

Life changes. We expect change. I never expected this. Many of life's changes we choose; I never would have chosen this.

Much of what happened I either don't remember or have only fuzzy, vague memories. My husband, Joel, kept our friends informed by email; so I've been able to gather some of the facts from those emails.

On Wednesday, April 12, 2006 I went to the emergency room about one in the afternoon. I had gone to bed the night before with that uncomfortable feeling I got whenever my gallbladder was acting up. By morning the pain was intense, nearly unbearable. After describing the pain and other symptoms over the phone to the doctor, she told me to go to the emergency room. I called my husband at work to come and pick me up. I gave my two-year old girl, Fiona, a hug and kiss goodbye. Who knew it would be three weeks before I saw her again.

After being seen in emergency, I was taken by wheelchair to an exam area. My memory is fuzzy after that. A doctor talked about a procedure where they could get to a gallstone causing all this pain. My throat would be sprayed to numb it, a sedative would be given, and something would be inserted down my throat so they could get to the gallstone. Months later I found out the procedure was ERCP (Endoscopic Retrograde Cholangiopancreatography). I have a vague memory of laying on my left side for the procedure and of being shown an x-ray or photo of the gallstone. It was very large and blocking the bile duct. During the procedure the doctors were able to make a small incision in the duct to release the gallstone. Though that went well, I was now diagnosed with acute necrotic pancreatitis. This meant my pancreas was digesting itself and dying. The doctor made it clear to my husband that I was not well.

I spent four days in ICU. My husband says he was there much of the time. I have only vague memories of us talking that first night. My 18-year old daughter, Rachelle, says she came to visit me. I have no recollection of that at all. I remember the bed being uncomfortable. My long legs seemed to always be hitting the end of the bed.

On Saturday, April 15, 2006 the nurse in ICU wanted me to sit up in a chair. It felt like I sat in that chair all day. That evening I was moved to a room on the third floor of the hospital. I hadn't had anything to eat or drink since the day before I'd been admitted to the hospital.

The next few days I spent surviving. At least one person came to visit somewhere in that time. My husband came often though he says I fell asleep often when he was talking to me. I spent a lot of time sleeping. I didn't realize that my life was hanging in the balance. I didn't know my chances weren't good. I had IVs to keep me hydrated. I'd been on oxygen and it was drying my nasal passages. And I wondered how the healthy mother of a two-year old could get so sick overnight and be so close to death.

Somewhere along the line my body ballooned with fluids and I was swollen everywhere. The nurses were concerned about my rings and so I held my hands up in the air until the swelling reduced enough to take my rings off. No one had any idea it would be months before I put them on again. My stomach was so swollen that, as one person later told me, it looked like I was twelve months pregnant!

A physical therapist came to take me for a walk. I wondered how in the world I was supposed to walk when I barely had the energy to stand. He was very kind but insistent. Walking would help me get better. The first time I walked from my bed to just outside the door - with a walker - and that was plenty. Two days later I could walk to the end of the hall and back, maybe 30 feet total.

I started marking the days on a pocket calendar. It was now the ninth day. Though I don't remember, apparently my pain is suddenly much worse this morning. Though I had started on a clear liquid diet (consisting of tea, broth, Jell-O, juice), I'm now told I can no longer take in anything orally, not even water. They start TPN (Total Parenteral Nutrition). This goes in through a PICC (peripherally inserted central catheter) line, directly into my heart. A feeding tube was inserted through my nose 'just in case'. In case my body continued to be unable to

take in food orally. The doctor asked my husband to come to the hospital that night so he could talk to us. It was not looking good. He explained to us how serious my condition was and that I could die. The doctors are concerned about infection that might require drainage and/or surgery. Antibiotics were started and I prayed all night long while pushing the button every ten minutes to administer more pain medication in addition to the constant pain medication I received by IV.

Friday morning, April 21st, the doctor came in and looked ecstatic! My condition had improved overnight. There was a long ways to go but things were looking better. Another week passed. Friends came to visit. I was always tired and slept a lot. Physical therapists took me for walks in the hallway. To keep my mouth from getting dry I would suck on ice chips or swish water around in my mouth and spit it out. Finally I could drink water.

