# THEIR CHOICE, OUR RESPONSIBILITY

TRACY C. COYLE

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## PREFACE

Do you consider yourself a person of character, integrity and principle? Do you believe we are born, created or endowed with the inalienable rights of life and liberty? Do you believe we have the right to make our own decision about our life and when to end it? I am not talking about suicide, or even assisted suicide. I am talking about that moment, that instant when the decision is to live, or to let go.

This is not a discussion about right to life, or the dollars and sense of medical intervention. This is about a choice, a decision that sometimes must be made at the time when thoughtful consideration is a luxury you don't have.

### THEN

You are sitting in a waiting room outside of an operating room and the love of your life is inside having surgery. After an interminable wait the doctor comes out and tells you everything went great and your love will be out in a few minutes and you can see her then. And he turns and walks back into the operating room and you let out a sigh of relief and a deep breath you didn't realize you were holding.

And three minutes later he comes racing out and says,

"You have to let us intubate her right now or she will die!"

You have until you turn this page to give him an answer...

### NOW

The only way you are going to give the right answer then is to spend some time now, right now, finding out what it is. You see, it is not YOUR answer that you must give.

There are lots of books and essays and columns and articles that will give you all the reasons why your answer should be one way or the other. The correct answer is the one your loved one has decided he or she wants you to give. At that moment, your answer can and only should be, their answer.

Start with how we got to that point that day.

We left on July 19th and drove down to my parents in Chicago. We left such a mess in Madison. Victoria had a bladder infection and we had to stop often and her mobility, an issue for the past couple years, started to haunt us. CJ and I had to empty the moving trailer and completely repack it at my parent's house to get a better weight distribution. We left in the afternoon of the 20th but only averaged 90 minutes of driving before Victoria had to have a restroom break. That went on for the next 4 days as we traveled, every 90 minutes or so a bathroom break and every other stop we got gas. Fortunately, the AC worked as it was close to 100 degrees most days.

We arrived on Monday very early (July 26th) and slept until mid-day. We started looking for a place to live that afternoon. On Tuesday Victoria did not feel well and on Wednesday she didn't want to go out and slept most of the day. [Now I know she had a stroke.] And by Sunday, August 1, she was in the hospital.

Victoria was diabetic and had high blood pressure. For almost thirty years she took medicine, saw doctors and cheated on both. That is not an indictment, it is life with chronic illness. The only way to keep ahead of the problems is to keep doing what you are supposed to do even when you feel fine and everything seems ok. It is one of the reasons almost every household in America has a medicine bottle with two or three antibiotics left in it.

Victoria's health had been slowly declining for several years and she was reaching a point where the complications were piling onto each other. It was not a matter of what next but of, what now.

Victoria was an attorney and in early 2005 she was interviewed on local TV concerning the Terri Schiavo case. Victoria spoke about the importance of living wills and health care powers of attorney but the most important thing she said was for people to make sure their friends and family knew, preferably in writing, what they wanted in the event of something like Terri Schiavo's situation.

Terri Schiavo had a heart attack and suffered severe brain damage as a result of lack of oxygen. For years she was maintained on life support and when her husband sought to end it, Terri's family fought him. The fight went to the Supreme Court and eventually even Congress and the President were dragged into it. Never had there been a media circus like it around something so devastating to the people actually involved.

She and I talked about it often in the context of her clients, but also for each other. Both of us knew people that had been kept alive on machines for extended periods and neither of us wanted that for ourselves.

For Victoria, the stroke was the final straw that killed her kidneys. She would require dialysis for the rest of her life three hours a day, three times a week. Victoria would spend most of the next four months in the hospital.

## THE TALK

Everyone hates talking about his or her own death. We can barely talk about the death of others even far removed from our daily lives. Yet we all need to understand that we all will die one day.

I know that comes as a shock to some people, especially the younger adults, but not just old sick people die. Sometimes it is young sick people and even middle age healthy people.

Jim Fixx started running in 1967 at age 35. He weighed 240 pounds (110 kg) and smoked two packs of cigarettes per day. Ten years later, when his book, Complete Book of Running (which spent 11 weeks at No. 1 on the best-seller list) was published, he was 60 pounds (27 kg) lighter and smoke-free. In his books and on television talk shows, he extolled the benefits of physical exercise and how it considerably increased the average life expectancy.<sup>1</sup>

Fixx died at 52.

