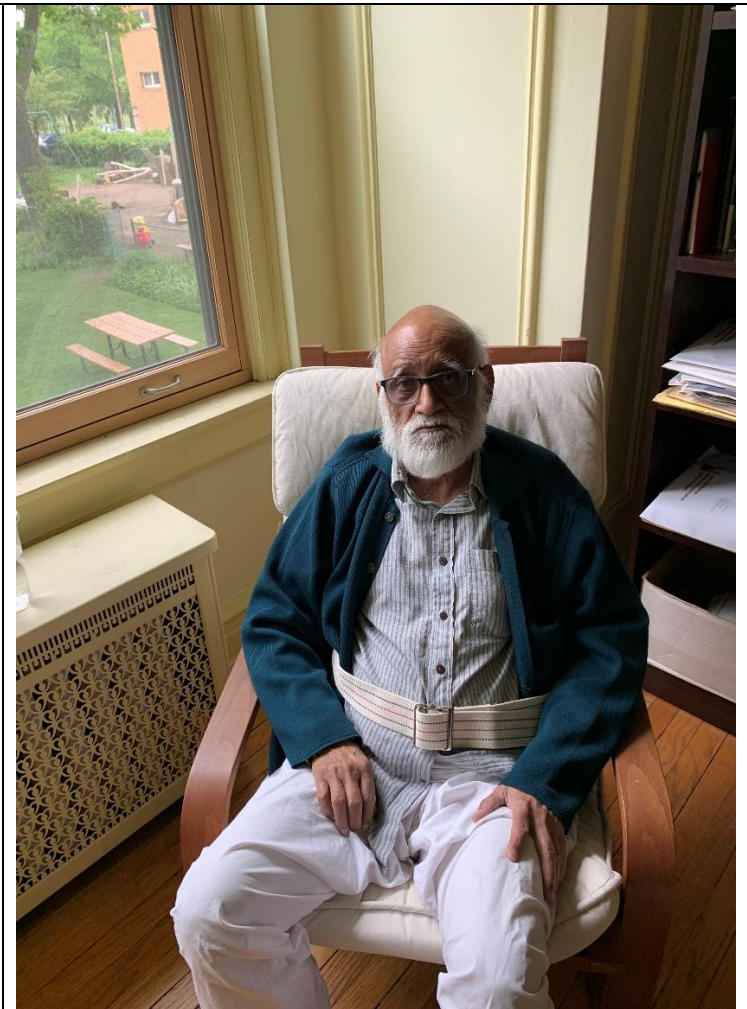


May 25, 2022 – Wednesday He was released on his own recognizance today. The assisting doctor came to say good-bye as did the discharge coordinator. We drove home and he climbed the back stairs to his apartment and we entered. Walking is definitely pretty good. Earlier today the bathroom door was removed, the new showerhead/hose installed and the tub bench put in place. We had some ravioli for lunch and then he took a nap. An old friend came by to chat and I went to Walgreens to pick up the meds the Rehab Lab had put in. The line was far too long and I turned round. It has begun to rain a little now and there is a tornado watch in effect for the suburbs. He is sitting by the window doing his exhalation exercises.

Here is a picture of him in the chair beside the window that overlooks the garden. He is happier than this pic, taken without my glasses on, indicates. The “seatbelt” is a “grab” belt to make it easier to grab hold and balance him if that should prove necessary.

With him home I think this will be the last update. Fingers crossed!



May 24, 2022 – Tuesday Yesterday we were given notice of our Medicare right to appeal the decision to discharge on 5/25. This right exists in the 48hrs prior to discharge. Reviewing primarily the physical therapy reports as they address walking and balance, these are largely “Goal Met” indicating ability to walk for a goodly distance and without assistance though the therapist recommends that he be shadowed while he is walking. Consulting one of my cousins who is a doctor it does not appear that the discontinuation of Heparin injections is something requiring weaning. Therefore, it seems like it’s time to be released to my tender mercies at home.

Balance remains an issue. The scale is to 56. He entered at a 35 and is leaving at a 48.

As his apartment is in a co-op the building maintenance people will be replacing the showerhead with one of those hose things and removing the door so that it’s possible to enter his bathroom while leaving the tub bench in place.

