disease and a disability. I finally understand how much energy it has taken her to just do the work of survival and daily living. She is thriving at this point. My commitment to her has not changed. She is the most important person in my life, and the love of my life. I hope, over the long run, I can be an inspiration for her. I think her getting involved in the film and its distribution has been empowering for her. She has grown into her desire to carry her HIV status, as well as her disability, public, and she has been incredible as a public speaker with the film during the Q&As.



7. In the film, you say you would've died without your Zen practice. Can you say more about the ways Buddhist practice helped you endure?

Within the Zen tradition, we often sit for seven days in a row. There's something very predictable about the long sits. About day four, everyone is praying for their knees to stop screaming. You sit on your cushion, nothing changes except perhaps the slant of light, and yet one period (40 minutes) you are in misery and the next, you are ecstatic. Nothing has changed except the slant of light and yet... everything has changed inside of you.

I learned through so much sitting meditation that everything changes, that nothing lasts for very long at all, and everything will be okay. In sitting Sesshins (seven day sits), you see how your mind works. You see how it creates pain and suffering. And you develop some familiarity with the pain that's created by your own mind. What I learned from Zen is that everything changes and that the greatest pain comes from fighting what is.

8. In the film you shift from feeling great despair and expressing suicidal thoughts about being so dependent to being more hopeful and accepting reality. What do you think caused a change in your perspective?

It is not as if I have come to "accept" being so dependent. It's a work in progress and it changes all the time. About two years after I got out of the hospital, I started giving Grand Rounds on my case. I realized that there is no reason I should be alive today—at least no medical reason. I was bleeding so badly, I had brain contusions, so many broken bones... Why did my body decide to stay? I have no idea how to answer that, but it's clear that my will to survive—my life force—is why I survived and am here today. My willingness to get through the despair has been about honoring that life force—that very primitive and oh-so-powerful life force.

My family has always called me a Mack truck. I have always had a very strong will. And my will is what was keeping me alive in getting me through the journey I had to go through. I did it the way I have done everything in my life.



#### GRACE FAOS

# 9. What were the financial implications of the accident, the insurance headaches, etc., and what kind of support did you receive from your community of family, friends, and colleagues?

For starters, in the beginning, the financial headaches were enormous. While I had a durable power of attorney for healthcare sitting right at my bedside, I had never had it notarized. I named Fu my power of attorney for healthcare. And I had a will that also had not been notarized. And, we did not have a joint checking account so Fu had no access to the cashflow that had provided for Sabrina and household expenses. I was in a coma.

People came forward to help, but in order to access my funds, Fu had to become my conservator, a process that was costly in terms of energy, time and money. So, initially Fu and my long-time friends experienced all of the headaches. My work partner at Laguna Honda, Victoria, struggled to organize my financial affairs as a long-time employee of the San Francisco Health Department. Those processes took about 3 months both for Fu to become my conservator and therefore have access to my money and Victoria to arrange disability payments provided by the city and establish a sick fund account so that city employees could donate their sick time to me. Employees from the City and County of San Francisco generously donated over a year of sick time so that I received full pay for the entire year I was hospitalized. This was an amazing gift.

I was also fortunate that for some reason I had purchased disability insurance that covered me until I turned 65. Altogether, during my year in the hospital, and until turning 65, I was actually receiving about the same income I made when working as a full-time physician.

More than financial aid and money, people gave time. Fu ran my life and that of our family, and she did it superbly. Zen Center relieved her, for two years, of all community teaching responsibilities so she could care for Sabrina and me. Green Gulch gave us a new house in which I could use a wheelchair, with an adapted bathroom. They helped build a stone path between our house and the central area of Green Gulch so that I could go everywhere in my wheelchair. They forgave my payment, very modest, of room and board until I felt financially able to pay rent again.

Once I was awake and competent, (about 15 months after the accident), I took over all of my own affairs. I was surprised—it was like running a small business. Fu had done a great job getting and keeping me out of debt and, nonetheless, it took hours every day to follow up on hospital bills, equipment, and the activities of daily living. In truth, it was like being CEO of a small business with several employees who were like family members and were great!! I had Iva who had lived next door to me, been the treasurer of Green Gulch, and was a Buddhist priest who had moved out of the community, and Nygosi, a Nigerian woman whom I hired on the spot at California Pacific Medical Center when I was done with being hospitalized. Both of them helped me attain a level of independence and



comfort and provided Fu with respite. Initially, I needed someone available 24/7 because I needed so much oversight and presence, in case I fell.

My three siblings (a brother and two sisters) were there throughout the whole process and took turns staying with me and caring for me during the times that Fu was away from home. In fact, I was helped all the way through my recovery up until the present in that I have a whole community of people and institutions that "took over" so that I could focus on my own well being. The resources and help I had available to me made my experience so unlike that of most people with similar conditions. The help made the time almost "luxurious!"

## 10. What forms of treatment did you get during rehab outside of what was formally given to you?

I had been in therapy, of course, for years! Early on, that form of treatment seemed very beside the point. When I was first at Kentfield Rehab Hospital, many people came to try to provide treatment. I had people who would massage me, provide me with Reiki work and Rosen bodywork. Unfortunately, I feel that I wasn't able to take advantage of these therapies at the time. I think my body was just too traumatized, a fact that I didn't realize until about two years after the accident. In any event, none of the bodywork felt particularly good.

Later, about four years after the accident, I had a session with Peter Levine, the founder of Somatic Experiencing therapy. I found that particularly helpful. And I went back into psychotherapy, which I had to do mostly over the telephone. Doing it in person was too costly in terms of time, energy and money. In the beginning I was mostly dealing with trauma and trying to adapt to my changing body habitat. I had experienced a lot of loss. Very quickly, however, I realized that my situation was unique (this is true of every person's experience, but it took me a while to realize that). I wanted to meet other people who had suffered my kind of losses. I found my best teacher was my Buddhist practice and my Buddhist teacher, just because he could reinforce everything that I'd already learned about accepting "what is."

I feel like I'm just about ready to take in the wide array of alternative treatments that are available. After all, I work in the pain clinic specializing in alternative treatments. I found that meditation, sound therapy, and massage work very well and help make me more relaxed and comfortable.

I've also been extremely fortunate to have a woman who volunteered to do yoga with me. When it was clear that I needed more support than she could provide, she took me to see her teacher, Manuso. He is a superb lyengar yoga teacher whom I trust completely! He assigns a bunch of his assistants to me during each class and they manage to get me into most of the day's poses. I am completely contorted, but it actually was the first time I began to experience pleasure again with my body.



#### GRACE FAOS

## 11. Did you finish sewing and are you still interested in being ordained as a Buddhist priest?

Yes, I did finish sewing. And I am still in a dialogue with my teacher about ordination. I suspect that I won't get ordained. The accident left me totally incapable of performing the prerequisites—such as going to Tassajara, our monastery. Or doing most of Zen practice, which is very body based. And I am no longer living in the community, so I no longer share daily sitting.