Traditional marriage vows speak of in sickness and health and till death do us part. For many people the healthy and richer and poor parts are much more relevant and talked about.

For Victoria and me, there was no traditional ceremony, but we made vows to each other just the same. Victoria was just 40 and already dealing with the diabetes and hypertension and I knew then a long and healthy retirement was not in our future. I figured it would be hard but I knew that before we said vows.

Your spouse will die. No one gets out of here alive. For all the planning you both will do for your future, spend one day talking about the worst day in your future lives.

Throughout the last year, there were times when Victoria was very depressed. She did not like dialysis, she did not like how she had to live her life (not able to do much for herself she hated the commode that sat next to her chair in the living

<sup>&</sup>lt;sup>1</sup> http://en.wikipedia.org/wiki/Jim\_Fixx

room and she hated feeling sick so often). She often said she did not want to keep living her life like this. And it was hard for her and CJ and me. Her health was a daily issue and while our expenses were lower after the move, my business had been slower that year than the year before also. It was a struggle. Which made Victoria feel worse because she was not contributing but also costing us. We had good days and bad, but she always came back to "this is not how I want to live my life".

Sit down with each other, talk and then put it down in writing. It does not have to be a formal statement - though it would be better if it were - but make sure it is written, not some half finished letter on a computer somewhere. Then sit down with your families, together if possible.

This is not the time to get your family to agree with your decisions. This is the time to tell them what your decisions are. Tell them if and when the time comes you don't want them wondering what is the right answer. You want them to know that you have thought about it, discussed it with your spouse and made a decision that you want them to respect. The last thing you want is family fighting over your care in a court room, or worse, in front of millions of people on TV.

## **TURNING POINT**

While Victoria was in the hospital that Fall after the stroke, I began writing a book on rights called An Assertion of Right. My primary argument was that we each are born with unalienable rights that can only be infringed upon if we let them be. That fundamentally, every act we take is a matter of free will and that the exercise of that free will was an assertion of right.

People have a right to their lives. We have the right to live them as we choose and to seek happiness, whatever that means to us. There is no limit to that right except the boundaries of others right to live their life freely.

It is also our right to choose to stop. It is our right in the face of the daily struggle to say enough.

#### Friday, Sept 23rd

Victoria was not feeling well so she did not want to go to dialysis. We didn't go.

Here it is. In retrospect, this was the point, the decision that set us on a course that would bring us to the end. Victoria would eventually face a decision that I either had to support and agree to or I had to violate my vows to her and the principles that I have come to regard as fundamental to who I am. That Friday morning was like many other mornings. Victoria was not feeling great and she didn't want all the fussing with getting in and out of our truck, driving out to dialysis and dealing with the cold clinic space. She just wanted to stay comfortable in her chair and watch her shows on TV.

This was always her choice. I sometimes made an issue out of it, especially if she 'just' didn't want to go. Other times I made no issue and accepted it without comment. I don't recall my making any issue on that morning.

#### Sunday, September 25th

Quiet weekend, Badgers won on Saturday. Victoria developed a little cough...more like a clearing of the throat, but as the day went on, it got worse. One of her little vices were cough drops...she liked to suck on them. The doctor and pharmacist didn't see a problem as they had less sugar than hard candy. I asked if she was still using them, she said yes. By evening it was a full cough. By 11pm she said she was having trouble breathing. We tried some things (like inhaler for her asthma) but at about Midnight we called for the paramedics.

#### Monday, Sept 26th

There was fluid in her lungs, not a lot, but she had a temp and doctors were concerned it might be pneumonia. But the other thing concerned them A LOT. Her potassium was 7.9 This is a dangerous, even lethal level. Potassium helps the body's electrical system/muscles operate. Too little, a serious problem also that she had last October, is bad, too much and the heart and other muscles can just stop without warning. They gave her meds to bring it down fast (which she threw up) and admitted her. Every doctor and nurse for the next two days yelled at both of us for her not doing dialysis on Friday. They did dialysis on Monday and her potassium got back down into normal range.

She didn't dodge the bullet. The high potassium would do its damage.

#### Tuesday, Sept 27

After another dialysis treatment and no sign of pneumonia, Victoria wanted to go home, I wanted to take her. Doctors practically begged for her to stay one more day for another dialysis treatment. I agreed; Victoria resigned herself.

