

“How I Met Alma ”

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I have been working as a musician at a San Francisco hospital and cancer center for the past 14 years. playing music for people who are recovering from surgery, receiving treatment, chemotherapy or radiation, for their care givers, friends and for the staff. The following is a true story and all the names have been changed.

One day in August 2005, while I was playing the dulcimer on 6 East, the surgical inpatient unit, the social worker asked me if I could work with a patient on piano. “She has a piano her husband bought her but she doesn’t know how to play. Maybe you could help her. She’s been in the hospital for a long time, almost a year, and the exercise would be good for her manual dexterity. If nothing else, it would give her something to do.”

When I went in to see Ms. Valerio she had already put tape with numbers on the keys of her piano. She showed me the instruction booklet which listed the notes of the songs by number. “You’re ready to go,” I said. I couldn’t help smiling to myself a little.

“Yes, I’m ready,” was her reply.

We started with ‘Twinkle Twinkle Little Star.’ I wrote out the numbers for the notes for the right hand above the lyrics, and after she’d played through it once or twice successfully she announced, “Okay, but I want to play with both hands!

Maybe there are some exercises you can show me for my fingers. They are weak, especially my left hand,” she exclaimed, wiggling her third and fourth fingers.

“Alma, you seem very determined.”

“Do you mean goals ? ”

“Yes, goals.”

“I have goals. I want to get well, I want to go home and I want to learn to play the piano.”

I showed her how to play a scale with each hand, with the traditional fingering and an exercise she could do with just her ring and pinky finger on each hand, and then we moved on to the left hand. I showed her 3 note chords for the accompaniment.

“I want to learn to play ‘Happy Birthday’ for my daughter’s birthday.”

“When is her birthday?”

“November 28.”

“Well, we have almost three months and you’ve pretty much learned it the first week, so you’ll be fine. We’ll practice a scale to warm up and then the right hand in short sections, then the left hand in short sections. Then we’ll try both hands in short sections and we’ll practice singing the melody with the chords, and then singing with both hands. This is how I practice even now, in simple short sections. Your brain will put the sections together. There was a man in China who was in prison. He was a classical pianist and was not allowed to play the piano for 14 years, but he practiced mentally every day, imagining the keys and the notes on the pages in his mind. When he was released he could still play the songs he’d been practicing while he was in prison.”

“Really ?”

“Sure. I mean he had to build up the strength in his fingers again but he didn’t lose anything. So it helps to imagine your notes on the piano while you’re lying in bed, to imagine in your mind playing a scale or even to just sing the song to yourself.”

As I got to know her, I learned that Alma had been in the hospital for ten months because her skin produced defective collagen and would not heal properly. She did not have cancer. She had undergone 3 or 4 major surgeries to graft synthetic skin onto the wounds, but none of the procedures had worked well enough for her to go home. Alma was 28 years old and had a six year old daughter and a 19 month old son. Her son was only 8 months old when Alma was hospitalized. Her husband came every day to see her, usually after work. He drove 30 miles from the East Bay across the Bay Bridge in rush hour traffic, and her children would come to visit a couple times a week.

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Halloween Clown

Every year for Halloween and Christmas I stroll through the hospital and cancer center in my clown costume with the doctor scrubs and a surgical gown over my costume, and even the operating room booties on my feet with bells on my ankles over my red and white striped socks, playing my accordion. Even though I have been performing for many years as a traditional silent European style musical clown, this is not ‘Jimbo the Clown’ but ‘Jimbo the Cardiovascular and

Thoracic Surgeon.’ He wants to help the ‘other’ doctors. I knew if I went into Alma’s room she would probably ask me at some point to entertain at her kid’s birthday party, so I thought about it and decided, “sure, I’ll do it if she asks.” When I came into her room she got a big kick out of it and laughed and laughed. The next time I saw her we’d been talking for a while, and out of the blue she asked, “do you ever entertain at kids’ parties as that clown?”