## 12. Do you still live at Green Gulch? How has your relationship with Fu evolved?

I moved into an assisted-living facility in April 2015 located about 15 minutes from Green Gulch Farm. I still work at Green Gulch on Sunday and Monday afternoons, and I attend the priest meeting on Monday morning.

Since the move, Fu and I see each other when Sabrina comes home from college and we spend time together as a family. We also have some contact around Mack [the dog], who stays with me a few nights a week. The transition was initially quite painful for me—losing my home and daily access to the community I have been a part of for 25 years. But I also know it was a necessary change—Fu's 24-7 caretaking was not a sustainable situation for either of us. It was not fair, and I think we've both felt better since we began living apart.

#### 13. What's happened to the pain clinic?

The pain clinic continues to thrive. All of us on the team still can't believe this is considered a job; we are having such a good time. I suspect it's the spiritual connection that we all share that helps keep our spirits buoyed and helps our patients.

# 14. Where did the idea come from to make a documentary about your recovery and how did you decide to participate?

The idea for making a film originally came from my daughter Sabrina. While wandering around with Helen and Mark at the Marin County Fair on the 4th of July 2008, six weeks after my accident, she said to Helen: "How about you make a movie about my mom?" I had just that morning woken up from 46 days in a coma, and everybody was delighted, of course. What could Helen say to Sabrina other than, "Yes!" However, Sabrina had other ideas about this movie. For one, it was supposed to star Sally Field as me. And two, Sabrina assumed that this would be a Hollywood blockbuster and that we would all make a lot of money...

Anyhow, the idea percolated for several months while I was in the hospital, and Helen and Mark decided they were up for documenting my recovery once I was discharged. I like to joke that I made the decision to participate, in part, because I was brain damaged at the time. What I mean by that is I had no filtering mechanism that would lead me to say, "I don't want to be this public."



Ultimately, I was willing to participate because I wanted something good to come out of the whole ordeal of the accident and its aftermath—something that could help other people in their own lives when faced with trauma or suffering. Making a movie seemed like a viable vehicle to do that.

## 15. What was it like for you to see the film for the first time? How has it been to watch the film with audiences?

When I first saw the film on the big screen with an audience, I was somewhat overwhelmed. I had not fully realized what my experience—my physical experience—had been. I was unprepared for the fact that it would trigger PTSD—just seeing the accident footage, the surgeries, and all of the struggles I went through. But with multiple viewings it's become much easier, and I have come to appreciate it as a fine movie. And a funny movie! There are places in the film when Fu or Sabrina and I watch it together when we just start to laugh. There are parts of the film that nobody but us thinks are funny. I enjoy it when audiences laugh during the film and appreciate our quirky sense of humor.

It's been very gratifying to watch it with audiences because people watch it with so much heart and so much attention and so many questions and so much gratitude.

## 16. What was it like having the filmmakers document your journey?

I really didn't think about it much at the time, but now I am struck by what generosity they expressed with their time filming, editing, and finishing a beautifully made movie. At the time, the filming was just what was happening, and Helen and Mark just became part of our family, with the camera fading into the background most of the time.

## 17. Was there ever a time when you regretted the decision or wished you could have stopped?

There was never a time of regret about the decision to let the film be made. However, there were times when I wondered if it was ever going to end and, if so, how? There were times when I was feeling desperate and had no idea whether I could come through giving the story a non-tragic ending, and that was unnerving.



#### GRACE FAOS

# 18. Were there times when you felt the filmmakers understood your experience better than your friends, family, and healthcare providers?

This is an excellent question, and, surprisingly, the answer is yes. Especially when it was particularly sticky between Fu and me, the filmmakers, who walked with me on this journey, seemed to have a better understanding of my emotional state than anybody else did. They were my witnesses, and the camera, my mirror.

## 19. What impact do you hope the film will have on people in general and within the healthcare field?

I'm hoping, of course, that the film will have a positive impact both on the people watching it and on the healthcare field in general. I know that as a physician I rarely had a sense of the entirety of a patient's experience with disease or disability. The film is an honest portrayal of what it's like for a family system to undergo the kind of change that comes from this kind of trauma/disability/disease. To the extent that people understand that disease and/or trauma really is a family and community affair, then, in my mind, the film has been successful.

I feel that the film has been successful in showing that while the disease or disability may be in one person's body, it nevertheless affects everyone who comes into contact with that person,—whether family, friend, neighbor or healthcare professional—because we are interdependent. For healing to occur, everyone affected must participate in the healing process.



#### FAQs FOR NANCY (FU) SCHROEDER

# 1. How do you think your training as a Buddhist priest prepared you to take on the role as caregiver to Grace?

The primary practice for a Zen Buddhist is seated meditation, which is basic training for dealing with whatever is happening...in particular, not running away or getting too scared to respond. Both of those impulses were pretty rampant from the first moment I got news of the accident. I am grateful that practice not only allowed me to "show up" but also helped me not to get too caught up in mental elaborations around the particular circumstances of Grace's accident. As the night nurse said to all of us the first evening of the first day..."You know, she's still alive."

# 2. You made a five-year commitment to care for Grace. How did you come up with that time frame? Did you ever second-guess that commitment?

My commitment to care for Grace was mostly based on the time frame that involved Sabrina's years in high school. She was about to be a freshman the year after the accident, and I was committed to doing what I could to maintain our family connections while Sabrina was still at home. If Grace survived, clearly she would need care at home for a long while. It wasn't at all clear how disabled she would be, either physically or mentally, so my commitment was to support her under whatever circumstances until she could take on her own care or it became clear that she would need to transfer to a long-term care facility.

I didn't second guess the first five years but it took an additional two years for Grace to be ready to make that move. I must confess, those years were quite challenging for me and it may have something to do with having completed the five and not having agreed to any additional years...they just happened. I got pretty cranky and was not very kind or generous emotionally during much of the last two years. Grace moving on to another care facility has been a great relief. I have gotten my own life back.



#### FU FAQs

3. You say in the film that you would "never have taken on the mantle of adult responsibilities had they not been dropped on you." How did the accident affect your role as a mother and your life as an adult in the world outside of Green Gulch Zen Center?

I was, by choice, a monastic from the time I was 29 until I was 40 years old. I lived in a monastery for 3 years and I continued to practice as a single person within a residential Buddhist community until I entered into a relationship with Grace. She came to Tassajara at about the time I was going to ordain as a priest. A short time after that, having moved to Green Gulch together, Grace and I adopted a baby girl, Sabrina, who was chronically ill and not expected to live more than a year.

I had held many positions in the community involving responsibilities for everyone...cooking, managing the guest program, director, etc. but I had not managed a household of my own since entering the Zen Center's communal life. I did not have to think about taxes, employment, health insurance, rent, gas prices, groceries, or most of the other things that occupy adults in our society. With Grace as a co-parent, a well-paid AIDS physician, I did not have to think about Sabrina's health care or educational accomplishments, I did not have to pay for her schooling or clothing or any other thing she continuously either required or requested. Once Grace was in a coma I was responsible for all of

that and a great deal more, including caring for Grace as her primary care giver. I became a single parent: the payer of all bills, the transporter, the cheer leader, the one who helps with homework, fixes things, etc. It was a huge assignment and my only real option was to grow up and to do it fast.