#### Wednesday, Sept 28

They wanted to discharge her and have her go to the clinic for dialysis. We said no, do it in the hospital, that's what they wanted. They set dialysis for late in the evening, we said no; Victoria got discharged and we went home.

#### Friday, Sept 30

At dialysis, Victoria's heart rate was around 50. This is significantly lower than usual (normally around 100). I noted it. The rest was uneventful. Badgers won on Saturday - she watched the whole game without falling asleep.

#### Monday, Oct 3

Over the weekend, her heart rate stayed around 50 and again in dialysis it stayed there. Blood pressure did its usual up/down/up/crash/up during dialysis. The crashes we tried to limit and generally they were not bad (a reading under 100/60).

#### Wednesday, Oct 5

Dialysis. Heart rate now occasionally dipping into the 40s, 48,49. I am concerned. After two years close to a 100 - and being worried about the stress that was causing, the reverse was happening and I liked it even less. Dialysis techs and nurses are also now concerned. She is scheduled to see her regular/primary doctor on Thursday, we'd bring it up with him.

#### Thursday, Oct 6

Appointment with primary doctor, he listens to everything we tell him. He listens to Victoria's chest. He is concerned that she might have bacterial endocarditis. It is an infection of the heart caused by dental surgery. Yep. Victoria had two teeth pulled in July and it might have gotten into her bloodstream. The doctor wanted Victoria to have an echocardiogram done to check and he called a local cardiac clinic to get us in right away. We left to that appointment.

When we got there about 10 minutes later, we were told we'd have to wait about 2.5 hours. Victoria, hating every second she was in her wheelchair said no and said we were to go home. Which after a little argument from me, we did. I didn't push too much, I hoped at home she'd reconsider and I could get her in on Tuesday. Her heart rate was now consistently in the upper 40s, 46-48.

#### Friday, Oct 7

Victoria woke up and said she wanted the echo. I called and the earliest they could get her in was Tuesday the 11th. She said no because we had a follow-up with the podiatrist on Thursday and she hated Monday dialysis, Tuesday doctor appt, Wednesday dialysis, Thursday doctor appt, Friday dialysis. So the echo was scheduled for Oct 18th. Long delay. We went to dialysis and her Nephrologist was there for his regular weekly visit. He listened to heart and said, after dialysis, he wanted her to go to the ER and have an EKG. The echo would be good, but he wanted to know what was going on in the heart. We finished dialysis and CJ was just getting out of school. So we picked her up and took her home, then went to the Urgent Care.

I thought urgent care instead of the ER because if it were just the bacterial infection, they could give her the antibiotics without all the push for doing it in-patient (getting admitted into the hospital, which of course she hates). Urgent care put her on the EKG and called for paramedics' 15 seconds later. They took her next door to the hospital about 15 minutes later.

Lots of discussions, lots of sitting and waiting. Victoria wanted to go home. I said we needed to wait until they decided about the pacemaker. The doctor at Urgent Care told me what they saw that concerned them: It is called a third degree block. The top part of the heart was no longer talking to the bottom part. The two parts were running independently. The natural beat of the lower part of the heart is around 40bpm; this is why the heart was slowing down. The natural rhythm of the heart was 'disassociating'; the halves were getting slowly out of sync. We are talking about milliseconds here. But at this point, it had apparently been over a week that the block was there. THAT was a problem. The correction was simple, a pacemaker. No open heart surgery, no general anesthesia. Victoria was very scared of it all. I said, if there is an easy problem with the heart, this is it. Heart rate 45-47.

There will be few things that will tell you that ultimate decisions are coming at you. Sometimes they will explode without any warning, other times circumstances will suggest dire possibilities but when everyone is aware of them, it seems less likely.

Victoria was in the hospital for the eighth time in fourteen months but there was no expectation of a great moment. Victoria was as anxious as anyone in her position would be. But she had grown to hate being in the hospital and I was trying to determine how much of her anxiety was based on that and how much on the upcoming procedure. Her condition was serious but we'd been here before.

But our time was up.

