My Elder Care Diary

OCTOBER 2007

Dealing with dad's fall – the nightmare every elder care giver dreads

Tuesday, October 16

Ken and I just returned late Saturday night, 10/13, from a very nice few days in Florida for some R&R. After some intense research, we had made arrangements for a woman to come in from a home healthcare agency while we were in Florida, to just be available to our parents while we were away. We needed the assurance of having someone in the house while we were away in case of an emergency, which we knew our parents were not capable of handling.

Much to think about

Ken's mom has early Alzheimer's, among other problems; my mother has severe scoliosis, osteoarthritis and osteoporosis; and my dad is diabetic. Our fear was that one of them would have a major problem and not think to call 911.

We were so proud of ourselves that we made the first step to getting outside care for our parents in our home. We knew that this is something we would eventually have to address down the road.

Our parents did just fine while we were away and seemed to accept the caregiver. That made us feel pretty good. We started doing business as usual.

I went into work Monday morning and had to leave work later in the morning to take my mother-in-law to her skin doctor. She had a basil cell cancerous lesion removed from her face about 2 months ago. This visit was to see how she healed from the surgery.

If only I had grabbed him in time

On Tuesday, my dad had a very early doctor's appointment for some throat problems he was having. We were getting all our referral appointments, etc. and ready to leave the office, when my father lost his balance and fell in the doctor's waiting room.

He went down so hard on the floor… I just thought he had to get up. But he did some major damage to his leg.

This was my mother's, and our, worst nightmare… my dad going into the hospital. He took total care of her, as she's practically helpless. Anyhow, 911 was called and he was taken to the ER, where the X-rays showed he had a very bad fracture of his femur in his left leg. He was admitted to the hospital and our nightmare began.

I dreaded telling my mother

After he hurt himself, I dreaded telling my mother. Ken stayed with my dad so I was able to go to my mother and tell her the dreaded news. I knew she would go off the deep end, but after the initial shock she came around like a real trooper.

I even got her to go to her scheduled doctor appointment with my mother-in-law for their flu shots, and then I took my mother over to the hospital.

She is unable to walk any distance and has a very hard time sitting in most chairs. Once my dad got a room, my mother was up and down between the wheel chair and chairs in the room. Then she would get settled and had to use the lady's room. She's not able to do any of this by herself. I'm not used to manipulating a wheel chair.

I was back and forth at the hospital 3 times that day. My dad had his surgery at 10pm that night and I stayed until 12:30am. I think that had to be one of the longest days of my life.

I slept on the sofa that night, so that I could help my mother get up and back into bed during the night. Of course, couldn't sleep at all and my mother gets up very early in the morning…anywhere from 4am to 5am.

After the trauma, the real challenge begins…

Sunday, October 21

We came to visit Dad today. He was sound asleep when we came. Ken's mom, Jean, came along to see Dad…was first time Jean saw him since his accident.

It sure is a difficult time of life. It's every bit as hard to take care of elderly parents as it is children. My mom is up at least once every night…most of the times 2 times to go the bathroom. She has a horrendous time getting in and out of bed…getting into bed the hardest. It would break your heart to see her.

I've become the primary caregiver

In the morning I'm now doing everything for Mom that Dad did for her. She needs help getting her medication together, help with breakfast & lunch, dinner, etc. I'm sure he was totally exhausted taking care of her…she's totally dependent on someone. Dad's doing better today… more lucid. Good to see him a little improved.

I totally lost it tonight. Mom needed help, Jean wanted help, plus taking care of dishes, etc. I could have screamed…was running from one thing to another and started to snap at Jean. I finally broke down in tears… don't know what to do.

We're starting to look for help. Not sure what we'll do. Right now life really sucks. I have no time to myself. Ken's at his wit's end dealing with all of this during a challenging time in our business. He helps as much as he can, but the burden right now is mostly on me, and it's overwhelming.

Who else is there to do this?

Monday, October 22

After taking care of Mom this a.m., I was finally able to get to the office for about 3½ hours. So hard to get anything done. I came home around 1 p.m. to get Mom some lunch & then bring her over to visit with Dad.

This is another problem… can't have anyone else bring her, because she needs help going to the bathroom. So, unless something changes, we're here 7 days a week.

Dad fell out of bed this morning. He didn't hurt himself…doesn't remember it. Said the night was long. Ken and I are continually researching and discussing options. So frustrating. Doesn't seem to be any real answer. Feel trapped and exhausted.

So many responsibilities…

Tuesday, October 23

Well, it's another day. This morning went a little better. Could I possibly be getting used to this routine? We started checking with the county today as to help available to our parents. I also called a rehab provider for Mom to see if she qualifies for anything. They will call back.

Dad's very tired today… falling asleep. I think this is his sleepy time…sitting in a wheel chair. He had P.T. today around 10am… not eating a lot.

I think either he still has anesthesia in him (almost positive) or he's depressed about the whole situation. It's probably a little bit of both. Still needs help when goes to bathroom. Did have a shower last night… that's progress. We're still with Dad… he's sleeping.

Mom gets restless. When we first got here it was tough for her to settle in. Wheel chair hurt with and without pillow…ended up in a regular chair. Once she got settled, had to go to the bathroom. Very frustrating! Sure wish I could drop her off to visit with Dad… would make life a lot easier.

It's really tough having so many responsibilities. We have young grandchildren out-of-state. Breaks my heart not to see them more often. I really need that special time with them.

Sometimes it's difficult to be grateful, but we're working at it

Friday, October 26

Dad looks really good today. Had physical therapy for a couple of hours today. Mom and Dad are discussing Jean (Ken's Mom). She's been having a hard time remembering things. She sleeps a lot off and on during the day, many times doesn't realize that she's been asleep.

We try to avoid waking her up when she's been asleep a long time… she's not the same person. She really scared us last night. She was belligerent and not the person we knew. A totally different personality popped out of her. It was an angry personality.

Anyhow, I feel so bad for all our parents. It's so hard watching them deteriorate. They want to still do things, but really aren't capable of doing them anymore. Sorry. Can't wallow in this stuff too long. It gets to you.

Anyway, I feel so much better about my dad today, as far as mentally coming back to where he was before. He can remember where everything is at home. He seems to be eating better now. I'm grateful for that.

We discover a great home health care program!

Monday, October 29

Today was a good day. We had a representative from senior services in our county come and go over some programs with us today. We've been looking for some in-home care programs that our parents could qualify for and were given great information today.

If you have no in-home care insurance, it can be almost as costly to have care at home as in a nursing home… that is 24-hour-a-day care. We really need some in-home care for my mother. My father had been taking care of her, but since his accident, I've been caring for her.

This is really hard, since I do have a job that I go to daily. It's also difficult physically since she can't do anything for herself. Once my dad comes home from the Rehab Center, he will not be able to do this for her anymore. Plus, he will also need care.

The JACC Program – at last some help!

We found out from our county representative that we have a valuable program for seniors that qualify income-wise. The program is a New Jersey program called the JACC program.

Check out if your state has a similar program. If your assets as an individual are less than $30,000 and as a couple are less than $60,000, you may qualify for in-home care (bathing, etc.).

They also provide meals, transportation, day care programs, etc. It seems like a good program for our parents. We knew that, even before my dad's accident, we needed to start looking for some kind of program to get some assistance for them.

We are going to apply for this program for my parents. It's far from enough (maximum 8 hours of care for one individual, 16 hours for a couple) but it's still helpful.

What makes this program valuable is that the state is more flexible than Medicaid on the 5-Year Lookback. So assets can be shifted to take advantage of the program and Ken and I can keep the funds in a separate personal account.

If mom and/or dad need to go into a nursing home, we can use the funds for their care, since the 5-Year Lookback will recapture the money anyway at that point.

A new stage – physical therapy

We also today had our first visit from In-Home Physical Therapy. Today was just an evaluation of my mother to see what type of therapy she will qualify for. This is a wonderful service.

The therapist is an extremely gentle, caring person. She tested her strength and mobility in her limbs. She started her with a few exercises today and was very encouraging as to being able to make mom a little bit more mobile.

She's also recommending occupational therapy, as well, for her. Mom has a hard time doing many things that all of us take for granted. It's very upsetting to her not to be able to take care of herself.

My hope for her is that she'll be able to do a lot more for herself, so that my father won't feel so obligated to try to help her all the time.

We're feeling some hope for a change

I feel that between the in-home care provided by the county and my mother getting a little more mobile with the physical therapy, that my parents will be able to remain comfortably in our home. Of course, unforeseen accidents or major health issues could always alter everything.

As to my father, he's doing well today. He did call me this morning and told me that he's having a hard time sleeping at night. Said he feels closed in at night time… his nerves are getting to him.

Guess you can't blame him. Can't imagine sitting day-after-day with nothing to do. His appetite is not good either.

He always loved to eat, but can't seem to get his appetite back. Said the food just doesn't taste right. The healing process for this kind of fracture is very slow. I just feel so bad for him and wish the whole healing process was a little faster for him.

Another strange day

Tuesday, October 30

My mother and mother-in-law had a foot doctor appointment today. Even though everything revolves around my dad's convalescing, life does still go on as usual. So, today I did as much work as possible at the office, came home and made lunch for my mom.

Then we had to prepare for our appointment with the foot doctor, which is about 20-25 minutes away. My father always went with us in the past and was able to get my mom out of the car and into the doctor's office, while I parked the car.

Now, I not only have to get my mom out of the car and walk her inside the building, but now I have to abandon my car out in the street while I accomplish this, and then come back out and find a place to park the car. It's

amazing how the absence of one person can make such a difference how we accomplish things that seemed easy before, but now difficult.

Anyhow, we did ok at the foot doctor's office. From there we went to see my dad, which is about another 20 minutes back again. I was rushing from one place to the other all day.

But, it was worth it. Dad was happy to see all of us and seemed to be in pretty good spirits. The bad thing is that he can't sleep and either he has no appetite or the food just doesn't tempt him.

Dealing with dad's frustration and anxiety

Wednesday, October 31

Hooray!! No appointments of any sort today. Just a normal hectic day. Dad called this morning and again did not sleep last night. I feel so bad for him. Seems like he's reaching out for help from us, but not sure what to do.

So far, I have asked the nurses to give him something to help his closed-in feeling at nighttime (anxiety). Found out he already is on something and can't have anything on top of it.

I brought him a portable CD player with soothing music he can listen to at night when he's not sleeping. Hopefully, this will relax him enough to sleep. When we visited him later in the day, he seemed much happier.

He finally went to the main therapy center today, which is about 20 minutes away. It did him the world of good to get a change of scenery today. He's now allowed to put 25% weight on his injured leg. Now learning to toe walk on that leg. Dad's making some progress. It may be slow, but it's positive progress.

This has been hard on mom. Before this accident, she did not go out of the house very often. Now she goes out every day to visit my dad. It's very exhausting and uncomfortable for her when she goes out.

NOVEMBER 2007

Fourteen doctors – for one person – amazing!

Thursday, November 1

Today, Jean has a doctor's appointment, but Ken is taking her. There is no way I can do that today. This is a brand new doctor for her, a pulmonary specialist.

It's amazing. She has a different doctor for almost every part of her body… that's the truth. It's amazing today that we cannot go to just one doctor to help us. She honestly has her family doctor, heart doctor, foot doctor, gynecologist, oncologist, vascular doctor, neurologist, gastroenterologist, eye doctor, retina specialist, hearing aid specialist, skin doctor, chiropractor and dentist. No wonder we're always running to doctors.

And on top of that, there are all kinds of tests, x-rays and blood tests, constantly running to the drug store. And this is just for one person. Then you multiply that by my mom and dad.

No wonder I'm always trying to catch up with my work. I hate it every time a doctor wants one of our parents to go see a specialist. Selfishly, I really don't want to see another doctor, but know I can't feel that way.

The health care dilemma – who's paying for all this?

We love our parents and will do everything we can to give them the best healthcare. But you can see why our country's health care costs are out of control. It costs a fortune to provide quality care to the elderly.

My dad is pretty much the same today. Still can't sleep at night, but now the nurses and attendants are aware of his problem and let him come out into the big room with the big screen TV. That seems to help him.

We had to cut our visit shorter than normal with my dad today, so that I could get mom back home for her therapy session today. I'm still feeling very encouraged with the therapy for her. I feel any little improvement with her strength will be a plus for my dad when he comes home and for the rest of us, as well. I know it's hard for her, but think it will be very beneficial to her.

When a senior is forced to do more, could it really be beneficial?

Friday, November 2

Still getting at least 2 to 3 hours a day in at work. Really have to make every minute count when I get into the office. Dad was pretty much the same today when we visited him. Was really nasty out weather-wise… Noreaster brewing out in the Atlantic today.

Mom really minds coming out in weather like this. This is so different for her to have to go out every day. When Dad was home and ok, she wouldn't go out for days sometimes, because she just wasn't up to it.

Maybe in some respects this is a good thing for her. I know she's frustrated about the whole situation, but maybe it's making her just a little bit more independent.

She usually crashes after we have dinner at night. I try to get her nightie on fairly early in the evening before she falls asleep. Makes it easier for her and for myself.

What weekend? Just another busy day

Saturday, November 3

Really have a very busy day on Saturdays. Like to try to make a good breakfast on Saturdays and Sundays, since it's too crazy during the week. Always change the beds and do laundry in the morning. Always take my mother-in-law grocery shopping in the morning and any other errands she needs.

But, this morning she was not feeling well. She was dizzy and not herself. So, she decided to stay home today. I went out shopping by myself. After shopping and lunch, Mom and I went to see Dad. We brought a goodie bag for him today. He seemed pretty good, but was in pain when we left. Still not sleeping or eating much.

Got him a new CD player today. The one I bought last week stopped working. He can play music to help him sleep. Guess he did use it.

Would be so nice just to see him a little more accepting of being here and concentrating on getting his leg healed. I got my mother and mother-in-law settled with their dinner and then Ken and I went out to dinner, just to get me out and both of us having some alone time. We really need that time.

How can you get a senior to accept his situation and not fight it so much when he's miserable all the time?

Sunday, November 4

Dad wasn't doing too great today when Mom and I arrived. Donna, a good friend, was visiting with him, which was nice for him. He was very uncomfortable and having pain in his upper leg. I found out from one of the nurses that he has not been sleeping at all. Does not want to get into bed day or night… wants to sit either in his wheelchair or straight chair in his room.

We tried to get some ice or heat for his leg, but the nurse said it wasn't ordered and didn't seem to want to get it for him. Between Mom, Donna, myself and the nurse, we were finally able to persuade him to get into bed to get the pressure off his leg. Seems to be more comfortable now and finally sleeping.

Everyone said how badly he wants to come home and we all tell him he has to cooperate to help his leg heal. I really do feel for him! Not sure how long it will be until he gets home. He still is not eating, so I think I'm going to bring in some spaghetti and meatballs for him tomorrow.

Mondays are always interesting

Monday, November 5

Mom has her rituals that she likes to keep. She takes her weekly pill on Mondays and always gets up real early in the morning. So, I try to keep her on schedule as best as I can.

Today there was a caregiver conference and met with the social worker, nurse and physical therapist. Dad sat in on part of the meeting. It was a good meeting.

We were able to tell them some of our concerns and problems and they gave us an update on his progress. He will be here at least 3 more weeks… they definitely do not want him to come home before he can put full weight on his leg. He will most likely have home therapy, which will show him how to get around in the house.

At that point they will decide if he needs more therapy to improve his walking. I expressed some concerns I had with Dad in regard to his pain in his leg and whether or not he could get a leg rest for his wheelchair. Also discussed his not sleeping and not eating because of hard time swallowing.

I was totally impressed with how quickly they responded to our concerns. Within 15 minutes of coming back to my dad's room, they had a new wheelchair with leg-rests.

They also requested I get him new sneakers to help with the swelling and be easier to get on and off… Velcro closings. While I was in the store purchasing the sneakers, I had the speech therapist on the phone with recommendations for Dad's difficulty in swallowing. Never had problems addressed so quickly.

A different kind of Thanksgiving

Dad will be staying here at least through the end of this month.

We'll be spending Thanksgiving at the convalescent home.

This will be a very different Thanksgiving! The speech therapist would like Dad to have the barium swallow test done, but Dad didn't seem to want to do

anything more now. Told the speech therapist I would talk to Dad about it. I personally would like him to get this problem taken care of before he comes home. Maybe we could start with a clean slate and not have to go to all kinds of specialists.

When we arrived back home, it was time for Mom's physical therapy. She's coming along. She was stretching her arm and leg muscles to allow her to be more flexible.

Mom is not in love with physical therapy, but I think it could do so much for her if she really puts her mind to it. Of course, I don't know what her pain level is like. The therapist is gradually trying to show me how to stretch Mom's upper thigh muscles…anything to get her more loosened up.

I can't believe how exhausting this is.

I really haven't had any time to myself since this whole ordeal started. Ken and I take at least one or two hours on Saturday to go out by ourselves and that's it. When I finally have time to myself, if I don't have to do any makeup work from the office, I fall asleep. That's pretty pathetic.

Wishful thinking

Thursday, November 8

Well, a lot sure has happened since Monday. Since our meeting with the team for Dad's care on Monday, we pretty much assumed he was going to be in the convalescent center for Thanksgiving. Now, he's saying he can come home for Thanksgiving. I need to speak to the physical therapy people. Dad said he had a horrible time sleeping last night. I think it's so bad that he could just scream!

I've been trying to get a sleeping pill for him since he came in. For some reason or other, they haven't been too anxious to give him any. I keep trying every day. Hopefully, they'll get one for him tonight.

Mom saw the occupational therapist for the first time today. This can also be a great opportunity for her to become a little bit more independent. The therapist will work with her to help improve her short-term memory, help with her personal-care skills, etc. I'm just so hopeful

On a roller coaster

Boy, things sure change from day to day. I feel like I'm on a roller coaster and can't get off. Seems like I get one thing straightened out and then a new problem arises.

I was really trying to figure out how we were going to work getting Dad home and into the house using a ramp, plus the anxiety of him reinjuring himself by putting his whole weight by accident on his leg.

I spoke with our social worker about how confused I was about Dad coming home before Thanksgiving. First we were told he will not be home and then 3 days later Dad told me he'd be coming home for Thanksgiving and not coming back to the convalescent home.

She reassured me, along with the physical therapy people, that he needs to stay until he has full weight bearing on his left leg. Well, selfishly I was relieved, but I do know how Dad must feel.

He's been there 3 weeks already and not happy because he can't sleep at night. If that were me, I'd be every bit as bad if not worse. But, he knows it's in his best interests to stay there until he heals more.

Every day seems to be a new adventure.

Today while I was attempting to transport Mom via wheelchair into the convalescent center, the front wheel broke on the wheelchair. Thankfully, it didn't push her forward when the wheel broke. Believe it or not, I wasn't even upset about it.

We were rescued by Dad's roommate's son. He and an attendant brought us a wheelchair to borrow for our visit. So, guess what Ken and I are doing tonight? You guessed it! Off to the store to get a new wheelchair.

We did find one… called a transport chair, which will be fine. It pushes so much easier than the old one. Maybe it was a blessing in disguise.

So many stories here

Coming over to the convalescent center sometimes makes me feel so sad to see all these elderly people that were once active, lively, happy people.

I can tell there are so many great stories in all these people. I hear some of the stories and really do enjoy them. I hope their stories are not lost in time.

It's amazing what you learn about your parents when so much close time is spent together. That part of this experience I will never regret. Just wish aging didn't have to be so difficult for a good majority of people. Someone's elderly parent said that aging is not for sissies… how very true.