The outfit assigned by the State of Illinois to provide “homemaking” assistance has not yet found a person for us to interview for the homemaking let alone for the promised start on May 26. It’s still good that there is such a service (it is outside of Medicare) and you may want to check your state services.

We have received the form for a handicapped parking placard good for 6 months. Prescriptions are awaiting pickup at the Hyde Park Walgreens.

We shall see in ensuing days whether a planned trip to Austin and North Carolina is wise.

Link to a study on frequency of recurrence of stroke as time passes. Incidence in the first 90 days following first stroke appears be under 4%, but rises to 20% in ensuing 5 years. This is part of NIH, but based on German insurance records: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6891883/>

May 22, 2022 – Sunday

Picture: **“I have not yet given up the ghost”**

A sunny day today, but high of only 62. Sunday is a day of self-help and reflection with no formal therapy scheduled. A quick trip to Costco for the Flonase and loratadine in the formulations that he responds best to. The generic flonase provided is different somehow. These differences have been reported elsewhere and are not a universal consequence. After dropping them off with him and a brief chat, his visitor for the day arrived to chat before lunch.

Outside, Northwestern had graduation ceremonies for some schools today so the gowns were on surrounding streets.

At Vista, checked on the garden bed, no “weeds”. Gazed on art at the Smart and then had brunch with a couple friends from Kenwood at a place called “Roux”.

The “hot tip” on Simplification, was a bust. On to the Belmont on June 11.

Back home, my wife locked herself out, but was able to find an open window.





May 21, 2022 – Saturday A drizzly day today. Staying in and spoke by phone. An intense hour in a harness walking followed by a lunch of lasagna. Slept through the night last night. He will have a Sunday visitor at 11am until lunch is served. For my part today, lunch at Morry's, groceries from TJs and a quick browse at Powell's with a purchase of "Metazoa" a book speculating on the paths to consciousness that have evolved in the animal kingdom (plants remain beyond our ken although these fungi-based networks and exchanges of nourishment between trees of different species lead to speculation). The Preakness will be run today and a friend has given me a "hot tip" on Simplification, so it's off to the OTB parlor soon.

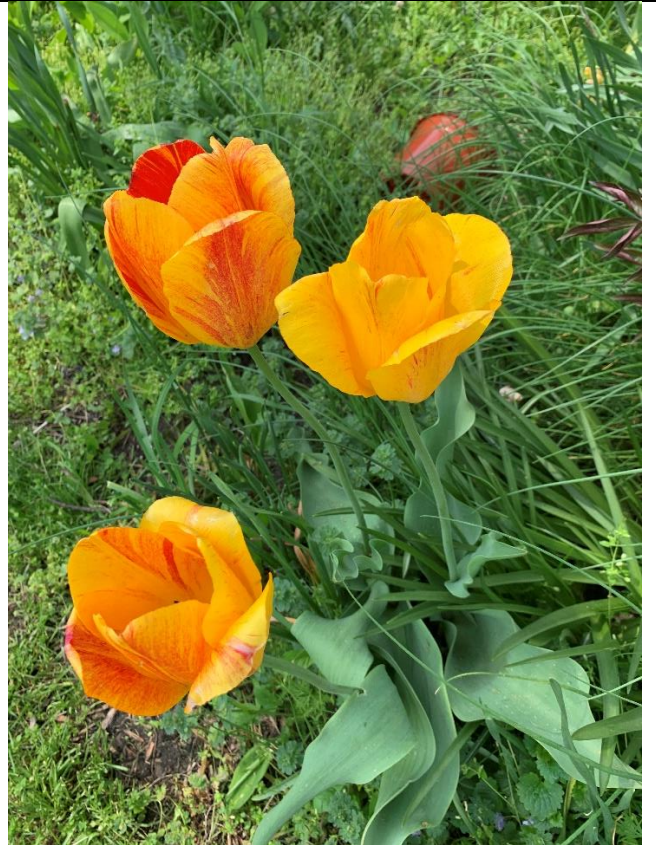
May 20, 2022 – Friday As the inpatient time winds down, had a meeting with the team to have some questions answered. Note that people have been very happy to answer questions and discuss what they're doing and why, but this was a setting with all together.