“Sometimes,” I said with a smile.

“How much does it cost ?”

“It depends. For you it would be lunch. Feed me.”

She hesitated, “really?”

“Here’s my card with my picture on the front. Just let me know when it is, I’ll be there.”

“Thank you.”

I was playing the dulcimer in the hallway when her doctor walked by and asked the name of the instrument I was playing. He thanked me for the music. “I’m working with one of your patients, Alma, and she is learning to play the piano.”

“That’s wonderful.”

A few days later he was making rounds with several of his residents and came over and asked me, “what is the name of that instrument again?” He wanted them to know about the dulcimer.

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A short time later Alma had a setback. Her wound started hemorrhaging again and she had to go on bed rest and couldn’t sit up to play the piano. The nurse who was her wound specialist suggested that I might help Alma write a letter to her kids, Miguel and Margarita. The implication was she might not survive to see her children again. I felt I wanted to approach this in a different way.

The next day I saw one of Alma’s nurses, Lisa, in the hallway and I asked how she was doing today. ”Pretty well. Sometimes it seems like Alma takes one step forward and then two steps backwards, but she’s making progress since she’s been here.”

“Lisa, I like your way of looking at it, focusing on progress and moving forward

and not 'what might happen.' ”

When I saw Alma I asked her, “I have a friend who kept a journal for each of her two daughters while they were growing up. She would write down her memories of their childhood. Sometimes not even every year, but what it was like to be their mother, their first day at school, their first soccer game. Things like that. Until you can start playing the piano again, would you like to try that? Think about it and let me know next time.”

“So it wouldn't be just about being sick?”

“Oh no, it could be about anything you want. How you met your husband, maybe.”

“About some of the people here, the nurses,” she added.

“You mean some of the good things that have happened while you've been here?”

“Yes.” I was beginning to understand the depth of this woman.

The next day she told me, “I think the stories would be a good idea.”

“Great. I brought a book with me about writing your own personal history. It starts with early childhood, then middle childhood, then teenage years and adulthood and gives you ideas about different memories. Here's one from teenage years, 'Something I was grateful for when I was a teenager.' I didn't really expect her to respond but as I continued leafing through the pages she began speaking,

“When I was a teenager, I was very happy...”

“Whoa. Wait a minute let me get a piece of paper and pen.” And so I wrote down word for word exactly what she told me. I jotted down keywords very quickly to keep the conversation flowing and I would ask her questions, and later incorporate them into her story. This one would describe how she met her husband,

“My Teenage Years”

By Alma Valero as told to Jim Murdoch

I was born in Pasadena and moved to Costa Rica when I was 6 and then later to Mexico. When I was 15 years old I came to this

country to live in Bakersfield with my sister, Veronica. Veronica is 10 years older than me and lived with her husband and two girls, 4 and 2. I was happy there because I came to stay with her like a vacation for eight months and wasn't going to school and could do whatever I wanted to do. Because I am Christian, I respect myself. I did not want to embarrass anyone in my family. I set limits for myself and that made me proud. All my life I've been sick, since I was two months old. When I was little, like 2 years, they had to let me out of the hospital because they didn't know what was wrong. They still don't know what is wrong, why my skin doesn't heal. But I was happy when I was single. My parents loved me so much and they showed it.

When I got married my husband loved me, but I didn't know it until this happened. He would always be with me. For two months he stayed with me here at the hospital and didn't work and just stays with me. He didn't leave me alone, ever. Now he comes every day to see me. Sometimes he works here in San Francisco or close by. He goes all the way home to Antioch, takes a shower and comes back. He works construction so he has to be clean when he visits.

We met each other at church when we lived in Guadalajara. I was 18, he was two years younger and we got married when I was 23. We were only boyfriend and girlfriend for eleven months before we were married. He moved to Guadalajara from Michoacan and started coming to our church that week. We would only see each other at church every week. After about six months we started to talk a little. On February 8, Raul and I were at a party, playing a game, "Gestous Senas," (Charades). He got mad, I tried to help him not to get mad. He got mad because he was losing...