The first shock was going to the bank and discovering that Grace had not transferred any funds to our joint account which had a negative \$400 balance on that day...and asking them to please put some more money in there from her other accounts...the banker stared at me unbelievingly and said, "We can't do that." I then was informed I needed to get a lawyer and file a court order to become Grace's conservator...with that, my adult life began...and it continues to this day. I am sincerely grateful for all that I have learned and accomplished in the multiple roles I was "forced" to take on. Adult life is not nearly as bad as I feared!



4. How did you deal with the stress of being the primary caregiver to both Grace and Sabrina? What support did you seek out and how did you manage to balance your life and prevent burnout?

I didn't stress so much, mostly because of my years of meditation...truly beneficial under almost all circumstances...and I do have a lot of energy as it turns out. I actually liked being needed and also liked not having to wonder if I was doing anything useful for anyone else. As it is our primary vow as Buddhists to live for the benefit of others, whether true or not, it felt like I was doing just that, all day, everyday.

In addition to my natural endowment of energy, I also took up some very fun things, as friends recommended I do. I began sculling on the bay and really enjoyed the serenity of being on the open water several times a week. I took an after hours art class at my daughter's high school which continued for many years, during which time I learned that I have a talent for drawing, painting, and print making which continues to delight me, particularly having believed I couldn't do any of those things that I had always longed to do. I also had a wonderful therapist who helped me prior to and throughout the ordeal of the accident and its aftermath. He was an indispensible source of support and perspective.

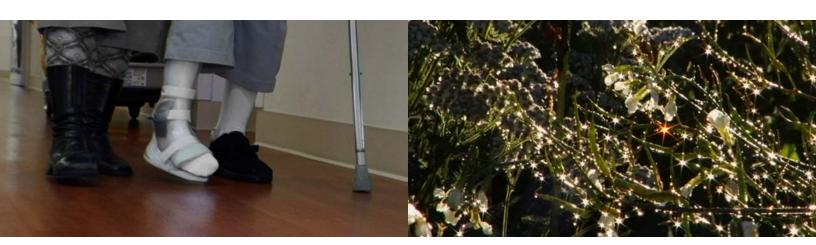
## 5. What kind of support did you receive from Zen Center, family, friends etc that helped you manage—individually and as a family?

Zen Center was incredibly supportive both to me and to Grace during the year she was hospitalized and for the many years after her return home. Following the accident I was basically given a two-year leave with full pay and continuation of my health insurance and housing at Green Gulch. Grace was not asked to pay rent of any kind for over two years (which she had been paying as a "spouse" working outside of the community...about \$800 a month for room and board).

Zen Center also helped to raise funds for Grace's care and provided information about her recovery. Quite a lot of money came in during that first year that helped with renovations and building a pathway so that a house became accessible for Grace when she returned home. In fact, had we not been offered the house Grace would not have been able to live here since it is the only accessible housing at Green Gulch.

When I was invited to become Abbess (in 2014) I was given an additional \$800 a month as "parsonage" to help with household expenses including some of Sabrina's. That is no longer part of my support now that Grace has moved away.

Zen Center also gave Grace a position in the office and designed the desk so that she could sit there. They have supported having students volunteer to help her



#### FU FAQs

with walking and driving places (we don't usually ask the students to help with our personal lives as senior level residents...unfair advantage could be taken. In Grace's case it was not an issue. People have been offering to help her and care about her very much on a personal level).

And, of course, there's the fiscal sponsorship and support for the film, which we are all very grateful Zen Center took on.

Personally, I have many long time and dear friends in the Zen Center community who offered their support. I always had a compassionate ear or two available to me. I also have my Zen teacher of over 30 years who offered excellent counsel on the emotional challenges that came up in the last few years. He is Grace's teacher as well and could hold both ends of our relationship without either of us feeling "triangulated". I have not felt alone for most of my adult life having chosen to study and live in community, and that has served me very well throughout this period of time.

## 6. What role do you think humor played in your role as caregiver and your relationship with Grace?

I think humor, of the good-natured kind, is medicine in and of itself. I could often bring Grace up out of "the pit" by using humor with her and helping her find the lightness that is often lurking in there. Most of the suffering that really was upsetting her wasn't so much the physical pain, as extreme and unpleasant as it could be; her real suffering came from how she was thinking about things...her losses, regrets, shame, etc. Those are the very things the Buddha discovered as optional suffering. We can change our thinking and that can relieve a lot of what is unnecessary for us to bear. It often takes help in doing that and I think I was a good help to Grace much of the time. When I'd lose my sense of humor...everything in the household went south.

## 7. What were the biggest lessons you learned during the years you were Grace's primary caregiver?

The old AA adage..."one day at a time"...also, "don't forget to breathe." And then there's eating good food and doing something you enjoy between rounds of difficulty. Spending time with old friends. Spending time alone.

#### 8. What role do you play in Grace's care now?

Grace moved into an assisted living facility in April of this year (2015) which has relieved me of the role of primary caregiver, except for the times she is back at Green Gulch when Sabrina is home. I do have a role as co-parent, which will continue for life, especially whenever Sabrina is home. And I expect that I will be caring for Grace during those visits.



## 9. What was it like being filmed and having the filmmakers around as "witnesses" to the family's journey?

Very beneficial... it's amazing to have your life reflected and shown to you in this way. I don't think most people ever have the opportunity to see themselves from all angles and in all situations as we have through the process of making this film with our dear, dear friends Mark and Helen.

## 10. What was it like for you to see the film for the first time? How has it been to watch the film with audiences?

Watching the film has been a supremely unique experience. "That's me?" I ask myself. I think we all have a strange experience hearing our own voices which is doubly so in seeing myself on film. I began to appreciate the film itself after several viewings... the artistry of the camera work, editing, sound mixing, music, etc. Quite a large number of people helped produce, pay for and create this movie. All we did was go on about our lives...

## 11. What impact do you hope the film will have on people? Are there specific communities you hope get the chance to see the film?

I have already heard a great deal of positive regard for the possibilities that this film offers to people with disabilities, to care givers, to those who work in the helping professions, doctors, rehab specialists, and so on. I think people also find the peek inside our Zen community intriguing the same way I find it intriguing to look in on other culturally diverse communities. There are many people these days interested in Buddhism and sharing values with this tradition. I think it will also be supportive of those who have taken this path as their religious practice.

# 12. Other thoughts about compassionate/ contemplative care—more on your role as caregiver?

It's a great privilege to care for other people when they are truly in need of help. I think it's important to know one's own limits and also to recognize when the support may actually be hindering the person being cared for from regaining their independence. That transition is pretty scary, as I've seen with both my daughter and with Grace (me too). But without letting go of the care-giver-receiver dynamic it's almost impossible to find out how one can continue to grow. We all have learned from the whole process and that will go on for the rest of our lives.



