Ken

LVAD

Hi. I have been putting this off for about six weeks now, probably due to laziness, but I don't really know why. Since my entering the LVAD program I seem to be quite the procrastinator. I am now exhibiting some signs of slight internal bleeding so I would like to get this done before I might have to go to the hospital again. I'm not sure I am doing this in a way that would be advantageous to anyone, but perhaps I will learn something. When I was younger I could write fairly well, but it WILL be interesting to see how this turns out.

My name is Ken. (I am imagining a group of people waving and saying, "Hi Ken".) I am a white male, 70 years old. In my early childhood I grew up in Brooklyn, New York. Growing up there in the 1940s and 1950s was wonderful. We were very poor but everyone else in our neighborhood was also. I had no idea that my life was anything exceptional. But someone once wrote a book about growing up there and it was called "We Had Everything But Money." How true. Anyway, as I grew up I always made friends with smokers and drinkers. That became my lifestyle for many decades and it put me where I am today. Tethered with a LVAD, with lung, kidney, and liver damage. It is that reason why I am not eligible for a transplant.

I never said, "Why me?" because I know the answer to that. There have been guilty feelings because I thought I was fairly healthy when I got married in 2000. I have had an absolutely wonderful life and my wife is what I always say, the icing on the cake. I have traveled quite a bit and we were both looking forward to many trips. We did make a few before I got sick but the grand trips I had in my head are now almost impossible.

(This is more intense than I thought it would be. I was expecting to sit here and knock it off in an hour or so. This is how far I got in about an hour and I stopped to take a break. It is now the next day.)

I think that just about anyone reading this is aware of the physical downsides to this situation, but I will briefly mention them just to keep my mind on track for now. I am constantly connected to electricity, either by tether or by batteries. When I go anywhere I have to tote a backup set of batteries and a backup controller. These are not D cells. I must be taped up when I want to take a shower because I cannot afford to let my bandage get wet. There are bacteria even in 'pure' water and an infection would possibly be fatal. Or at least another trip to the hospital for a cleansing and possible another operation. I cannot go swimming and I don't want to chance boating.

For me this is difficult because my greatest joy is spending time at the beach or boating. I am tired a lot and I cannot accomplish things like cleaning the garage or having a garden. It has been said that I should be able to do these things, but it is really very difficult. Before the pump, I would spend eight hours or so cleaning the garage or doing the lawn and flowers. Now, when I spend an hour being active, I become very tired, and usually only accomplish about 15 minutes' worth of activity of pre-pump work. I used to do a lot of painting but I can hardly lift my hands over my head for more than a minute. When I go shopping I use the cart as a walker and stop frequently to rest my legs. This is not always the case. Usually after some bleeding and my hemoglobin is low.

We lived in the Traverse City area and we really loved it. Plenty of water and wildlife. A photographer's dream. My cardiologist told me that I was getting worse and I would need the pump. We moved to southern Michigan and I checked into the hospital in October 2013.

I already had bleeding problems, lung damage, kidney damage, and liver damage. It took a month for one of the doctors to decide to do the operation. I thank him in my mind with God almost daily, as I do my wife. She is the most wonderful thing that has happened to me and I have had a wonderful life. She is the icing on a seven-layer cake. I digress. After the operation my bleeding problems continued for several months. I was discharged on Christmas Eve and had to return and be re-admitted the next day. Same thing happened on New Year's Eve. Except I stayed home for 3 days before I had to go back. It took a few more weeks and many tests before they did find the source of the bleeding and corrected it. I was very despondent because I did not want to leave my wife alone. We had just moved and the finances were not as good as they are now. I still worry about her finances if I leave. My pension will be lost and she will take my social security but lose hers.

I was home for a year without bleeding of consequence and January of 2015 I had to return to the hospital. I was expecting to go back for treatment every few months but I was lucky. A year off and I forgot about the bleeding. Just kept taking my meds and doing some exercise. My bleeding was corrected in January. I was sent home and in March there was more bleeding. Back for a week and once again I was sent home.

That brings me up to today. Mentally, I have become quite listless. I seem to be content with spending my time on line. I start many projects, but finish very few. I am not unhappy, but my wife feels that I am depressed. I don't think so. I thank God just about every day for being alive and I thank Linda every day for tolerating being my caregiver. I thank U of M for their excellent medical care. I seem to be obsessed with death but not necessarily mine. There were periods in the past two years where I became very irritable. Perhaps it was some meds, perhaps it was my circumstances, or perhaps it is frequent in people in my health situation. I don't know, but I do know that I am working very hard to become the person I was before now. I am a bit more pleasant now and I feel good for that.

Well I hope I covered everything of any importance. I hope this is legible. I hope that someone can glean something from this. I have tried to be honest. I think the tone of this statement is more or less negative, but I am adjusting and I am definitely glad for the added time that I have here with my wonderful family. As time goes on I am slowly selling some possessions that I know my wife wouldn't know what to do with after I am gone. And I am going through thousands of pictures and sending negatives and prints of people from my past. They are no good to my wife and this way she won't have to worry what to do with them.

In any event, I am not sad about the way things turned out up to now. I feel bad because I don't want to see my wife alone. I am slowly getting things in order.