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The wound nurse told me. "We can't really figure this out so I'm bringing the top wound specialist from the university hospital for a consultation. There is some underlying cause that we are missing."

I thought: "skin, kidneys, acupuncture, Chinese medicine," and left a message for the acupuncturist who comes to the unit as part of a pilot program to give acupuncture treatments to surgical patients to help the healing process. Turns out one of them has been massaging her feet every time she came on the unit. Perfect.

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“When I am strong enough they are planning to do an operation and use my own skin from my leg to close the wound. Maybe in November. What would that feel like to take skin from my leg? Do you think it will hurt?”

“Probably. It might feel like a burn or when you fall and skin your knee. It would sting for a few days.”

“I want to tell you the whole story of how I came here.”

### “The Story of How I Ended Up Here”

By Alma Valerio as told to Jim Murdoch

On October 15, 2004 I was at home preparing to go to sleep. I was pregnant and had a lot of pain in my stomach. We thought there was something wrong with the baby so we went to the East Bay emergency room. I was in so much pain but they couldn't give me anything for three hours because I was pregnant. The ER doctor decided to look inside and they found a little bulge in my large intestine and it exploded.

The doctor told us that we had to decide whether to try and save me or the baby. We both could not survive. He told us, “if you decide to save the baby, it is only 12 weeks old and will be in an incubator and not have a very good chance to live.”

My husband and I decided to save me. They had to clean everything inside me because of the contamination. They had to remove a large part of my intestine. The doctor told my family that I would only live for three hours because my blood would not clot, it was flowing out like water. “Do you want us to try to save her or to let her go peacefully?”

Thank God this doctor was there from Oakland, Dr. Whitestone who knew of a medicine that would help my blood to clot. The medicine arrived from Oakland in one hour and they would wait 30 more minutes to see if it worked. They took me to the operating room and I died for 7 minutes. It was God. It was very difficult, my family was very worried, they were praying, they were crying. The doctor told them, “if she lives, she is going to live like a vegetable, she won't be able to walk, to talk, to think. So you decide what you want me to do, keep working on her or let her die in peace.”

My husband decided to keep going. And then I was okay. It was God. God let me see, speak, talk. I went home and I was walking a lot at home and then I came here with a lot of infection in my stomach. Dr. Whitestone referred me to this hospital to Dr. Antonio-Gonzalez. When I met Dr. Whitestone I thought he was an angel. When my blood was flowing like water he called his hospital in Oakland for the medicine that stopped the bleeding.

It is a sad story. It is wonderful to know God is always with me and has never left me. These doctors are experts. So I'm here waiting for the wound to close so I can be with my kids and not spend another Christmas here. When I arrived here I was very, very sick and very weak. I had a fever for a week. I was dying because of the infection. The nurses here thought I wasn't going to make it. Dr. Antonio-Gonzalez saw me and started to fight the infection with antibiotics. They thought they would do the surgery to close the wounds but Dr. Antonio-Gonzalez told me he had to wait to do the surgery because I was so weak and sick because of the infection.

When they did the operation and tried to graft synthetic skin onto my skin to cover the wound, my skin ripped because it is very delicate. This is a new illness. The doctors don't know what to do to treat my illness. When I asked him, "what is wrong with my skin?"

He said, "we don't know."

On Tuesday I'm having another surgery. I'm excited about this one because they're going to use my own skin to cover the wound, skin from my leg to cover the wound in my stomach. I'm very happy about the operation because I have faith that everything will be all right and this will be the last operation. I feel like Dr. Antonio-Gonzalez is very intelligent and he knows what he's doing. He has been a very important person. Whenever I see him my face turns to a smile. He has the intelligence of God to tell the other doctors what to do. I trust him. I trust God. He told me, "I know you have faith in God. That's why you're still here."

