Part 2 of Greg's Journey

Day 403c-96a

We drove Greg to the hospital arriving there at 6:30 a.m. and I accompanied Greg through the initial process. A blood test was required as well, so Greg went to the lab. The waiting area was full so we sat outside, and he had the blood drawn. Once this was completed we went with him to the staging area for Day Surgery. There Greg was treated well by the nurses getting him ready for surgery and we, his parents and his two sisters who work in Calgary, took turns visiting with Greg.

Close to 8:00 a.m. Greg was rolled out of the area and off to the final step before surgery itself. We learned from Greg later, that Dr. #9 had talked to him just prior to surgery. That conversation included the following:

> A question of Greg as to why Greg had waited so long before coming in to get this dealt with. (a question that was not helpful at this stage)
>
> The name of the Oncologist that would be managing Greg's chemotherapy treatment.
>
> And he told Greg that they may start chemotherapy in advance of getting the pathology results because of the advanced growth of the mass in his abdomen and the problems it was causing with his circulation.

As family, when we later learned this, it was disturbing. We have difficulty understanding how any of this was expected to help Greg as a patient a few minutes before heading into surgery and on to treatment.

Lesson #7 *Pay close attention to how your doctor acts as it gets closer to the next big step and if you detect a change, very carefully revisit all of your previous concerns with them to ensure that all are covered to your satisfaction. It seems to us now, that Dr.#9 was showing some last minute concerns with respect to the rapid development of the mass and as a result, seemed to be challenging Greg for putting this doctor in this position. The fact that he indicated to Greg that accelerated treatment would be undertaken (even though later we learned that this just is never done) and misled Greg about it, now raises more questions about Dr. #9's motives and credibility.*

Shortly after 10:00, Greg's sisters noted that Greg was "in recovery" on the screen on the wall and then about 10 minutes later, we all were relieved to see him wave to us as he was rolled by the waiting area back to the space where he would be held until release. There we were able to rotate through staying with and talking to him while the nurses monitored his condition prior to his release to go home.

The nurses went over the things that Greg was expected to do with the incision and his medication and also the things that he would be watching for at home. He was shown the standard form which set this kind of information out. We had assumed that Dr. #9 would also come by to check on Greg prior to his release and to provide his comments post surgery and any special instructions. When we asked the nurses about this it was explained that this wasn't necessary as the surgeons often just put their instructions on the release papers and in this case, all that was expected was routine. We questioned this but were assured that there was nothing out of the routine for Greg. This included remaining for an hour of monitoring and demonstrating the ability to pee.

Lesson #8 *Do not assume that the surgeon is going to ensure individualized care is taken with you. In Greg's case, his situation was not a routine day surgery and indeed Dr.#9's comments to Greg shortly before going into the operating room showed that it was not routine, yet he did not follow up with a pre-discharge visit himself. He also did not bother to even go so far as to ensure that given Greg's situation with his abdominal mass restricting his blood circulation, special comments or instructions were given to the discharge team. At the time it was a surprise to us but looking back, it is very difficult to understand why Dr.#9 did none of this. Taking a little time to provide us with some precautions and some things to watch for would have been very helpful and having specific alerts and instructions for any other doctors who may see Greg later we believe would have saved his life. .*

When an hour passed and Greg was unsuccessful in this one task, it was explained that sometimes it took longer for the freezing to come out and in addition to the fluids Greg had, he was given he was given a popsicle. After another 45 minutes passed, Greg was able to pee and after one last check that there was nothing more that needed to be done, we rolled him out to the parkade. On the way home, we stopped for the prescribed medication at a pharmacy and then got Greg to our home. Greg rested fairly well that afternoon but then when it came to sleep at night, had more difficulty managing his pain. Greg was not someone who liked to take pain medication or medication of any kind and he continued to try to get by on the minimum. As the freezing came out, his discomfort increased still he was relieved to have been able to get through the surgery as the next step of his expected journey to recovery.