#### FU FAQs

#### 13. What is happening in your life now (2015)?

I am very grateful to have my own home and to be able to make choices about how I use my time. Becoming Abbess has given me a wonderful role within the small mandala of practice here at Green Gulch. I enjoy ritual and thinking about these Buddhist teachings, both of which are required in my current position. I will be able to go to Tassajara, our monastery, in January and lead a 90-day practice period with a number of the students that I have been working with for many years. Although I still find myself reflexively wondering if Grace is alright and whether I need to hurry home, I am beginning to relax and remember that I am no longer solely responsible for her care.

14. People have said that your care for Grace appears a bit unbelievable and "saintly" in the film. Can you shed any light on the reality behind the scenes and how/ whether you maintained your equilibrium throughout your years of care giving?

Grace was so severely injured and deeply appreciative, as most wounded people or animals are, that it was a privilege to care for her...a feeling I think many people who work in the care giving professions have about their work. So, yes, there was a lot of joy for me in helping both her and Sabrina. I was truly needed in obvious ways.

Before the accident I felt more like the "other" parent who was along for the ride...Grace paid all the bills, decided the vacations, brought home the goodies, provided Sabrina with a private school education... none of which I could have contributed to as a life-long monastic. Yet, after the accident, I was able to provide my family with a home in this beautiful valley, and that was very satisfying. However, it is worth pointing out that I do not own this home and will be moving out of it pretty soon into a much smaller space so that another family can make use of it with their kids.

Saintliness is an idealized notion that really has no referent in the real world as far as I can tell...I've certainly never met a saintly person and I live with some pretty lovely people. I do have a practice that has two very strong components...one side is asceticism, also called "Avoiding evil"...meaning a wise restraint...in other words, not saying or doing in response to what the Dalai Lama calls "pathological emotions" that often arise within us humans, such as "God, I hate her!" or "Maybe I'll just run away and leave this mess for somebody else"...etc.

The other practice is called "Doing good" and of course it's what I enjoy the most. I was a good caregiver and I was a good cook, a good driver, and those abilities make me happy and seem to make other people happy...to a point. These teachings helped me maintain some degree of steadiness throughout the process, though I certainly had many frustrated and impatient moments, too. It's all part of the experience of being a human being and what my "practice" all these years has been about.



#### FAQS FOR SABRINA SCHROEDER-DAMMANN

### 1. What do you remember about the accident and the immediate aftermath?

I remember very little about the accident. I do not remember anything about the actual accident itself, but I do remember that, after the accident, chaos ensued. Looking back, I feel that at that time I was rather calm. I remember it being around my birthday and being upset about not having a party. I also remember that a lot of extended family was around. I attribute not being freaked out to being very young [age 15 at the time of the accident].

# 2. What was it like being filmed while you were a teenager and having the filmmakers around as "witnesses" to the family's journey?

To be completely honest, I was probably the worst person during the filming process. I was a very moody teenager and didn't take to being filmed very well. I was more interested in my room and my computer. However, when I was filmed, I actually enjoyed it. If I am being honest, I love being in the spotlight. Looking back, I think being filmed was a valuable experience because it was actually helpful to have the whole experience documented and to see the changes that happened to all of us. Seeing the film now helps me see how much Grace went through and how much all of us went through.

## 3. What did you learn about Grace and Fu and their relationship from watching the film?

Watching the film, I realized how complex Grace and Fu's relationship is/was. However, I knew most of what was revealed so very little was a surprise. It was interesting to learn more about what they went through when they adopted me as a baby and also how I affected them and their relationship.

# 4. What tools or strategies do you think helped you and your family get through such a difficult experience?

Personally, my tool to get through the hard times has always been humor. I think it is extremely important and can lift people up. Even in the most difficult of circumstances, there is always room for humor and laughter. I also think that our family's large community of friends and family gave us support and helped us through the most difficult times.



#### SABRINA FAOS

5. How have you adjusted to having Grace go from being the primary parent "who was up for trying anything, even if she didn't want to do it" to being limited in what she could do for and with you?

In the beginning, it was very hard, but I have had to learn to adapt. Grace used to do everything and was up for anything. That being said, after the accident, I was forced to become more independent. It wasn't a quick realization; it actually unfolded over time. I would get homework in school and Grace couldn't help so I just sort of had to do it. In some ways, I believe the accident got me to college. It forced me to grow up.

6. How has it been for you to have a parent in a wheelchair, negotiating physical disabilities that are more severe than your own? Have you and Grace "bonded" over this issue?

I give Grace a hard time about being severely disabled because I have always been disabled, and I don't think of being disabled as a big deal at all. Due to Grace's disability, I have actually learned a lot about the varying degrees of disability. The movie has made me feel more sympathetic toward Grace and all that she has been dealing with since the accident.

7. Why did you wait until several months after the film's official premiere to finally see it? What was it like for you to see the film for

### the first time? How has it been to watch the film with audiences?

I wasn't ready to see the film. The accident was very traumatic so I didn't really want to think about it or see it again. However, I did finally see it in New York with my god-sister Aarin. It was important to see it away from familiar territory. After seeing it, I loved it and enjoyed seeing how different audiences reacted to it and how moved people were. In fact, I ended up appearing at lots of screenings with Grace and the filmmakers to take part in Q&A with audiences whenever I could be there. It's a little embarrassing seeing myself as such a sassy teenager, but I think people can relate to me and I enjoy talking with audiences about the whole experience.

8. What impact do you hope the film will have on people? Are there specific communities you hope get the chance to see the film?

I think the film impacts several different groups. The lesbian community, the AIDS community, the disabled community, and the medical community can all learn something from this film.

9. How are you doing now? What are your plans for the future?

Right now, 2015, I am beginning my senior year at Pitzer College. I am majoring in political science and still figuring out what I want to do in life.



#### FAOS FOR HELEN S. COHEN AND MARK LIPMAN, DIRECTORS

## 1. How did you come to make this film about Grace and her family?

States of Grace is a labor of love that emerged from a desire to witness and document a friend's remarkable journey following a tragic, life-altering event. Dr. Grace Dammann, the primary subject of the film, is a dear, longtime friend of Helen's. Our daughters, now young women, had been buddies as toddlers, and we maintained a close friendship during the years that followed.

We received the devastating news that Grace had been in a head-on collision on the Golden Gate Bridge while we were traveling overseas in May 2008. We returned home to the frenzy and panic at the trauma hospital, where Grace's large circle of friends and family kept vigil. Would Grace live? If she survived, would she have any brain function? What would her quality of life be like? How would she, along with her family and community, face the daunting unknowns that lay ahead? These questions consumed us all for the many weeks she was in a coma. We waited and agonized while the doctors performed surgery after surgery attempting to mend her shattered body.

The idea of making a film about Grace didn't surface until after she regained consciousness, nearly seven weeks after the accident. To everyone's shock, Grace awoke on the Fourth of July singing "You Are My Sunshine" and asking philosophical questions, indicating that her mental faculties were miraculously intact. Coincidentally, we had taken her daughter, Sabrina, to the Marin County Fair that day. As we walked around the dusty fairgrounds, Sabrina—who had been in the car with Grace and survived the accident with only minor injuries—brought up the idea of making a movie about her mom.