## HER CHOICE, MY RESPONSIBILITY

#### Saturday, Oct 8

I got to the hospital early (8am) after leaving late (2am). Victoria said she didn't expect me until later. I said I was up and no reason not to come right away. We sat and talked about normal stuff. Couple jokes and smiles. Some seriousness when her anxiety would increase or she got quiet. Cardiologist came by and said that the pacemaker was necessary and that they were getting a team into the hospital - they didn't want to wait. The surgery would be much sooner than later. About an hour later they moved her to ICU for prep and closer monitoring. Heart rate was consistently 42-44.

ICU nurse Ed and Lisa. Ed was the primary. Nice guy. We continued much the same was as earlier. Banter, talking, holding each others hand. It was a good day. About Noon the surgeon that was going to do the surgery came in. Okay guy. Nothing extra-ordinary. Basically gave us a rundown of what would happen. 1 1/2 to 2 hours, no complications expected except the catheter for dialysis is close to where the pacemaker will go...he didn't expect any problems. Off he went. More general talk. Ed said we made quite a pair. I said: "We are a royal pain in the ass. She's the royal, and I'm the pain in the ass." Victoria said, "Right, Queen Victoria."

She got a little quiet and again said she was scared. We talked for a minute and Ed interjected that the surgery would be no problem but that they had everything they needed if something went wrong. I said, "Wait a second...Victoria is a DNR."

He paused and looked at Victoria who said 'With qualifications'. That was not how they had her in the computer...they had her as full code. "Absolutely not." Victoria said. He said he had to change it in the computer, but that he needed Victoria to talk to the doctor about it. He got the doctor on the phone and Victoria reiterated no machines, no intubation. That is how I understood her wishes and she clearly stated them to the doctor. The conversation ended and the changes were made in the computer. About 20 minutes later, they took us to the OR (just across the hall from the ICU. The waiting area is at the front of a long hall (50') that ends at the OR. After giving her a kiss and saying I'd be waiting, she said she wanted me to be the first person she saw after. I said I would and she was wheeled down the hall. I took a nap in the waiting room shortly after that.

Sometime later...don't know how long, the doctor and Lisa came out to say the surgery went well, pretty much as expected. A slight issue with one lead being near the dialysis cat but he didn't think it would be a problem long term. That she was starting to come off the local and she was anxious and upset. I said we had not had a chance to give her Xanax before surgery so he said he'd give her something to help and that they would be done in 15-20 minutes and she'd be brought out to ICU then. He and Lisa walked back down the hall.

Not 30 seconds later, over the hospital PA, "Code Blue, OR Colorado. Code Blue, OR Colorado. All teams, Code Blue" Within a minute people started coming in at a run and down the hall to the OR. About two minutes later Lisa came out of the OR at a run, with the cardiologist 10 ft behind running. As she came up I asked if it was Victoria and she just nodded. The doctor arrived and said:

"We need to intubate her now or she dies."

There it was. The moment. Everything else forgotten, all the documents and discussions, all the effort to make sure everyone knew exactly what Victoria wanted in that moment, gone in that moment.

The doctors and hospital, in that moment, didn't care that Victoria had just two hours earlier clearly stated what her choice was when faced with this decision. Victoria could no longer state or enforce her decision. The doctors and the hospital would not consider the papers, the legal documents, the forms and procedures designed to inform them for just this moment. They wanted a person, anyone, to actually decide.

Was it CYA? Was it a belief that all the quiet talk with nothing on the line was meaningless? Or was it the hope that when faced with the choice, people would choose to fight?

Survival is a strong instinct. Humans will fight through hell to survive and doctors seeing **the** fight all the time want people **to** fight. But even in those moments, free will and choice must be given their rightful place.

I don't want to make this decision. Please no I don't want to make it.

"I can't. I can't do that to her. No." "You've got to understand we have to." "No." "I'll go put her on a bag and give you a minute or two, but we need to..." as he ran back down the hall, Lisa right behind.

Individual liberty, the freedom to decide how we live our life does not end when the choice becomes when to end the fight. Victoria, over many discussions and years of little comments had made clear, to me, to our daughter, to friends and family, in word, deed and writing that her choice in that moment was no.

If you believe you have the right to make decisions for yourself, and that others have the right to make decisions for themselves, then IN THAT MOMENT respect that choice. A minute later (could have been 2 or 3) another nurse came out and said that she was not stabilizing and that I could come in if I wanted. I said yes and walked down with her to the OR.