Day 405c-97c

Greg was able to move around very carefully, with sharp pain from the incision. He spent most of the day resting, although as the day went on, the swelling in his legs increased and along with it, pain and discomfort. I returned home from work and we decided that we had to talk to Dr. #9 to make him aware of what was happening and to get it dealt with. There had not been the expected call from the Tom Baker Center either. Closer examination of the paperwork from the hospital showed that there were no contact numbers for Dr. #9. There was only the standard Health Link number or to go to Emergency. Given the special character of Greg's problems, we didn't think that either of these options would be helpful and felt that speaking to Dr. #9 would

be critical. Second best would be to find out who the Oncologist was that Dr. #9 told Greg about and then to talk to him about the advanced treatment spoken of.

Day 406c-98a

Friday morning at 9:00, the time that the Urology Centre was scheduled to be open, I started calling every 5 minutes in an attempt to get to Dr. #9. Each time the recording came on saying that there was no one available. Each time I cut the recording off, waited another 5 minutes and dialed again. Finally I let the recording play out completely and learned that the Centre was closed all day that Friday. This also was a long weekend with Monday being a holiday so there was no way of getting to speak to anyone there. Dr. #9 had not given us any way of contacting him and indeed, the Urology Centre itself didn't provide anything but the office numbers of the doctors and on the web site explained that patients are not able to call these doctors directly. I tried to search out the names of Oncologists but none sounded familiar to Greg. He had to work from memory as Dr. #9 had told him this name while he was on the stretcher immediately prior to surgery.

Since there was no way to leave a message and no email contact at the Urology Centre, I decided to send an email outlining Greg's condition and our concerns and sent it to the Prostate Centre which was at the same location . That email was not responded to that morning, or at any time since.

Lesson #9 *Never, ever let your doctor leave you without a surefire method of contacting them (or someone you and he/she trust) 24 hours a day. We did not know that the clinic wouldn't be open on Friday (making it extended to a 4 day closed holiday weekend) when we had talked to Dr. #9 pre-surgery. We also were guilty of assuming that post-surgery, among the instructions there would be special notations of what to do and who to talk to in the event of concerns arising. These were multiple erroneous assumptions we made where Dr. #9 is concerned. Experiences since have shown in some instances some doctors do indeed provide this kind of instruction and contact information and actively encourage calling them if anything worries the patient or family involved. The Dr. #9 demonstrated the lack of all three critical care characteristics. His care was not continuous, not collaborative in any way and certainly not patient centered at all.*

I then decided to try to call the nearby Prostate Clinic on the chance that someone there would know how to reach Dr. #9 and a very helpful woman answered immediately. Once I explained our predicament and concerns, she said she would walk over to the Urology Centre and see if she could find someone there and call me back. She did call back a little later to say that she had found a woman there and together they had looked into Greg's file and found a copy of a letter to a Dr. #10, copied to Dr. #2 introducing Greg and describing his condition. This person said that she knew Dr #10 and that he was an excellent doctor and that she would call to the Tom Baker Centre herself to see if she could find someone that could help. About 30 minutes

later, a woman from Tom Baker Centre called back. She explained that she had Greg's information there and after he had his surgery (She didn't know that this had already occurred) and the pathology results were back, they would set up an appointment for Greg to come in and meet with them. There the treatment regime would be explained and timing set for it to begin. When I asked about the treatment starting before pathology, she said that this was never done and nothing would begin until the pathology results were back, likely in 7-10 days time from submission.

Now we were left in a position where things were not the same as what Greg had been told. It raised questions about Dr. #9 and left us feeling very frustrated and isolated.

Lesson #10 *Don't simply trust your doctor's judgment and recommendations unless you have very good reasons to. You may have a long enough history to feel confident in her/his judgment and actions and that may be ok. If this is not the case, then you must make sure that you take all the steps you need to in order to validate their plan or recommended action before you allow them to proceed. Had we known at the time that Number one: The Tom Baker Centre does not call the patient until the pathology results on the tissue are back and Number two: They never start chemotherapy until they can develop a specific treatment regime, with that knowledge we likely would not have trusted Dr. #9 with Greg's treatment and ultimately with his life.*

Checking on Greg's conditions with family and friends, we were advised to quickly get Greg back to the hospital emergency department at the hospital where he had undergone the surgery. There they would have all of Greg's records and should treat him with top priority as the timing was little more than 48 hours after his operation. Greg and I left right away and headed to the hospital an hour's drive away.