My mother's biggest fear was that something would happen to my Dad and he'd have to go to the hospital, and then what would happen to her?

Well, it did happen and I always did tell her I would never let anything bad happen to her if at all possible. So far, I've kept my promise and intend to keep doing so.

One great thing that has happened through all this, my grandmother (stepgrandmother) who is 95 years old, has been such a great person to talk to about all these problems.

Her mind is still so sharp and totally understands everything we're going through. She still lives alone in her own house, drives her own car, takes her 97-year-old sister to the store and doctor, bakes for her church bazaars and friends and neighbors. Pretty amazing lady!

Was talking to our son tonight and I told him that this is the hardest thing that we've ever done. If someone had told me we'd be going through all this a year ago, I would have said they were totally crazy. Little did we know.

Can't wait to see our grandchildren! Really need to hear some lively screaming and hollering and running through our house again. They are really good at it!

The night ritual - heartbreaking

Wednesday, November 14

I just got my mother tucked into bed for the night. It's such an ordeal for her to get into bed. It must take her a good 10 minutes just to finally get her body down into a prone position. She needs help straightening out her legs.

She can only sleep on her right side and cannot change her sleep position during the night. She can never sleep on her back, as she cannot straighten out her back to put her head down.

I'm still looking for a solution for her, as she goes through this ritual about 3 times a night… not sure what it is. She's totally frustrated and upset by the time she finally gets settled into bed.

The past couple of days, as usual, offered some new challenges. The big challenge is shuffling everything around to fit in Mom's therapy, visits to Dad, helping my mother-in-law with her problems and issues, getting my work done at the office, etc.

My mom has therapy 5 days a week, physical therapy and occupational therapy. It's very difficult for her, because the muscles in her body have atrophied so badly and she's stooped over so badly.

The therapists have given her some very good exercises and tips on how to get herself up out of a chair by herself and walking properly with a walker, etc. I'm just hoping she doesn't get disgusted and give up. Guess it's hard to push yourself when you hurt and feel so weak.

Dad finally is accepting his situation

Dad's spirits seem to be a little brighter. I think he finally has accepted staying at the rehab center until he can put 100% weight on his leg.

He also has finally started to eat a little more. Eating has been an issue for him. He's finally going to get a barium swallow test next week, which should show why he has so much difficulty with his swallowing.

He was finally able to get his hair cut today. Think any change they can have, while they are waiting for the healing process to be over, is a good thing.

Just can't imagine what it must be like sitting day after day and having nothing to do. My Dad doesn't like to read, so there's nothing to occupy his mind. I just feel so bad every time I go visit. At least my Dad is coming home… a good percentage of the people there will not be going home again and some of them may have been basically forgotten by their family.

We made reservations to have our Thanksgiving dinner at the convalescent home. My Mom is already stressing about being able to sit at the table. Most chairs she cannot tolerate anymore. No matter what happens that day, we will be together and that's all that matters.

Waiting for dad to come home – more anxiety

Friday, November 16

Well, Dad has been at the convalescent home for a month now. He wants to come home so badly. I wish he could, but there is just no way I could care for him at home. I could see him forgetting himself and getting up on his leg and reinjuring himself.

I just refuse to go through this all over again. If we're lucky, he should be home in about two more weeks. Once he gets 100% weight bearing status on his leg, then he will be allowed home.

The days must seem endless to him. He doesn't read, can't seem to concentrate on TV or listen to his music. I know he is depressed and very uptight.

I had to ask the nurse if they could give him something for his anxiety. They did give him some kind of medication and seems to be a little bit better. But, I know he won't be happy until he gets home.

I am concerned with all the medication he is on right now…between the Prozac, anxiety medication, sleeping pills, plus his diabetes, blood pressure and cholesterol medication.

I am definitely going to have to take control over dispensing his medication. He used to dispense his medicine and my mother's medicine…not anymore! I'm also going to have to deal with his blood sugar levels.

His insulin has been all switched around since he's been in the rehab center. There are many issues to be addressed.

Alzheimer's is traumatic for everyone

My mother-in-law, Ken's mother is, unfortunately, becoming more and more forgetful. This is really scary. She does not remember her appointments from one day to another or who is taking her to the appointment.

Did not remember who did the dishes last night… she rinsed them and I put them in the dishwasher. She's having a harder and harder time getting out the words to describe things… I know she's totally frustrated and feel so bad for her.

She constantly is saying to me, "I don't know what is wrong with me." This situation for her is only going to get worse.

Progress… and frustrations

Tuesday, November 20

Dad finally had his barium swallow test done for his throat problem. Hoping that they will be able to determine what his problem is. The speech therapist said his voice seems to be getting a little stronger.

It appears that his voice is the strongest when he feels confident in what he is saying. The speech therapist said he needs encouragement that he's doing well. That's one thing we will have to work on when he comes home.

Between all the situations with our parents, I continually find myself getting more and more frustrated. I really do have to watch myself around them and not show my emotions… they are extremely sensitive to everything these days. It takes so much patience and understanding when I'm with them.

My mother is so unbelievably slow and sometimes I'm so tired and my tolerance level these days isn't the greatest. My mother-in-law can take up to 15 minutes or a half an hour to explain something very simple, plus she goes over it again and again.

I feel badly when I start losing it… I try very hard not to. But, I am human and have bad days too. Once in a while I do have a breakdown and end up crying. But, a good cry is actually good… it releases all those pent-up emotions. I've been pretty good lately.

A very different Thanksgiving and a full moon

Friday, November 23

Thanksgiving was very different this year, including leading up to the holiday. Normally, I would have been running around preparing all kinds of food, like everyone else.

This year, since we decided to have our dinner with Dad at the convalescent home, I didn't do any cooking for Thanksgiving. I really did miss all that.

But, believe it or not, I went into the grocery store the night before Thanksgiving to get my free Thanksgiving turkey and a few other items.

In the past I would have avoided doing that like the plague. But, it was the best thing I could have done. I actually felt good doing it… my whole mental outlook was so much better.

The one good thing about having Thanksgiving dinner at the convalescent home was that we didn't overeat. We were served a decent size plate of food… just didn't have the extra servings of turkey and all the trimmings, like we're all guilty of doing.

It was also good to see Dad eating decently again. He had been losing weight… total of 12 pounds, but he's gained about 4 or 5 pounds of it back.

He misses being home so much and Thanksgiving has made it that much harder.

My mom and dad haven't been separated like this since my dad was in service during the Second World War. This is very difficult for both of them.

Boy, on Friday, I think the full moon definitely affected our household. My mom had herself convinced that something happened to me… I was upstairs getting dressed to go shopping and she thought I was too quiet.

She had herself convinced I had a heart attack. She is so paranoid about something happening to me or my father. She knows she should not be such a worrier, but can't help herself. And, then when I came home from shopping, my mother-in-law was all dressed to go out shopping.

This kind of thing is maddening, and thank goodness does not happen too often.

I'm convinced as we grow older that the person we once were in the past is magnified greatly as we age…

especially people with dementia/Alzheimer's. For example, my mom was always a worry wart, but today she is 10 times worse than before. My mother-

in-law always liked her food hot, but today likes everything so scalding hot, including sandwiches that would usually be eaten cold. In her world, everything revolves around food.

It's a little scary watching all this happen to our parents and wondering what we are going to be like in our older years. A lot of this aging stuff I'd rather not observe and be made aware of possibly happening to myself or Ken some day.

Guess we all like to think we're going to age very gracefully and not end up being unable to take care of ourselves. My mom keeps saying to me over and over again that she never wanted to do this to me. This definitely was not my parents' dream or Ken's mom's dream.

I saw an interesting article in the November issue of Health Magazine regarding creating a Family Health Tree

This really makes a lot of sense to me, especially now, since we're going through all our health issues with our parents. It's a real eye opener to realize that we could end up having some of the same problems that our parents are facing right now.

My mother's mother passed away when she was 76. If she had lived to be my mom's age (85) she probably would have been every bit as bad with her back as my mom is right now.

I also had a back problem (spondeliothesis & stenosis) which I had corrected with surgery a year ago. After seeing what my mom was going through, I vowed I would do everything possible not to go through the same thing.

Sometimes it's hard to find out information about our family's past health history. My mother-in-law knows nothing about her family health history. I do feel knowing about the family health history can be a help in preventing the same problems occurring in ourselves and our children.

5 days left!

Thursday, November 29

Dad finally received his discharge date from the rehab center… 5 more days. He can't wait to get home… was all choked up when he was told he could finally go home. I'm sure it had to feel like an eternity for him… it will be 7 weeks this Tuesday since his accident.

The bad thing is that the orthopedic doctor only wants him to put 50% of his weight on his bad leg for 3 weeks and then 75% for 2 weeks and then 100% after that.

I'm obviously very nervous about him coming home with his leg not totally healed, but I could not let him stay at the rehab center any longer. He would have totally been bummed out and maybe even made a break for it.

I have to admit I'm rather surprised he's able to go home this soon after the orthopedic doctor's update on his progress. He keeps talking about different things he plans to do when he gets home.

I keep telling him the first week home, he's going to sit in his reclining chair or use the power wheel chair to get around. He's already talking about going grocery shopping in 2 weeks. I told him I didn't think so, but he just kind of ignored me.

Who's the parent?

I'm beginning to feel more and more like the parent, rather than the other way around. They seem to be more and more childlike as they become more dependent on us.

My mom basically won't do anything without asking me first. But, yet some things that are so bazaar, she'll do and not think twice about it.

She has her good and bad days… just like all of us. But, I feel so frustrated when she has one of her bad days. Today was just one of those days. She had to have anything that needed to be done, right that minute … could not wait.

We just clashed all day long. She was negative about everything and anything that we talked about. Of course, this is nothing new, as I've discussed in the

past. She will never change and I know it, but I still don't think anyone should go through life expecting only bad things will happen.

I drive my mom crazy with my optimism. She can't understand how she can have a daughter so the opposite of her. Well the truth is that I refuse to go through life thinking my glass is always half empty. My glass is always at least half full!!

It's so tough watching a parent going downhill before your eyes

Ken's mom also has her good and bad days. These past 7 weeks were very hard on her as well. She didn't come with my mom and me when we visited my dad.

She stayed behind and kept herself busy either with some chores, reading or sleeping. But, we noticed her memory was getting worse. She asked me twice when we were going to eat our Thanksgiving dinner after it already happened.

Each time I told her, it took her a few minutes to remember and when she did she was so disgusted with herself. I order medication for her and she keeps asking me to order the same thing over and over again. It's amazing and scary how quickly her memory is going downhill.

We started the process of liquidating my parents' assets so that they qualify for the JAAC program. I hate doing this, but it's the only way they will qualify for any assistance.

Home care is not covered by their long term insurance and could become very costly for them and totally wipe them out without ever going into a nursing home. We're trying to protect them as much as we possibly can.

DECEMBER 2007

Home at last – new challenges

Wednesday, December 5

Well, Dad finally made it home yesterday. Hallelujah!! Everyone at the nursing home was very nice. They all seemed to take an interest in Dad because he couldn't sleep at night and was always going out to the main room to watch TV and eventually fall asleep. They all felt so bad for him that he couldn't sleep at night.

Now that he's home the pressures on myself have increased tremendously. I realized it would be a huge responsibility when he came home, but between Mom & Dad, it takes me almost all morning and a good portion of the evening to get them settled.

I'm now dispensing medication for both of them. My mother's medication is pretty easy, but my father's medication is more complicated. He's diabetic and his insulin and Prandin were totally changed while he was in the nursing home.

So, now that he's home I was a little uncertain what to do. The Visiting Nurse came on Wednesday and what a life saver she was. She totally went over all his medications and put a call into Dad's endocrinologist.

We basically kind of went back to his old regimen. The nursing home has to pretty much treat all diabetics alike, I'm sure because of time restraints and personnel. But, he seemed to do ok at the nursing home.

We now have the visiting nurse, physical therapist and a home health aide coming to help him through this period of time. They are all very special, caring people. The nurse will be coming 2 times a week.

I believe the physical therapist will be coming 3 times a week, and the home health aide 3 times a week. My mom also has a physical therapist 2 times a week and an occupational therapist 2 times a week. Our home has become a real zoo. But, I'm so thankful that my parents are able to get this kind of care.

I think I learn something new every day about being a caregiver

I took my Dad to the doctor today to go over his medications, etc. I called to see when the visiting nurse would be coming and found out that she couldn't come today because the insurance would not allow it.

Cannot have the nurse come to the home and also go to the doctor on the same day. Good thing to know. Actually makes sense to me. There is no reason to have a nurse come to the home when the patient will be checked over by their physician.

I thought my dad would do a lot better once he got home, but if anything, I think he's worse. He was probably like this at the nursing home, but just didn't realize how bad he was.

He's so anxious and on edge. He told the doctor today he can't stand to have his legs elevated…makes him feel like he wants to climb the wall.

We talked to the doctor about the Prozac he's been taking ever since he went into the hospital. He was not on it before he was admitted to the hospital. I think it was on a list I had given to the doctor where Dad had his fall.

Guess I thought it was crossed off, or else told them he didn't take it all the time. Any how, it was probably given to the paramedics and then given to the hospital and then to the nursing home.

I'm convinced that the Prozac is making Dad have all these anxiety problems. He's now taking another medication and am hopeful that this will take care of his problem.

He's also developed a bed sore that needs to be watched. On top of all this, he's constantly up on his leg and I swear at times he's putting pressure on that leg.

I just can't seem to get through to him how important it is to take care of that leg. It's really worse taking care of elderly people than little kids.

On a happier note, Ken and I went out and got our Christmas tree today. It was so nice to do something positive. It's amazing how appreciative you are of small moments of joy when you're going through a period like this.

Life sure is both hard and interesting sometimes

Sunday, December 9

On the positive side, my father is doing much better. He's been off Prozac for 2 days now and is doing so much better. He's still not sleeping in his bed at night, but between his sleeping pill and being off Prozac, he is getting a little sleep at night. Now I have to get his blood sugar from going too low during the night.

Hopefully, by this coming week we'll have his meds and bed sore all on the right track. Now, if only his leg would heal. He so badly wants to help me, but I'm petrified he's going to reinjure himself and start all over again.

I'm learning with my mom that we seem to get at odds with one another early in the morning and at bedtime. She's so used to being on a schedule, and when her schedule is messed up, she becomes very upset. I'm the opposite and very flexible with what I do…I have to be that way.

So, I have to try much harder not to get her upset in the morning, but it's so hard with only about 5 hours of sleep a day and getting right out of bed at 5-5:30 in the morning and digging right in.

I have to keep doing this until my dad's leg is better, then he will take over again. I know they don't want to put me through all this, but there is no alternative. I try so hard to take good care of them, but realize I'm human and can't get all things done totally right.

Alzheimer's is such an insidious disease

On Saturdays I take Ken's mom grocery shopping and any other errands she needs to get done. I will not let her go in any store or anywhere by herself.

Up until the end of this summer, she was going into the library and drugstore by herself. She's extremely unsteady, has a hard time hearing or

understanding other people and has a hard time communicating with people… can't get out the words she wants to say.

So, I try to stick close by her whenever we go shopping. Yesterday she was writing a check out for cash and could not remember how to do it.

While I was in the post office she finished writing it out. From the post office we went to the drugstore and then straight to the bank…probably about 15 minutes from the time she wrote out the check.

By the time we got to the bank, she did not remember writing out that check. I was totally shocked and amazed.

Her memory is going downhill so fast…just can't believe it. Ken's been taking her to her doctors to help me out and I know it upsets him too seeing her deteriorate so rapidly.

I think she does realize what is happening to her and gets so upset whenever she does something like that. She's still dispensing her own medication and I really would like to take over that responsibility. I think she's doing it properly or else I would have insisted I do it for her.

My responsibilities have increased ten-fold

I just hope we can keep caring for them without totally ruining ourselves. I've taken over all financial responsibilities for my parents, doing their shopping and taking care of their prescription needs. And, of course, all the calling back and forth about many miscellaneous things.

Ken's mom also needs a lot of additional help. In the past week, I virtually have had no down time to myself…maybe 10 minutes here and there every once in a while. It does get me down every once in a while and I try to shake it off as much as I can.

Today I decorated the tree and put on some Christmas music and think I enjoyed decorating the tree this year more than any other time.

Then when Ken got home, we got all the Christmas decorations out and put them up. It was wonderful therapy. It seems like anything I do that does not include being a caregiver becomes such an enjoyable thing.

I just look so forward to our Saturday nights out. Ken and I don't stay out long, just enough time to get reacquainted with each other. We're both so unbelievably busy…not a good thing.

I'm so looking forward to having our family come for the holidays. It seems like it's been forever since we've seen them and played with our grandkids.

Can't wait! Definitely need some young children running through the house and making some noise. Will be great!

The adventure is getting more intense every day

Thursday, December 13

Can't believe so much time has passed since my last entry. Every day is such an adventure for both Ken and me. Ken has been extremely busy with the business and also getting his mom to all her doctor and dental visits.

Ken is taking his mother to the doctor who treats her for Alzheimer's on Monday. She has been going downhill quite rapidly for the past couple of months.

She can't remember things that she did 15 minutes ago and has a hard time following simple instructions that are written down for her. She sometimes will come down in the morning totally confused.

One morning she came down and said she wasn't feeling well, but could not describe what was wrong with her.

She's very aware that she's having these problems and keeps saying that it's not her. It's very hard for her to communicate as well. She constantly is struggling for words to describe what she is talking about.

It's frustrating to her and also to us. Not sure if any other medication will help her, but at least maybe we can understand how to deal with her situation a little bit better.

Dad has been a real challenge to me, so much more than I ever thought he would be. He's such an easy-going guy and we would never think he would do the things he's been doing.

Under normal circumstances he's quite rational. He refuses to keep his leg elevated and as a result his leg is very swollen. He refuses to sleep in his bed and ends up sleeping sitting up, with his legs on the floor.

He's been doing this ever since he was released from the hospital to the nursing home. I thought it was just that he couldn't relax in the nursing home, but he's been every bit as bad at home. He's very anxious.

The physical therapist explained to me that it's very normal for an elderly person who was previously a caregiver to experience these problems.

They are upset that they can't help the person they were caring for before they were incapacitated. Dad did everything for my mother and now he watches me take care of her.

He's not able to get out and drive and do the errands he did before. So, I guess when I think of it like that, I can sort of understand.

Another trip to the ER

Yesterday, the visiting nurse came to see him and saw his leg. She spoke to Dad's doctor and she wanted Dad to go to the ER. That was the last place in the world I wanted to go, but knew it had to be. The nurse was concerned that he had a blood clot. The only way to find out was to go and get an ultrasound of his leg.

Thankfully, everything was ok. The doctor seems to think he may have early stage cellulitis, which we need to watch. If it gets worse, he'll have to go on antibiotics.

The physical therapist told him some of the bad consequences of cellulitis and none of it was good. He's diabetic and, if it got bad, he could lose his leg. I kind of think this finally sunk into him and he's been elevating his leg more today than he has in 8 weeks.

We finally filled out the application for the NJ JAAC program. The caseworker came to the house to go over everything with my mom and dad.

They need to know their medical history, medications they take, any medical equipment currently in the home, financial information with all kinds of records, birth & marriage certificates, etc.

If they qualify for the program, it will be well worth it. They currently have a wait list for the program.

Christmas will be different this year, but I can't wait!

I just can't believe that Christmas is just a little more than a week away. Ken and I have been so busy with all of our responsibilities that the time has kind of just passed us by. Years past, I would have been so stressed out over Christmas by now that is, not having more shopping done, etc.