There were like 20 people in the room and about 5 or so around her head working. The cardiologist came back to me and said he didn't know what went wrong, everything seemed to be ok, but as soon as he got back she stopped breathing. Respiratory was working with a mask and bag and trying to get air into her lungs, which unexpectedly were full of fluid. They had not been at the beginning of surgery as they had a chest x-ray from right as they started and they were clean. Dialysis had been called and were on their way to try and get some fluid off. She had started breathing again, but she was struggling. The heart was beating (duh...it had a mechanical stimulator planted in her chest to make SURE it was beating). The cardiologist again said she needed to be on the ventilator and again, I said no. Clearly enough that everyone heard. The look they exchanged was clear, this wasn't going to work. They continued as I moved into a little room with a large door and window facing into the OR, got on the phone and called CJ. I told her to get a ride immediately to the hospital, come to the ER and I'd get someone to meet her and bring her to the OR.

I went back into the OR and they all stopped and looked at me. The cardiologist said, "we have to put her on the machine, nothing else is going to work".

I said no.

They went back to work.

This was not a philosophical debate. This was not one ideology competing with another. This was Victoria's decision to make, and she had made it. Now I had to either support and defend it for her, or violate my own belief in a moment of grief and desire to prevent losing her.

I was not matter of fact. I was crying. I was beyond upset. I was offered tissue, water, consolation I took none of it. I repeated several...a lot of times, that I could not do it to her, that was not what she wanted, that I couldn't. For most of what follows, I spent crying at some level....

She was breathing but they were supporting her. They were trying to rouse her. I came to her side and while they continued their efforts while I tried to talk to her. Her sats (oxygen in the blood) were fluctuating widely. Blood pressure was ok but they couldn't get enough oxygen in. They wanted to move her back to ICU and as they were getting her moved I said, "Open your eyes and look at me you bitch", to which she opened one eye and moved her head towards me. A little 'yea' from a couple people and I said, "We are going back to the room."

We got back to her room in the ICU and they put a C-PAP mask on her face to force air into her lungs. She was more aware and trying to talk. I tried to understand, but 'hurt' came through. The mask was on tight and she tried to take it off twice, I told her it was 'not a machine', it was just a mask and she had to leave it on. She said no and I ignored it. She asked why her arm wouldn't move and I said it was tied down so she didn't lift it up and disturb the pacemaker, she said no it hurt and I tried to move her a little off that side to give it a little room. At this point CJ had arrived and I told Victoria I was going to bring her in, she said no, but I ignored that too. I went out to meet her and talk to her. We talked and I said it was bad and that a lot of things were going on but that I wanted her in there. That she could stay out if she wanted, she said no and we went back in. Here I am making the case for someone to make their own decisions and yet ignoring her decisions. As far as CJ being in the room, that was not just Victoria's decision to make. CJ was almost 17 and it was going to be the last time we were going to be able to see and talk to her, I wanted CJ to have that chance. As for the mask, Victoria's wishes were that everything that could be done short of machines taking over was to be done. The mask was within that framework.

Am I justifying my decisions now? No, I was making decisions then on the basis of calmer heads making the choices when the moment was not threatening to over-ride everything else. When Victoria realized it was not a machine, she did not fight it any longer.

By this time the 'head respiratory critical care doctor dude' came in and wanted to know 'her history', why she was at the hospital.

Yea, I got time for this, I need to tell you what's going on? What the hell you got these 20 OTHER PEOPLE doing?!?

I started the story with low heart rate and our coming there on Friday. The cardiologist chimed in with 'we don't know what caused her to crash and that surgery had gone well....'

Yep, by this time I was getting tired of said cardiologist with his protestations the surgery went well but the patient DIED shit....

I got back next to Victoria who had settled down some but was trying to say something. She said 'hurts' and tried to point to her chest (?) or shoulder and said where was she, I said in the hospital room and that they were trying to get oxygen into her; she said hurt again and then she threw up. I got my arm under her and lifted her to a sitting position with my right arm while ripping the C-PAP mask off with my left. She threw up all over the pacemaker wound dressings and arm with IV connections. It was green and smelly and it had a couple peas in it. Peas? She hates peas. How could she have peas? I let her lean back and the 'head dude' said he wanted to talk to me outside the room. I had CJ come stand next to Victoria and I walked out.