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When I saw Alma the following week, she was incredibly excited, "They are going to do the surgery on Tuesday, November 1."

“That’s in one week.

“One week,” she repeated almost in disbelief. “What will happen with these stories?”

“They’re yours. I’ll type them up and give them to you. If you want you could read them into a tape recorder and you would have the tapes.”

“That would be good practice for me. I want to tell my story to the people at my church.” I told her about Lance Armstrong, how sick he was, how he almost died and how he has used his experience to offer encouragement, and hope to other people.

“That’s what I want to do. My husband knows all the details of everything that happened, because I don’t remember everything...”

“You were asleep for a lot of it, it was kind of like you weren’t really there.”

“Yes, I wasn’t there.” We both smile.

“Do you think these stories could ever be a book?”

“Sure. When things calm down a little, you can do it with your husband. The same way we practice the piano, a little bit at a time. Work together on one of the stories, put it away, come back to it again later when you have time.”

I told Alma about a physician, Larry Dossey who is very interested in prayer.

“He has collected research that shows prayer helps people being prayed for even if they don’t know it and it helps the person doing the praying also. He has an altar in his office and every morning first thing he looks at a list of the patients he will see that day and says prayers for each of them.”

“Oh, that’s wonderful,” she replied.

“I think so too and so I thought to myself, ‘what could I do that would be similar with music?’ And I decided to play a short song first thing in the morning that would be a musical prayer for people to get well. Now I hope all the music that I play is like a prayer for people, to help everyone and so during your surgery and afterwards, wherever I’m playing, I’ll be thinking of you, playing for you to get well.”

“Thank you.”

“Alma, I have a question. You say some really nice things about Dr. Antonio-Gonzalez here at the hospital. Would it be okay if I give him a copy of these stories?”

“Yes, of course.”

I dropped off a copy at his office the week before the surgery. On Tuesday her surgery was scheduled to begin at 1 pm. When I arrived she was still in her room, so I sat in the hall a few doors down and played the flute. A slow relaxing meditative song, a Celtic song and even our song, ‘Twinkle, Twinkle Little Star.’

When I went into her room, her family and her pastors were with her. Her smile, her eyes, her face, she was absolutely beaming, so happy, so confident and optimistic. “This is the image I will remember,” I thought.

Later I saw her doctor visiting with another patient. He was explaining something and when he finished, he turned to leave, but then he thought of something else he wanted to say, turned around and continued his explanation. I have never seen a surgeon do this. They are often walking out the door as they are finishing their sentence. When he finished he came over and thanked me, “I really appreciate you taking the time to give me a copy of her stories. It was nice to hear all of this from her perspective.”

Later that afternoon while Alma was in surgery I returned to 6 East to play out in the hallway. After a few minutes I laughed to myself when I realized I was sitting outside her room, “like the cat waiting on the porch for her to come back.”

Her surgery lasted 8 hours on Tuesday and when I saw her pastor the next day he said there was ‘a little complication’ and they had to do some more. The surgery on Wednesday lasted 6 more hours.

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The ICU....waiting

When I returned on Thursday to see how Alma was doing, her ICU nurse Talia shook her head and said, “she’s intubated and non responsive.” The surgery apparently did not go well and she was now heavily sedated in order for her body to hopefully stabilize.

As I played in various locations around the hospital and Cancer Center, I continued to bring the image to my mind of Alma on that morning of her surgery, smiling, happy and optimistic. As I played I would use the music to visualize the

suffering leaving her body and healing taking its place. I would also do this in the morning at home when I first woke up as part of a meditation practice. It wasn't always very easy. When I saw her in the ICU she really wasn't recognizable because of swelling in her face and of all the tubes sticking out. Her hair was how I knew it was her.

Her family, a brother, two sisters and her two kids were there in the waiting area all day and her husband stayed the whole first week. On Friday afternoon around 5 o'clock I was walking back from the ICU and saw him and a social worker talking quietly in the ICU Family Waiting room. It was dark outside and the lights in the room were turned down low. I never found out what they were discussing but a little flash of intuition came as I passed, "how long do we want to keep going with this ?"