#### 2. When did you start filming?

The trauma of the accident was still too painful and Grace's future still too uncertain for us to seriously contemplate filming for quite a while. But as the weeks and months unfolded, Grace's recovery and spirit continually amazed and inspired us. We began to think that Sabrina's idea held real promise. As seasoned producers of social issue and educational documentaries, we were ready to dig into a more artistic project and eager to create a verité film that followed a deeply personal story over time. Mark was also itching to move out of the editing room and pick up his camera again, getting back to his love of cinematography.

In 2009, near the end of thirteen months in residential rehabilitation hospitals, Grace was released for an afternoon to celebrate Sabrina's sixteenth birthday at a nearby Chinese restaurant. We videotaped the party as a trial run and were completely captivated by the experience; we just knew her homecoming and recovery would be a remarkable journey to follow. When Grace left the hospital for good a week later, we were there with our camera to start shooting in earnest, never imagining this film would become such a passionate, consuming project for us for the next five years.

## 3. How did you get such intimate footage of Grace and her family?

Right from the start we wanted the filmmaking to be as unobtrusive and observational as possible, so the two of us comprised the entire production crew. We had a unique opportunity to capture the experience in an extremely personal and intimate way, given our history and closeness with Grace, Fu, and Sabrina. All three of them gave us uncensored access to their lives, and we showed up as often as possible to bear witness to their unfolding new reality.

Helen conducted the many interviews with the family, as well as Grace's friends, doctors, and therapists—sometimes using formal interview setups, sometimes organically as scenes unfolded. Mark, who managed both camera and sound, frequently shot on his own, showing up at countless doctor's appointments and physical therapy sessions—as well as sleeping on the living room couch in order to capture the family routine through the night or to document 5:00 a.m. trips to the hospital for Grace's surgeries. To film during times when we weren't around, we gave Fu a small digital camcorder; two of the more poignant scenes in the film come from her footage.



# 4. What was it like for you to witness such intensely personal experiences with Grace and Fu during the five years you were filming?

Though it was difficult at times to straddle the line between filmmaker and friend, there was a kind of magic in the intensity, intimacy, and emotion of the experience for all of us—and our friendships deepened through the process. For Grace, the filmmaking became a way to process her own feelings and experiences as she was going through them. For us, it was both a privilege and an emotional challenge to witness her arduous healing and rehabilitation process; her struggle to come to terms with her profound limitations and dependency; and her determination to make meaning out of her radically altered life and identity. We were often astonished at Grace's resilience in the face of great struggle, and it was heartbreaking to share in the profound losses she had to endure.

# 5. You captured some darker and more difficult moments in Grace's recovery along the way. Did you ever consider leaving them out of the finished film?

We knew early in the filmmaking process that it would be essential to show some of the darker moments in order to convey a realistic picture of Grace's experience. One of the toughest challenges during the editing process was finding the right balance between hope and despair, resilience and resignation. We came to understand that showing just a few of the difficult moments was sufficient to communicate the depth of Grace's struggle and to give the audience a better appreciation for Grace's tenacity.



## 6. Why did you decide to include the nature imagery? Where did you film the birds?

Green Gulch, Grace's home at the time of the filming, is an incredibly beautiful meditation center near Muir Beach, full of gorgeous flowers, organic vegetables and eucalyptus trees. In one interview, Grace talked about how living in a place of such beauty sustained her through the long, difficult years she worked with AIDS patients. Early in the filmmaking process we knew we would need to use nature imagery in order to sustain the audience and provide the space for people to absorb such a challenging, complex story. We also wanted to make a poetic film that would engage the viewer on many levels.

The birds were filmed in Gridley, CA at a wildlife sanctuary on the Pacific Flyway. In the winter months, thousands of snow geese and other migratory birds gather there to rest and refuel. When Grace and Fu saw the film for the first time, they protested that these weren't birds one would see at Green Gulch, but they quickly came to appreciate their beauty and metaphorical power in conveying emotional and spiritual aspects of the story.

# 7. When you started filming you couldn't know what would happen and where the story would lead. How did the film evolve over time?

When we started filming, our focus was on Grace's recovery and there was a great deal of hope that she would walk again and function independently in the world. During the first year at home, friends offered to take her trekking in Tibet or vacationing in France once she was ready. As time passed, expectations shifted and we saw the film shifting as well, to be more about the family's resilience and Grace's process of coming to terms with her limitations rather than a typical "hero story." This evolved along with our awareness of Fu's role as caregiver and the shifting dynamics within the family, making it clear to us that these were going to be critical parts of the narrative, ones we did not anticipate at the outset.

During production we were often asked what we thought the ending would be and we would reply that we didn't know, that we would know it when we saw it. Grace would occasionally leave us messages about what she thought would make a great ending and it became a running joke among us. We never imagined we would shoot for five years, but after Grace went back to work and as Sabrina's graduation approached, that seemed like a natural stopping point, especially given the fact that Fu's 5-year commitment was timed to coincide with Sabrina's graduation. It's trite but very true that graduations mark both an ending as well as a beginning and that moment provided a way to convey the open-endedness of Grace's story.



# 8. You weave together many complex themes and each person's story and back story so effortlessly throughout the film. How did you map out the chronology of the story?

Editing this film was an extremely complex process that took about 7 months of work over the course of a year. We had collected about 200 hours of footage chronicling countless doctors' visits, therapy appointments, visits with friends and colleagues, intense family moments, interviews and much more.

Initially there were many voices in the film telling the story, describing Grace, and talking about their own personal relationship to Grace's journey. But the more we edited, the more those voices dropped away and the more we focused on Grace, Fu and Sabrina. It brought a clarity and intimacy to the film that we were looking for. Work-in-progress screenings encouraged us in this direction and most of the interviews we had spent so much time shooting wound up on the cutting room floor.

Even with that evolving focus, we initially relied much more heavily on Grace and Fu's interview bites to tell the story. It was only over time that we came to trust the power of the verite footage to convey the story with a minimum of commentary and voice over.

There were close to 40 different cuts of the film before we finished it.

### 9. What are some of your favorite scenes that didn't make it into the film?

There was a wonderful scene in which an occupational therapist who was working with Grace at home put on some music so Grace could "dance" and work up a sweat. As Tina Turner's "What's Love Got To Do With It?" blared through the house, Grace moved back and forth in her wheelchair, the OT danced around her, and Fu came dancing into the room. The dancing continued to Aretha Franklin's "R-E-S-P-E-C-T" and was one of those great moments you hope for as a filmmaker. Unfortunately, the cost of music rights was prohibitive and we couldn't find an elegant way to weave the footage into the arc of the film.

Other beloved scenes that didn't make it into the film: home movie footage of opening presents and dancing with friends on Christmas Day; Grace's first haircut after the accident; a trip to the Container Store after Grace moved back home; a difficult, emotional exchange between Grace and Fu about how they were going to spend their free time one summer with Sabrina.