We arrived and walked into the Emergency department where it wasn't as busy as we expected. We were met by an orderly and were directed to an admission window where Greg provided the initial information. From there, Greg was directed to another window where additional information was given. While Greg was doing that, I had a call from my brother on my cell phone. He told me of a conversation with a doctor friend of his re-emphasizing the need to have Greg carefully checked for blood clots and that ultra sound was the most reliable way of doing that. I walked back and provided this information to Greg while he was at the second window. After he finished there he was directed to sit in the waiting area which we did until his name was called. There were a couple of other people doing the same thing but there was lots of space there and it seemed to not be that busy for the Friday of a holiday weekend.

When Greg's name was called, we got up to find out where to go next. I was stopped by a male orderly and told that I would not be allowed to accompany Greg. He would take Greg back to see the doctor and when it was ok, he would come and get me to join Greg. To this day, I don't understand how Greg's care (or any patients' for that matter) is improved or well served by denying a family member, in this case a father, from accompanying him to be examined.

Lesson #11. *Do not accept a policy that takes you as a family member away from a critically ill patient. Fight for the right to accompany and support them. I will regret to my dying day, not being with Greg to make sure everything was done to ensure he was safe from blood clots. It is much too dangerous to expect anyone in a compromised health condition to advocate strongly enough for themselves in this situation. There is no place for a policy that is institutionally self-serving as this one. It certainly is not in any way shape or form, in the patient's best interest.*

About 45 minutes later, a woman called for Greg's father and I was taken back to the space where Greg was laying on a bed, alone. He explained that Dr. #11 had done an examination and talked to him about his condition. The doctor had also ordered a blood test to check his liver function but didn't expect it to show any problem. It was the doctor's opinion that the swelling was because of the extra fluids Greg had been given around the surgery that hadn't had a chance to work out of his system.

In a few minutes, Doctor #11 stopped by and provided further explanation to both of us. He explained that he had looked at the charts that Greg had brought with him, and the information on Greg's electronic file.

Lesson #12. *Do not assume that the Alberta Health Care system uses leading edge recording and referencing procedures, policies or technology. We later learned that what currently is in place is undisciplined, and does not use common hardware or even software systems able to communicate within it for all patients or even all players in the system. We know from our experience in animal agriculture and the care, monitoring and treatment of individual animals there, the Alberta Health Care system is 20 years behind in providing for its patients what is and has been available for animal husbandry. In multiple instances, Greg's own due diligence in demanding hard copies of tests done along the way, and providing them to doctors down the line, meant that these doctors got more information and quicker, than from the electronic system.*

He explained that the mass's pressure on the IVC was impacting on his circulation and was causing the swelling. He said that he was confident that there was no blood clot as when there was, there would be an area of localized swelling and redness associated with that. Greg did not show those symptoms. He said that when the results from the blood test came back and if they did as anticipated, Greg would be free to go home. He also said that he would place a call to Dr. #10 to insure that Greg's situation was known by that doctor in order to make sure that Greg got started on his treatment at the Tom Baker Centre as early as possible. He went back to see other patients although it didn't seem that busy with other cubicles empty.

While we were left in the cubicle, I asked Greg about his impression of the doctor and if he was happy with the examination and tests. Greg said that it all seemed ok.

Lesson #13. *Do not assume that your family member patient, when on their own, is able to ensure they are taken care of as they should be. I was sensitive to Greg needing to make his own decisions and make his own judgment and did not press him on what he had talked to the doctor about while I was prevented from being with him. While there is no certainty that I would have been successful in changing the outcome of the investigation, I deeply regret not making that strongest possible effort to insure everything possible was done before we left the hospital.*

We heard Dr. #11 being paged to take a phone call and saw him pass by but not take the call. He was paged again and did not respond. About 5 minutes later, he came by the nurse's station and at that time, he was asked if he had taken the phone call. He explained he hadn't heard the page and went to an office space to see if the call was still on hold. Surprisingly, Dr. #10 was still waiting on the phone and a conversation occurred between them. We couldn't hear the conversation very well but did hear enough to know that Dr. #11 was explaining Greg's situation to the person on the other end of the phone.

Dr. #11 came back and told us that he had been able to talk to Dr. #10 about Greg and that he would be taken care of as soon as the pathology results were back. He also reported that the liver function test came back normal and that Greg was free to dress and go home. Greg asked for a hard copy of the results (as he had been doing at every instance on his journey through the medical system) and the doctor said that he would have someone make a copy for him. He then disappeared.