Among the post-discharge medications was mention of daily injections of heparin, a blood thinner. While I've observed this being done in the room, this was news to me. When raised as to the level of skill required for this, the doctor stepped forward to say it was being withdrawn from the list. One never quite knows what to make of such. Is it unnecessary or is it to account for what's possible now that it's not a trained nurse in attendance. As a practical matter, a daily aspirin is also on the medications list and blood thinners have their own drawbacks as cuts and bruises simply may not stop bleeding. At this age stroke is a leading cause of death and aspirin, statins, and management of blood pressure by life choices are the best preventatives. As a friend had mentioned to me, her aunt had a stroke in her 80s and lived another 12 years without another one. Naim notes that his paternal grandmother died of a stroke. I don't believe this happened to any of his siblings, however.

No dietary restrictions, notwithstanding the relative weakness of the right side, of the mouth. Although the acid reflux has resurfaced as an issue, the volume of his voice remains in range. Possibly will start with metformin, but is not diabetic. His ability to expel air with force is at 100% for his age. While walking is good, a suggestion is he consider using a hiking staff. Kneeling to garden is possible, but the getting down to do so may be practiced more. He is said to be able to get up on his own, but always good to have someone nearby and a support.

May 19, 2022 – Thursday A day of preparation and discovery. The commode seat over toilet will require removing the toilet seat and lid for best fit. Duh. Same for a toilet seat height adapter. The tub bench will fit his bathtub fine, but the bathroom door swings into the tub meaning the simplest solution will be either removing his bathroom's door or placing the bench in the common bathroom where the door swing is less of an issue (the common bathroom also already had grab bars in the tub). After living with it for years, how his refrigerator door opens will likely be flipped. His therapy schedule is longer today. They are working on dressing himself. Naim will have 2 visitors after supper today, so given the schedule and other visitors, I will not be going down there today.

Tulips in his garden plot at Vista Homes.



May 18, 2022 – Wednesday No news is good news. On the whole, he is on the mend. The right fingers remain unfaithful. Had a call today with Jillian the discharge coordinator. The therapy team's evolving recommendation is currently for 24/7 assistance with walking for the near-term. He is viewed as a high risk for falls from distractions. However, today he reports that while walking the therapist asked him to count down backwards from 100 by 7. He did so while walking throughout. A tub bench was obtained gratis on Craigslist (reduce, reuse, recycle). Jillian's own recommendation is for assisted living for a month. Here we must think about the real or perceived cloud of liability for any but the most cautious recommendation. On the other hand, recalling the stress of providing care when my mother declined a skilled nursing facility to be cared for by us, that was definitely a bad decision. She was in a great deal of pain and limited mobility. He is not in pain and has much greater mobility. We also spoke about outpatient therapy and as the people at Shirley Ryan are so highly recommended we may continue with them downtown. However, UC Hospitals also has the full range of outpatient therapy (speech/memory, occupational, physical) and is in Hyde Park. This would be on a 3hrs/day 3days/week schedule. Thank goodness it is spring and not winter!

Vista Homes is a co-op and keeps a closet of items no longer needed by other residents. An over-the-toilet commode was obtained from there. A friend of Naim has offered a toilet seat adapter and a walker to just have on hand. **Monday** for therapy it was quite a full day for him and I did some paid work and spoke with a highly-recommended in-home aide who is not available (another couple appears to be

vacationing, a third has not called back). **Tuesday** was also a full day of various therapy. As he was having a visitor after supper I did not venture down.

May 15, 2022 – Sunday Today was a day of rest for scheduled therapy. He also gave me “the day off” in terms of a visit, but I have begun to schedule visits (650.207-6246, tj612806@yahoo.com) and he had 2 visitors today..

I’m not sure if the pic to the right will be visible, but it is an impressive view from the physical therapy room. His view is of other high rises of the medical complex this building is part of.



May 14, 2022 – Saturday Today was to meet and go over with the several therapists for eventual discharge. You may find some useful nuggets here for your future reference.