[Mark also had to let go of his fascination with the surgeries and medical details that we learned were putting most audiences to sleep!]



### 10. How did making this film change you—as individuals and as filmmakers?

Perhaps more than anything else, making this film has been a lesson in gratitude; gratitude for being alive, for breathing in and breathing out, for art, for the love in our lives, the warmth of the sun and the breeze in the trees. Both Fu and Grace are Buddhist teachers in different ways and we absorbed their teachings in the process of making the film.

As filmmakers, we learned the joys and tribulations of verite filmmaking through this project, the first film we've made in this way. As difficult as it was just to follow and witness an unfolding process, it was a powerful life lesson in being present. And we both got to apply our varied artistic sensibilities and bring poetry and beauty to this story.

# 11. What impact do you hope the film will have on people? Are there specific communities you hope get the chance to see the film?

We've been overwhelmed by the response to the film and how this very unusual story resonates so broadly. Our hope was to move people to think about their own lives and inner and interpersonal resources in new ways, and to be inspired by Grace's (and Fu's and Sabrina's) strength and resilience throughout this ordeal.

We also hope that the film will be a teaching tool and a resource for health care professionals of all kinds – from people working in rehab hospitals to therapists and chaplains working with patients and families dealing with trauma and illness. So we are excited to be launching this educational phase of the distribution. It's been such a privilege to travel with the film and with Grace, and to see the film inspire so many people. And it's especially gratifying to see how the film is offering Grace a new platform for inspirational speaking and teaching, within the medical community and beyond.



Written by Grace Dammann, Nancy (Fu) Schroeder, Sabrina Schroeder-Dammann, Helen S. Cohen & Mark Lipman

Edited by Helen S. Cohen





# States of Grace CASE HISTORY

### GRACE DAMMANN CASE HISTORY

#### **Accident and Emergency Treatment at John Muir:**

Grace Dammann is a 68 y/o female physician who was driving across the Golden Gate Bridge on 5/21/2008. She was restrained. Her daughter was sitting beside her in the front seat, and their dog was in the back seat. She was traveling northbound in the far left lane, when a driver going south had a symptomatic episode of atrial fibrillation (which had never been diagnosed), passed out, crossed over the median strip of the bridge, and hit the car in front of Grace's, then hit Grace's car directly on the driver's door.

Bridge traffic was stopped for an hour while the police and fire departments extricated Grace from her vehicle. Initial notes by the first responder gave her a 10/10 pain score and noted that she had obvious four extremity fractures. She was given a Glasgow Coma Score of 15, and vital signs of: BP 122/71, HR 124, pao2 79, RR 22, pain 10/10. She was taken by helicopter to John Muir Hospital, in Walnut Creek, the nearest trauma center. En route, she was given 50 mcg of Fentanyl IVP, and 4 mg of Zofran. She received another 50 mcg of Fentanyl, during helicopter transport, for pain.

Transport records include the following physical findings:

General: able to speak in complete sentences

Back: unable to lie flat. Rotated at pelvic level. Lt iliac crest 1.5 inches higher than right

Chest: equal rise and fall bilaterally. c/o difficulty breathing

Rt leg: open tib/fib fx at level of ankle, cannot move foot, distal pedal pulse present

Lt leg: tib/fib deformity above ankle, obvious deformity upper femur. Intact sensation and circulation

Rt arm: multiple abrasions r hand and forearm, tenderness w/o loss of function or obvious deformity

Lt Arm: deformity mid radius/ulna. Intact sensory, limited motor, circulation intact

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On arrival at John Muir, helicopter trauma crew noted that VS were now BP 85/40 with all other VS being the same (HR, RR, GCS, Pain).

In the ER, the patient was noted to be pale, shocky, able to answer some questions, with a BP of 80/40, HR 130-140, decreased breath sounds on the left. She was initially treated for profound anemia with uncrossmatched blood. She was intubated for severe respiratory failure, and given normal saline for hypovolemic shock. A chest x-ray was done which showed haziness, thought to be caused by a ruptured diaphragm.

The patient was triaged directly to the OR for presumed eventration of abdominal viscera into left lung cavity, with some component of a tension pneumothorax. She also had open fractures of the left upper extremity at the level of the elbow, and both lower extremities at the level of the ankles. There was a femur fracture on the left and "multiple other fractures".

In the OR on the day of admission, the following procedures were performed:

- 1) diaphragm tear/perforation repaired and abdominal viscera returned to abdominal cavity
- 2) chest tube placed in left chest
- 3) liver lacerations repaired
- 4) right radial artery laceration repair
- 5) retroperitoneal bleed around the pelvis packed.
- 6) abdomen, which was developing severe swelling and could not be closed (compartment syndrome) was left open, covered with saran-wrap, and a wound VAC was placed
- 7) multiple I&D's were done of open joints and external fixator's were placed
- 8) left femur fracture repaired with an intra-medullary rod
- 9) intra-operatively, multiple x-rays were done. They showed:
  - a. severe comminution for a segment of about 4 cm up the tibia/fibula associated with proximal fibula fracture on the left
  - b. right tibial bi-malleolar type pattern with possible fracture below the level of the talus laterally on the fibula with a comminuted fibula fracture starting about 4 cm from the joint extending proximally
  - c. severe comminution medially (on right?) as well and a subluxed ankle joint which was open
  - d. superior and inferior pubic rami fractures on the left, with no femoral neck fracture, but type I sacral fracture posteriorly
  - e. left forearm with segmental radius and ulnar fractures at the proximal third of the radius and ulna about 6 cm from the radius and olecranon respectively; another segmental fracture was oblique and comminuted, about 2 to 3 cm from the ulnar head; and there was a comminuted extra-articular fracture of the distal radius
  - f. left femur with a comminuted mid-shaft to proximal third femur fracture with medial comminution
  - g. previously mentioned chest x-ray with elevation of the diaphragm

The patient was then triaged to the ICU for warming and treatment of developing coagulopathy.

#### **ICU Hospitalization at John Muir:**

On hospital day 1 (5/22), a right chest tube was placed to treat hydrothorax and treatment was continued for diffuse intravascular coagulopathy (with all Factors including 7, platelet transfusions, and 48 units of red blood cells.) She had a cardiac echo and a CT scan of the head showing multiple small hemorrhagic injuries enhanced by the diffuse intravascular coagulopathy. Cervical spine CT was negative. Cardiac echo was also negative.

On hospital Day 2 (5/23), an IVC filter was placed. On hospital day 4 (5/25), a right thoracostomy tube was placed and the patient returned to the OR for open reduction and internal fixation of the right radius and ulna, with two plates placed; and right upper extremity unstable elbow dislocation with open repair of the lateral ligament.

On hospital day 6 (5/27), she underwent a second look laparotomy with removal of packing and primary closure of the abdomen. In addition, in consultation with an ID specialist, her antibiotics were changed. On hospital day 9 (5/30), patient underwent an open reduction/internal fixation of the surgical neck humeral fracture, comminuted intra-articular distal humerus fracture, comminuted radius and ulnar forearm fractures proximally. Distal radial and ulnar fractures on the left also received internal fixation. She had a total of three plates placed on the left side.

