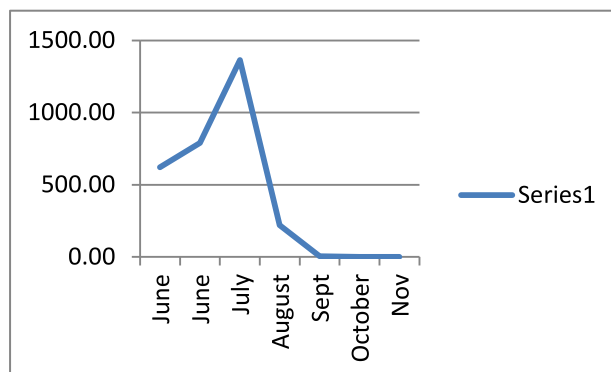
Duncan's Health – June 2015 to March 2016

It started in June when Duncan's PCP Tom discovered that Duncan's PSA was in the 600s. We've heard that insurance companies discourage doctors from monitoring PSAs in patients over 75 and we are forever grateful to Tom for not paying attention to them. Duncan's PSA jumped from the 600s to the 700s and then to the 1400s. A CAT scan showed no cancer in the prostate, but a bone scan showed cancer in his ribs and his spine. At that point Duncan was put on Casodex, a preliminary treatment before starting the hormonal treatment which is standard for this condition. His PSA dropped to the 200s and when he started the hormone Lupron it dropped to 6 and now, some 9 months later, it is under 1.



Lupron is the standard treatment, and there have been ongoing studies to find out if combining other drugs with the Lupron might be more effective. The oncologist at our local hospital had been involved in a Dana Farber study which found that a combination of chemo and Lupron provided good results. She strongly recommended that we try this combination. We felt a bit like being in a classroom as she drew circles to show us how the cancer often develops, explaining that it thrives on testosterone, that the Lupron would kill off most of that, and that the chemo attacks the testosterone cells that the Lupron might not handle. "The study shows that patients taking the Lupron/chemo combination tend to have a 10 month longer life expectancy than those on Lupron alone." She is a young woman; I asked her if she knew what per cent 10 months was of Duncan's age of 85 years.

We visited several doctors before making up our minds about the treatment. It really was and is up to us to make the choice and we wanted as much advice as we could get. Our children, and in particular Duncan's daughters Eroica and Rowena, have been valuable allies, suggesting alternatives, doing research, and being the other pair of ears at visits to doctors. We saw a urologist who is Duncan's son-in-law's doctor and we plan to go on seeing him – his perspective is human and he told us things that we have found helpful throughout. Perhaps it is that he doesn't have a dog in the race – he's not telling us what we should do, he's just "chatting" with us, answering questions, and clearly drawing on his wide knowledge of the field. One point he made was that, as Duncan's PSA had dropped significantly by the first time we saw him (to the 200's), it was not impossible that the PSA could drop to the single digits or below and that the cancer at that time would be pretty much in limbo. As the PSA has continued to drop we were perhaps even more comforted by that than we might have been.

We saw the physician at Beth Israel who had done a TURP operation at the time of Duncan's ecoli episode some 3 years ago, and we went also to visit an oncologist at Dana Farber for a second opinion on the Lupron/chemo treatment. Mark at Dana Farber is a tall good looking man who has wonderfully large feet. Duncan loves to write his doggerel verse for him. (Add a limerick here) On our first visit Mark told us that there was a trial going on which added not chemo but Enzalutamide to the standard hormone. Enzo, like the chemo, would go after the testosterone that the Lupron couldn't catch. The

trial would be divided 50 – 50 between patients taking Enzo and patients taking Casodex. The participants would be randomly assigned to one or the other, and would be told which side they were on. He invited us to consider joining the trial and informed us that the Enzo, which has been approved by the FDA for some other uses, costs about $8,000 per month. If Duncan agreed to join up the drugs would, of course, be free, and we would come in to Dana Farber every three months for an appointment with the team. We would also be in touch with the team regarding any medical issues or questions we had. In addition to adding to the exhaustion suffered by people taking Lupron, the only significant side effect of the Enzo was the possibility of epileptic seizures, especially in people with a family history of epilepsy.

We were happy to sign on. Clearly the Casodex had been a good intervention early on, so it seemed we'd be ahead of the game whichever side of the trial we ended up on. And of course, having the chance to see a team at Dana Farber regularly and having them in touch with how things were going – hey, we don't live in an area with the best medical facilities in the world for nothing! Duncan's schedule included an Exgeva infusion every month to help with bone loss and a Lupron shot once every three months, both done at our local hospital. Trips to Boston to see the Dana Farber team were monthly at first but after a few months, once every three months. The team at Dana Farber set up Duncan's regular blood draws at our local hospital to keep us from having to drive in more frequently. Our local oncologist assumed we'd shift our care to the Dana Farber team. "No way! We like you, and we really want to support and to take advantage of our local hospital."