The following Monday, November 7, there was no change. Her situation was not looking good. The outcome was not what they had expected. She was so hopeful, so optimistic and had been through so much, it was so sad. And at this point there was no other way to look at the situation, there was no other place to go, it was so sad.

The chaplain suggested I ask if I could play for her in the ICU. Even though I was directing the music to Alma wherever I was playing, I thought that live music would help put the room in a better mood. The ICU nurses agreed and everyone really appreciated the music and the relaxation it brought. So I played there on Monday, Tuesday and Wednesday. As I was finishing, and taking off my gown, one of the OB GYN oncologists was writing notes about one of her patients. I knew her pretty well from playing in different places in the cancer center and she has always been very friendly and supportive. She turned to me, "you really have a wonderful bedside practice."

I realized how my relationship with Alma had now extended and brought music into the ICU for the nurses, the patients, their families, and for the other doctors and staff who come here. I could come back Friday afternoon and play again around 5 o'clock. In the next two days I began to dread that idea, not knowing what I would come back to. When I arrived on Friday at 5:30 I actually checked my messages and then called the chaplain to see if there was any news.

No messages, no answer ....I went to the ICU and Talia said, "You won't believe it. She's awake and talking!"

"What happened ?"

"We decided to try and extubate her or we were going to have to do a

tracheotomy because the breathing tube had been in so long. She deserved a chance to breath on her own. We just took it out this afternoon.”

I put on my gown and went into her room. Her sister, Monique was there holding her hand and quietly reassuring her. I sat about 10 feet from her bed and began playing the dulcimer. After a few seconds she lifted her head off of the pillow, looked right at me with pretty wobbly eyes, going off in different directions and plopped her head back down on the pillow.

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On Monday November 14, I was playing in the hallway back on 6 East and one of the resident doctors asked me if I would go down to the ICU at some point to play,

“Ms. Valerio was asking for you.”

A few minutes later one of the physical therapists came over, “Alma wants to know if you will come down and play for her again.”

“What ? She remembered me playing for her on Friday ?”

“She wanted to know where you were.”

I couldn’t believe it. So I went down and sure enough, “yes, I was very happy to hear you again.”

“During your surgery and then when you were here in the ICU I would think of you whenever I was playing.”

“I didn’t realize how long I’ve been here, how serious this was. Thank you for coming.” She had always used that phrase each time as I was leaving, “thank you for coming.” From now on whenever she said it, it had taken on a new charm.

On Tuesday afternoon she was back in her old room on 6 East and I was playing the dulcimer for her. As far I knew the surgery had not been successful and no one had mentioned what the next step would be. I didn’t know how much of this Alma knew, so I just decided to continue. That really had been the lesson, ‘stay with what is happening.’ It has been reinforced many times and even though the uncertainty of the present might not always very comfortable, it’s part of compassion. As Black Elk, a Lakota holy man expressed, “being a companion, accompanying someone during a difficult time in their life, whether they survive or not.”

It was November 17 and her daughter's birthday was approaching. I knew she wouldn't be going home in time but I also knew she would bring up her party and my offer to entertain as Jimbo the clown. I was curious how long it would be, when she would ask.

The next day I was playing for her with a new twist. I had gotten a harmonica rack and a harmonica in the same key as the dulcimer and was playing them together. She was watching me very closely and when the respiration therapist came in to do her breathing exercises I asked, "do you do these exercises with her every day?"

"Oh no, every four hours, she had a pretty bad lung infection when she was down in the ICU," replied the therapist.

"Would it hurt her to play a harmonica?"

"Not at all, it would be great for her lungs. They've become so congested from infection."

"Alma, I'm getting you a harmonica."

She smiled, "oh, thank you."

I continued playing for her and a few minutes later kind of out of the blue she asked, "do you know any Christmas songs?"