Hospital day 14 (6/4), the patient underwent an open reduction and internal fixation of the right humeral fracture and also the open right ligamentous repairs. On hospital day 16 (6/6) she underwent open reduction of the left tibia plateau and had three plates placed. On hospital day 20, (6/10), patient underwent a tracheostomy and percutaneous gastric tube placement for feeding. Throughout this period she had persistent fevers (with negative cultures) which subsided with conservative management. She was treated, at one point, with Vancomycin for staff epidermidis.

At the point she was ready for transfer to a lower-level facility on hospital day 27 (6/17), patient was neurologically able to open her eyes to sound and spontaneously moved her left upper extremity and both lower extremities. She was not awake or alert enough to answer anything or speak. She had an elevation of liver function tests on the day of transfer with an alkaline phosphatase of 594 and an ALT of 21 and SGPT of 190. She had a total bilirubin of 1.39 (down from the high 5's). Previous liver ultrasounds and gallbladder ultrasound had only shown sludge in the gallbladder with no thickening of the gallbladder wall. She had been in the IUC throughout her hospitalization at John Muir.

#### First Rehabilitation Stay – Kentfield:

On 6/19/2008, 29 days after the accident, she was discharged to Kentfield Rehabilitation Facility, across the Bay, having emerged to a vegetative state with eye opening. On admission to Kentfield, she had no evidence of visual fixation, no evidence of visual tracking, no command following and no evidence of meaningful interaction with the environment.

At Kentfield, her hospital course was notable for the following problems:

1) **Grand mal seizure** (7/10/08—more than 6 weeks after MVA) initially treated with Dilantin then switched to Keppra. No further seizure activity, ever.

- 2) **Heterotopic ossification** (HO) seen on multiple x-rays performed at a John Muir follow-up visit with her orthopedist on 9/10/08. Reviewing her films, her orthopedist stated: "Currently, upper extremities are dominated by essentially bony ankyloses and heterotopic ossification, causing no motion at the left elbow. Patient was started on Didronel. Surgery was planned on her left elbow. She was not a candidate for any PT of those extremities until the HO matured.
- 3) **Vegetative state.** Treated with Sinemet and amantadine, patient awoke on July 4 after about 45 days in a comatose state.
- 4) **Status/post multiple traumatic fractures.** The patient was noted to have generalized weakness (R>L). She was also noted to have a tightness of the ankles particularly on the left with an equina varus deformity which was not helped by splinting, PT, or ROM enough to allow weight-bearing through a plantigrade foot. Nerve conduction studies were performed on 10/31/08 and showed lower motor neuron deficits including severe bilateral peroneal neuropathy with acute denervation, and moderate tibial neuropathy on the left and mild tibial neuropathy on the right, all with acute denervation noted.
- 5) Impaired functional ability. The admitting physician at Kentfield stated: "Dr. Dammann had marked contractures of virtually all joints due to her multiple fractures, and forced immobilization due to these fractures. Aggressive occupational and physical therapy was provided."

At the time of admission, the patient was completely dependent in all aspects of basic care. She was incontinent of bowel and bladder, she was dependent on a tracheostomy and required frequent suctioning. At the time of discharge, she was able to participate in all activities of daily living although she was limited by four-extremity weakness, right side greater than left, and by the bony ankyloses and contractures throughout her body. At discharge, almost 6 months later, as a result of her elbow contractures in relative extension, she required maximum assistance for grooming, hygiene, and dressing. Commode transfers (via sliding board) improved to a minimal to moderate assist. She was practicing ambulation using the LiteGait device. She was continent of bowel and bladder. The feeding tube had been removed and she was on a regular diet. The tracheostomy had been weaned. The IVC filter had been removed. Patient was discharged from Kentfield on 12/13/08.

#### Transfer to Lower Level of Care at Care Meridian, and elbow repair at UCSF:

Grace was admitted to Care Meridian on 12/13/08, a facility at a lower level of care than Kentfield. The plan was for her to have surgery on her left elbow to remove the heterotopic ossification in hopes that she would get some function and therefore be able to participate in acute rehabilitation. That surgery was performed at University of California San Francisco on January 8, 2009.

Elbow contracture release and lateral ulnar collateral ligament reconstruction, an 8 hour procedure, was performed by Dr. Lisa Lattanza. The patient was placed in a continuous motion machine and returned to Care Meridian for care. When she was seen by Dr. Lattanza at 3 weeks post-op, it was clear that the lateral collateral ligament repair had been destroyed by the CPM Machine. She had heard the ligament snap.

On February 20, 2009, Grace simultaneously underwent two surgeries:

1) repeat reconstruction of the left collateral elbow ligament and 2) a left open Achilles tendon lengthening, open z-lengthening of the flexor hallcuis longis tendon(making it 3-3.5 cm longer), and open flexor tonotomies on toes #2, #3, #4, #5.

Once again, Grace returned to Care Meridian, non-weight bearing on the left, with a directive to remain in the continuous motion machine 20 hours/day while her arm healed. She was strictly non-weight bearing on her leg for 6-9 weeks.

#### Transfer to Ralph K. Davies Rehabilitation Facility for Acute Rehab:

Grace was admitted to Ralph K. Davies, a rehabilitation facility, on 4/15/09 for acute rehabilitation. She had the following findings on initial history and physical examination:

Affect appropriate, no changes in level of consciousness. Manual muscle testing revealed:

- 1) symmetrical weakness about the shoulder external rotators
- 2) severe weakness of hindfoot and ankle muscles on the right
- 3) seemingly less severe weakness on the left (the lower limb placed in splint that was not to be removed)
- 4) right elbow nearly flexed in contracture
- 5) bilateral hand intrinsic muscles, symmetrically weak, with some wasting of the interosseus, without fasciculation
- 6) no spasticity found in upper limbs, but Ashworth I spasticity of right knee
- 7) great toe interphalangeal joint position intact on the right, equivocal on left
- 8) testing of gait and station not possible (not safe to do so)

On discharge two months later, findings included:

- A left wrist and finger drop and paresthesias about dorsal left web space were attributed to aggressive use of the CPM machine. EMG studies revealed severe axon loss left radial neuropathy, severe left ulnar neuropathy at the elbow, longstanding
- 2) The heterotopic ossification was stable, with right elbow severely fused. Her right ankle was essentially fused (later surgery on both was planned)
- 3) A bilateral foot drop, which was found at Kentfield, was the result of peronal and tibial neuropathies and presumed sciatic neuropathy found at RKD
- 4) The symmetrical proximal weakness improved, and was thought to be the result of critical illness myopathy

- 5) A restless leg syndrome was controlled on Mirapex
- 6) A late post-traumatic seizure was controlled on Keppra with plan to continue anticonvulsants for 2 years
- 7) Hypothryroidism: stable on levothyroxine
- 8) Depression: stable on Sertraline
- 9) Pain: well controlled on 25 micrograms of Fentanyl

Because of limitations in use of both her arms and legs, the patient returned home somewhat dependent in all of her ADL's. She was continent of B&B. In terms of her traumatic brain injury (TBI), she was found to be without functional sequelae.