Physical Therapy 5/14 – Weekend duty therapist. We learned about putting on the cinch strap (by the “teeth” then over the teeth so they’re hidden by strap). Using the underhand grip to be ready to pull up if a fall is imminent. On stairs going up follow 1-step behind, and descending stairs, be 1 step in front to break any fall and brace. Be careful yourself if walking down backwards!

What to do if he falls? 1. Ascertain if conscious, bleeding, in particular pain, can move limbs, seeing double, breathing ok, dizzy. Particularly, if dizzy or seeing double, pain, moving, could be another stroke. Blood thinners make internal bleeding a strong risk from a fall. In doubt, call 911. Getting back up, in his case, see if he can get on hands and knees. Then he sidles on hands/knees to object he will use to stand, such as a low chair or ottoman. Since the right side is the weaker side, have the right side closest to the object to be used. Place right forearm solidly on object and he is to place weight on that forearm. Next shift left leg from being on knee on floor to left foot flat on floor. Now he uses the left leg to stand up, you can provide some assistance with the cinch strap (use the underhand grip), but if he can’t stand up on his own, then it’s a good sign to call 911.

Speech/Language 5/14 – Weekend duty therapist. Can spell aloud, but writing out requires greater concentration. Speech strategies: increasing his volume (taking a breath, slowing down), over-articulation. In an “occupational” sense the speech/language is working on logic and memory. In particular, reviewing what one has written and one’s reasoning for it. Setting the Exhalation Strengthening device: Determine level at which one cannot force air through and then set at 80% of that. The screw determines the level in tandem with the quarter marks. Be sure he exhales, then pauses the 15 seconds (keep breathing normally) before the next exhalation. 5x = 1 set, pause 1 minute between each set, 5 sets/day.

Occupational 5/14 – Weekend duty therapist. We looked at bathroom – tub bench, commode or adapter seat for toilet height. Bedroom is close to bathroom. Dry feet and put on the traction socks before stepping on the floor tile. Kitchen – since he can stand and walk, his turn-around kitchen is good

and narrow is an advantage in this instance. Might have to shift around what is stored where. Rollator walker with a turn-around seat and auto-braking might be a good device, but will consult with physical therapist. A wheelchair may be ordered for getting out and about if driven around.

Nursing Care 5/14 – Turned out not to be necessary. Was on schedule, apparently pro forma, but is for those with wounds, tracheotomy, serious stuff.

May 12, 2022 - Thursday

SPEECH: A double session today. Another person's session had canceled so the therapist came round to see if he wanted to do more work, which he did. Very impressive to me that such happened at all. Earlier there had been pressure testing of the tongue's ability, which is in range for age group. However, it appears the "slowness" is in the loop between brain and tongue. He was also given the steps of a pizza recipe to put in proper order which he did. Then a set of sentences containing statements from which to make entries into a "checkbook". This he also did. **CORRECTION!** – He had been told the checkbook balancing sentences were in chronological order, however, he discovered that technically that was not correct. I'm not sure how to put this to describe correctly to you gentle reader. The chronological order of the sentences, but one, is based on the action in the sentences. That sentence has been placed where it is based not on the action to enter in the checkbook, but on the due date of the bill (the action is to write the check before the bill is due). He pointed this out to the therapist who was resistant to the idea, but **Naim is correct**. To be consistent with the intent, the sentence should have been placed earlier in the order. Of course, perhaps this is **the double-secret test of cognitive ability** to see who catches the "error". 😊 Will it be corrected in future iterations? I secretly hope it will find future utility and come to be known as "**the Naim Observation**".

WALKING: The physical therapist spoke with me and we are now moving into deeper testing. Distance walking without assistance within 6 minutes has increased. He walked backwards successfully. He walked between 2 parallel lines with his eyes closed quite well, straying outside only a few inches at the end. New test is to do a "sobriety test" (my term) by folding arms across chest as though in a straitjacket and walk on a line on a ground placing one foot, heel-to-toe, immediately in front of the other. This was impossible so this will now be worked on as well.

HAND/ARM: While eating his supper, Naim observed that if he picked up a grape with his right hand and held it as one might while conversing, his right hand's grip would eventually loosen and the grape would drop. Not so with the left hand. This will be raised with the doctor and the therapist.