But this year, I'm so much more laid back about the whole holiday. I love to hear the Christmas music in the stores when we do go out Christmas shopping; it just makes me feel good.

We know we can't make Christmas quite the same as years past, but I think this Christmas is going to be more meaningful to us in many ways. Our children & grandkids will be coming the end of this week and we just can't wait to see them all.

JANUARY 2008

The Holidays Were a Whirlwind

Sunday, January 6

It's been several weeks since I made any entries to this diary. So much has happened, not sure I can begin to remember it all. For one thing, I had no idea how Ken and I were ever going to get through the holidays with everything that we had to do.

But, we did it and we really did have a very nice Christmas with our family. Family makes all the difference in the world!! All the problems we've had with our parents seemed so much easier to handle when our children and grandchildren were here.

This was the first holiday that I was not so uptight about everything. Years past, I would have been up all hours shopping, wrapping gifts, baking, preparing different foods for the holiday, etc.

In other words, stressing out big time. This year we had plenty of stress, but we did make sure that we still had our couple of hours on Saturday nights leading up to the holidays.

Busier and busier

Friday, January 18

Boy have we been busy with parents and business, both Ken and I! I didn't realize it was so long since my last entry, so this will be a recap of what has been happening.

We did have a very nice holiday. The one bad thing that happened was that my dad fell down on Saturday night before New Year's Day around 11 at night. He fell hard again and our family was still visiting.

We all ran into my parents' apartment and found my dad on the floor in the bathroom. He had a gash in his head and was bleeding, but not real bad. He was shaking, probably upset from the fall.

We didn't know whether we should take him to the ER or not. We really didn't want to if we didn't have to, since he had been through so much in the past few months.

We kept an eye on him and our son stayed up and checked on him every once in a while. The next day he seemed to be improving and the gash seemed to be ok.

He was still weak and wobbly, but little by little seemed to be getting stronger. The weird thing was that he didn't remember how he fell and actually doesn't remember falling. He does remember Ken and our son picking him up.

Back to quiet… back to our reality

The next day our family left, which was New Year's Eve day. Of course, the house was so quiet without all of them again. Dad seemed ok that day…he rested most of the day.

The bad thing was that he had no appetite, which is not normal for my father. Prior to his first fall, he had a bottomless pit when it came to eating.

I tried to get him to eat, but he just picked at his food. For the most part, he had been monitoring himself for his blood sugar and also doing his own insulin injections.

Dad told me on New Year's Eve that the needle bent and was not sure how much insulin he had injected into himself. I didn't think too much of it.

The next morning, New Year's Day, we started out with a real bang. His blood sugar was high and so I assumed that he either didn't get any insulin or else not enough.

So I gave him another insulin shot that morning. At lunch time, his blood sugar had shot up to 410, which was way out of line for my father. So, I called his endocrinologist and luckily he called back within 5 minutes.

Couldn't believe it…New Year's Day!! He said we should go to the ER and get checked. He thought my dad could be dehydrated. Diabetics' blood sugar will go high if they are not properly hydrated.

I know dad was drinking quite a bit the day before. Anyhow, we spent New Year's afternoon sitting in the ER. Dad had a CT Scan, blood work, urinalysis, was checked over, and everything seemed to be ok. His blood sugar was still high at the hospital, but it did come down quite a bit.

He basically ate nothing that day. The doctor said he could have had some sort of an episode that made him fall, but wasn't sure. Sometimes after a fall, a person can exhibit almost flu-like symptoms. So, we still don't know for sure what caused him to fall.

One possibility is that he was taking Ambien, a sleeping pill, which the doctor said can be addicting to some people. Dad just wanted that pill every night, but he'd only sleep for a few hours and then be walking all over the place and really kind of out of it, and also started walking without his walker.

It became a real problem. Anyhow, we kind of think that may have been part of the problem with his fall.

Crisis again

My father seemed to be getting better, but then two days after New Year's he fell again. I believe it was 2 times that one day. He became so weak and developed diarrhea, became incontinent, and was just plain totally out of it.

Ken and I thought we were going to have to have someone come in and care for them 24/7. Dad's care was just getting so beyond us. We just did not know which way to turn.

I believe that week was the worse week of my life with caring for my parents. I wasn't able to get my work done at the office and was constantly cleaning up after my dad.

I was totally frustrated and exhausted. By that Saturday night, when I got into bed, I had serious back pain and had myself convinced that I did some serious damage again to my back.

I had back surgery a little over a year ago and was perfectly ok. I guess, between trying to get my dad up and the stress of it all was just too much on my back. Thankfully, after one whole day of being good to my back, it's ok again!

Anyhow, Dad did stabilize over the next few days. He was still very weak and not himself, but by the following Monday, we returned to Dad's family doctor. She changed his sleeping pill and also gave him a Vitamin B12 shot.

From that point forward, he seemed to do a real turn around. Still don't know what was wrong for sure, but we do think the Ambien had a lot to do with his problem.

Some people should not take certain types of medication and I think Dad is definitely one of them. I also remember when I was much younger, I worked for a doctor, back in the 60s and elderly people were always coming in to get a B12 shot.

I think I remember reading that this vitamin B12 shot is making a comeback in the elderly generation. It could also be making a very positive effect on Dad. Anyhow, we're getting him back!!

There really is a light at the end of the tunnel. Didn't think we'd ever be able to say that about Dad again.

Ken's mother's dementia continues to be a challenge

Kind of backtracking now. Just to bring us up to date with Genevieve, Ken's mom. Last week was her week. She went to her eye specialist, foot doctor (all 3 went to the foot doctor), skin doctor and the dentist.

Ken and I thought she was getting better with her mind. The neurologist tried a new medication on her and it really seemed like her memory was getting better, not searching for words as desperately as she used to.

But, then she seemed to go backwards again. She can't remember what doctor she's going to and many times she can't even remember the doctor. Usually she'll remember them when she sees the actual doctor.

It seems many times like her hearing is getting worse, but we think her mind can't process what she's hearing properly. The only way she can hear is to totally focus in on the conversation, which does not happen very often.

She seems to be falling asleep more and more during the day and has gone downhill dramatically in the past few months. Hopefully, she'll feel much better when nice warm spring weather returns. We all will!!

My mother also continues to be a real challenge!

We've been having a physical therapist and an occupational therapist coming to the house for her. I think in some respects she is getting stronger…so does the physical therapist.

She is able to get in and out of chairs so much better than she used to. But, at the same time, she'll say how weak she is and how much she hurts.

The occupational therapist is pushing her to try to do more and more tasks. She's encouraging her to do her word scrambler puzzles again. She used to love to do them, but just totally lost interest in everything.

She can't concentrate on reading anything. The one and only thing she does enjoy is music…especially music from the 40s. Music is her first and one true love…very therapeutic to her.

Each and every new day for Ken and me seems to have some sort of new challenge waiting for us, but we are ready and able to face whatever is being thrust upon us… some days are just harder than others. Guess that's the case for most families.

Believe it or not, life is getting a little bit better with our parents!

Sunday, January 27

Dad is making a tremendous recovery. For as bad as he was, he's done a total turn-around. We had ourselves convinced that he would need total 24-hour in-home care, so needless to say, we are very relieved.

We went back to Dad's orthopedic surgeon last week and he said he was healing very nicely. He's now walking with a cane and doing a good 50% or more of the chores that he used to do.

He wants to do everything, but there is a limit. He's still getting physical therapy, but that will most likely end in a couple of weeks, as well as the home health aid.

They've all been so wonderful to my dad. We would have been totally lost without them. Dad's so anxious to get back outside again.

He and my mom both feel totally housebound. He made sure that we found the power cord to his scooter so he can get that all charged up and ready to go.

We also went to Motor Vehicle on Thursday to get his license renewed. Dad still has to prove to me that his driving skills are ok.

The doctor said it would be ok for him to drive, as long as his reaction time is good. So, I think he'll be doing most of the work and chores that he did before the accident.

I would never have believed that 2 weeks ago! So, now I am able to get up about an hour later in the mornings. It's so wonderful!!

As to my mother, she has certain problems that will never change

Her physical therapy ended last week. She really did do well with it. Her legs and arms are actually pretty strong, but for some reason she doesn't seem to have the strength to do a lot of chores.

But, on a positive note, she gets in and out of chairs by herself…not that it's easy for her, but she knows that she can do it and has to do it.

She also got over the fear of getting a bath in the tub. We have a special bench for the tub. One side of the bench legs sits in the tub and the legs on the other side sit on the outside of the tub.

She's able to sit down on the bench on the outside of the tub and then rotate her bottom so that her legs are in the tub.

She was petrified the first time she used the bench, but now she does quite well with it. Her power wheel chair is also great for her. It has a power lift in it and when her back is hurting badly, she can sit in the chair and get the weight of her upper body off of her lower spine. This also forces her upper body into a more upright position and helps her breathe easier.

She still is receiving occupational therapy two times a week. This is really great, because the therapist is constantly challenging her mind. She's constantly trying to get her to solve certain puzzles. She also had Mom sitting at the organ and playing a song for her. She used to love playing her organ.

She also has her in the kitchen, doing minor things…like getting herself a drink of water or getting something out of the refrigerator.

We just found their boom box, which was hidden in the closet. While Dad was in the nursing home, we were trying everything we could think of to make his stay a little better.

One thing we got was some CDs of big bands from the 40s. Anyhow, now Mom and Dad are playing these CDs and totally enjoying them…especially Mom.

She always said music was therapy to her and how true it is for her. She even enjoyed the music so much that she was moving her feet while using her walker.

As for Genevieve, Ken's mom…she's an adventure every day

We never know which Genevieve is going to show up in the morning. She always seems her best if she gets up at her normal time in the morning. When she sleeps in a lot later in the morning, it seems to throw her off the whole day.

She loves to keep busy…that's the only way she's happy. I came home from work the other day and found her on the floor in the living room.

I don't know how long she was there, but my guess is it was a good half hour or more. She was all over the floor trying to get herself up, but just couldn't do it.

Mom and Dad were over in their apartment, which is really just a room away, but they never heard her and didn't know she had fallen.

I tried one time to get her up, but there was no way in the world I could get her up without totally destroying my back.

I called Ken and he came right home. It was even hard for Ken to pick her up. Luckily, Ken was able to get his mom up. But, I told her that if Ken is not in town and it's just me, the next time we'll have to call 911.

Ken and I are making a big push for all 3 of our parents to get some kind of Medic Alert device. Even though they all share the same house, they don't know what has happened to each other at times.

We wanted them to get one over a year ago, but they all fought us on it. Guess they didn't see the need for it. But, I think they realize it's necessary now.

Caregiving at 95

My grandmother, who is 95 years old, is still in great shape, living alone and still driving. Her sister, who is 97, was also living alone until last week. She fell in her home and no one knew about it. Neither my grandmother nor her sister have a Medic Alert device.

When my grandmother's sister fell, she was obviously alone and unable to get to a phone. She lives in a row home and was able to get to the wall and pound on the wall. Her next door neighbor luckily heard her and was able to help her.

She was hospitalized and had broken ribs and a fracture of her spine. She stayed with my grandmother for about a week, which was very difficult for my grandmother. It's a little hard to become a caregiver at the age of 95.

After staying with my grandmother for a week, her sister had to go back to the hospital with a different problem and from there went into a nursing home. She was told she could no longer live alone.

So now my grandmother has the task of putting up her sister's home for sale. My grandmother had power of attorney for her sister. But, luckily, her sister transferred the power of attorney over to one of her previous neighbors.

Ken and I always dreaded what was going to happen to my grandmother and her sister when they would need help. My dad and I have power of attorney for my grandmother.

My father is also an only child and my grandmother is my dad's step mother. So she has no one else to care for her when she needs help.

Her sister has no one else either. We feel very bad for my grandmother, because she could use some help from us right now.

Luckily, she has the most wonderful friends and neighbors in the world who have really stepped up to help her. Don't know what we would do without them.

It really becomes a major problem when a husband and wife are both only children and have elderly parents and a grandparent with an elderly sister who all have health problems. But, someway, somehow, problems do get solved

FEBRUARY 2008

Silly, silly me!!

Friday, February 15

I really thought Ken and I were finally getting a handle on our lives again. We had about a week with no major catastrophes. Dad was helping Mom again with some of her personal needs. The really nice thing was that I could sleep in until 6am instead of getting up around 5am every day.

Dad was almost at the point of being fairly independent again. Then, last week, he pushed his activity too far… his intent was good, but the outcome was very bad.

He decided he wanted to get the tractor out of the shed so that he could take the trash cans out to the street. When opening the double doors to the shed (they were warped from dampness), he had to push to get them open.

When they finally opened, his body went right along with the doors and, consequently, he fell down.

Ever since that happened, he's had bad lower back pain. Two mornings in a row he could not get out of bed. I had to have him roll over onto his stomach and slide out of bed onto his knees.

Since those 2 occurrences, he's been sleeping in a chair. He went to the doctor and then had X-rays to determine if he fractured or broke anything. He's now on pain pills and not doing well at all. We're still waiting for the results.

A major setback with Ken's mom

The same night that my dad hurt his back, Ken's mom started acting strange. Her balance was not good at all. She was standing at the kitchen

counter and started to slide over. This happened a couple of times. That night, Ken had to walk her upstairs… she couldn't do it without help.

The next morning (6am) she called for us. She fell out of bed and had no control over her legs. We called 911. They came right over and transported her to the Emergency Room.

After several tests, including a CT Scan, it revealed she had a brain hemorrhage (mild stroke). It affected the right side of her body. She has some strength and movement in her right leg and arm, but not good control. She also has a very difficult time speaking… can't get the words out.

That same morning she went to the Emergency Room, Ken was also due at the hospital for surgery (same hospital). It was a very difficult morning for Ken.

His Mom's in the ER with a stroke and he's due for surgery in 1½ hours. We finally had to leave his mom and have Ken report in for his surgery. He finally got all his paperwork done and was ushered away to change into typical patient surgical attire.

I then went back down to be with his mom in the ER and stayed with her and made sure she was all settled into her room.

The rest of the day was spent going back and forth between Ken and his mom. Ken's surgery was delayed four hours. That was horrible for him and agonizing for me waiting for him to come out of surgery.

Then, after I got Ken home that night and settled in and my mom and dad settled, I went back to the hospital to make sure Ken's mom was doing ok.

I do believe that had to be one of the hardest and longest days of both of our lives. If we had ever known something like that was facing us, I think we both would have turned around and run away. So much for our feeling of getting our lives back again!!

MARCH 2008

It's heartbreaking watching Ken's mother

Monday, March 10

Well, Ken and I just got home from visiting his Mom. It has been a major nightmare for her and totally heartbreaking for us. After being at the rehab facility for the second time, she just doesn't want to be there and wants to come home so badly.

She's been going back and forth between reality and non-reality. Tonight she told us about a person that was so mean to her and said she can't bear to stay there anymore and that she's so afraid.

She wants to take off a week to see how it goes and hopes her job will still be there. We kind of think that she's referring to her therapy sessions. She's in an acute therapy facility and it's probably too much for her. She thinks they are mean to her because they make her work so hard.

It's so hard to avoid self-pity

I'm backtracking from here. So much has happened with our parents that it's almost impossible to keep up with my entries. Ken and I both go on our self-pity trips, which I guess is kind of normal.

Luckily, if I'm feeling really down, Ken has been there for me and can bring me out of it. The same thing with Ken when he's feeling down. So far, we haven't been totally depressed together…that one is not good!!

One thing that is so hard to accept is that our parents never had to care for elderly parents. In their mid-sixties my parents were still very independent and leading normal lives and not having to care for anyone.

That wasn't the way it was though for Ken's mom. Her life at that point in time was not easy. Her husband (Ken's Dad) had a bad stroke and was not able to care for himself for many years before he went into a nursing home.

She visited him every day at the nursing home and took care of him as much as she could during that time. She never got over his death.

For Ken and I we have a very difficult time getting away just to visit our children and grandchildren, let alone taking a trip together. With spring and summer approaching, I think we'll all feel better…just being able to get outdoors and take walks and go swimming for some R&R.

That sounds really great! It will even help my parents. They hate being housebound and I can't blame them. It would drive me crazy!

Please don't get me wrong by everything I'm saying above…I'm just venting. Ken and I both want to keep our parents home as long as it is humanly possible.

We think it's the right thing to do. We hate the thought of them having to sit in a nursing home for the rest of their lives.

It's not bad when the residents are able to socialize and interact with one another…it's just when they get to the point that all they do is sit and stare, it's so sad. Getting old is definitely not a fun thing for most of us!

At last… progress!

Well, now that I'm done venting, back to Ken's mom. She spent almost a week in the hospital. She had her good days and her bad days. She was transported to a local rehab facility for therapy.

The day she was transported, it was such a miserable day, weather wise. I think she was very frightened when she arrived at the rehab center…she just didn't know what was going on.

I met her there and she was crying when I got there. We got her calmed down and settled in and she seemed to be accepting everything.

When Ken and I visited her at the rehab facility for the very first time, she was in the gym watching a dog training show. We both were so happy to see her there and participating in something.

She went to therapy every day and really seemed to be improving and for the most part seemed to be relatively happy and looking forward to getting well enough to come home.

A turn for the worse

She was at the rehab center for at least a week or more and then she took a turn for the worse. We got a call from the rehab center that they were taking her to the ER because she was not responding to them.

Well, if you can believe this, Ken had another out-patient surgical procedure done that very same morning as his mother was being taken to the ER.

Of course, Ken could not be with his mother after just having a surgical procedure done. Can you believe it? Both times that Ken had a surgical procedure done were the times that his mom had to be sent to the ER.

I think that is really strange! Anyhow, she was in pretty bad shape when I got there. She was constantly trying to clean imaginary objects.

They, of course, did a lot of tests, including a CT scan. She did not have a full-blown stroke, but something they referred to as an event.

Anyhow, it was enough that it really set her back, big time! She spent another week in the hospital. During her stay this time, she became very uncooperative and belligerent with the nurses.

She never remembered being in the ER and didn't seem to remember our visits from one day to the next. It was extremely hard for her to communicate early on during this hospitalization. She seemed to get a little better after a few days.

Her doctor told us that she has a lot of different problems going on. She's been on Coumadin (anti-coagulant) for years because of her irregular heart beat.

She's been on this medication to prevent having a stroke. But, she had to come off this drug, because of the brain hemorrhage. So, now they are having a major problem with her blood.

Without the Coumadin, she most likely will develop blood clots, but with it she'll have possible bleeding in her brain. Then on top of that the arteries on both sides of her neck are 50% clogged. So, she has some major problems.

Back to rehab - but it's not working out

The rehab facility where she was prior to this hospitalization did readmit her as an acute therapy patient. She hated being in the hospital and couldn't wait to get out. We told her she was going back for therapy and that she would feel better.

Well, this time, her brain is so messed up that she doesn't know what's real and what's not. We never know which Genevieve is going to show up when we visit her.

She's been at the rehab facility one week now and has to have someone sit with her around the clock because she wants to keep getting up, won't eat and doesn't want to take her medication. At this point, it brings us pretty much up to date.

More evaluation concerns

Tuesday, March 11

The rehab facility is having an evaluation of her to determine whether she stays in acute therapy. Ken called them this morning to more or less give them our input to her situation.

We both feel she should be moved out of acute therapy and transported to a sub-acute facility. Hopefully, she'll be a little more accepting of it.

It's so hard to see her so unhappy. She wants to come home so badly, but there is no way she's well enough to come home for even 24/7 homecare.