Sunday evening, April 23rd, I was suddenly being moved to another room. Not to worry; there weren't enough nurses on this wing to take care of all the patients so I was being moved to another wing where there were plenty of nurses to handle all the patients. I felt very fortunate to have a private room.

Tuesday, April 25th, a CT scan is done to check for pockets of fluid in the abdomen. My fever continues to run just below 101. At least three antibiotics are being administered and in the next day or two my temperature goes down some as does my white blood cell count. The surgeon prefers not to do any surgery or drainage as long as there is improvement. My weakened condition would make it risky.

May 1st was my 20th day in the hospital. My red blood cell count has been dangerously low and I've started shots to increase production of red blood cells. Though I'm on continuous pain killers through the PICC line, last night was the first time I didn't need the extra pain medication I could use by pushing the button. I'm exhausted all the time but starting to get bored a bit.

My two-year old was being taken care of by her big sister and a very kind family. I was starting to miss her but thought since she didn't seem to be asking for me that it might be best if we left things alone. What if she came to visit me in the hospital and then started fussing and crying a lot, making it hard for her to be consoled by anyone? The very next day my older daughter told me that while she was rocking her little sister to sleep the night before she said 'miss mommy' and 'mommy sick'. I broke down in tears and asked my husband and daughter to bring Fiona to see me the next day.

Wednesday, May 3rd, my Fiona saw me for the first time in three weeks. I could see her coming down the hall. It felt so good to see her. It made me smile and lifted my spirits, my heart, my hope. Survival was necessary for her, for my husband, for my other children. Now I'd see her nearly every day. Now I'd be able to carry on no matter how much longer I had to be in the hospital. She looked hesitant to get too close seeing me with a tube coming out of my nose and IV tubing everywhere. But as the days pass, she becomes more comfortable and we talk and read and visit quietly. The nurses notice my spirits have been lifted. All the hospital staff, and especially the nurses, have been extremely kind and have taken very good care of me.

Somewhere along the way I woke up with a pain in the neck, quite literally. I thought I'd slept in a strange position. I didn't mention it to the doctor. It felt worse as the day went on and I finally felt a swelling. Looking in the mirror I saw a large swelling on my neck. The doctor was already gone for the day. The next day the doctor looked at it but didn't know for sure what it was and said we'd keep an eye on it. He mentioned something about a possible blood clot. This worried me as it was so close to my head and heart area. After another day I asked the doctor if we could find out for sure if this was a blood clot or what. An ultrasound shows it is and anti-coagulants and blood thinners are administered. That means besides being given a pill once a day, two shots a day are administered also. Though I'm worried, the doctor says having a blood clot in the leg is more worrisome. I'm still not sure why.

Yet another week passes. I don't really like being here. Yet I know it's where I need to be in order to get well. All my resources, my energy, my concentration needs to be on getting well. Friends visit and some bring magazines, books, crossword puzzles. I read a little, play around with a crossword, watched Dr. Phil in the afternoon. My concentration fades quickly and it's hard to do anything but sleep and rest. Bathing consists of having a nurse use a no-rinse shampoo to wash my hair and no-rinse liquid soap to bathe either sitting in bed or in a chair. My hair stays in braids so as not to get tangled. Everything I do wears me out.

The amount of pain medication I need has been slowly decreasing. By the end of this week I'm off the pain medication I've had continuously for the last three weeks. There's discomfort on my left side. I think it's the hospital bed. I ask the nurses for a pillow to prop under my left side. I cannot ever get comfortable. A nurse mentions I may be going home soon. My husband and I are surprised by this because neither of us feel I'm ready. Yet I want to be home. It's scary thinking about going home with the feeding tube. I'm still running a low-grade fever. This doctor says it's probably just from the blood clot. I never thought to question that. Can blood clots cause fever? I have read it's possible. But looking back, the low-grade fever and pain on my left side were symptoms of something far more serious. I've learned that a patient has to take control of their recovery; doctors don't know everything. And seeing a different doctor every week makes it difficult since each week another doctor has to review the case and find out what's been happening.