#### First Discharge to Home (13 months after the accident) and further elbow surgery:

The patient was discharged home on 6/16/2009, where she stayed until February 11, 2010 when she was admitted to UCSF for the debridement of right elbow heterotopic ossification, with contracture release, anterior capsulectomy, ulnar nerve neurolysis, transition medial collateral ligament reconstruction with tendinous allograft.

#### Second Admission to Ralph K. Davies for Rehab

She was admitted to Ralph K. Davies, from UCSF, on 2/18/10 for progression of her gait ambulation, and ADLs, for a safe transition back to the community. At the time of admission, she was non-weight bearing on her right upper extremity.

On admission to RKD, physical exam was notable for the following:

Age-appropriate woman, neurocognitive exam grossly within normal limits (higher executive function and testing, deferred). Alert, oriented to person, place, date and hospital name, without delay in rhetoric or verbal responses, without perseveration, tangentiality or impairment of language pragmaitics. She was organizing well. She was able to problem solve complex hypothetical clinical situations well. Cranial nerve exam was without abnormality.

Right upper extremity in a CPM machine, currently at 0-135 with 80 degrees supination, 80 degrees pronation, non-weightbearing.

Weakness of 4 extremities without interval change from last admission, except that LUE shows ataxia.

Sensation appears otherwise intact, patchy in upper and lower extremities.

#### Second Discharge Home (22 months after the accident)

Grace spent almost a month at Ralph K. Davies Acute Rehabilitation facility and was discharged to home on 3/15/2010.

On discharge, her condition was as follows:

- 1. **Activities of Daily Living:** At the time of discharge, pt. required max assistance for upper and lower extremity dressing, moderate assistance for bathing, supervision eating and grooming. She required minimal assistance transferring to and from bed, chair, wheelchair, tub, and ambulating on level surfaces. She requires max assistance for negotiating stairs.
- 2. **Right ankle pain** in the context of HO and contracture prompted the fabrication of a patellar tendon bearing orthosis to unload the affected joint. Ankle surgery planned for three months.
- 3. **Possible cognitive impairment** after severe closed head injury can be further evaluated when a return to work is anticipated.

#### Final Reconstructive Surgery at UCSF and Third Rehab Admission to Ralph K. Davies:

Grace underwent her final surgery, again with Dr. Nancy Kadel at UCSF on 9/03/2010 to correct a severe eqinovarus deformity in her right leg/foot. She underwent a Splatt procedure (transfer anterior tibia tendon transfer, posterior tibia tendesis and medial ankle joint contracture release. She was transferred to Ralph K. Davies as non-weightbearing for nine weeks for rehabilitation on 9/07/2010.

On admission, she was noted to be age-appropriate, alert, oriented x 3, able to follow 1-step lateralized commands, exhibiting no paroxysmal changes in level of consciousness or affect, without aphasia or neglect. Cranial nerve examination revealed no abnormalities. Motor exam revealed symmetrical bilateral weakness in the upper extremities with bilateral wasting of hand intrinsic muscles, with no fasciculation. Right leg was casted.

#### Third Discharge to Home:

At discharge, the patient was listed as requiring the following assistance: maximal for bathing, upper body dressing and grooming, and total assistance with lower body dressing, toileting, and household ambulation. She required minimum assistance with transfers and had a trial with a sling based walker.

Grace continued with outpatient rehab. In June of 2010, she had extensive neuropsychological testing to determine if her cognitive function would be improved with the addition of methylphenidate—either 5mg QD or BID, or 10mg QD or BID. Each dose and dosing schedule change (e.g. QD or BID) was followed by extensive neuro-psychological testing in order to determine the optimal dose. Grace's was found to be 5mg BID.

In October of 2011, Grace's physiatrist cleared her to practice medicine without restrictions. She established a clinic for residents with chronic pain at Laguna Honda Hospital, the largest SNF in the United States.

In January of 2012, Grace experienced 2 falls within 3 days of each other. Neither resulted in LOC. Both involved unprotected damage to the head. In the first instance, she hit her head sharply on the corner of a dining room table, in the temporal area. The second resulted in loss of balance in the bathroom where the back of her head got the full, unbroken force of her head making contact with a tile floor. An MRI of the cervical spine done on 02/10/12 showed no evidence of severe canal stenosis or myelopathy. Nonetheless, self-care skills, particularly involving transfers, suffered. A head CT of 2/1/2012 revealed no subdural bleeding. B-12, methylmalonic acid and copper were all normal. Because she suffered a slow decline, she was readmitted to RKD on 3/04/2013 for acute rehabilitation for increased disability resulting from spasticity.

#### Fourth Rehab Admission to Ralph K. Davies:

On admission, pertinent new physical findings were:

- 1. Motor exam revealed Ashworth 2 right upper and lower limb spasticity.
- 2. Interval worsening of right (60-130 degrees) but not left (35-140 degrees) passive elbow range of motion.
- 3. Weakness affecting right shoulder external rotation and flexion, right ankle dorsiflexion and plantar flexion, left finger abduction, and ulnar dip flexion muscles and left interosseus manus atrophy.
- 4. Sensory exam revealed ataxia on left finger-nose with eyes closed.
- 5. Gait exam not safe to perform.

Review of hospital course, by problem, revealed the following new findings:

- 1. Cognitive impairment predominately affecting attention, especially in regard to self-monitoring moor procedures.
- 2. Heterotopic ossification of right elbow confirmed by asymmetrical uptake (versus left elbow) on triple phase bone scan. Initiation of further treatment with Indomethicin was begun, with no positive results.
- 3. Spasticity treated with 5mg of diazepam daily resulted in significant functional improvement.
- 4. Single post-traumatic seizure with no recurrence. On long slow Keppra taper.
- 5. Pain: well controlled on 37microgm/hr. of Fentanyl.

#### Fourth Discharge Home:

On discharge (3/22/2013), examination of gait and sit to stand revealed that they (sit-stand) were performed independently with the following gait abnormalities: a) fixed and internally rotated right hip and associated narrowing of base of support; b) severe compensated right stance phase Trendelenberg with associated foreshortening of right stance phase; and c) moderately severe right hemi-ataxia.

#### **Surgery for Small Bowel Obstruction:**

Grace had one more hospitalization for a small bowel obstruction in January of 2014. Conservative attempts at management failed and a previous midline incision (from repair of the diaphragm) was reopened both above and below the umbilicus. Extensive and dense omental adhesions prevented the use of a laparoscopic procedure. Adhesions were lysed, but there was evidence of chronic obstruction from a tight adhesive band. Further exploration revealed two other areas of tight obstruction. In one case, the small intestine was twisted around the adhesive band. Two different areas were resected. Grace spent three days in acute rehab after the abdominal surgery, at which point, she was declared at baseline, and that is where she has remained.

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