"Sure."

We sang 'Jingle Bells' and 'Silent Night' together. She sang "Silent Night" in Spanish. I learned the first line and sang with her,

"Noche de Paz, Noche de Amor."                      "Night of peace, Night of love."

It sounded so beautiful in Spanish. Two weeks intubated, her survival very much in question. "Christmas has changed, it will never be the same." The emotion was overwhelming and I struggled to continue playing, "I'll always remember this," I thought.

"I'll bring some more songs next week, I really like all the Christmas music."

"Me too. It's my favorite time of the year. I heard on the TV that there are 47 Christmas songs."

“We’ll have to do them all,” I laughed.

“When I get out of here I’m going to have a party for my kids.”

There it was, a day and a half out of the ICU...”you still have my phone number?”

“With the clown’s picture, yes.”

“I’ll be there, just let me know when it is. Alma, is it okay with you if I let the other people who work here read your stories?”

“Oh sure.”

Over the next several weeks I made sure everyone who knew her had a chance to read the stories and understand Alma’s motivation, wanting to use her experiences to offer encouragement to others. I put a copy of the stories in the break room for the nurses on her unit to read at their leisure, for the nurses in the ICU, the physical therapists, the social workers, the residents who worked with her main doctor, the chaplains. Even one of the patient care assistants asked me, “did you write those stories?”

“No, I told Alma about a friend who kept journals for her two daughters as they were growing up. Alma liked the idea and she told me the stories and I just wrote them down.”

“Man, there was some serious stuff in there.” I knew he has a two year old son so I said,

“You should start keeping a journal or notebook for your boy.”

“You’re right, I should.”

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I think everyone in this process, including Alma came to see a fuller picture of who she is. Learning to look beyond what appear to be limitations. A friend describes, “‘the disabled’ who are not disabled.” Yes, what she had been through was incredible and tragic but as the positive developments emerged, she had become much more than a “just a patient.” Our sense of community also deepened as we all got to know each other better. And now she would slide quite easily into her new role as a singer and musician, sharing her love of music.

The next time I came I brought the lyrics to all the Christmas songs which I

also play with the seniors at this time of year. When I arrived she was talking on the phone in Spanish with someone who I thought was her little son. The tone and the warm emotional quality of her voice was very sweet as she called him 'nino' ( boy) several times. When she hung up I asked, "was that Miguel ?"

"Oh no, my husband. He's coming later this afternoon and I asked him to bring me some lemons or some limes for me to put in my water. I have been so thirsty lately. They really taste good."

"Alma, when I saw Raul a few days ago, I was surprised, he looked good, rested and happy. He doesn't look tired or worn out by everything that's happened."

"No, he's always the same."

"He's right with you every step of the way. After everything the two of you have been through, it's beautiful how close you have become."

"Yes, he told me that he doesn't ever want me to see him upset. Because he thinks that might make me feel bad. But he told me when things were difficult and during the surgery when he went out to the van, by himself, he would cry."

"He told you that?"

"Yes."

"That's really healthy, really good that he talks about it. So if he forgets the lemons and limes, is he in big trouble?"

She smiles, "oh no, but I'll remind him and tease him. We have a joke, to close your hand with the little finger sticking out like a bull's horn and put your hand on the side of your head."

"Like you're going to charge ?"

"Yes, but now my kids are starting to do this, so I don't like to. I close my fist and shake it and make a face."

"'Problemas Grandes,' 'Big Trouble,' if he forgets those lemons and limes."

Alma laughs. I take out my accordion and we sing some Christmas songs. A little while later, Raul calls again and the affection and love in her voice for her 'nino' is genuine. 'Heart laughter.'

On the way to my car I saw the wound specialist and told her about singing

Christmas carols with Alma earlier. She filled me in on some of the details, “actually the surgery worked. At first we thought it didn’t, but it seems like there is a door of opportunity opening and maybe we should see how far we can push and try to get her home, so she can watch her kids grow up.”