A nurse came and had some papers for Greg to sign and Greg asked her about the test results copy. She said she would take care of it and did that a few minutes later.

Dr. #11 came back and once again this time, Greg asked specifically if it was ok to go home, which he explained was an hour away from the hospital. He also said it would be possible to stay with family much closer in the city. Dr. #11 said there was no need as he had done all he needed to, to be confident that there were no clots and there was no risk in being at home. He said that Greg just needed to rest up and get ready for the start of treatment. He went on to joke about being prepared for a lady at the Tom Baker Centre who was sometimes hard to deal with and then said he was kidding and that the lady was his spouse and a great person. He went on to wish Greg the best.

Lesson #14. *Be sure all of your concerns have been absolutely met. Again we were faced with dealing with a brand new doctor, who we had not met before, and being faced with trusting his best judgment. (This best judgment was isolated from adequate earlier supporting information or instructions from earlier doctors in our view). It is human nature to try to be optimistic and positive in this situation and that resulted in Greg and I, accepting his view. If Greg had been more thoroughly examined, and/or if he had been kept in hospital under appropriate care for the risk of blood clots, we believe the outcome would be different and we would still have Greg with us today.*

We left the hospital relieved that all had checked out ok and headed home about 2 hours after we arrived at emergency. That evening we all were more relieved and Greg rested fairly well. His incision seemed to be healing and the pain levels in his abdomen were not as severe as before. He was able to walk around a bit more freely and as a result, made an effort to walk up and down the hall to help the healing process.

Day 407c-99a

During the night, Greg got up to go to the bathroom and just before 6:00 a.m. was heard to go to the bathroom again, then back to his bedroom across the hall and then return to the bathroom. He had gone back to his room for some medication and then to the bathroom to take it. My wife had heard this part but I did not. What I did hear was the horrible, sickening thud of Greg's head hitting the floor when he collapsed shortly thereafter. I jumped out of bed and ran the short distance to Greg, finding him face down on the floor. He seemed to be in a sort of seizure and I struggled to get him rolled partly over so I could check and make sure his airway wasn't obstructed as the result of the fall. I got a gag reflex when I checked and a couple of short gasps but he wasn't breathing and was starting to turn blue. One daughter called 911 and the other called Greg's older brother who lived with his own family, half a mile away. We were encouraged to begin CPR and I did that, continuing until I physically couldn't continue and my daughter switched me off. The ambulance arrived fairly quickly after that and examined Greg, dragged him out of the small space in the bathroom and into the kitchen where we all could see them trying to get Greg back to us. We provided them with the brief explanation of Greg's operation and having taken Greg to the Emergency department at that hospital less than 24 hours before. We also told them about the restriction on the IVC from the mass in the abdomen and gave them the folder of tests and history that Greg had been gathering. I asked one of the attendants about getting STARS and was told they were doing everything they could right now. They needed to get the ambulance closer to the house so some of us moved vehicles while they continued to work on Greg. They then got Greg on a stretcher and loaded him in the ambulance and headed for the local hospital. We all got dressed and quickly followed in our vehicle.

At the hospital, we were taken to a waiting room while Greg was taken into the emergency department. I walked down to see what was going on and to again, provide them information papers that Greg had kept. I talked to one of the ambulance attendants there and again asked about STARS. Then I was told that STARS only came if there was a heart beat and up to that point, there were not able to get one. They continued to work on Greg.

I went back to the room and told the family there, it didn't look very good. A nurse came and said that family could go down and see what was going on with Greg if we wanted to. One daughter came with me and we saw Greg getting worked on without any apparent success. We returned to the room and I told the family that I thought we had lost him. It was an extremely stressful time involving pain, sorrow and anger. In a little while, Dr. #12 who was the attending

doctor at the hospital, came and said that Greg had been declared dead. He started to try and explain what had happened while he was involved but we were too upset to hear this late explanation and asked to be left alone. After we had a little while to ourselves, we decided we wanted to go home. We told the Doctor #12 that no one was to touch Greg's body without my specific permission. We said that there had been too many terrible mistakes made by people concerning Greg and that we wanted to know what had really happened and we were not going to allow other people to make decisions without our involvement again.