My husband is trained to care for me and the feeding tube. Sunday, May 14, I go home. I've spent 33 days in the hospital. I'm glad to be going home. Worried about having the feeding tube still. A nurse will come out Monday and check on me. I'll be on the feeding tube for at least three more weeks and told I could be on the anti-coagulants for up to a year. For every day in the hospital, the expected recover time is one week. That's 33 weeks of recovery I can expect, over eight months.

On Monday, May 15th, a home-health care nurse came out to check on me. She took my temperature and pricked my finger to check my INR (International normalized ratio) level. This is a method of monitoring the accuracy of the blood thinning treatment I was on. She also arranged to have someone come out later in the week to help me bathe as I was too weak to do this on my own. My temperature starts to go up and hits 102. Tuesday night as I'm reclining in the big chair in the living room my heart starts pounding hard and fast. It feels like when I used to get panic attacks. Five minutes pass and it doesn't feel like it's going to stop. Considering all my body has been through, we decide to call the nurses and get their advice. They tell me to go the emergency room.

We stop the tube feeding and go to the emergency room and check in. After a few minutes I feel sick and vomit. While waiting to be seen, the palpitations stop. They had lasted over an hour. Once I'm seen, my pulse is checked; it's 154 when it should be well under 100. Who knows what it was when my heart was pounding. The medical staff decides I'm dehydrated and start an IV, pumping in two liters of fluid in a very short amount of time. They also restart the tube feeding. After being rehydrated and my temperature coming down, I'm released to go home.

Wednesday a nursing assistant comes to the house to help me bathe. She has me sit in a chair in the tub while she uses the hand-held shower to wash my hair and bathe me. It feels like such an ordeal just to get clean.

Thursday the home-health care nurse who is my case worker comes to see me. She says I look terrified sitting in that big chair. Of course I'm terrified because I'm not really getting any better. I've been running temperatures of up to 102. The nurse tells me she's going to call my primary doctor because she's worried about these high temperatures I've been having. That afternoon the doctor calls me to say she wants me readmitted to the hospital since I'm running high temperatures and am not improving. The nurse calls also to confirm this.

Thursday, May 18th, 5:30 p.m. or so and I'm readmitted to the hospital. I wonder how I'm going to keep doing this and who's going to take care of our little girl? I'm not sure I can keep on going without some sort of help. My mom's already let us know she couldn't come up to help out until the end of June. Fortunately the Stephens

family takes Fiona into their hearts as one of theirs and she's very well taken care of. How much longer will I be hospitalized? What's really going on?

On Friday the doctors have another CT scan done. The IVs keep going bad, causing my hands to swell. By Sunday night both hands have had it and I'm unable to use them. Joel spends the night and helps me drink water.

I end up spending the next 2-1/2 months in the hospital - twice as long as I had just spent in it and that felt like a long time. The hours turn into days, the days into weeks, and so forth. I'm very grateful for all the care the nurses show.

The infection in my abdomen is worse yet no one wants to do surgery because my blood count is so low. Though I'm taking shots to increase my blood count, it just doesn't seem to want to come up very much. I'm still on a feeding tube and am unable to eat anything other than clear liquids - and even then I don't eat much. It's finally decided that the antibiotics are not killing the infection so it needs to be drained. Two drains are inserted in my abdomen and remain there for about six weeks.

And the effect all this is having on my family! Though I'm shielded from most of it, I later learn just how hard it's all been. Rachelle has become a substitute mommy for Fiona. Fiona is with the Stephens family so much that she at times calls Beth mommy. Joel's stress is so tremendous his blood pressure becomes worrisome. He sees the doctor and the doctor says it's all this stress causing his blood pressure to raise and suggests he see a counselor and prescribes some medication for those times when the stress becomes too much.

My mom comes to stay for a week late in June. We think maybe I'll be able to come home soon. But that doesn't happen. Summer has come and I'm stuck in a hospital room unable to enjoy it. One very kind nurse suggests my husband take me outside in the wheelchair to enjoy a little fresh air and sunshine. We do that and it feels good to be outside.