The PSA has stayed low and the cancer is in remission. As Mark put it: "if we could see it, it would look like dead leaves on a tree." And yet Duncan's health, and that hugely important "quality of life", has been pretty bad. I'll describe several of the issues we've faced in the pages that follow. These include tiredness, eye issues, fainting, diverticulitis, and severe back pain. Unfortunately, though I had hoped that as I drafted this the "Job's Syndrome" would come to an end, it looks like you'll have to sign in for Chapter 2 where I'll deal with the next part of the list.

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Shortly after the cancer diagnosis Duncan's eyes began to hurt. They were red and watery. It looked like that common eye issue from our youth "pink eye," known to the medical community as conjunctivitis. Tom gave Duncan an antibiotic, but it didn't seem to make much difference. After a time we went to see the local ophthalmologist Dr. Z. Conjunctivitis is sometimes viral, so he suggested that Duncan stay off the antibiotics to see if it might have just run its course. But it hadn't, so he prescribed another antibiotic. The next time we saw Dr. Z things looked better, but then it got worse again. Dr. Z, feeling at a loss, sent us to Dr. S-, an older and therefore perhaps more experienced ophthalmologist at a hospital down the road. Dr. S-, along with his intern, did the usual testing of vision etc. and found, as had Dr. Z, nothing wrong with the eyes themselves. He prescribed an ointment that might help with the stinging and itching, but confessed that he was not sure what the problem was.

This was in November, and I wanted to visit our son and daughter-in-law, 4 grandkids, and their 4 dogs in Albuquerque NM. I really didn't want to go there and leave Duncan to deal with the eye issue all

alone, so I talked him into coming with me. We had to sit in different rows on the plane. A flight attendant asked him if he was OK – that's how bad his eyes looked. I had thought that perhaps going to the high desert might help, but Duncan has a mild allergy to dogs and cats which shows up mostly in his eyes, and that probably at least offset any benefit of climate. The eyes weren't looking good. Holly and Evan suggested that we try a visit to Arlo, the local acupuncturist.

One visit cleared up the eyes. Duncan described how the acupuncturist put a needle below the nail on his left little finger. "This is a channel to the eyes," Arlo said, and Duncan could feel the heat and moisture flowing into and escaping from his eyes. Over the course of several treatments during the week we were in Albuquerque Duncan's eyes cleared up – totally. But what we discovered, on returning to Massachusetts, was that the "cure" was for the most part a relief of symptoms. Duncan went to our local acupuncturist several times, but the itching and stinging and redness still returned.

Duncan gets basal and squamous cell carcinomas fairly often. He needed to go to a dermatologist to have a MOHS surgery. She asked him, "do your eyes hurt?" and when he said yes, she told him that his lower eyelids were turned in. We remembered that the plastic surgeon who often did the final work on his carcinomas had told him, several years ago, that he needed surgery on his lower eyelids. We had rejected the suggestion. He had little to no irritation in the eyes, and frankly I suspected it was just what plastic surgeons want – to have an excuse to do surgery on your face to make you look 10 years younger than you are. We visited Dr. Z again. He told us that he had several patients who had eyelashes on the inside of their lower lids and sometimes he had had to remove them to restore their eye health.

When we saw Dr. S- again and told him of the dermatologist's comments he recommended that Duncan set up an appointment with Dr. Susan Tucker, an ophthalmological plastic surgeon at Lahey Medical. She told Duncan that all that was needed to take care of this issue was a simple operation consisting of three shorts cuts. He booked the appointment. It took a couple of months after the surgery for his eyes to completely heal, but they are completely fine now. The eye issue had nothing to do with the cancer or with the treatment. Like most of Job's problems it seemed to be plaguing us for no good reason.

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On Friday November 13 Duncan experienced the first of what might be what they call vasovagal episodes. Duncan was tired; it had been a busy week. We had dinner at Kathleen and Jeremy's. Duncan passed out at dinner, having had a bourbon & cider followed by a glass of prosecco. We do not know how strong the bourbon & cider was. He's not much of a drinker, so what seems like nothing to me can be way too much for him. Duncan was sitting upright in his chair, eyes open – but didn't respond to questions. He was pale and sweating. When the EMTs arrived he had regained consciousness and was joking with them. He stayed in the hospital overnight on medical advice and was told in the morning by the cardiologist that his case was "innocent".

On February 11 Duncan saw his chiropractor, whom he visits regularly to deal with back issues which have been bothering him for many years. She manipulated his neck during his appointment and that afternoon his neck was hurting. We went to see a play at the Gloucester Stage – Duncan felt it would be ok, and it didn't hurt too much during the play. On the way home, however, Duncan's neck hurt each

time the car went over a bump. When he got home a hot shower seemed to help ease the neck. After that he applied a hot pad. That night he woke up in great pain in the neck. He applied a cold pack. He was not sure he would be able to sit up. Beebe had suggested that they spend the night downstairs but Duncan hadn't wanted to. Now there was some real concern that he would not be able to get down the stairs, or even that if we called the EMTs that they would not be able to carry him down. After several hours of careful resting he was able to get up to go to the bathroom. The next morning he felt much better. We went out for breakfast and he ate a large breakfast of sausage and eggs. His PT appointment was later that morning. Deb started him on the bike, then tested his balance. She went away briefly and he felt very dizzy, sat down, complained of a pain in his chest and passed out. However, like the last time, he did not fall over. Deb called the ER and he was taken there; we left later in the afternoon "against medical advice."

