2019

The complicated news from MSK as of the end of January 2019

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NOW WITHOUT HESITATION

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The prologue:

MSK gave me a prognosis for the first time, when we met with our oncologist on Thursday, January 24, 2019. The prognosis is six months.

The reasons:

I had been having difficulties. A scan back on December 11, 2018 had determined that my cancer was again in action. Shaping a response to that took time, both because of the holiday season and because I'm sure the doctors wanted to be as careful as possible. The conclusion they seemed to be coming to, even before we met on January 24, was that there were no good affirmative treatments likely to be available. We had no doubt this was a reasonable assessment of the situation, but felt that it might still be true that even a treatment unlikely to succeed was better than no treatment at all. Our oncologist's view was, we thought, evolving to the opposite perspective: that if no treatment was likely to be successful then there was no point in trying them at all.

What decided the issue was a series of scans in late January, which included a January 15 X-ray of my abdomen as well as a CT scan, that same day, of my abdomen and pelvis done during my digestive blockage visit to MSK's Urgent Care ward (a visit I blogged about as well). They also included an MRI of my pelvis on January 22. I had yet another scan on January 25, but that was to diagnose whether I had suffered a broken foot or not, and didn't otherwise contribute to the study of my condition.

In truth, the information in theses scans is hard to keep clear and distinct. One scan is referred to as comparing its findings with data from a scan done a couple of days later, but I had no such additional scan that day. Another

scan attributes the wrong disease to me – saying I have colon cancer when I actually have a different illness, cholangiocarcinoma. These mistakes are a bit unsettling, but the general import of the scan results nevertheless emerges clearly.

If the scans proved determinative, what led MSK to determine that they should do the scans in the first place? Their concerns were triggered in good part by the MSK physicians' growing suspicion about a lesion, a damaged area, in my right iliac bone, which is part of the pelvis. MSK had been aware of this spot since approximately April 2018, but had not been particularly suspicious about it. Now, however, yet another scan in December 2018 had shown growth in this spot, and growth is important. For our part, we too had hoped not to need to pay attention to this spot. After all, I didn't think I had any symptoms of it at all – but over the weekend before the scan I began to realize that maybe I did have symptoms, perhaps from walking further than was comfortable, perhaps from such minor motions as bending over to do the dishes. Mostly not a lot of pain – but cholangiocarcinoma is full of minor, yet ultimately meaningful, symptoms. Meanwhile, growth is cancer's specialty, so the fact that this spot had recently started to grow was a bad sign.

The scan series in January 2019 appears to have confirmed two thoughts for our oncologist. The first is that the cancer has escaped from the liver and reached the bones as well. One report, on still another CT scan done on January 15, 2019, indicated this but not elaborately; a second, on an MRI scan done a week later, January 22, 2019, left no room for doubt. There has been a lot of damage to the bones of the pelvic area, presumably the result of its infiltration by the cancer, and all of it appears to have taken place in the last 12 months. Parts of the bone have probably died. All of this makes me vulnerable to things like bone fractures, including hip fractures, which would put me right away in a wheelchair.

When the skeleton weakens, you are at greater risk both for "spontaneous" fractures, which can apparently take place while you're doing nothing more strenuous than sleeping, and for fractures caused by impact and accident. There are things that can be done to reduce the chances of incident, such as installing assistive equipment, like guide bars, machinery to help me get

around the house; as we do more with this I may blog about our progress, but in any case this effort is now underway.

As to the impact and accident fractures, for me those are more likely than they otherwise might be because of all the water I'm still retaining, especially in my feet. The water retention is another impact of my damaged liver (and of its interaction with the diuretic medication, and in turn with my kidneys). The water retention in itself isn't a big problem, and doesn't contribute to my underlying cancer in any direct way. However, in the Department of Irony, currently running strong, a couple of hours after we got home from our Thursday meeting last week with the oncologist, at which we'd received a lot of precautionary guidance, I fell at the bottom of our stairs. Fortunately the fall was only two steps down. I landed hard, but even more fortunately the fall didn't fracture anything; it caused "just" a sprain. My left foot did take on some remarkable colors right away. Depending on how many separate sprains I gave myself, recovery could take as long as six or seven weeks. So far, however, things seem to be moving quite quickly and positively.