My body has been so traumatized and poked so many times for IVs and blood draws that I don't want to be touched at all. I begin crying more often and the very nice nurse that suggested we get outside now suggests I talk to a doctor about anti-anxiety medication. Though at first resistant to the idea, I realize that I need something because I'm feeling anxious constantly. The medication helps.

The days and weeks continue and friends come to visit. I'm very encouraged by this though I'm still tired most of the time. Joel comes and stays with me as much as he can. Each day takes all I have just to get through it. My day starts by getting blood drawn around 6 a.m. I try to sleep a bit more but it's not easy. Breakfast comes around 9 and about 10 a nursing assistant comes in to help me bathe. At 11 I go for a walk around the nurse's station. Lunch comes about 12:30. I nap after lunch, go for another walk, then watch some TV, then nap some more, take another walk, dinner around 6. Joel comes after work and spends the evening. We take another walk, watch some TV, fall asleep. Nurses change shift and someone comes to check on me near midnight and then again around 4:30 in the morning. Day in and day out it's the same old thing and that's all I have the energy to do.

As the weeks pass, it's decided I can start on a liquid diet again. We start with one juice a day, then two, then some tea, broth, add some Jell-O. None of it is causing problems. So the doctors and nutritionist decide to go ahead with a soft diet and if I can eat enough calories, I can get off the feeding tube. Now I can have soft, creamed soups and even meat that's already been cut small, shredded, similar to canned chicken. It's finally decided the feeding tube can be removed! A very kind nurse does just that. It feels very strange, not really painful, though I do make some noise as it's removed. But what a wonderful relief it is! Now I can take my walks and can hold my head up. I was always worried about that tube and walked stooped over holding it so it wouldn't come out.

Early in July it's decided that since the nurses aren't getting much out of the drainage tubes anymore, they'll hook them up to a constant low-suction device. Anytime I want to get out of bed, someone has to come unhook them temporarily. Then it's decided that the interventional radiologist once again drain the tubes. They do this and discuss the possibility of the continued infection now being caused by the fact that the tubes have been in so long and that it's possible the infection will clear up if the drains are removed.

So the doctor decides on Saturday, July 15th, to pull the one tube. When he tries to do so, I feel quite a bit of pain. Something isn't right. They call in a physician's assistant who explains there's some sort of lock or valve or something that needs to be turned or something in order to remove the tube. Once this is done the doctor pulls the tube. Though it only takes a few seconds, the pain is incredibly intense, causing me to cry out. A nurse passing by my room wonders what's happening. Though the pain is very bad for the first hour, it diminishes and within a few hours, though still on pain medication, I feel that it wasn't so bad. The doctor says if all goes well, he'll remove the other one the next day.

All went well so the doctor is going to remove the tube Sunday. I ask my husband to go wait far away and ask that the door to my room be closed so that when I cry out in pain this time I don't scare anyone outside my room. Well, apparently, this tube is where the worst infection was and when it's pulled, I yell. It hurt like you wouldn't believe. And this time the pain lasts all day. In fact by that night I really wanted more pain medication and mentioned it to the nurses. Of course I'd already had all they could give me without talking to the doctor. But before long the pain did diminish and I survived.

By the next day things were improving. No more fever, I was eating more, my white blood count was improving and it looked like I'd be able to think about going home. By the end of the week, it looked like the infection was gone. I hadn't run a fever all week and I was eating. My red blood count was still low, but I was continuing to take the Epocrit shots to increase red blood cell production. I had been taking antibiotics and pain medication intravenously and the doctor said if I could take them orally and all went well, I could go home. Saturday night was the last of the antibiotics by IV and I was started on oral antibiotics. Sunday the doctor said it all looked good still and I'd probably be able to go home Monday as long as I didn't have a fever and the new doctor on Monday morning agreed.

This was exciting. I so wanted to go home. I still had a long recovery but in the past week had really started to feel like I really was going to live through this ordeal and be able to go home. I prayed hard Sunday night about going home the next day.