This is hard on both of us, but especially more so for Ken. It's totally different when it's your own mother or father going through these horrible times. You want what is totally best for them and you don't want to see them unhappy.

Getting back to my dad… his general practitioner had him get a regular X-ray on his back after his fall (the day before Genevieve went into the hospital) and then we went to his orthopedic doctor who treated his broken femur.

I was so afraid he reinjured his hip again. His orthopedic doctor sent him for a CT scan of his lower back, which showed he had a compression fracture of one of his lower vertebras.

He just went for an MRI to see if they can do a procedure called a vertebralplasty (I think that's right) on him.

This is a minor procedure, where they shoot in some sort of cement to repair the fracture. Sometimes the patient has instant pain relief and sometimes it takes a little longer.

My dad is really hoping and looking forward to having this procedure done. Other than his pain in his back, he is doing relatively well at this point in time and looking forward to doing some chores again.

He's been helping my mom more and more. They help each other as much as they can.

Mom has her good and bad days. Some days her back bothers her more than other days. She no longer has therapy at the house. The allowable amount of time has run out, but it was very valuable to her.

She knows she has to do her exercises to keep her from getting worse. She's bent over worse than ever and cannot take any kind of stress whatsoever.

Her occupational therapist would like to see her get some pool therapy this summer. I'm hoping we can do this for her. My mother used to love the water, but is fearful of it now. I do know that as warmer weather comes, she will definitely feel better.

My mom and dad both love to sit outside on their deck and just enjoy being outdoors. I think spring makes us all feel better!

Later today we should know what the prognosis is for Ken's mom. Right now she's the hardest one to deal with. We really do hope that she can get well enough to come back home again… she wants that so badly.

In the meantime, life does have to go on as usual. Ken and I are both still working, so we need to work around all our personal problems with our parents as best as we can.

Another set back

Ken received a call this afternoon from the rehab facility that his mom had been transported back to the hospital ER again. She was unresponsive, had a fever and a lot of congestion.

When we arrived at the ER, she didn't talk at all and was asleep most of the time. Occasionally she kind of had her eyes open and just looked like she felt totally miserable. She was diagnosed with pneumonia and also a urinary tract infection. They admitted her to the hospital later that night.

The next day she appeared to be very feverish and again unresponsive for most of the time we were with her. I believe she did say a few things, but not very much. All we could really do that day was hold her hands and let her know we were there.

Two days after she was admitted there was a big improvement. She was sitting up and looking so much better. She was able to converse with us again, but kept asking the same question over and over again.

She still is constantly talking about events that are either not real or are from the past. We were hoping that by some small miracle her mind could start coming back again. But, we don't think that is going to happen.

They had to move her to another room at the hospital, because she needed a care companion to stay with her around the clock. So, she is now in a room with another patient who has similar problems.

Ken's mom also has big mittens on her hands so that she can't pull out her IV and other tubes. She hates having them on and just doesn't understand what

she was doing to herself. She still is not eating and has lost another 5 lbs, making it a total of 15 lbs she has lost.

Researching nursing homes - it's not fun

Ken and I have been checking out various nursing home facilities and we found one that is very bright and cheery when you walk in. We realize that the most important thing about the nursing homes is the staff.

That, unfortunately, we won't know anything about until we have his mother in the nursing home for a while.

She'll initially be going into the nursing home as a sub-acute rehab patient. But, we think the reality of the situation is that she may be staying at the home permanently.

As much as we would like to bring her home, we think it's just not possible. She can't do anything for herself, including eating. We know when she is feeling better she'll be begging us to bring her home. She just doesn't realize how sick and bad she actually is.

Hope for dad

My dad is going for his vertebralplasty tomorrow morning. Of course, with every procedure, there are usually several tests to have done before the actual procedure. After having a regular x-ray on his back, he then needed a CT scan.

From there he went to the doctor that does the actual vertebralplasty. That doctor sent him for an MRI to see if he was a candidate for the procedure.

After finding out he can have the procedure done, he then had to go for blood work. So now, here we are the day before the procedure. He's hoping beyond hope that his pain will be gone. He has not slept in a bed in about 5 weeks. He's tried a couple of times, but once he gets in bed he can't get out.

I dread every time he needs a surgical procedure done because of his diabetes. He can't eat in the morning, so I'm hoping that he doesn't have one of those mornings where his blood sugar is low.

Of course, every time my dad has to go to a doctor or have any kind of procedure done, my mom gets herself all upset from worrying. They always went together to each other's doctor appointments or procedures. So now it's hard for my mom not to be with my dad.

I'm increasingly worried about mom

Mom has been doing her exercises that her occupational therapist had given her. I think she does realize that if she doesn't keep herself active, both physically and mentally, she will go downhill much faster.

I noticed today, especially, that when she walks, she's bent over more than ever. I think her head is even below her waist when she walks. I think she would give anything to be able to stand up straight and walk normally again.

Every time I ask her if she wants anything from the store, she always tells me a new back. I feel so badly for her, because she was a very active woman who loved the outdoors.

Today is dad's procedure

Tuesday, March 18

Well, here we are the morning of Dad's vertebralplasty. We got lucky this morning… his blood sugar was 160 at 5am. I feel pretty good about that. I was so afraid he was going to have one of those mornings with a reading below 80.

I have to say this was a fairly smooth morning for having a surgical procedure. Everything was right on time… he just had to wait a little extra for the doctor to arrive. He came through the procedure with no problems and virtually has no pain.

I'm sure he'll be pretty sore where they inserted the actual cement, but other than that, we're hoping for a full recovery (no pain in the lower back).

My fear now is once he's feeling pretty normal, that he'll get himself into trouble again… his balance isn't the greatest. His mind wants to do as he always did when he was younger. Hope his body agrees with his mind.

Of course, Mom was worried sick about my dad this morning. But, she also got through it with no major trauma. I still have to make an appointment for Mom to have a renal ultrasound.

I'm dreading that! Mom does not do well with any kind of procedure, because she can't lay flat. I'm trying to make sure I have a clear calendar before even attempting it.

Ken's mom is not doing well

As for Genevieve, Ken's mom, it's not good. Last night when we saw her, she looked like she went through a major battle. Her hair was totally a mess, her gown was half down her arms and her covers were half off the bed.

Her thumb was out of her mittens and she was pleading to get the mittens off. Again, it appeared that she didn't eat her dinner. I'm not so sure I could have eaten it either.

It was all pureed food… mashed potatoes, spinach (a green glob) and probably meat (a brown glob). Guess she's now having a hard time getting her food down.

She did have an MRI yesterday, but they did not have a record of the results yet. She does recognize both Ken and me, but cannot remember our names.

She does not know where she is staying and still cannot remember anything that she said after 5 minutes or so. When we tell her how sick she was, she's always so amazed.

We think she doesn't remember our visits from one day to the next, but she's always so happy to see us. The nurse told us that she still does not have any discharge date from the hospital.

It's always an adventure to go visit her. We just don't know which Genevieve is going to greet us. It's so sad and depressing.

Old age isn't for sissies

It seems like when the majority of elderly people reach a certain age, that all they do is go to doctors, have tests and take a lot of medications. My grandmother is one of the fortunate ones.

She's now 95, going on 96 and I feel she's really in great shape. She's feeling very put-upon right now, because her 97 year old sister is in a nursing home. My grandmother, along with one of her sister's friends, has been cleaning out her house.

Plus, my grandmother visits her sister every day at the nursing home and tries to encourage her to eat and participate in the activities at the home. So now, my grandmother is feeling the stress of all this.

This is not good for a 95 year old person. I'm hoping that this doesn't hurt her!

Easters are a lot different now

Wednesday, March 26

Can't believe Easter has come and gone! The past few years Easter has been very different for us. Years ago it was filled with lots of excitement and anticipation… coloring Easter eggs with the grandkids, Easter egg hunts, going to church Easter morning and, of course, Easter Brunch!

The past few years have been very quiet, as our parents aren't able to travel and our children and grandchildren now spend Easter at their own homes. We still go to church on Easter morning, but it's now just Ken and me.

This year my dad's birthday was also on Easter. So, we had a double celebration. He turned 85 and I told him he has to start thinking young. Guess it's kind of hard when you hurt all over.

Catching up on the parents

Well, again, let me backtrack to catch up on how our parents are doing. My dad had his vertebralplasty last week and was pain-free when he first got home. But, by the time I got home from work that night, he was in a lot of pain again.

The anesthesia wore off and I think the pain he was feeling was more from the actual procedure. The next day he was pretty good, but not totally pain-free.

The third night after the procedure he did sleep in the bed for the first time since the beginning of February and was able to get out of bed by himself. His back is not totally pain-free, but it might gradually improve.

He goes for an x-ray of his back tomorrow and then back to the doctor next week. We'll have a better idea at that time what his prognosis will be.

My mom has been kind of status quo. She's not in good shape, but she realizes that not too much can be done about her problems. Most of her health issues are all related to her back. She doesn't go out very much any more, because it's too difficult for her.

I try to get her to do some of her exercises that the occupational and physical therapists had given her. She does do some of them, but gets tired and discouraged very easily. I've also been trying to get her interested in some games and puzzles to keep her mind challenged.

As for Ken's mom, Genevieve, she's another story. She was discharged from the hospital March 19th around 8pm. We went to see her early that night before she was discharged to prepare her for the move to the nursing home.

She was in pretty good spirits, but, of course, her mind was very much the same. We kept telling her over and over that she was leaving the hospital that night and going to a new place for physical therapy. We were hoping beyond hope that she would remember, but of course, she didn't.

Transition to the nursing home didn't go well

The next day, Ken got a call from the nursing home to tell him his mother was there and settled in. But, the night she arrived, she was extremely combative and screaming for Ken.

The next morning they found her on the floor… she fell out of bed. I went to see her that afternoon to make sure she was calm and not too confused.

But, by the time I got there, she was perfectly ok. She was dressed in her clothes again and looked so much better. We took turns going to see her for the next couple of days and she seemed to be doing ok.

She seemed more mellow and talking a lot, but no longer agitated. Again, she talked about the same things over and over again and asked the same questions many times.

Seems like this is how her mind is going to work… not remembering anything for more than a few minutes.

Saturday, Ken and I both went to see her later in the afternoon. We happened to catch her at dinnertime. But, we were really quite surprised by her reaction to us.

She's always been so animated and happy to see us. But, this time, she actually didn't utter one word to us and we're not sure if she knew us… we think she did.

Ken and I fed her dinner and managed to get her to eat a fair amount of food, but when it came to her dessert, she started to fall asleep.

The health aide told us that she had a very busy day and was probably just worn out. So, we said our goodbyes to her for the day and were hoping beyond hope that tomorrow would be a better day.

Improved!

When we went back to see her on Sunday, she was much improved. She was very happy to see us as usual and was talking a lot. She still seemed subdued, but that's ok… it's much better than seeing her in an agitated state.

Monday night, I think, she seemed almost like her normal self with the exception of her mind only being able to remember things for a few minutes.

She was sitting in her wheelchair eating an apple, when we came in. She even had her fingernails painted. Couldn't believe it! She really looked great.

Before she had her stroke, she had to have an apple every day. She seemed to remember how much she enjoyed her apples. She talked about her afternoon activity over and over again.

We always ask her what she had for dinner or if she had a good night's sleep and she can never remember.

Another Twist

Well, the next day was unbelievable again! Ken had an outpatient procedure done to break up his kidney stone for the second time. So, I'm thinking to myself, "Are we going to get through this without his mom going to the Emergency Room?"

We made it through the day without any phone calls, so we're assuming his mom didn't have to go to the ER today.

Ken was not feeling well enough to visit his mom last night, so I went the usual time. When I saw Genevieve, I couldn't believe it. She was in a lounge chair in

her pajamas and had two brush burn marks on her forehead. The nurse could see how shocked I was and said they put a call into us. I told her no one ever reached us.

Anyhow, she tried to stand up that morning and fell down. They had to take her to the "Emergency Room" and thankfully they didn't have to admit her.

We thought we made it through Ken's procedure this time without his mom going into the hospital, but we didn't! I just think this is the most bazaar thing! She almost senses when her son is having some procedure done and ends up being in the hospital herself.

So, we've pretty much resigned ourselves to the fact that his mom is going to have her good days and her bad days. She just can't remember that she's not well and can't get up and just walk around like she always did. It's still an adventure every time we go to visit her.

A pleasant surprise

Friday, March 28

Yesterday I took Mom and Dad for x-rays. I've been putting off Mom's x-ray, because any type of procedure for her is very difficult. I finally decided to bite the bullet and made an appointment for both of them to have their x-rays done at the same time.

That has its good and bad points. They both really need me with them whenever they are having a procedure done.

But, this time Dad thought he would be ok, which he was. So, I went with Mom for her ultrasound of her kidneys. The technician was so caring and nice to my mom.

Between the technician and me we were able to maneuver Mom around enough for the ultrasound. Anytime Mom has to get up on an exam table and lie flat, it's a major problem. But, I think she did better than usual this time.

Usually an event like this will totally exhaust her, but this time she didn't mind it at all.

Ken went to see his mom Thursday night, but she was sound asleep when he got there. He tried to wake her up, but had no success. The nurse did tell him that she had an hour and a half of therapy that day and was probably why she was all worn out. Plus, she was up all night.

The night before she slept until 10pm and then was awake all night. The nurse told Ken that she has her group of people who don't sleep at night at the nurse's station every night.

Amazingly, she said they talk to one another. I guess they have their own way of communicating, because she said she had no idea what they were talking about.

Then last night, Ken again went to see his mom. This time she was awake and again was in her own little world. She always knows Ken and is happy to see him.

But, when she talks it's always about something that is a total fantasy. She still doesn't remember what she ate or even that she had therapy, which she did that day. It's just amazing how her brain works! It's always an adventure going to visit Genevieve!

APRIL 2008

I'm grateful

Friday, April 11

Time sure has a way of getting away from me. Dad has been improving every day. My only problem now is that I'm like a mother hen who's hesitant to allow her young children to leave the nest.

Now that he's feeling much better, he's just raring to start doing all kinds of work. I realize this is a good thing. My problem is that I don't want him to fall and break more bones. The thought of him doing that again just gives me the chills.

He thinks he can putter around like he always did. The problem now is that he's out of shape and not as flexible as he used to be. Dad is driving again and seems to be handling that ok.

Mom won't allow him to drive anywhere without her in the car, which is a good thing. They are now doing a lot of their own errands, which does free me up a little more. I am grateful for that.

Mom seems to be backsliding a little bit. It's really hard to tell sometimes if she's really feeling a lot weaker or if she's more depressed than usual.

She's been so fearful of ending up in a nursing home like Genevieve, Ken's mother. There is not a day that goes by that she thinks that she has gone downhill since Ken's mom had her stroke. I keep reassuring her that she's doing just fine.

I think she misses her physical and occupational therapy sessions with the girls. She used to complain that they were so hard on her, but the reality of it is that she looked forward to them coming. It broke up the day for her.

At least now with the warmer weather coming, it gets both Mom and Dad out of the house. This past winter was hard on them…especially since Dad couldn't get out to do any errands. So, barring any catastrophes, they should have a pretty good summer.

As for Genevieve, she's another story

So far, she's made five trips to the Emergency Room. The last two times it was not necessary to admit her. Last Thursday the nurse at the nursing home called 911. They said her lips were blue, her skin tone was very pale and she was limp like a rag doll.

They took her over to the Emergency Room and again did all kinds of tests on her. Nothing abnormal showed up this time, so they transported her back to the nursing home.

Ken was with her first at the ER and then I came to relieve Ken. She slept the entire time she was in the ER and never woke up until she got back in bed at the nursing home.

I went back to the nursing home to see if she needed anything after they got her all settled back into bed. She was surprised to learn that they transported her to the ER and then back to the nursing home again. She was not aware that anything had happened or been done to her.

She still cannot retain any new information or event for any length of time. Our youngest son came home to visit her on Monday night and we're not sure if she remembers him being there.

She did know who he was…so far she seems to remember all of us. Once in a while she doesn't remember my name and I think sometimes she's not sure who I am, but she always remembers Ken.

Some days she seems to be pretty lucid and then other days she's talking to us about doing things that day that she never did.

She very often tells us about preparing food for people or family that's visiting and also will tell us how worn out she is from working so hard. She's, more times than not, in her own little world.

Getting mom involved

Ken and I spoke to the head of activities on Tuesday night. She wanted to know her hobbies and interests. Genevieve really brightened up when she heard the name John Wayne and the movie "Quiet Man".

She absolutely always loved John Wayne and I believe the movie "Quiet Man" was her all-time favorite movie. The activity director was going to try to get that movie for her.

They are trying so hard at the nursing home to find something that Genevieve will participate in and spark her interests. They've been trying to get her to play bingo, but she always refuses.

We're not sure how involved she could be, because she can't concentrate on any one thing for long.

Ken is out of town on business for a few days and won't be seeing his mom. She constantly asks for Ken, so I'm a little concerned how she will react to not seeing him for a few days.

I told her about Ken yesterday, but she won't remember. Hope she'll be satisfied with just my visit.

Ken and I watched a TV show last week on public TV about 3 or 4 different families caring for their elderly parents. It was very interesting and very hard to watch because it just hit home so hard.

These families were going through much of the exact same things that we are going through, except we have 3 elderly parents.

We can handle our situation as long as they don't all have a problem at the same time. I guess our biggest problem right now is finding someone to take our place when we need to go out of town. This is a major problem that we still have not figured out.

Well, I made it through with Ken out of town for 3 days

Wednesday, April 23

I was really concerned as to how Genevieve would react without seeing Ken for so many days in a row. But, she got through it like a real trooper.

Then, on top of Ken being out of town, he had 3 different surgical procedures the week of his return, which meant he couldn't get over to see his mom.

And, the jinx seems to be broken with Ken and his mom going into the hospital at the same time. Halleluiah!! Thankfully, each day since my last entry she seems to be getting brighter and more alert each day.

So, she was aware that Ken had several surgical procedures done and would ask me how he was doing and was so thrilled when she heard he was ok.

Our visits with Genevieve vary according to how alert she is. Some days she's asleep when we come in and has a little difficulty totally waking up.

But, those days seem to be getting fewer and farther between. She still thinks a good percentage of times that she is somewhere else, I think sometimes back at her house.

She'll tell us about different things she wants to get at the store or else she thinks we are picking her up to go out to dinner.

Of course, she's always disappointed when we tell her she has to get better before we can take her out to dinner. She is eating better and getting stronger.

She also exercises with the rest of the residents on her floor. She shows us the different exercises she does and is very proud that she's able to do them.

We got Genevieve new reading glasses, as she lost her old glasses somewhere in the nursing facility. She was constantly complaining that she couldn't see anything. She really needs glasses for distance, as well, but we felt her reading glasses were the most important for the moment.

It was the best thing we could have done for her, as she was an ardent reader. We brought in a book for her and she has been attempting to read it.

She keeps losing her place, but she tells Ken and me what she has read to date. Her speech therapist has her read from her book and then has her tell the therapist about the story.

My mom and dad are presently status quo

My father had a dexa scan and just recently received the results. He has severe osteoporosis, which explains the fractures he's been having. So, he is going to have to be extremely cautious about everything he does. I told him I'm going to wrap him up in bubble wrap!

He is also now on Actinel, which is the same medication that my mother takes for her osteoporosis. The doctor put them both on the monthly version of the medication, which is great! My mom always would stress big time about her weekly pill.

The doctor also put them both on calcium with vitamin D. Hopefully, this will reverse the deterioration of my father's bones. He is very frail and unsteady and obviously a major risk for falling.