The following Monday November 28, I brought Alma her harmonica. We worked for a while on ‘Twinkle, Twinkle Little Star.’ I inverted my harmonica with the high notes on the left so she could mirror my movements. I would use my hand to indicate the direction, either inhale or exhale, like a conductor, “ blow, blow, slide up two holes, blow, blow, inhale, inhale, blow ....”

Then we sang ‘Silent Night’ in Spanish, ‘Noche de Paz, Noche de Amor.’ ‘Night of Peace, Night of Love.’ Since we’d last sung it, I’d found the entire song in Spanish and printed a copy for each of us. She explained the Spanish phrases that I didn’t understand. I played accordion and we sang. As we finished Alma was gasping, “I need more air.”

“Are you all right?”

“Yes, but I need more air to sing. The NG tube makes it difficult to get enough air.”

An NG or nasal gastrointestinal tube goes down a person’s nose and into their stomach to drain any fluid. It has to be taped against a person’s nose and is quite uncomfortable.

“Okay, we’ll do it again without the accordion. Take two slow, deep breaths and we’ll sing just the first line together... ‘noche de paz.’ Okay, take two slow, deep breaths and we’ll do the next line... ‘noche de amor.’” We went through the whole song line by line, breathing in between each line. We spent about 45 minutes doing this.

At the end, “Alma, can you hear your voice is much stronger?”

“Yes, I can feel it. It feels good.”

The next time I saw Dr. Antonio-Gonzalez, I told him about our work with the harmonica and singing ‘Noche de Paz’ line by line and breathing, and how it helped Alma. “That’s wonderful,” he smiled and shook my hand, “thank you so much for everything that you are doing with her.”

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The wound nurse told me with genuine enthusiasm, “we are seeing real progress with her wound. I think there is a door opening. There are still obstacles but

maybe we should push a little more now and see if we can get her home for Christmas.”

Two of the obstacles that Alma would have to overcome and have removed before she could go home were the wound vac and the NG tube. Alma had a wound vac covering the main site where they had operated. This is a sponge like device that at times presses against the wound and has a tube to drain fluid away from the wound and help it to heal.

Whenever I first saw Alma, I would always ask, “how are you?” Usually she would reply, “pretty good,” or “better,” or sometimes, “I’m sleepy.” This time I asked her, “How are you feeling today?”

“I’m fine.”

I had to laugh to myself, “fine ? Yes, you really are, you’re fine.” The notion occurs, ‘with our thoughts, we create our world,’ and as you say, you’re fine.

The possibility of Alma going home was becoming more realistic. Shortly afterwards the wound was healing so well they were able to remove the wound vac and she continued to make progress. The NG tube would be clamped and observed to see if any fluid backed up. The next day there was no fluid backing up so they were able to remove the NG tube. The plan was to have her go home in 2 weeks,

December 22nd or so. Alma wanted to focus on the songs that would appeal to her kids and so we would literally rehearse, ‘Jingle Bells,’ ‘Rudolph’.....she wanted to understand all of the English expressions like, ‘bells on bobtail ring,’ in ‘Jingle Bells,’ and in ‘Jingle Bell Rock,’ ‘to go glidin’ in a one horse sleigh.’

“Okay, what’s another one,” she would ask ?

“‘Deck The Halls’ is an old song from Wales in England, several hundred years old at least and the words are all very old. And kids usually like the ‘fa la la la la’ part.”

“Yes, my kids will like this one.”

When we sang ‘Joy To The World,’ Alma commented, “beautiful.”

“Yes, I think so too, I especially like the line, ‘let every heart prepare him room.’”

“Alma here’s an old hymn from the 1800’s that I think you would like. The words

are beautiful.” We sang it a couple times and I showed her how to play it on the harmonica and it became one of our favorites.