He said the throwing up was confirmation of what he thought happened:

Victoria spent the entire surgery flat on her back. As they were finishing, she threw up but because of her position, instead of out, it went into her lungs. The peas said the stomach was full of dinner from Thursday and her Friday lunch. (Soup) It was the most acidic, vile, rotting crap you could imagine, poured right down into her lungs. Battery acid or bleach would have done less damage. The lungs were full not of fluid but bile and stomach crap and it would have been destroying tissue from the second it got in there. She needed the ventilator now but he couldn't say that even that would delay things more than a day or so. And even if they could get her stabilized, it would be months and months of hard recovery, all the time on the ventilator. Otherwise, all they could do would be to make her comfortable.

There it was. The choice to use every medical trick in the book to fight what was almost certainly a losing battle. This was the situation that we talked about, the circumstances neither one of us wanted to face for ourselves or for each other. A period of existence where the choices were not in our hands but in the hands of doctors and machines.

My greed could change this. Five times I had been asked to allow them to put her on the machine. Five times in the middle of grief and agony, of them ignoring every written and spoken word of Victoria specifically made for this moment. Five times that I and millions of others in my position have had to say...

I said no. Make her comfortable. I went back into the room. I talked to her and she said 'not my life', which I understood to mean this was not the life she wanted to live. I said, "It was

ok. No more fighting. No more fighting. It's ok. We're done. You're done, you don't have to fight anymore. No more pain. Just go to sleep and it'll be ok". She said, "Ok, sleep," and her face relaxed and she leaned back and closed her eyes.

They put a regular air mask on and everyone else left the room. CJ and I stood with her and I told her she was going to leave soon. Her breathing got slower and harder. After about 5-10 (?) minutes, Victoria stopped breathing for about a minute and a half...her lips went white and I opened an eye and it didn't move or change. She started breathing again, very labored, for about 2 minutes, then stopped again. I said to CJ she was gone and we kissed her and went and sat at the foot of the bed in a large chair. Ed continued to hold her arm and said she still had a pulse. She didn't breathe but once or twice again and after about 10 minutes, he asked the dialysis tech to check for a pulse. There was none. It was about 6:40pm.

## CHOICE AND RESPONSIBILITY

Not so much then, but later...how could it have been so late. It seemed like less than an hour passed from the Code Blue to the end...

They let us stay. We left after about 10 minutes after I asked if CJ wanted to stay or go somewhere to just talk or be with each other. She said, the beach? We left and made it to the beach, Torrey Pines - a favorite of Victoria's that she and I had been to just a month or so ago to watch the sunset- to watch the sunset. We stayed and talked a little for about 30 minutes then went back to the hospital so I could collect Victoria's things and say goodbye.

One of the OR nurses (who kept trying to give me tissue or water) caught me in the hall - it was clear SHE'D been crying. She said they wanted to say thank you to me for standing up for Victoria. For respecting her wishes when everyone and everything demanded otherwise. I said, "Sometimes doing the right thing, hurts a lot...thank you" and I left.

We went home, CJ ate a little something, and then we both went to bed.

It is our choice to make the decision for ourselves when we will say, enough. For many people there will be no dragged out opportunity to weigh the details or consider the choices. Death will come sudden and the choice will be beyond our control.

But I have watched (somewhat indirectly with my sister's in-laws and my Aunt) as the choices of people have been ignored because in the end, whether it took just once, or five demands of the doctors to DO SOMETHING, family abdicated their responsibility to make sure the choices of their loved ones were respected. How often has the situation played out when a loved one said, 'I can't live without her' or "I can't just let him die'.

Those are the wrong answers to give. They are not our loved one's answers, they are OUR answers. If we are going to honor our loved ones, if we are going to give them the respect and trust we vowed, then we must, MUST give their answer.

God I miss her. I have said "it was the wrong decision for CJ, it was the wrong decision for me, but it was the right decision for Victoria" and in the end, I told her it would always be her choice.

I don't second guess. Victoria made thousands, millions of decisions over many years that led up to that point on Saturday. I only made sure that the last one was listened to...by everyone...including me.

She is the love of my life. The mother to our daughter. I love her. And, I know she loved me and CJ. The pain and suffering of the last year are done and she doesn't have to face more. That is my comfort.

One day, one hour at a time....

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