Dr. #12 responded by saying that given Greg's age and his otherwise healthy condition, he would be recommending that an autopsy be done to find out the cause of death. I told him again that that nothing was to be done without specific approval from us.

We left the hospital and started to drive home. About halfway home, I got a call on my cell phone from an investigator at the Medical Examiner's office. After expressing her condolences, she explained that she had got a call from Dr. #12 recommending an autopsy and that we had some concerns about anything being done with Greg's body. She explained that the Medical Examiner office was not part of the health care system but was part of the Department of Justice. She assured me that there would be a full investigation all the way back to Greg's first examination months ago and all of that information would be made available to us. She explained that she is a mother of a son very close to Greg's age and that she was a former health care worker for more than 20 years. She said that she left that world for her current position because of her frustration with the health care system. She gave me her phone number and explained that with our permission, Greg's autopsy would be done likely early in the next week, after the Monday holiday. She also said that it may be a day or two later as well, because they do them in the order of priority and holiday weekends tended to be busier and involved some deaths that needed prompt investigation.

When we got home, every one of us were hit very hard by the loss of Greg. We each felt frustrated with a system that had let Greg down time after time. We had expected that when it became obvious to the doctors involved that they had not performed as they should, that Greg would have been better taken care of from that point on. Obviously this had not happened. Above all, we each felt very sad in thinking about what Greg had been going through on his own. He had made the choice to not have us worry but that also meant that the ever increasing concerns and his weakening physical condition must have made it extremely difficult for him. Every one of us thought about the extra support we now wished we each could have given him and each of our own opportunities to do our own intervention on his behalf in the totally inadequate health care system. The heavy burden of these thoughts will now be with each of us for the rest of our days.

Lesson #15. *If you have concerns about your own health, while you may also feel that it would be best for everyone to deal with it yourself and not worry others, choose a couple of people, close friends and/or family, to help and support you through it. It is too big a task for anyone to*

take on alone and those closest to you may well worry but would much rather be able to help than not.

Later that day, my brother and sister-in-law retrieved Greg's package of information that we had left behind at the local hospital.

Our many extended family members provided some welcome support and remained close at hand and involved as needed all of the coming days.

The next few days became very heavy for us and during this time, a call came to our home number from Dr. #11 expressing his sincere condolences and saying that he had made a terrible mistake and that he wanted us to know how sorry he was personally.

I also took a call from Doctor #13 who indentified himself as the Dr. who would be heading up the investigation of what had happened at the hospital where the surgery had been done and its Emergency Department.

I took a call from a person who identified himself as the provincial safety person and who said that he would ensure that a full investigation would be undertaken.

I took a call from another person who identified himself as the person in charge of patient safety for the City of Calgary and who said he would ensure a full investigation would be done.

Day 106a-414c We buried Greg

Greg's funeral was held in our local community centre. More than 600 people attended on relatively short notice, from all the different areas where Greg's life had touched theirs. When the opportunity was given for those that wanted to share their memories of Greg, heart wrenching descriptions were given of Greg's sensitivity, his selflessness, his support and his commitment to family, friends and community. Some also spoke of his tenacity and commitment in all things he did from his own physical fitness to his always positive outlook and his vision of things possible in the future. All of this strengthened our resolve to try to follow Greg's example and work toward something positive coming out of this terrible tragedy.

Early questions that stood out for us:

How could what is represented and protected as "the best health care system in the world", so badly have left Greg waiting without the care he needed to survive? How could it take so long, with all of the technology and expertise and research being done the various forms of cancer, to diagnose and act on this most rapidly growing cancer in Greg's body? How could so many different doctors, at each of the different opportunities, have let this happen? Where was the collaboration, the accountability for Greg's care as a patient? The biggest concerns were around the last days when the operation was done and there was no opportunity or any way to contact the surgeon. He was the person most closely connected to the risks and remedies for Greg as

the swelling and discomfort increased. How is it acceptable to have the total lack of special instructions and information noted on Greg's file in time to be of any value in today's computerized and connected world? How could the emergency doctor decide it was not necessary to take *all* of the available steps to insure that there were no blood clots in Greg's system when clearly the combination of restricted blood flow and the recent surgery should have been recognized as major contributors to that risk.

We all resolved to work toward trying to minimize the chance of this happening to anyone else in the future.