And, of course, he wants to do a lot of work that he shouldn't even consider. But, I have to admit that he's become a little bit more cautious than he was before. The one good thing with my father is that his blood sugar and blood pressure have been very good.

My mother is still pretty much the same. She's very worried that her mind is getting worse because she has a hard time remembering things. She's also convinced that she had a stroke, which is possible that she did a while back.

She's very bent over and extremely weak and not getting any better. But, if it were not for her back and her extreme weakness, she'd be in pretty good shape.

Escape to Virginia!

Monday, April 28

Well, I had a little break this weekend and went to visit our family in Virginia. We haven't seen them since Christmas, so was a real nice treat for me. Unfortunately, Ken and I can't travel together right now because of the situation with our parents.

So, this weekend Ken took care of my mom and dad and also went to visit his mom. Luckily, my parents didn't have any problems. Ken's mother is getting stronger and stronger every day now.

It's just totally amazing! We never expected her to be anywhere near where she is right now.

They reevaluated her for physical therapy and she is now getting 2 hours of physical therapy a day. Before, she only did some exercises from her wheelchair, which all of the residents do, no matter how bad they are. We have no idea how much improvement she will have.

But, once she's alert and knows she has to do something to get better, she totally focuses on doing exactly what she is told. So, who knows, maybe she'll make it back home.

We're taking it one day at a time. We really do feel that she does have a chance as long as she doesn't have any more setbacks.

MAY 2008

Up and down

Thursday, May 15

I'm happy to say that our parents have not had any major problems since my last entry.

Genevieve, Ken's mom, had been improving by leaps and bounds and really had us thinking that she might have a chance to come home. She kept asking us about coming home and saying that she thought she was doing a lot better.

Of course, we would keep telling her that she had to keep working hard with her physical therapy and get a lot stronger before she could come home.

It seemed like she improved mentally to a certain level and then started to go backwards, not a lot, but just enough that we noticed she wasn't quite as sharp.

We had a really hard time determining whether she was walking on her own or not. She'd, of course, tell us that she walks all over, but we never saw her walk and saw no walker for her to use.

She usually will fixate on something that she's upset about when we come in to visit her. One time she was very upset about one of her nurses or aides. We

were never able to figure out who she was referring to, but she kept saying that she doesn't think they like her.

She finally admitted that she wasn't her normal self earlier and that probably was part of the problem. She said she didn't complain to that person anymore and that everything was ok now.

Dealing with complaints

She also is a very private person and doesn't like it when the male aides help her with her personal needs or problems. She had been complaining to us so much about various things that we finally had to call social services to go over all her problems and concerns.

Initially, we had a very hard time getting to speak to someone who could give us some answers to her problems. But, once we were able to speak to the proper person, they took care of all her issues.

One thing in particular that is kind of funny is that she always loved her breads and pastries. And, for some reason or other, they had marked down on her diet preferences that she dislikes bread.

Genevieve finally asked us why we told them that she doesn't like bread. Of course, Ken and I never said anything about that. Most likely, when she was way out of it, she probably kept refusing bread and they assumed she didn't like it. Now, she finally is getting her bread again and is really enjoying it.

We feel so bad for Ken's mom

When we did speak to the woman from social services, she basically told us that Genevieve was not able to care for herself. She is not able to walk by herself and she cannot use the bathroom facilities without the assistance of an aide.

This got to be a real problem for her. Her legs started to retain a lot of fluid and the nurses were afraid that she might end up with cellulitis.

So, the doctor prescribed a diuretic to get rid of the excess fluid. She didn't understand why she was going to the bathroom so much and kept telling us that something had to be done to correct her problem. She kept soiling herself and this really upset her big-time! Well, of course, they did tell her about taking the medication to get rid of the swelling in her legs, but she didn't remember it.

Anyhow, Ken finally asked the nurse about her using Depends to help her with the incontinence. The nurse said it was a great idea, but it was extra for them to supply them.

We were just amazed that they didn't use something similar to Depends so she wouldn't soil herself. We went out and purchased Depends and hopefully, that will be the end of that problem for her.

On the very positive side, she has finally started to go to different activities. In the beginning, she wouldn't participate in anything. So, we are happy that she is now participating in some social functions. They do provide quite a few different activities at the nursing home for their residents.

It is going to be a long haul for Ken's mom and for us

We have been visiting her every day since her initial stroke. We only missed visiting her one time since February 7. During the week, Ken and I take turns going to see her and on the weekends we go together. It is difficult for us, but it does mean so very much to Ken's mom.

My dad is doing real well. He's had no major problem since his back episode. I'm really afraid to get too relaxed about his situation, because he's very susceptible to a fall or a diabetic episode of some sort.

I did just take him to see the dermatologist about a small growth behind his ear. The dermatologist removed the growth to have a biopsy done.

The dermatologist said it is definitely skin cancer, but needs to have it sent out for biopsy to see exactly what type of skin cancer it is. So, we'll know in a couple of weeks what he needs to have done next.

My mom is basically the same. Dad woke me up earlier this week to help with Mom in the middle of the night. She had diarrhea and some throwing up and was quite sick with it. Any time she gets any kind of an intestinal episode, it's much worse for her than it is for the rest of us.

I think she was probably on the toilet for a good hour or so and from being so bent over she felt like she couldn't breathe. I think she thought she was having a heart attack. But, luckily, after about 2 hours, the diarrhea and throwing up subsided and she was able to go back to sleep.

Other than that, her health has pretty much stayed the same. I think she is getting weaker, but that probably goes with her condition. I feel so bad for my mom. She wants to be outside working in the gardens and walking around so badly, but she just can't do it.

Life is such a wonderful gift

It's so hard watching our parents' health deteriorate before our very eyes and not being able to do anything about it. We know it's a natural process, but seems so hard and depressing on them and us, as well.

I guess in our minds we will always feel that we haven't aged, but realize it's the physical deterioration of our bodies that prevents us from doing things that we always used to do.

I just signed up this week for Social Security, can't believe it! But, in talking with the woman during my interview, I told her that we have my parents living with us and she said to me how lucky I am, at my age, to still have my parents. And, she is totally right!

Anyhow, I just want to let everyone know how important it is to live every moment of our lives to the fullest and enjoy everything and everyone around us while we can. Life is great and such a wonderful gift, even when it's tough going!

The challenge of only children marrying

Friday, May 23

I was driving home from work late yesterday afternoon and heard this interview on National Public Radio with Chinese adult children who had no siblings. It was so interesting to me because I never heard any remarks from anyone who was remotely in the same situation as Ken and me.

They spoke with one woman who is married to a man who also is an only child. She was so concerned about her situation later in life when her parents and her husband's parents are in need of their care.

She mentioned that she and her husband are totally outnumbered by 4 to 2. She said it will be a major burden to them when their parents need their care. No siblings to come in and take turns to help them.

Ken and I have found that to be a major problem. It's really funny, because when you're young, that's the last thing in the world anyone thinks about.

I know we certainly didn't think about it, not that it matters when two people fall in love. You certainly are not going to not marry one another because you're both only children.

That would be totally ridiculous. But, it really is a major issue down the road when all your parents are frail and ill all at the same time. What do you do?!!

Ken and I have had a rough time coping with our situation

We don't have 4 parents to care for, but 3 are enough! It hasn't been too bad, so far. They seem to be taking turns with their real serious issues. But, there could come a time when we will not know which way to turn.

I think the hardest time for me so far has been when my father broke his hip (femur). I was really dealing with 2 people at the same time. My mom was totally dependent on my dad and was suddenly left at home without

him. That was and still is her biggest fear. When he hurt himself I was totally new at care giving. I still remember that very first day and first week of caring for my mother and running back and forth to the hospital to see my dad with my mom.

I honestly didn't know how Ken and I were going to do it. But, it's amazing how one can adapt to a new situation and the longer you deal with it, the easier it becomes.

Unfortunately, now, I very rarely have time to myself…Ken and I both are in the same boat. As for myself, when I do have a little time to myself, I feel guilty doing nothing.

I don't know if this is normal or not but I can't seem to sit still. My other problem is when I do finally decide to do nothing, by nothing I mean read or watch a little TV, I fall asleep. Is that exciting or what?!!

Anyhow, life is good and we both have come to realize how precious and special it is. And, by taking care of our parents, we know that we are giving back to them for all the years they took such special care of us.

Now for an update with our parents

Genevieve, Ken's mom, has been pretty much status quo. Her biggest issue is an incontinence problem, which has been brought on by a diuretic they are giving her for fluid retention in her legs. They are very concerned about her possibly getting cellulitis, which is not a good thing!

She's been on the medication for at least 3 weeks now and her legs seem to be getting a little bit better. Hopefully, they will be able to stop the diuretic in another week or so.

She still, everyone once in a while, comes out with some off the wall remarks. She did ask Ken last week, where he lives. He described our home to her and told her about her apartment upstairs. It seemed like she did not remember it.

The need for a patient advocate

We also found out how every patient in a nursing home needs an advocate, family member or someone looking out for their well being. Genevieve lost her hearing aid last week and we had to really keep reminding them to keep looking for it.

Ken also had to speak to someone a couple of times about helping his mother put her hearing aid in her ear in the morning. This is something that she can no longer do, but really needs so she can hear what everyone is saying to her.

Anyhow, there were a couple of things we asked the social services person we would like to have done for his mom and discovered they were not totally doing for her.

So, between discovering things that were or were not being done through his mom, we were able to go back and get them corrected. We realize there are a lot of different aides and nurses that work in these facilities and that sometimes it takes a while for any sort of routine to set in.

A quiet Memorial Day weekend

Monday, May 27

We got through Memorial Day weekend without any major catastrophes. It's still hard to spend holidays without the rest of our family. All of our holidays used to be filled with all kinds of excitement and chaos, which believe it or not, I totally miss.

I don't like total calm and quiet anymore. Anyhow, on Memorial Day we took my mom and dad with us to visit Ken's mom. We spent our visit outside in the garden area at the nursing home, which was very nice.

Genevieve was so happy to see my mom & dad. We were so afraid she'd beg us to bring her home, but she didn't say anything. She does often mention about giving her a chance to try it at home.

I have to admit that she is very strong. I took her to the ladies room for the first time a couple of days ago and was totally amazed how she was able to pull herself up out of the wheelchair by hanging on to a grab bar.

I could tell that she is totally unsteady and not able to move around by herself. The way she is progressing, she just might be able to come home again. Right now, we just take each day at a time and address whatever problem presents itself for the day.

My mom and dad were also very happy to see Genevieve. They didn't know what to expect, but they were so happy to see her looking like her normal self.

We know they could not have handled visiting her, not even as recent as a couple of weeks ago. But, we will now take them over to visit with her more often. Genevieve definitely needs to see them.

My mom is definitely getting weaker

A lot of my mother's problems are that she is losing her will to keep fighting. I know she hurts a lot and gets totally frustrated trying to move around. She has no interest in eating or doing anything socially.

I am hoping beyond hope, that when the new community center opens up in our township that she and my father will be willing to participate in some of the senior activities. They both need something to take their minds off all of their problems.

My father still has to deal with a skin cancer issue behind his ear. We were told that it's not the bad kind of skin cancer and can be cut out. We will find out in a couple of days what the doctor intends to do.

JUNE 2008

Warmer weather is so much better for my parents

Tuesday, June 3

Can't believe that summer is practically here. Thank goodness! It sure is welcomed at our household! My parents hate being shut in the house during the cold winter months.

Even some of the nice spring days that we had, my mom felt it was too cold to go outside. She must have extremely poor blood circulation!

We built them a deck off of the back of their living room that has a beautiful view and is also in an extremely peaceful and serene area. Their deck looks out over an open field that has 2 baseball fields that are used about once a week by the church during the spring and summer months.

They can watch the geese, humming birds and butterflies when there is no activity at the ball fields. The church behind us plays their church chimes at noontime and at 6:00pm, which they enjoy a lot. Anyhow, they do enjoy their deck during the warmer weather.

My parents are getting more and more frail, but holding their own

I took my dad to the skin doctor last Friday to have his cancerous growth removed. The doctor did it right in his office and Dad didn't seem to mind it at all.

He's on antibiotics now and we just have to make sure that he doesn't get an infection. He has a couple of routine doctor appointments coming up, but nothing major.

As for my mother, I took her to her general doctor for some problems she was having. Mom has become extremely weak and has a very hard time getting around when she goes to any of her doctor appointments.

I am very seriously considering checking on a doctor in our area that makes house calls to patients that are homebound. It's really a major problem for

someone like my mother to try to maneuver themselves around in a doctor's office and it's also very embarrassing for them.

I know my mom thinks everyone is looking at her and thinking how awful she looks. I try to tell her otherwise, but it doesn't seem to do any good.

A return to therapy for my mother

My mother's doctor felt it would be good for her to have more occupational & physical therapy. It seems like the moment she stopped with her therapy this past winter, she started to get weaker and weaker. She tried to do some of the exercises on her own, but didn't seem to have the willpower to do them religiously.

The occupational therapist came to the house to do a reevaluation of Mom this morning. I'm hoping it will motivate her a little more and possibly help her get around a little bit better. She grumbles when they make her do the exercises. But, the minute that she no longer has the therapy, she misses them.

I want to do everything I can for her to keep her out of a nursing home, because she will be in total agony if she has to leave home. She needs constant attention and she will not get that in a nursing home.

Ken's mom, Genevieve, is making a miraculous recovery

Unfortunately, she still is not well enough to come home. We know in her mind, she thinks she is ok and going to come home and do work around the house like she always did. She even said to us that she'll go up and down the stairs on her butt.

We are going to have a family conference with her social worker, nurse and therapists to see how realistic it is to bring her home. Her apartment is

upstairs at our house, which is a problem. Ken and I have some very serious thinking to do on how to handle her coming back home.

We almost don't want her initially to go back upstairs to her apartment, because she won't have any way of getting around to visit with my parents or being able to have meals with us, etc.

Ken and I are scared to death

We realize how desperately she wants to come home. But, the reality of this is that Ken and I are scared to death to have her come back home. It's going to be a major burden on all of us and we just don't know if we're able to handle all of this.

Right now we are taking each day at a time with her. She's reading her books on a regular daily basis again, which is wonderful! She is also now able to have her meals in the main dining room downstairs at the health center, which she thoroughly enjoys.

Our visits with Genevieve usually consist of being told about any major problem she's had for the day. Usually, whatever problem she's having is totally magnified in her mind. It had been quite consistently about her incontinence problem.

She had herself convinced no one else in the facility had this embarrassing problem that she had. Then finally one day, she noticed that one of the other patients did have the same problem. Since that has happened she hasn't been quite as bad, but she still hates for it to happen to her.

Her other problem she fixates on is her hearing aid. She makes sure we take it out every night before we leave. The other night, according to her, she had a problem with one of the aides about not having her hearing aid in her ear.

Again, since she can't hear or grasp half of what is being said to her, she magnifies the problem in her mind. So, when Ken visited her last night, most of the conversation was geared toward that problem.

I guess on a positive note, Genevieve doesn't really understand or know how long she has been sick. This is a very good thing, because by nature, she is a very impatient person and would have gone totally bonkers if she knew she had to be in a nursing facility so long for her recovery period.

The reality of getting old

Tuesday, June 24

Can't believe it's been so long since my last entry! I was driving past our bank the other week and noticed there was an ambulance and police car next to a little house where we do our banking. I felt so bad and started to tear up when I saw that.

There is an elderly couple that lives in this little house (cottage). I only know this because I would watch them when I was sitting at the drive-up teller, which faces right into their house.

The couple would sometimes be taking groceries into their home, or tending their flowers or the elderly man would be cutting their grass. They were a couple much like my parents.

Well, I just felt so bad for them because now their lives would never be the same again. I don't know these people and it should not have affected me the way it did.

I guess I've developed a real soft spot in my heart for seeing elderly people getting sick and having to give up life as they previously knew it. It really is very sad to think what they have to give up.

I see my parents going down hill right in front of my eyes and I can't do a thing about it. I try, but the reality of it is that nature has to take its course. My mother is constantly saying to me of late that she should just kick the bucket. I hate it when she talks like that.

She has been getting weaker and weaker and I think she is just plain tired of her whole situation. I can't blame her, but she still has to make the best of her life. She's now getting up about 4 times a night to go to the bathroom, which she cannot do by herself.

So not only is she not getting any sleep during the night, but neither is my father. I know they both think they don't sleep during the day, but they do. They have to get their sleep sometime!

My dad is also now complaining about his back bothering him again, which I know is from him pulling my mother up all the time. This is getting to be a real problem and don't know how we are going to address this problem.

If Dad continues to pull my mother up out of bed and chairs, he will be in bad shape, as well, again.

So fortunate to have each other

The occupational therapist is still coming to the house two times a week and that is a very good thing. She observes the two of them interacting as a couple. She continually tells my dad not to be pulling my mom up.

For some reason she can't seem to get herself up anymore. There for a while she was doing a great job. I think that since Dad has gotten better, she went back to her old ways and is relying on him a lot again. She doesn't realize she's doing it.

Plus, Dad totally babies her and will do absolutely anything for her. My mother and father are so lucky and fortunate to still have each other.

I went to Pennsylvania last week to pick up my grandmother and bring her back to our home to stay with us for a few days. She's also been having a rough time.

Thankfully, she's very healthy for a 96 year old woman. She has her 97 year old sister's home to get ready to be sold. The whole process has been extremely hard for her. She goes in to see her sister every day at the nursing home, plus still tries to do all her normal daily activities that she always did. Anyhow, it was a nice change for her, as well as for the rest of us to have her visiting with us a few days.

As for Genevieve, Ken and I go to visit with her every day. She wants to desperately come home. We did have our family conference and were

basically told that she will always need 24/7 care. To look at her sitting in her wheelchair, you'd think that she could handle herself without any problem. But the reality of it is that she needs verbal prompting for so many things. Even with her eating she has to be reminded to double swallow so that she doesn't choke on her food. She needs help with virtually anything that she does.

The other day I saw her walk with her walker for the first time. She took off at a real fast pace with the nurse running after her and trying to tell her to slow down. She was always real fast in everything that she ever did. But, with that fast motion, she is not thinking and not in control. The only time that she uses the walker is in a group exercise class. The instructor walks with each of the residents a couple of times around the room. Other than that time, she is confined to her wheel chair.

She still has incontinence issues and will always have that problem as long as she's on the diuretic medication to get rid of the fluid in her legs. Her memory is much better, but she still has a lot of problems. The other day she called Ken by his formal name, Kenneth. After his name came out of her mouth, she asked him if that was his real name. There is a lot that she cannot remember.

We still plan to bring Ken's mom home

But, despite all her problems, we are definitely going to bring her home to see if we can handle her. Ken has started preparing her for coming home by telling her certain issues she'll have to face and also the possibility she might not be able to handle staying at home. Of course, this now is getting her very anxious. She's not able to handle anything too stressful, which is totally understandable. My parents can't handle anything other than their normal day-to-day routine. I don't think this is an uncommon emotion among a lot of the elderly people.

The other day when I was visiting with her she had a major problem to tell me about, at least it was in her mind. She started out by saying, "I have something to tell you, but don't know how to tell you."

Well, every time she starts out a conversation like that, I brace myself for the absolutely worse scenario. I'm thinking, how bad can this be…she's in a nursing home.

Her problem was that she had a toothache and didn't know what to do about it. She was suffering with it several days (which is something she always did when she had a problem) and finally it got so bad she had to tell me.