Monday, July 24th, the new doctor came in, said I heard you want to go home, and I agreed whole-heartedly. She saw I had no fever and gave me the all clear. I was going home! The nurse came to show me how to administer the Epocrit shots. Though not thrilled about having to do this, I accepted it. All went well.

I was home, Fiona was thrilled, and I was exhausted. I spent my days reclining in the living room chair watching Fiona watch PBS. I forced myself to shower every day, particularly to be sure my drainage wounds stayed clean. Eating was a tremendous chore. I started my day with my protein shake and then tried a piece of toast. Three days a week I had to give myself the Epocrit shots. I hated doing this. I usually had to take my anti-anxiety medication before I could do this. The first time I did it, my hand shook the entire time. I had two different antibiotics to take as well as iron tablets. In addition to the oral pain medication, I continued using a pain patch. And I was still taking anti-coagulants.

So I had to go in to the lab a couple of times a week and have blood drawn so they could check my INR levels and adjust the amount of medication I was taking. I hated this too. My veins were in such bad shape it usually took a couple of tries before they could get it or find a vein that wouldn't shut down on them.

Within a couple of weeks of coming home I went to see my primary care physician to follow up on my progress. She was on vacation and I saw another doctor instead who was very kind. I had lost a few pounds the

last couple of weeks in the hospital and another 7 pounds the week before I saw the doctor. He suggested I not lost much more. On August 14th I had to have another CT scan to monitor the progress of the psuedocysts. Apparently the scan showed reasonable progress, though it did have gallstones.

About a week later I ended up with some sort of viral infection that caused my temperature to spike up to 102. It also caused sores in and around my mouth, making the already difficult process of eating even more difficult for me. I lost another 10 pounds within the next few weeks; however, when I saw my doctor my weight had stabilized and I was no longer losing. Altogether I lost over 30 pounds within about a six-week period. This also caused substantial hair loss. It took nearly five months after coming home before my hair started to grow back in.

When I came home in July it was as though my whole life had been on hold. Even the daily calendar Rachelle had with pictures of Ireland still had the April 12th date on it, the day I went into the hospital to begin with. No one wanted to look at the pictures without me. It took us until December 15th to work our way up to December 1st. Yes, as of today, December 15th, we are still working on it.

I spent a total of 101 days in the hospital. That means 101 weeks of recovery, nearly two years. On November 2nd, I was home from the hospital 101 days; the same amount of time I was in. And yet even now, on December 15th, it feels as though my stay in the hospital was longer than the time I've been home.

This coming Monday, December 18th, I have my gallbladder removed. Dr. Sullivan thinks he can do it laparoscopically and that I should come home the same day. I need to have it gone so I don't have to worry about any more stones. Then I can even start adding some fat to my diet. But of course I'm worried that my body will react badly and that I may be in the hospital for a while again. I sure hope not. The Stephens are going to take Fiona Sunday night and keep her for a few days so she won't have to go through the fear of abandonment.

It's been very difficult these last few months. I cried alot and continued, and still do periodically, to take an anti-anxiety medication. Everything took so much out of me. I was just thinking when I made the bed the other morning how difficult that was a couple months ago. I was so weak when I first came home that I couldn't even pull the sheet up on the bed.

I plan on filling in so many more details. Just for now, though, recovery at home has been difficult and slow. Turning over or laying on my side was so very difficult and sometimes I could barely do it. Dealing with the loss of appetite and regaining it, and worrying about having lost 35 pounds in 2 months were very, very difficult. Taking a shower was scary and exhausting for months.

I went in for another CT scan on October 18th and the doctor said things were progressing fine. Another CT scan again December 7th in preparation for December 18th gallbladder removal surgery. The surgery went well and I recovered nicely, though it did set me back about 3 weeks from where I had been.

Today, June 14th, 2007, nearly one year later, I am doing very, very well. I still tire easily and don't have the stamina I once did. I have constant discomfort in the side where I had the serious infection. However, life is good. I'm very thankful to be alive and in another year I think it will be almost as though this never happened.

I'm finally ready to post this and share it with the world, December 6, 2007, nearly 2 years after this all started. Though I still tire easily and suffer from periodic discomfort, I can say I feel 95% recovered!