The second conclusion our oncologist and her colleagues have reached is that my liver has already been seriously damaged. One measure of such damage is the growth of the cancer itself, and the January 15 CT scan of my abdomen and pelvis lists a number of growing, and probably new, changes in my liver and bile duct of this sort. Other evidence comes from blood testing of liver function. My general sense is that my liver and kidney blood numbers were good until the conclusion of the high-intensity radiation treatment this past summer, and that at that point they began to deteriorate. It's easy to see what caused the damage: notthe water retention, but rather the combination of three years of different powerful treatments, including chemotherapy and, most recently, high-intensity radiation. These all did their job, staving off or pushing back the cancer for years – the oncologist has been happy to have me as an "outlier" to the normal course of the disease – but the price was liver damage. I've recently read that actually the liver handled over 500 different functions in the body, not just the 400 I'd seen referred to earlier. Any of those may now be malfunctioning.

What's bad about liver damage is that there is no cure for it. It is possible for the liver to regenerate, but that is a slow process and one under nature's guidance; there seems to be little if anything a doctor can do to bring about regeneration by direct medical intervention. There is no "liver-all" pill to take 3 times a day! The only method available to doctors of which I'm aware is resection – the complete surgical removal of part of the liver, but MSK has never seen me as a good candidate for this approach. That means that any heavy-duty treatment that gets applied at this point runs the risk of deepening my current liver problems, and if the liver stops functioning, that is really the end.

What is to be done next?

That in turn suggests that what's ideal for me is to stick with exactly what I now have. The status quo has its inconveniences, such as water retention, but they can all be managed. Evidently, however, our oncologist anticipates a continued deterioration of the liver, presumably as a result of a continued growth of my cancer.

To stave that off as long as possible therefore becomes our next goal. Happily, there is something that can be done about this: the application of low-intensity radiation. High-intensity beams are too powerful and too dangerous, but low-intensity beams have been in use for a number of years and their capacity to slow, though not end, expansion of the cancer in the bones (and perhaps even in the liver itself – a point I want to ask more about) is evidently well-established.

One other point: I exaggerated a bit when I said that MSK took the view that there was nothing truly affirmative to be done. There is one treatment available which, though not very promising for patients with my kind of cancer (it wasn't designed with this illness in mind), still could conceivably help and even help a lot: Keytruda. This is the drug that helped Jimmy Carter fight off brain cancer. MSK is comfortable with trying it because they feel they know very well what its potential downsides in the body are, and they're mild. So they are quite confident that Keytruda won't undermine what's left of my liver functioning, and though it likely won't improve matters either, it will succeed or fail without further weakening me.

The only problem with Keytruda is that it is very expensive – I think over $10,000 for each treatment, with the treatments every three weeks. Merck, which makes Keytruda, enables many potential patients to get around this problem by giving them access to the drug as a "compassionate use" under federal law; no doubt this is only partly an act of charity, while also serving as a way for Merck to continue gathering data on its drug, with a view to the widest possible use and sale of the medication. In any case, we and MSK have applied to receive the drug as a compassionate use. Decisionmaking at Merck this month has apparently been slow, for reasons no one outside the company is sure of, but we will continue to press the point.

There may be other possibilities, though with the difficulties my liver and kidneys now face I may not easily be able to qualify for most experimental trials. Even if I can qualify, we'll have to determine whether these experiments make sense for me. For example, we've certainly considered the "CAR-T" experiment at the National Institutes of Health, a trial in which the patient's immune system is more or less entirely removed, re-trained to focus on cholangiocarcinoma, and then returned to the patient's body. The general sense Teresa and I have is that steps like these are a last resort, or no resort at all, because they do pose serious risks of danger to the patient – especially, we assume, one with a damaged liver already.

And meanwhile:

I plan to live the life I've lived, valuing and spending time with my family and friends. I also plan to continue the final steps in the work that I've had underway, the biography of my late South African friend Arthur Chaskalson, roughly since I received my diagnosis in 2015. I've often felt since I became ill that each day in itself is a wonderful thing. In recent months my sense of this has wobbled at times, so now I mean to remind myself, and to take joy in each remaining day. And if there turn out to be a lot of those remaining days, so much the better!