The unfortunate thing about all of this is the dentist for the nursing home comes once a month and he was just there!

Well, her dentist was more than willing to come to the nursing home to check her mouth, but he doesn't have privileges at the nursing home.

So, now we'll probably have to take her to her dentist and he'll have to check her in the car, because there is absolutely no way for her to get into his office. I think this is ridiculous that a dentist can't come into a nursing facility when a patient has a major tooth ache.

It just doesn't seem fair to the residents! Ken and I are constantly learning new problems that have to be dealt with every day.

Putting in an insurance claim

Ken just contacted her long term care insurance company to start filling out all the paperwork for her nursing home care. Her Medicare coverage will be exhausted as of tomorrow.

We have to say they did cover her for a long period of time. Between her secondary insurance and Medicare coverage, it was extremely helpful. I just started to fill out her paperwork for her long term care insurance yesterday, when I received a phone call from the nursing home informing us that all of her benefits were expiring in a couple of days and to expect a bill shortly.

Boy, they sure don't waste any time. We realize that they need to do this, but it's just kind of like a reality check as to Genevieve's status going forward.

JULY 2008

I think our life is in for a very big change.

Thursday, July 10th

We will most likely bring Genevieve home from the health center next month, unless something drastic medically prevents it. She has been constantly talking about coming home and expressing her anxiety about it at the same time.

Her doctor did not encourage us to bring her home, but at the same time said he would not prevent it. He told us she definitely needs 24/7 care.

We're not sure if we can handle it. We've been looking at all the alternatives of care for her…from adult day care to actually hiring a live-in companion for her.

We really won't know how much care she will require until we bring her home. We will have to make some changes in our home to accommodate her.

Her apartment is on the second floor, so we will need to get a stair glider to get her upstairs. She will probably need a different bed among many other things.

Can we handle this?

I know we could handle her if one of us was able to be with her at all times, but that is not realistic. Ken, of course, has to be at work and I also have the responsibility of my parents.

So, we just initially will have to experiment and see how much Genevieve can really do for herself. We both are really very anxious about this!

But, in the meantime, tomorrow we will take her out of the health center for the first time. We both are taking her to the doctor's office to have her ears cleaned. That is another thing that the health center does not do for their patients.

The nurses are not allowed to clean the patients' ears and also the doctors don't do it as well. We were totally amazed that a patient has to be taken out of the facility to get their ears cleaned.

Genevieve's hearing aid was constantly squealing when it was put in her ear and normally that means she has a wax buildup in her ears. So, anyhow, tomorrow will be an adventure for all 3 of us.

Genevieve is also getting an evaluation tomorrow by an outside nurse at the facility that was requested by her long-term health provider. This should be very interesting as well. Guess we're in for a lot of new experiences.

AUGUST 2008

Life has changed dramatically

September 10th, 2008

I sure have a lot of catching up to do. So much has happened since my last entry in the summer. Obviously, life was just a little bit hectic for a while.

Our oldest son and his family spent 3 weeks with us. It was really nice to have them with us. Naturally, our house was very chaotic and noisy, but like I've been saying all the time, it was a really nice comforting chaos.

We just love having our children and grandkids visiting us. It puts everything back into a proper perspective as to what's really important in our lives.

Of course, while they were visiting, we still made our daily trips over to visit Ken's mom. She totally looked forward to that time each day and occasionally the kids went over to visit her, as well. She especially loved that! After our son & his family returned home, we started preparing for Genevieve returning to our home.

Preparing to bring Ken's mom home

It was very much like preparing for bringing a newborn infant home. We set up a home office downstairs, so that I could continue to do my work as well as keep an eye on Genevieve.

We had to make our home as safe and friendly as possible for her. We rented an outside ramp and a stair glider. We thought renting would be the smart thing to do since we had no idea how Ken's mom would do at our house.

We also got a wheel chair, hospital bed, 2 commodes and had a grab bar installed in the downstairs powder room.

We decided September 5th would be the day we would bring her home from the nursing home. All of the nurses and aides were sad to see her leave, but at the same time so happy for her. They all became very attached to her.

They told us it's so nice to actually see one of their patients get well enough to return home again…that doesn't happen very often. They gave her a certificate of achievement and then they all signed the back of it for her. She was so excited and so happy!

After we received her care and medication instructions from the nurse at the nursing home, we went directly to the pharmacy to get all her prescriptions filled. It's unbelievable how many medications she takes. I believe it's around 15-18 pills a day.

When we got home and Genevieve settled in, I had to tackle dispensing her medication. It was extremely intimidating to me. I wanted to make sure that was one thing I didn't totally mess up on. Of course, wouldn't you know it, one of her medications had a different name from the instructions I was given. I thought I knew which one it was, but I had to call the nursing home to verify the medication.

That night I sat down at the kitchen table studying all her medications and dispensing them into the new weekly dispenser we bought for her. That dispenser is a lifesaver and a sanity saver.

Genevieve watched me the whole time I was organizing her medication…did not take her eyes off of me once. She told me that she always took care of her own medication and thought she should still be able to do it.

I told her that I didn't think so…not anymore!! I vowed going forward, I will not organize her medication around her…I will make sure she's in another room.

Her first night home was a little unsettling for all of us

We just didn't know what to expect. The hardest thing was her sleeping during the night. We had the monitor on in our bedroom and, of course, we heard every little sigh and the talking to herself.

She was so restless that after 2 hours I couldn't take it anymore and went over to her and asked if everything was ok. I think the new surroundings and new bed just overwhelmed her.

We got up, I think, a couple of times the first night and possibly once or so the following night. But, she's been excellent since then. She likes to get in bed around 10pm and by doing that she's able to sleep through until around 7am the next morning. Occasionally she needs to get up earlier, but she's been doing great for the most part.

The nurse came the morning after she came home to evaluate her and go over all her medications with us. The service Genevieve has is absolutely wonderful and is covered by Medicare and her secondary provider.

She has an occupational and physical therapist and a nurse coming to the house two times a week to see her plus a home health aide to bathe her 3 times a week. It's such a wonderful support system. If we have any concerns, we are able to ask the nurse or therapists for advice.

A doctor that makes house calls?!

We also have a local doctor that makes house calls. When we first heard about him, we couldn't believe there was still such a service available. Of

course, it's only for patients that are housebound, but absolutely a necessity for these elderly people.

He's the most thorough, efficient and caring doctor we've met. He just has such a nice mannerism about him. He's not the only doctor doing this, but I don't think there are too many that make house calls. He even has people come to the house to do lab work. That totally amazed me!

OCTOBER 2008

Genevieve has been home 3 weeks today and has been doing beautifully

Wednesday, October 1st

It's been very difficult for Ken and me because we have no one else to cover for us. I had always been used to going out to work every day. Before Genevieve came home,

I would get Mom and Dad settled for the day and then go in to work…my office is only 5 minutes from our house. But now, I can't leave Genevieve without supervision.

Ken tries to get home every day so that I can get out and into the office for a few hours each day. But, that doesn't always work. It seemed like the first week was working pretty good.

But then things come up for Ken at work and he finds it practically impossible to get home. Or, the most recent problem we have is that now my parents have a lot of doctor appointments coming up.

So, naturally, Ken has to come home while I take my parents to see the doctor. This then prevents me from going into the office to take care of all the stuff that needs to be taken care of.

When that happens, I try to go into the office just for a few minutes after dinner to pick up the pieces that I may have missed during the day.

The treadmill never stops

This past week I had to take either Mom or Dad to appointments at least 3 different times. It totally messed up both Ken and me, but we just have to learn to deal with it as best as we can.

My father developed a new urinary problem that required a urology visit and then several tests to see what is causing the problem.

My mother has a blocked carotid artery in her neck and also needs a test done to see how severe the blockage is. Once we have this information, the doctor wants to talk to us about our options.

Then on top of all that, believe it or not, I have Jury Duty this coming Monday. I have to report for duty by 8:30am. I'll have to leave by 7:30 to make sure I get there on time. I'm just hoping and praying that they will dismiss me.

This will totally devastate Ken if he has to be totally away from his work for a few days. I put down my situation on the jury form that I sent in, but I was denied. I now have a letter from my parents' doctor, so they should, at least, let me come home…I hope!!

Miracles do happen!!!!

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I am so thankful, because Monday turned out to be a very crazy, hectic morning. The girl from the lab came to the house at 7:15am to draw Genevieve's blood and the day kind of progressed from there.

Ken called later that morning and asked if I would be able to go out and take care of my business and errands around 11am and I told him I was more than happy to get out of the house at that time!

Today I took Dad for a cystoscopy and, unfortunately, he does have some problems. I don't think it's anything too serious, but is necessary to get it taken care of. He has 3 tumors on the lining of his bladder, which have to come out. So, he'll be getting surgery around the end of October.

I was not looking forward to giving that news to my mother. She just totally goes off the deep-end with any procedure my dad has to have done.

And believe me, I'm not looking forward to it either! But, that's life and Ken and I both know that this is probably not the real bad times with our parents, even though it sure seems and feels like it sometimes.

It's been very difficult for Ken and me because we have no one else to cover for us. I had always been used to going out to work everyday. Before Genevieve came home, I would get Mom and Dad settled for the day and then go in to work…my office is only 5 minutes from our house. But now, I can't leave Genevieve without supervision.

Ken tries to get home every day so that I can get out and into the office for a few hours each day. But, that doesn't always work. It seemed like the first week was working pretty good.

But then things come up for Ken at work and he finds it practically impossible to get home. Or, the most recent problem we have is that now my parents have a lot of doctor appointments coming up.

So, naturally, Ken has to come home while I take my parents to see the doctor. This then prevents me from going into the office to take care of all the stuff that needs to be taken care of.

When that happens, I try to go into the office just for a few minutes after dinner to pick up the pieces that I may have missed during the day.

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NOVEMBER 2008

So much has happened in the past few months

Saturday, November 29th

The first few weeks after we brought Genevieve home from the nursing home were probably the easiest times since she's been home. I had been doing my office work at home and the weather was still relatively nice and mild.

Genevieve was receiving physical and occupational therapy and also had a home health aide and visiting nurse taking care of her. So, other than speaking with all the different people coming and going throughout the day, I was able to take care of my office work without too much difficulty. Plus, it kept Genevieve relatively busy and happy throughout the day.

But, then as she got stronger and reached a point where therapy was no longer needed, she gradually lost the various therapists. One blessing for us was that her doctor felt she needed some speech therapy.

So, while she continued on with speech therapy for another 4 or 5 weeks, she was also able to still have the home health aide and visiting nurse. But, then the speech therapist was only able to do so much with her and that eventually ended as well.

When that ended, so did the home health aide and visiting nurse. We were on our own!!

These services are covered through Medicare after a hospital or nursing home discharge. They are crucial services for the individual and their caregiver, as it's kind of like a bridge from the institutional care back into the real world of homecare.

We had these same kinds of services last year for my father when he came back home from the nursing home. They really are much needed services, because it helps the caregiver adjust to caring for the individual.

To most people, giving special care (almost nursing care) to individuals who can no longer take care of themselves is a very foreign thing.

These therapists, nurses and home health aides give all kinds of advice for when you are left on your own. I know we appreciated every bit of help we could get!!

Well, I could have cried to see all those wonderful people go. They were all such special, caring individuals. I now not only had to care for Genevieve, but also had to find some way to keep her happy and occupied. Believe me, that was no easy task and still isn't!!

The first time I bathed her on my own was quite interesting. She was very fearful of falling, so that complicated things. She has a very nice walk-in shower with a bar to hold on to.

But, she is very unsteady and has pain and weakness in her right arm (which is the arm she uses to grab onto the shower bar), so that makes getting into the shower a little difficult. But with practice we both relaxed a little more and showering did get a little easier.

Believe me, it's still an adventure when shower day rolls around. But, I've learned that if the arm is bothering her a lot, we don't do the shower.

Another incident perhaps

Now that she is feeling better and stronger, she wants to constantly help and do things for me. I appreciate the fact that she wants to help, but the reality of

it is that she is very limited in what she's physically able to do. She does still read her books, but not like she did.

She may have had a little incident again, because she's not able to concentrate on her books like she did before. She doesn't tell us about the stories in-depth like she used to do.

Her interests are very limited. She doesn't like to play games or do any type of puzzles. She just likes to do work and be helpful. So her big job is folding all the laundry, which is a very big help to me.

Believe it or not, she's basically only happy when she's working!! I told her she's working me really hard so she can have some laundry to fold. It is nice not to have to fold the laundry!

Mom and Dad continue to be an adventure

In between taking care of Genevieve, we still are caring for my mom and dad. Dad is doing quite well. He's been caring for my mother a lot now that he's recovered from his broken hip.

He was a very fortunate man to have recovered the way he did. Dad's main problem now is that he has a small growth on his bladder. We were all set to have the surgery, but his doctor needed a hip replacement.

So, that kind of postponed Dad's surgery until the urologist was healthy enough to perform the surgery. Dad really doesn't want to have it done and is uncomfortable with this particular doctor. I certainly understand how he feels. The only bad thing is that we don't know if the growth is malignant or not. We decided to get a second opinion from another urologist after the holidays.

Dad will always have his diabetes to contend with. But, thankfully, after a rocky start last New Year's Day with his high blood sugar level, we've been dealing with it quite well.

His blood sugar fluctuates a lot at times, but there is usually a reason that it does it. I used to get frantic when it ran real high, but I learned to relax and

how to deal with the situation. It's amazing all that we've learned through caring for all the different ailments of our parents.

The unfortunate thing is that his endocrinologist is no longer going to have private practice. It's all a sign of the times. From what we've been told, it's become too costly for them to be in private practice any longer.

So, they are going to work in nursing homes and a health clinic. This doctor is one of the best endocrinologists in our area and is very loved and respected by all his patients.

His assistant will be going with a new doctor, so we're hoping Dad can become a patient of the doctor she goes with. She gave us so many tips about diabetes and knows Dad's diabetic history.

Mom is getting weaker and weaker

I feel so bad for her and don't know what to do. She's getting physical therapy again to try to make her a little stronger, but I don't think anything is going to help her anymore. I really think she's given up the fight! She hardly eats anything and some days she can barely walk. She gets up at least 2 or 3 times a night to go the bathroom.

My dad has to get up with her, because she can't get in and out of bed by herself. Some nights she said she's up every hour. Needless to say, the next day they are both zombies!

Mom has been depressed and constantly telling me she should kick the bucket. I keep telling her not to talk like that. She feels she's such a burden to everyone and feels so badly about it.

I try to talk to her and tell her not to feel like that. She'll be ok for a while, but she's not a happy person at all. She no longer likes to talk to people on the phone.

She's basically waiting to die, which totally tears me apart. I can't imagine what it's doing to Dad. He's been so caring and good to her. No one should have to go through what my mother is going through right now.

She's totally lost interest in doing her word puzzles, which she always did. She basically can't concentrate on anything and worries about everything.

We have a hard time getting her to eat. She lost 71/2 pounds in one month. So now we're weighing her once a week to try to keep a real close watch on her.

Thanksgiving chaos (we loved it!)

Our son and family came home for Thanksgiving. That was so nice and chaotic again! I loved it!! My daughter-in-law and I made Thanksgiving dinner and it was so nice to have someone to help me in the kitchen.

My dad and Ken's mom peeled potatoes. I also had them peeling apples the night before Thanksgiving for the apple pies. We had a real joint venture Thanksgiving dinner this year. It was nice! Ken, of course, was the turkey carver. The guys cleared the table, but we couldn't talk them into doing the dishes!

Anyhow, between all the many depressing issues, there is always someone or something that will come along and lighten things up. We have to look for the good in everything. It's hard sometimes, but life is a learning experience, whether we like it or not! Ken and I are gradually learning, I think!

DECEMBER 2008

A different kind of Christmas Season

Wednesday, December 31st

When Thanksgiving was over and everyone's attention turned to the holidays, I believe Ken and I were both in disbelief. Can't really be that time of year already! But, indeed it was and we needed to start preparing for

Christmas! We both love this time of year, but when both of us have limited time to get things done to begin with, this kind of puts a ton of extra pressure on us.

Before Ken and I could even begin to deal with the holidays, I had to deal with cataract surgery on the second day of December. This was my second eye surgery within a month.

When my eye doctor told me I needed this surgery, I was totally upset and started to cry. I told him I can't do this because of caring for 3 elderly parents and had no one to help me.

But, after I calmed down and Ken and I talked it through, I became more rational and realized that there was no alternative. This was the first time we were faced with a situation where I couldn't care for our parents.

A live-in caregiver makes a huge difference

We decided to have a live-in caregiver for 8 days during my recovery period. The weird thing was that after the actual day of surgery, I was able to virtually do anything.

But, I could not lift anything over 10 lbs. or do any major bending. That was the reason we had to have someone come in and help with Ken's mom.

We had a wonderful person come and live with us for 8 days (we used her for both of my surgical recovery periods). She took complete charge of Genevieve and gave me a chance to get rejuvenated again.

These caregivers are out there and the majority of them are very loving, caring people. She even cooked some of the meals for all of us. This was great!

It's funny as to how upset I was over having to get these 2 procedures done, that it really turned out to be a very good thing. Plus we found out that we can have 24-hour live-in service for just 2 days at a time.

Wow! A long-term-care insurance company volunteers to pay more!

Also, after we had the live-in for my first eye surgery, we found out that Genevieve's long-term care insurance, Penn Treaty, will cover up to $100 per day for her in-home care.

The insurance company actually called Ken to bring it to his attention. We were so shocked and couldn't believe an insurance company would actually call and let us know about that benefit.

Usually, at least in our past experiences, you have to fight to get insurance coverage that you are entitled to. They do require quite a bit of paper work, but who cares when it helps pay for homecare.

I don't know how it works with most long-term care insurance policies, but before Genevieve had her stroke, we checked with the insurance company and at that point she did not have any in-home care coverage (at least didn't qualify for it).

So, it seems like this went into effect upon discharge from the nursing home. That's why we were so surprised. Guess that's a good lesson learned. Always double check on what type of coverage is allowed for different types of circumstances.

We also started the process to get Genevieve on the state JACC program and drug program. All the social workers are quite positive that she'll qualify for the program.

We're hoping it doesn't take as long for her to get on the program as it did for my parents. Of course, with the new year, any information from 2008 will have to be updated for 2009. Hopefully, it won't be quite as long of a waiting period for Genevieve.

Some nice Christmas Memories

During the first week of December, while the live-in caregiver was with us, Ken and I went out one night just to be together, and decided to pick up our Christmas tree.

The first tree we picked out was so beautiful that we just knew that was our tree. We brought the tree home and left it outside for 1½ days and then brought it into the house and put up the tree.

We naturally put water into the tree stand and we checked the tree the next day and the tree barely drank any water. We couldn't understand it and realized that the bottom of the tree seals up within 8 hours of being cut.

Well, the place where we purchased the tree cut off the bottom of the tree for us, but we did not immediately put the tree up or put it in water. We found out the hard way. But, believe it or not, the tree did not drop its needles and really didn't get dry until a day or two after Christmas. We got lucky!

Anyhow, Dad and I put the lights on the tree. I think he really enjoyed decorating this year, because he was laid up last year with his broken hip. We reminisced about how we used to decorate when I was a little girl. It was nice.

Dad and the caregiver that comes 2 days a week for them, put their tree up (an artificial tree). Dad also had her outside our house putting up lights with him. He was really in a decorating mood this year…good therapy for him.

Their caregiver and Santa came to visit them the week before Christmas…Santa even brought them gifts and goodies. It was such a fun time for everyone. I think that's the most we've seen any of them laugh and smile in a long time.