Abide\* With Me

\* to stay, dwell, or remain

Abide with me: fast falls the eventide;  
The darkness deepens; Oh with me abide!  
When other helpers fail, and comforts flee,  
Help of the helpless, O abide with me.

Swift to its close, ebbs out life’s little day;  
Earth’s joys grow dim its glories pass away;  
Change and decay in all around I see.  
O Thou, who changest not, abide with me.

I fear no foe, with thee at hand to bless:  
Ills have no weight, tears no bitterness.  
Where is death’s sting? Where, grave thy victory?  
I triumph still, if thou abide with me.

Hold thou thy cross before my closing eyes;  
Shine through the gloom and point me to the skies:  
Heaven’s morning breaks, earth’s vain shadows flee;  
In life, in death, O Lord, abide with me. William Monk 1861

“Today, I have to leave early, I go and play for the elderly people at a retirement home. Every month they have a party for everyone who has a birthday that month. They have a big cake and we sing ‘Happy Birthday,’ they all have cake and ice cream and we sing songs together. I do what we are doing here. I bring the lyrics and this month we sing all the Christmas songs. I go to about 15 places every month. It’s like going to visit your grandparents. You know, in English we don’t have very many dignified or respectful words for old people, we have ‘senior citizens,’ ‘frail’. I like the word ‘elderly’ or ‘elders.’ I think it’s from an older German or English word for ‘old’. In Spanish you have ‘viejos.’ Is the plural ‘Los Viejos’ or ‘Las Viejas’ ? ”

“Los Viejos, is better.”

“Oh, the little old ones.”

“Es mas bonita.”

\*

Alma is going home tomorrow. Her husband and sister came in a few days ago to learn how to change the dressings and all of her IV medications have been switched to pills or pain patches. Talia and then the two other ICU nurses come by and visit. Talia is very happy to see Alma doing so well, and is very emotional with tears in her eyes as she gives Alma a kiss on the cheek. When she leaves, Alma tells me,

“It’s difficult to say good bye.”

“Yes, it is emotional but it’s joy, we’re so happy for you. I think it’s the same feeling of joy in what you said before the operation, ‘your confidence, your faith that the love of God is always with us.’ I think that’s what we are feeling.”

“Yes. I’m not mad at God. God didn’t do this to me, God is helping me.”

“You know Alma, I remember when Lisa was singing with us in the room one day and said, ‘thank you **both** for bringing so much music to this unit.’ You didn’t always see the people walking by, hearing us, sometimes singing along with us and smiling. We did it together. And I realized while we were singing ‘Noche de Paz,’ that first time, because of knowing you, from now on Christmas will never be the same, it will always be better.”

“For me too. Thank you for being so nice to me.”

“It was easy.”

The day she left the hospital two TV stations came to interview her and her doctor. He explained that because her body produces defective collagen, her skin is very fragile and they had to develop a special synthetic collagen using some of Alma’s own tissue to cover her internal organs. In the interview Alma talked about the journal she had been keeping for the past year, “so that my kids would know everything that I’ve been through.” They showed her holding the stories we had worked on together. The TV interviews were her first chance to talk publicly and begin to share her story and offer encouragement and hope to others. That was my moment of gratification. Our relationship through music and writing helped put her in touch with her own ability to heal. She did it. I remember her comment the first day,

“Goals ? Yes, I have goals.....”

The TV crew followed her home and showed her sitting on her couch with her kids and her husband, everyone laughing and smiling.

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Afterward :

Alma has been back to the hospital several times in the past year to deal with an infection in her PICC line. She now enjoys eating solid food, even though she has very little large intestine and obtains most of her nutrition from TPN, a liquid supplement she receives intravenously. She is very happy to be home with her children and husband. She is still learning to walk again on her own, and in spite of this, Alma and her family recently went on vacation to Southern California Disneyland, and with the help of a wheelchair, had a wonderful time. Alma told me they are now planning a trip to Florida Disney world in November for her daughter's birthday. And as she pointed out, "I have to keep living."