On Saturday, February 13 Duncan spent a lot of time sleeping. On Sunday we drove roundtrip to Maine to see our grandson's soccer game and then later at home watched Downton Abbey. Peter and the boys arrived later that night. I don't think we paid enough attention to what I have started to call "charging the batteries." On Tuesday February 16 Duncan saw Melissa at PT at 6pm (Deb was on vacation). She worked on his neck and it "felt good." We met Peter and the boys at Jalapenos for dinner. Duncan had a margarita with dinner. When everyone except Beebe had left he again passed out. He had paid the bill but had not returned his credit card to his wallet. Sitting in the high chair at the table, he did not respond to Beebe's requests that he get up and come to the car. He was very damp, cold, and pale. After several minutes three of the waiters came over and asked if Beebe would like them to help him to the car. She agreed and went to get the car. When she got back they expressed concern that this might be a cardiac episode and that they should call the EMTs. Having been through this twice before, she declined and asked them to help him to the car. When they got home Peter helped him upstairs (Duncan again declined to sleep in the downstairs bedroom). Beebe and Peter spent some 15 minutes or so trying to get Duncan to remember the evening, but his memory of it was very sketchy. Beebe helped him into pajamas – his clothes were damp, probably because of sweat. During the night he got up several times to use the bathroom – he was reasonably steady on his feet. When he woke up in the morning he was able to clearly remember everything that happened the day before except for the time between paying the bill at the restaurant and the middle of the night when he got up to use the bathroom. He seemed fine, if very tired, the next day.

Many episodes have occurred since then. One came after a long day of driving for doctor appointments – both local and at Dana Farber, where Duncan had to show up for an appointment with the neurologist as the trial team wanted to rule out the possibility that the episodes were epileptic. We were having breakfast on Saturday morning. His daughter-in law Julie came in. Duncan was tired, then seemed quite unresponsive. She helped me get him into bed downstairs. He never seemed to lose consciousness, but the episode was a lot like the others, if less severe.

The most recent occurred on a Sunday morning. Duncan told me he had hardly slept all night and that he didn't think he'd go to church. I objected, saying that he didn't seem tired at all. So we went off to church, me a bit earlier as I was supposed to usher. Turned out it was a bad idea. Kathleen, the Music Director at the church, described the incident from her perspective in the choir loft (see sidebar).

Kathleen, Music Director at the Annisquam Village Church. Diary Entry April 3, 2016

Midway through the sermon yesterday, Duncan Nelson slowly tilted to the left in his pew until prone, as he was in his last scene as Schweitzer, our play of two years ago. (Duncan's Dr. Schweitzer is very tired and somewhat dispirited. The music, Goldberg Variation #1, puts him at rest, and he lies down on a pew, dreaming.) Yesterday, though, Dick Luecke, the first responder, helped Duncan stretch out and covered him with his coat while Beebe elevated his feet. Our hearts were in our throats until EMTs arrived. By that time Duncan had righted himself and made haste to persuade everyone that he did not need to go to the hospital. When the EMT's had left, he stood up, collected his thoughts, and declaimed, in verse, that he was grateful for the care, but was just fine...not to worry. (the verse?) He even came down for coffee, allowing us to congregate and cluck over him. It seemed that we had come from one of those 'thin places' though. He'd had such an episode at our dinner table only a couple of months ago (and we had just heard the Gospel story of Jesus raising the boy who had collapsed with epilepsy!) Such fragile creatures. *And* so strong!

The cardiologist at AGH had put Duncan on a cardiac event monitor to rule out the chance that the episodes were being caused by heart issues. The monitor had to be downloaded into a landline once every 24 hours or so. We hadn't realized this when we were shown how to the use the monitor; we don't have a landline. We brought it into the hospital to be downloaded a couple of times, but we were certainly what the medical profession likes to call "noncompliant."

One afternoon we had rigged up the device and Duncan was working at his desk. I was in the next room. I asked him a question, and when, after several attempts, he didn't answer I went to his office to see what was up. Sure enough it was another vasovagal event. I tried to get him to respond without success. We had been told that he should lie down flat – or more accurately, that he should be placed on a flat surface – and that his legs should be raised in order to increase the flow of blood to his upper body and head. I was not going to be able to move him by myself. I called his daughter who lives just down the street. When Roker arrived, taking quick stock of the situation, she moved him almost single handed to the floor and got his legs onto a chair. As before he came to and seemed ok, but the episode did raise the question of whether he should be left alone, and certainly whether he should drive.

The next sequence of issues includes severe back pain, constipation, more vasovagal episodes, and really extreme fatigue. These are pushing us to inquire further into the treatment he is getting and to question the wisdom of staying on the clinical trial, which pretty much rules out alternative treatments.