Our oldest son and family came to spend the holidays with us and, as always, it was so nice to have happy noise and laughter in our home again! I miss that so much and miss our kids and grandkids so very much!!

My grandmother made Christmas extra special

My grandmother needed me to come to Pennsylvania and take care of some paperwork for her. It's so difficult for me to get up to see her and help her with her problems. She's 96 and so much healthier than our parents. She's so amazing! Our son volunteered to go to PA to pick her up over the holidays so that she could spend a little time with the family. She hadn't seen anyone since early last summer.

It was such good therapy for our parents to see her and also good for my grandmother. She always feels so badly for my parents when she sees them because she knows how active they used to be.

I took her back home and was able to help her with the paperwork. It's really hard when you're an only child and have so many responsibilities with your parents and add on a grandparent as well. Ken and I are just so thankful she's so healthy and independent.

Our son and family stayed through New Year's Day. So, we really had a nice holiday and visit with them. It's just always so sad when they leave, because we know that we can't get down to see them like we used to.

JANUARY 2009

If anyone had told me…

Saturday, January 31st

Can't believe this year is over. If anyone had told me what we would have been facing for 2008, I would have headed for the hills so fast and never been seen again. Actually would never have done that, but don't know if I could have faced any of what we went through.

I guess when we were in the Emergency Room with my dad on New Year's Day 2008, we should have realized what we were in for. But, the weird thing is that that was the turning point for Dad. He's seen such improvement throughout the year…I'm really amazed!

We're only into the new year a couple of weeks and already we've had a few incidents. Mom is failing more and more every day. Dad now walks with her almost every time she goes into the bathroom and sits with her when she brushes her teeth.

He gets her dressed in the morning and gets up with her during the night. If it weren't for Dad taking such good care of her, she would have to be in a nursing home. She can barely feed herself now. I truly don't know how much longer Mom can hang on.

I just feel so bad for all of them. It's so horrible what some elderly people have to go through in their final days.

I know without Dad I couldn't take care of Mom. Maybe if I didn't have to keep a constant eye on Ken's mom, I would be able to do it. But, Mom is up anywhere from 2 to 4 times during the night and I know I could never do it. Mom and Dad both sleep during the daytime. I would be a total basket case.

Mom's latest problem is that she had a stool culture taken and it showed she has blood in her stool. So, of course, she went off the deep end and immediately said she just knows its cancer.

Well, the doctor never even used that word and said it could be something as simple as blood from her constantly straining to move her stools since she is so constipated.

I am constantly trying to boost Mom's morale,
but it sure is hard.

Several mornings she has told me that she was sure it was "it" the previous night, because she was in so much pain. When she says "it", she means dying. I really think she is very fixated on death, which I can understand.

I feel so badly for her, but really don't know what to do about it. The other day we went to see her pain doctor and he asked her what she did for fun. She couldn't think of anything and finally said music.

Music, especially from the 40's, perks her right up. She won't read, do puzzles or games. It took major convincing today to get her to help with a puzzle. She just can't seem to concentrate on anything. She's definitely a challenge!!

Dad is going to two new doctors. One is a new urologist. Dad was not comfortable with his original urologist. He wanted Dad to get surgery for 2 small tumors right away back in September, but then the doctor had to go into the hospital for a hip replacement. The doctor never called us as to what to do with the surgery…just left us hanging.

Anyhow, we decided it was best to go to a new urologist. If Dad does need surgery and has to stay overnight at the hospital, Mom will be a basket case. Not sure how we're going to deal with that one.

Dad is also going to a new endocrinologist. His original doctor was with a group of doctors that closed their practice down. We heard it was becoming too difficult financially for them with the health insurance reimbursement restrictions.

It's so hard to start over from scratch when you had such a good relationship with a doctor. Guess that's just a sign of the times.

As for Ken's mom, we had 911 come out for her.

She had difficulty getting out of her wheelchair to go to the bathroom. I was with her and so we tried a different way to get out of her chair. Well, she lost her balance, fell and hit her head on the wall…she took me with her.

When she hit her head, I thought we had a major problem, but she was thankfully ok. But, I had to call 911 because she's much too heavy for me to pick up. I'm getting to the point that I think nothing of calling them.

They came out and were so kind to her. The man was very tall and got under her arms and scooped her off of the floor like nothing. They said they make calls like this all the time. We were very thankful for them.

Ken and I decided to get live-in help on the weekends to give us a break from the constant day-to-day care of his mom. It's more R&R for me than anything. By doing that, I get to sleep-in a couple of mornings and relax and experience a more normal life.

So far it's been kind of frustrating having the help. We were unable to have the same girl 2 weeks in a row, so each time it was starting over with getting the girl acclimated to Genevieve's daily routine.

The first weekend that we did this we woke up in the morning with no heat. So, needless to say, we were running around trying to figure out how to keep our parents warm.

We were without heat for over 10 hours (the coldest day of the year), but were able to keep our parents nice and toasty warm with four different space heaters.

The second weekend was frustrating, because I took Mom to her pain doctor that day and picked up the girl (live-in helper) at the bus stop later in the afternoon.

Until I got done explaining everything to her, the day was gone. So, I guess once we get into some sort of routine or rhythm then I might start making better use of my 2 days to myself.

Today we have a new issue with Genevieve.

January 27th

She woke up this morning with a very red, swollen left cheek. Everywhere else on her face was fine. So, I called her wonderful family doctor and he was pretty sure that she has a case of the shingles.

So, in addition to all her medications she is presently on, she is now on additional medication for her shingles. So far, she has no pain or itching from it. Seems like her worse problem from the new medication is going to the bathroom more often.

One interesting thing I found out is that if you never had chicken pox you can get chicken pox from a person who has shingles. The doctor said anyone that is pregnant, has a weakened immune system or someone who has never had chicken pox should stay away from anyone who has shingles.

The homecare service we used called both of the girls that help us out on the weekends to make sure they had chicken pox. Both of the girls did have chickenpox, but one girl refused to come because she has a weakened immune system.

The other girl was unavailable for this weekend, so we were left without having one of the regular girls for this weekend. I refused to go through another weekend of starting over again with a new girl.

So, we're getting a girl that is used to Genevieve for just a few hours on Saturday night. At least that gets Ken and me a little alone time, even if it's just for a few hours.

Well, I was wrong about Genevieve not having problems with her shingles. She now has developed itching on her arms and legs, which the doctor says is not more shingles coming out on her.

He said shingles only stay in one hemisphere on the body. He also did not think her problem was related to the new medication she is on, but I still think it might be. He suggested a lotion to sooth the irritated areas on her body.

So far it seems to be helping her. Just hoping we can get her through her whole regimen of steroids. Her face definitely looks improved.

Ken's mom is a major safety concern

One thing that has become a real problem for me is dealing with Genevieve's constant insistence on doing things she should not be doing. She does not see any danger or repercussions from doing things that could be very harmful to her.

This is why she needs 24/7 care. Her problem is that she feels very strong and sees no reason why she can't be doing chores in the kitchen and walking around holding on to the counters.

The reality is that she is totally unsteady when she tries to walk. I caught her the other day standing and hanging on to the counter, wheel chair not locked and trying to water her plants. I unfortunately had to tell her never to do that again.

I guess in her eyes I look like a tyrant who will never let her do what she wants to do. I had to lecture her on the dangers of doing something like that when I'm not right by her. But, she will do it again…I just hope it doesn't result in a major accident.

I, unfortunately, have to try to do my office work during the day, as well as keeping an eye on Genevieve. So, as a result, she often gets very bored and that becomes very frustrating to me.

Some days I really do just want to run away from all of this, but I would never do it. But it is really hard and getting harder and harder every day. It's really nice when my parents' health aide comes to help them. It's not only extra help for them, but also an extra shoulder for me to cry on.

FEBRUARY 2009

What a February!

Thursday, February 19th

It's the middle of February and what a February it has been so far! We're now gearing up to take care of my father's bladder cancer and whatever issues the doctor discovers with my mother's bladder.

Late last year my father was going to a urologist who wanted Dad to have bladder surgery. We were gearing up for it, but then the urologist had hip replacement surgery so that kind of took care of my father's surgery for a while.

There were some issues with this particular urologist, so we decided to start over with a new doctor. We went to see the new urologist the first of February and the doctor said Dad needed to have the surgery to remove the tumors in his bladder.

Selfishly, all I could think of after the doctor said Dad needed the surgery was that now I'll have to be caring for my mother during the night.

I think Dad was actually looking forward to a little R&R time…even if it meant going for surgery. I totally understood where he was coming from!

Every night is a challenge - it's exhausting

My mom never sleeps through an entire night. Dad has to get up at night with Mom because she can't get out of bed by herself and always needs help getting back into bed.

When Dad broke his hip over a year ago, I took care of Mom during the night. Believe me, that first week of helping Mom 2, 3 and sometimes 4 times a night was destroying me.

But after a week or so, she was able to get in and out of bed by herself. But since that time, she's gotten much weaker and unable to get in or out of bed at all.

So, I now have almost a week under my belt of getting up during the night with my mother, and let me tell you I am exhausted, both physically and mentally.

I still have a few more days to go, before Dad is allowed to help Mom again. Neither one of them has been sleeping well the past week. Dad had a catheter in him and it was a little hard for him to get comfortable with the tube and bag he had to carry around.

The surgery was done last week and was successful. The doctor removed 10 tumors, 3 larger and the rest of the tumors were smaller.

The larger ones were cancerous, but not deep within the bladder…just the surface. So, Dad will be having medicine put up into his bladder once a week starting the beginning of March for the next 6 weeks.

It's basically chemotherapy, but not the kind that makes you nauseous and your hair fall out. Obviously, we hope he's right!!

Ken's mom is getting worse with her dreams and hallucinations.

The other day I was out of the house for a little while and Genevieve was at home with our caregiver. She was asleep when I left, so was hoping she wouldn't wake up until I returned home. Unfortunately, she woke up before I returned and told the caregiver she needed to go home…right now!

The caregiver is so wonderful and she told her she would, but had to finish her drink first. She was able to stall her until I came home. She was talking about needing to get home for the kids coming home from school. Also wanted a cigarette…she doesn't smoke. She did try it in her younger years…didn't like it. Then she was talking about New Year's Eve and staying up until the ball comes down. Once I came home and talked to her, she said, "Oh there you are!" It's just all very bazaar!

Ken took her to see the neurologist the beginning of February and, of course, the neurologist said she is getting worse. Ken told the neurologist about her talking in her sleep and he prescribed a mild sedative for her.

He thought this would help her. We have a baby monitor in her room so that she can call us if she needs us.

When she starts her talking, it sometimes starts as a scream and sometimes a laugh. Well, when you're in a deep sound sleep, it's extremely startling.

She has very sensible conversations in her sleep. We sometimes wait for whoever she's talking with to answer her. She speaks better in her sleep that she does when she's awake.

She's been on the sedative about a week now and she's still talking in her sleep. I wonder if this goes with Alzheimer's disease? I often hear about people taking off and wondering around and sometimes they are found miles from their homes.

I'm beginning to wonder if they are in a trancelike or dream state and just acting out their dreams when they wander.

More challenge with Ken's mom

We now need to go to the medical supply store for Genevieve and get her fitted for support hose. When the doctor told me that, I kind of moaned and groaned.

They are so hard to get on and off. The doctor wants her to have thigh high stockings no less. He wrote a prescription for a stocking donner. He said it's supposed to help get the stockings on and off.

I swear all these doctors are just killing me!!! Seems like every week I'm asked to do something new and different for our parents. Oh well! We'll just suck it up and do it!

Ken and I are our own support group

Ken and I are both going through a very difficult time right now. I'm pretty much doing all the care for our parents and Ken is trying to keep our business going practically by himself.

We always worked together and now it's almost impossible for me to help him anymore. Between tough economic times triggered by the financial meltdown nationwide, and our unusual circumstances with our parents, we sometimes get very down.

But we usually take turns with our low points. We try to keep each other's morale boosted.

MARCH 2009

Halleluiah!! Spring is finally here!

Monday, March 23rd

At least it is on the calendar. Our parents do not do well in the winter. Genevieve, Ken's mom, is constantly asking how warm it is outside. We have a screened-in porch, which she absolutely adores. We had a few fairly mild days this past month and she was able to sit out, read her book and enjoy the nice breezes.

Otherwise, she is not very content just sitting around. She gets very antsy, so we need to try to keep finding things that she's able to do. She's totally in charge of folding the clothes in the family.

A couple of her caregivers started to fold some of her clothes and she definitely let them know that folding was her job! Naturally, they all get a kick out of her and make sure she gets all the clothes.

Genevieve has been pretty much status quo. She talks a lot in her sleep and sometimes will wake up asking us about certain things that never happened but seem very real to her. She's always amazed that it didn't happen.

It also seems like she has a very hard time reading her books the past month or two. She used to really enjoy her books, especially Danielle Steele, but I don't think she's able to remember much of what she reads any longer.

I ask about the books she's reading, but she's not able to tell me anything about them anymore. I think she's just reading words at this point in time. I've given her the same books to read over at least 3 times and she doesn't remember the stories. We also notice she can't remember movies that she's seen.

We showed her the same movie 2 times within 3 days and didn't remember it the second time around. This just totally boggles our mind.

She also doesn't remember our son and family visiting us at Christmas time. Last week she said, "Does our family know I'm here and why don't they come to see me?"

She was amazed when I told her they were here not that long ago. I know she hates that her mind is the way it is.

My mother is doing very poorly.

She's become much weaker in the past few weeks. She now can't get up out of her lift chair without someone giving her a little help.

She's extremely pitiful and constantly saying she doesn't want to live anymore. It just totally breaks my heart to see her like this and don't know how to make her happy or more comfortable.

APRIL 2009

Wow! Time sure does fly!!!

Friday, April 17th

I wish I could say we were all well and traveling and having a marvelous time, but unfortunately, that's not the case. The extent of my traveling was going to Pennsylvania for my grandmother's sister's funeral.

left early in the morning and was back by 8:00pm the same day. My mother and father felt so bad that they were not able to go to the funeral…but that just was not possible. Ken stayed behind to fill in the time between caregivers.

It's always an adventure to try to go anywhere…especially for me. My mom and mother-in-law are always very anxious anytime I go anywhere…even just to the bank or grocery store.

My grandmother was amazing at her sister's funeral. She remembered most of the people who came to the funeral and there were quite a few there for a 98 year old lady.

I was amazed how many people came to her funeral. She worked in a department store for over 30+ years and even some of her customers came to her funeral to pay their respects. My grandmother knew her sister's friends from her church and her neighbors… I would have had a hard time remembering their names, but not her.

My grandmother was exhausted by the time we got back to her house. She looked so tired and sad and I felt so bad leaving her like that.

I've talked to her several times since the funeral and she misses her sister so badly…much more than I ever thought she would. They used to talk on the phone every day and my grandmother visited her at the nursing home at least 3 times a week. That really took a toll on her health and body.

I think she just pushed herself to get her work done and visit with her sister out of pure will. Now her body is rebelling and she has become extremely weak and tired.

I'm hoping she is able to snap out of it. When the weather breaks we intend to bring her down for a visit for a few days. I know she'd like to visit with my parents and Genevieve.

My mom and dad both fell 2 weeks ago while their caregiver was here.

My dad tried to catch her and as a result, they both fell. Between the caregiver and myself, we were able to pick up my mom. Dad was able to get up by himself.

Mom immediately got a big lump on the back of her head and also some swelling in the back of her neck. So we decided to play safe and called 911.

They came out and checked Mom out and felt she was ok. We watched her the rest of the day and she was ok…thankfully! Dad's back hurt him a little, but seems ok now.

Mom is presently getting physical and occupational therapy again. She needs it so badly. It's amazing how quickly she'll go downhill when she's not receiving physical therapy.

We tell her she needs to do her exercises, but she won't do them most of the time. But since the therapists are back, she seems a little bit better again.

She got to the point that she was not getting out of the lift recliner chair by herself. Now she is able to do that again. She just needs someone around her and after her to remind her to be a little bit more active and just keep nudging her along.

She's also getting a "Smart Rail" for her bed.

This is a quarter rail that is somehow attached under the mattress. It rests on 2 legs and has a rail that she'll be able to grab onto to help her turn and possibly pull herself up into a sitting position. We're just not sure how helpful this will be, but it sounds very promising.

We're also still dealing with her heel pain that she gets every night at 1:00am. It wakes her up every night like clockwork at exactly the same time. So far nothing seems to help her.

She's worn booties to bed, special slippers, boosted her foot with a pillow, put foam cushioning under the sheets, massaging, hanging her foot over the side of the bed.

The only thing that seems to make it better is for her to get up and walk around on it. I keep telling her when it gets that bad, to get up out of bed and try sleeping in her lounge chair. But, for some reason, she hasn't done that yet.

At my wits end

She used to have the problem of getting up about 3 or more times to go to the bathroom. I finally got her to accept wearing Depends to bed and going in the Depends.

Now that that is straightened out, she has the foot problem. I'm really at my wits end with this, because neither my dad or mom are getting any sleep.

So, the new thing is that we're putting ointment on her foot when she goes to bed and then again when she wakes up with the pain. We're hoping the heat from the ointment will take her mind off of the pain in the foot.

We're willing to try almost anything at this point. I think if she could get a decent night's sleep, she'd be able to deal with a lot more things better.

Chemo for Dad

As for Dad, he had been getting a form of chemo treatment for the last 6 weeks for his bladder. He had his last treatment this past Wednesday and seems like he had no major side effects from the treatments.

He had some minor issues, like a little bleeding and some diarrhea and little tiredness, but nothing major.

We won't know for another 6 weeks if the treatments were successful. The doctor will do another cystoscopy and hopefully give Dad a clean bill of

health. I'm sure he will have to have a cystoscopy every 3 or 4 months to make sure that no new tumors have grown.

Dad also had his first visit with his new endocrinologist. He had the same doctor for 5 years and then had to find a new doctor. His original endocrinologist closed down his private practice.

He and his partners are now working in a hospital clinic and nursing home. They were not able to make it financially in their private practice.

They were very good doctors and highly respected in the community, but guess could not make it because insurance and Medicare reimbursements were not enough for them to justify having a private practice.

All of their patients were very shocked at the close of their practice. Fortunately, the new doctor that Dad is going to see also has an excellent reputation.

His style of treating diabetes is a little different than Dad's old doctor, but everything his new doctor suggested seems to make sense. Time will tell!

Good days and bad days

As for Genevieve, she has her good days and bad days. Her mind is not nearly as good as it was and she is not doing as well with her balance and walking. She has gained quite a bit of weight and that might have something to do with her balance. She really does enjoy her food.

The caregiver that comes to take care of Mom and Dad brought Easter baskets for all of them. Genevieve has really enjoyed hers…it's almost empty already.

Genevieve is also getting physical therapy. It is mainly to try to reinforce in her the proper way to get out of her wheelchair so that she doesn't fall.

She's not too bad when she's totally focused on getting out of her chair to a standing position. Her problem is when she has an emergency (usually an urgent call to the bathroom), she will totally forget everything that she's supposed to do.

So, mainly the goal for Genevieve is to try to get her so used to getting in and out of her wheelchair, that it will be second nature to her…that she won't even have to think about it.

Ken and I will be totally amazed if that's even possible for her. Right now she can't remember things from day to day, so that would be a major accomplishment for her.

Another fall

She did fall in the downstairs bathroom a few days ago. I heard a lot of banging around in the bathroom, which is not unusual for her. But this time it seemed somewhat excessive, so I looked in on her and she was on the floor. Thankfully, she did not hurt herself at all. She told me she just sat down on her bottom. I had to call Ken to come home so that he could get her up off the floor.

MAY 2000

A Pretty Good Day!

Wednesday, May 27th

Well, as days go, I guess you could say this was a pretty good one for our parents. Genevieve slept through the night without talking or getting me up last night…yeah!!!

She had physical therapy bright and early today and pretty much made it through the day without sleeping and doing anything strange. She was able to be out on the sun porch all afternoon and was very content reading her book.

This is a first for her in quite a long time. If she were like this everyday, she'd be very easy to take care of.

My mom also had a pretty good day. She had occupational therapy early this afternoon and had a very good session with her therapist.

Her therapist has been especially good with getting Mom's self esteem back. Mom has been very hard on herself when she can't do something and in the end has become her own worst enemy.

Today after her therapy she went outside in her power wheelchair and then came in and sat out on their deck for a little while. Of course, she can't do any of this without either my dad or me helping her, but she did so much better today. Her attitude has everything to do as to whether she'll have a good or a bad day.

As for my dad, he kind of got off to a rough start today. He had an upset stomach early this morning, but once he was moving around more he felt better. He felt so good that he decided to go out and mow some grass.

He has shown the biggest improvement of all three of our parents. Of course, when my father is outside doing anything, Mom wants to see where he is at all times. She's so paranoid about something bad happening to him when he's outside.

JULY 2009

Genevieve's doctor recommended that we put her on the Hospice program

Saturday, July 25th

He perceptively saw that we needed to get some extra help with her care. We put her on the program the middle of June. Initially they provided a home health aid 5 days a week to help her with her personal care.

She also has a nurse check on her 2 times a week and a social worker and chaplain come every other week. They are all such wonderful, caring people.

We heard about the Hospice program before, but had no idea the extent of their services. We can call them anytime with any problems that we are having with Genevieve and they will guide us through as to how to handle the situation. They even provide certain supplies and medications.

The very first week she was on the program, I needed to call them. She went into one of her weird spells and was awake only to take her medication.

This particular time we were only able to get her to eat a small amount of food. She slept all day, didn't even get up to use the bathroom.

I believe she started Friday evening and this lasted through until around 3:30am on Monday. This was the longest of her spells. But once she came out of it, she was very alert.

The only problem when she had these spells was that she got weaker and her walking got worse.

Full-time live-in help

I believe it was about the middle of July when Ken and I realized we needed to have our live-in caregiver more often than just the weekends. We started out with just Fridays and Saturdays so that we could get some time together.

But it became almost impossible for me to care for Genevieve and my mother without some extra help. My mother needed extra care and Genevieve was requiring more care as well.

We had to get full-time help for Genevieve. She got to the point that I could no longer handle her by myself. Her legs no longer reacted the way they should.

Her caregiver is off from Sunday morning until Monday morning. I know that doesn't sound very long, but it seems like an eternity to Ken and me. Ken now helps me when we're alone with his mom, because I just don't have the strength to lift her.

The problem with her is that her legs and feet won't turn when she has to transfer from her wheelchair to her bed or toilet. Even her caregiver is having a harder time transferring her from one place to another.

There will come a time when she'll have to stay upstairs and that she will not like very much!

As for my mother, she has deteriorated a lot.

Again she's not eating like she should. She no longer is able to get out of bed by herself. Needs help using the toilet. She virtually is unable to do anything by herself. She has become a very pitiful person.

My dad, thankfully, is in pretty good shape and helps her as much as he can. I know it's getting to him. He's such a kind and patient man and will do anything for my mom.

AUGUST 2009

Well today is a new day and hopefully I'll be able to cope a little bit better than I did yesterday.

Saturday, August 29th

I believe yesterday was one of the worst days for me emotionally. I was such a bundle of nerves that I could feel myself shaking inside. I really cannot let this all get to me like this anymore.

It's just so difficult when my mother and Genevieve are both bad at the same time. I feel like I'm in a 2-ring circus and just keep jumping from one ring to the other ring.

They each have their own different problems and I have to kind of put on a different hat to deal with each situation.

The doctor came bright and early this morning and I was so thankful to see him. He's going to put my mother back on physical therapy again to try to keep her mobile. He's also going to put her on an appetite stimulant so that she starts eating a little bit better again.

He also wants her to try to go through with the MRI that the neurologist wants her to have. She was unable to do the test last week because she couldn't get her head back into the helmet far enough.

The imaging center called us back and said they have a technician that is used to dealing with patients like my mother. So, we'll try it one more time.

Taking my mother out into the car for any reason is very difficult, especially a doctor's appointment. I stopped taking her to the podiatrist that she likes because it's virtually impossible for her to get out of the car at his office.

They only have curb parking… totally unfriendly to disabled patients. I also can no longer take her to our family dentist that we all totally adore. Don't know what I'll do for her dental care. At least for her feet there is a podiatrist that makes house calls.

SEPTEMBER 2009

If it's not one, it's another…

Monday, September 21st

Seems like when we get one of our parents under control from a health episode, then we are almost always faced with a new problem with one of our other parents.

Well, sure enough when I came down first thing Monday morning to take care of my parents…help them with medications, breakfast, dressing, etc., I didn't realize I was going to be faced with a new adventure.

On this particular Monday morning, Mom was just starting to eat her breakfast. I believe she had a bite of a muffin and a sip of her coffee and then she started with chest pain and pain in her jaw.

She's had pain in her chest before, but not the pain in her jaw. I gave her nitroglycerin tablets…one tablet under her tongue every 5 minutes.

She said the nitroglycerin tablets burned like fire under her tongue. So after the second tablet, her pain was still there and I decided to call 911.

By the time the paramedics came, her pain was gone. But, they decided to take her to the hospital for further testing to make sure everything was ok.

Since this happened on a Monday, we were faced with another problem. Genevieve's caregiver was not back from her day off, so Ken was in charge of his mom.

If she would have been up for the day, that would not have been a problem. But, she was still in bed sleeping. Ken does not bathe and dress his mother…I can't imagine any son wanting to do that! Luckily, she slept until her caregiver returned, which was a blessing!

I told Dad to stay home, because I felt it would be too much for him at the hospital. It was a good thing, because by the time I was able to leave Mom and come home to get Dad it was almost 2:30 in the afternoon. Mom arrived at the hospital around 8am, so it was about 6 – 7 hours before I could leave her.

The doctor admitted her and felt she needed to have a heart catherization done. Thankfully, everything turned out ok. She didn't have a heart attack and her arteries were not clogged.

Dad was so lost without Mom and couldn't wait to see her. When we returned to the hospital, Mom was not in her room. She was having the catherization done.

We waited for her to return and other than being weak she really seemed ok. The hardest thing for her was to lay flat and not move for 3 hours. With her spinal condition, that is a very hard thing for her to do.

They couldn't wait to discharge her.

Dad and I went back to see Mom the next day and she was a totally different person! She kept trying to grab imaginary things in the air and kept seeing bugs on the nurses.

She was really a mess. I asked the nurse if they gave her any nerve medication and she said no. I don't know what made Mom so bad, but she was just totally out of it.

I really think she was driving the nurse and the aids crazy. I even overheard the doctor talking to one of the nurses about discharging Mom from the hospital.

I know I thought at the time there was no way that Mom could come home today! I couldn't imagine how on earth I would be able to take care of her in that state of mind! But, the doctor asked her a few questions, which she answered correctly and said, "Sure she's ok to go home".

Guess I gave him a pleading look and said they would keep her if I wanted them to, but I knew in my heart I couldn't do that to Mom. The doctor said I could bring her back if she was a problem. I knew that I couldn't do that too.

She was still out of it once we got home, but after a good night's sleep, she was in good shape the next day. I was so relieved.

The doctor at the hospital told me that some patients react the way my mom did just from being in a hospital. I still think she must have had some kind of medication that set her off like that.

We must keep the two peas together in the pod.

One thing that Mom's hospital stay reinforced with Ken and me is that we have to try everything in our power to keep Mom out of a nursing home. She would never survive in a nursing home!

Now that she's been home for a week she seems to be doing ok. She was extremely weak, but seems a little stronger. She's still getting her physical therapy twice a week to try to keep her mobile.

Dad is doing pretty well. He did have a hard time when Mom was in the hospital. I know now that he would have a very hard time without her for any period of time.

They are like two peas in a pod. Like my mom says, they basically grew up together. They got married at the ages of 19 and 20…that's a long time!

NOVEMBER 2009

It was a beautiful funeral

Monday, November 23rd

Genevieve was laid to rest last Friday next to her husband Paul at their family's church cemetery in Flicksville, PA

Here is Genevieve's obituary.

Smith, Genevieve (Levonas) 88, former resident of Bangor, PA, passed away on November 16th, 2009 at the home of her son and daughter-in-law, Ken and Marianne Smith, in Egg Harbor Township, New Jersey. A memorial service will be held Friday, November 20th at the Flicksville United Church of Christ, 1337 Lower South Main Street, Flicksville, PA - viewing 11am-noon, church service at noon with internment following in the church cemetery.

Born August 21, 1921 in Dickson City, PA near Scranton, she grew up in Dickson City with her sister Angie, brother Joe and half-sisters Mary and Albina - all now deceased. When she moved in her early 20's to Stroudsburg, PA for work, she met Paul Smith from Bangor, PA at a roller skating rink and it was love at first sight. They loved to dance.

In January, 1942 Genevieve married Paul Smith before he went off to war and, when he returned, they settled in Bangor where the y raised their son, Kenneth.

Genevieve worked many years at Blue Ridge Textiles and other blouse mills in Bangor, and was a member of the Flicksville United Church of Christ in Flicksville, PA.

When her husband developed serious health problems in 1978 and could not care for himself, she selflessly devoted herself for the next ten years to caring for Paul, never leaving his side until his passing in 1988.

After his passing, Genevieve volunteered for many years at Slate Belt Medical Center where she was recognized for more than 500 hours of valued service.

DECEMBER 2009

Declining rapidly

Friday, December 4th

Well, it's presently 4:30 in the morning. I've been up since 2:20am. My father called me this morning to get Mom out of bed, because she was in a lot of pain.

He can no longer get her out of bed by himself and she can't wait until it's time for me to get up because the pain is so severe that she can't stand it.

So, it took a good 5 minutes or more to get her out of the bed and then another good 10 minutes to get her into her wheelchair, semi-dressed and into her recliner chair.

After getting her nice and comfortable and warm, I tried to go back to bed and relax, but I was wide awake. It's really scary, because we want to keep her out of a nursing home. But, by doing so, it's physically very difficult for the rest of us.

My mother has been declining very rapidly since Genevieve has passed away. I don't know if it's coincidental or if deep down it's affected her as to giving up the will to live.

My mom used to do pretty well using her walker. But the past two weeks, she needs assistance using the walker when she is able to walk.

She walks only about 50% of the time and the movement of her legs is getting less all the time. Transferring her from her chair or bed to the wheelchair is torture for both my mother and for me.

get extremely frustrated and she gets extremely upset with me. So, it's not a good situation.

In 2003 she moved into her son's home in Egg Harbor Township, New Jersey where she lived comfortably with family around until her passing.

Genevieve is survived by her son Kenneth and wife Marianne; grandson Jeffrey Smith, wife Carolyn and great grandchildren Garrett, Ethan and Kolton

of Charlottesville, VA; and by grandson Gregory Smith, his wife Gretchen and great granddaughter Ava of West Pittston, PA.

Genevieve, who was known to family and friends as Jean, was a wonderful mother, grandmother and great grandmother to a family who adored her gentle good nature and quiet strength. She was totally devoted to her family until the day she passed and she will be deeply missed by all who knew and loved her.

FEBRUARY 2010

Having a hard time dealing with it all

Monday, February 15th

I haven't entered anything in my diary for over two months. I guess between the holidays, my mom deteriorating so rapidly and also, probably me feeling a little depressed and having a hard time dealing with everything, I've neglected putting any entries into my diary.

I think I'm able to handle and face it now. I was afraid my mother would react the way she has after Genevieve passed away. I believe it was almost within two weeks of Genevieve's death that it became necessary to put my mom on the hospice program. I can't believe the downward spiral Mom has been on physically.

She no longer walks with her walker. She can't stand up without someone basically lifting her out of her chair. Her mind has deteriorated to the point that she doesn't know where she is and becomes frightened easily because she thinks she's in someone else's bed.

She sees other people that we don't see. She also used to be able to handle taking her own medication throughout the day, but now that totally confuses her. She's unfortunately not the same person anymore and it's just so hard for me to watch her deterioration.

She unbelievably is following the exact same route of deterioration that Ken's mom took. I just can't believe it.

It was hard enough to watch Ken's mom go through her mental and physical decline. But, it becomes even harder when it's your own mother.

I know now how Ken had to feel watching his mom become this strange, confused person. It's extremely hard to watch and reason with someone like that.

And, my poor father, I have no idea what has to be going through his mind. They are like two peas in a pod and he's taken such wonderful care of her…to the point of totally spoiling her.

She was so bad one day that he just stayed in his chair and just kept watching her. I could tell that he was so sad! He keeps telling her that she needs to try walking at least two times a day to get ready for spring so that she can get outside.

She did actually walk a few days ago from her lounge chair to the bathroom with assistance. She was totally out of breath when she got there, but she did it. We were all so proud of her. That was the first time that she walked in over three weeks.

In some aspects what is going on with my mother, I'm sort of prepared for after taking care of Ken's mom for so long. But, I really thought that I wouldn't have to do this so soon.

APRIL 2010

Peace for mom at last

Wednesday, April 14th

My mother passed away on April 5th late in the afternoon with me by her side. I was so afraid this was where we were going, but oh so hoping it would turn out differently.

Mom continually went down hill further and further. We were able to get her outside a couple of times when the weather started to turn nicer. But, she just couldn't stand to be outside for very long.

Between being too cold and too uncomfortable, she just wasn't able to enjoy herself outdoors. She always loved to be outside and it was so sad to see her not wanting to be outdoors anymore.

Mom got to the point that I couldn't leave the house unless Ken or a caregiver was here to help Dad in case Mom needed to go to the bathroom. She could no longer get out of her chair without being lifted out of it.

On Dad's birthday, which was March 23rd, we finally had to get a hospital bed for Mom. We were hoping that she would just use it to sleep in at night and for the health aid to bathe her.

But, she was so weak that day that we put her into the bed and she never got out of that bed again.

On Dad's birthday Mom had a small amount to eat, but she also managed to eat a small slice of his ice cream cake. That was the last major amount of food that Mom ate. After that, it was jello or a little bit of soup or an ice pop. She had very little to drink.

We again are so amazed that she lived as long as she did after that. She became dehydrated. The nurse and all of us thought that Mom was hanging on for her 88th birthday, which was on April 2nd.

We gave her a small amount of ice cream on her tongue, so she at least had a taste of her birthday cake. That was all she would take.

I don't think that she was in any pain the last few days. She did not like to be moved when she needed to be changed. She was in pain during that time, but other than that, I don't think that she was uncomfortable.

I really thought she was going to pass away on Easter, but thankfully, she passed away peacefully the next day.

We'll all miss my mom, but I think we're all relieved that Mom is no longer suffering. I really think her life became a living hell to her, because she was in so much pain and could no longer do anything but sit in her chair and that was not my mom.

I hope in time, as we all heal, that we'll remember my mom and Genevieve as the women they were and not remember them for all the suffering they went through. They were both very special individuals. We will always love them both.

After my mother passed away, the trauma of the previous 3 years caught up with me and I found myself resisting doing more real-time Diary entries. In retrospect, it was probably a form of PTSD.

But the responsibilities continued. My father continued to need constant care. Thankfully, after my mother passed away, it was springtime, which meant there was something for Dad to do besides sitting inside and watching TV. He loved to mow the grass with the riding mower. We had a fairly large property, so that became his project.

Over the next 3 years, Dad, little by little, started to deteriorate more. We continued to have Gloria and Lucy, our caregivers, come in a few times a week to help him. He needed help getting ready in the mornings and also with his medication and meals. He also needed help bathing, pretty much everything.

I took Dad to Pennsylvania occasionally to see his mother (stepmother) and to put flowers on Mom's grave for holidays. He was always napping at home, but when he got in the car to go to Pennsylvania, he stayed awake the whole trip. Guess he felt he was my wingman and had to stay awake.

It got very difficult to take him to visit his mother, as he progressively became more frail.

My grandmother (Dad's stepmother) lived alone until she was 99. She had fallen and ended up in the hospital and then in rehab. She was not able to come back to her home after that and be alone, so she ended up in assisted living.

As a result, this meant now I had to go to Pennsylvania more often to take care of things for my grandmother and still had to figure out how to care for Dad at the same time. It was difficult for Ken to take care of Dad by himself, as Dad was diabetic and at times his blood sugar would get totally out of whack and needed extra help.

The summer before Dad passed away was totally brutal for all of us. We had a really bad storm right before the 4th of July. It was called a derecho (straight line winds). After the storm had passed, we had fallen trees and limbs and all kinds of debris everywhere.

Thankfully, we were all ok and luckily no damage to the house. But, we had no electricity for close to six days, which meant no water and normal use of toilets and it was extremely hot, 90 + degrees.

I remember it being so horrible for Dad… it was bad enough under normal circumstances, but the heat was unbearable for him. It was horrible indoors, and even outdoors in the shade was almost equally bad. The humidity was off the scale. He made it through ok, but we were so scared for him.

From that point on, it was pretty rough with Dad. He had a horrible time at night. He could not sleep and became very agitated and restless and, as a result, would wander around the house. On top of that his blood sugar was also totally out of whack. He would have extreme highs and extreme lows.

Basically, all through our parents' decline, I slept with a baby monitor next to our bed. It was necessary so that I would know when something wasn't right.

In my father's case, I would know when he was wandering around his room. He would get up or try to get up and many times would fall. Ken and I would go down to him and have to pick him up off the floor.

We finally had to get a bed with rails on the side to help him stay in bed. But, he still managed to get out and fall. We also got him a monitor that would go off on its own when he fell.

The only problem with that was that if we didn't call the company in time, they would send out the paramedics. So, there was no easy answer for us.

His health declined rapidly over the winter of 2012/2013. It was so hard to watch him continuing to get weaker and weaker. I prefer not to get into the specifics of that period. It was traumatic.

He passed away peacefully at home on March 6th 2013.

I will always miss Dad, but I do know that he is now with Mom and finally at peace.

Epilogue

That was it - almost 6 years of an intimate, close-up view of our parent's decline. It was indeed a lot of trauma, but it was also a time for growing stronger. As hard as it was, I am proud that I gave everything I could.

The bond between Ken and myself grew even stronger. We feel we did what was right for our parents. And after a period of grief and reflection, we were able to move forward.

Assembling this Diary and Resources Directory has been both challenging and cathartic. I hope it inspires you to take another look at your elder care planning. Although no one can anticipate all the twists and turns the future holds, there is tremendous value in planning for possible scenarios.

Brainstorming those scenarios, researching resources, seeking out now potential sources of help – financial, psychological, logistical, legal - seeking guidance on health care options for those scenarios – this is the investment we are all called to make.

How well you accept this challenge can, in no small part, determine how effectively you will deal with this potential new chapter in your life – if and when it becomes very real.

How aggressively you work at this now can make a profound difference in the life of your aging loved ones – and in your personal sense of fulfillment.

When you look back after their passing, will you feel you did everything you could to make their final time as comfortable and fulfilling as possible?

Embrace the challenge.

Plan.