DISCHARGE: Tentative transition from inpatient to outpatient may be May 25. **FRIENDS IN HYDE PARK:** If you have particular experience with persons who provide in-home assistance, please reach out to me tj612806@yahoo.com and 650.207-6246.

On a related note, a friend whose father had a stroke in Wisconsin, provided the following link and advice which you may want to have for future reference on facilities.

<https://data.cms.gov/provider-data/>

Has downloadable and sortable information on different types of providers, including skilled nursing and rehab. The downloads are pretty big but you should be able to sort by ZIP Code or city and then on the right side of the data tables are rankings from 1 to 5 on different metrics as well as any abuse cases that they've been cited for.

May 10/11, 2022 – Tuesday/Wednesday

No News is Good News: Not much to report that is new. Therapy of various sorts continues.

DISCHARGE: Tentative transition from inpatient to outpatient may be May 25. As I was leaving the discharge coordinator arrived so I stayed on for a lengthy discussion **FRIENDS:** If you have experience with this, please reach out to me tj612806@yahoo.com and 650.207-6246.

May 10 – Chat with Jillian Discharge Coordinator for AbilityLab. Staffing difficulties can result in less than 3hrs per day. Discharge date tentatively at May 25. Medical necessity, progressing, nothing solid to offer. Team recommends assistance with Laundry, Medications, Groceries = IADL “Independent Activities of Daily Life” compared to ADL “Activities of Daily Life”.

May 11 – Chat with Dr. Anscheul for AbilityLab. Attending physician. May 25 reiterated. Will schedule for soon a group meeting so I can have a direct and unified discussion about what is happening and what some things mean.

Aetna – Member Letter on Authorization. The AbilityLab Portal (access to which I have yet to receive) updates on the treatment side. On the Aetna side one must request to be kept in the loop on what they're authorizing with AbilityLab. Unlike Medicare, nothing seems to be certain with Medicare Advantage until perhaps the statute of limitations runs. While the tentative discharge date is 20 days from admission, Aetna at this point has only “pre-authorized” 7 days. Note the quotes, the “pre-authorization” comes 4 days after admission, so really it's maybe 3 days. Some of this can perhaps be attributed to the 4 days in hospital and then to AbilityLab.

SPEECH/MEMORY: Today was a device to exercise exhalation, perhaps to build volume of voice and/or stamina. It's not entirely clear the device was set properly. To calibrate the device your nostrils are clamped and you exhale sharply. If able to blow through, then the device is tightened. Repeat until breath is blocked. Then turn back ¼ turn. Not sure how good this is for a stroke recovery as it contains some warnings.

May 9, 2022 - Monday

SPEECH: An hour today. Strategies in describing the word one is trying to find.

WALKING: The physical therapist spoke with me and it appears he can pretty much walk well and independently, but lifting the right leg up, as to step into a tub, is limited. Looked at a tub bench.

HAND/ARM: Working with the putty on his own. Therapist used also a “hand cycle” to work on range of motion.

DISCHARGE: Tentative transition from inpatient to outpatient may be May 25. Will need to discuss the metrics for this and explore how this will work. **FRIENDS:** If you have experience with this, please reach out to me tj612806@yahoo.com and 650.207-6246.

May 8, 2022 - Sunday

SPEECH: The Sunday therapy is actually only 30 minutes, at least for this particular Sunday. **NOTE:** The therapist actually came 2hrs earlier than the scheduled time, so that affects thinking on visiting. Can see that right side of the mouth opens less than the left when speaking.

The social worker/discharge coordinator also inquired whether he had an **advance directive** on extraordinary measures and life support. **Have you done one for yourself?** I realize that I have not done one for myself, so that is now on my list.

MIND: He did a sudoku yesterday to completion, but feels it took him 1.5X longer.

HAND/ARM: Noticeable now is that his right pinky and ring fingers droop a little relative to the others. This is interfering with use of the touchpad. He has been given a ball of silly putty and a range of finger exercises to do that use it. It's not just something to squeeze generally. Rather each finger squeezes it in 3 different directions as well as pulls in a couple directions. Clever form of resistance training.

FRIENDS: I don't know how many of your emails he has been able to respond to, but if you have not yet heard from him, then **he thanks you for all your well wishes!**

May 7, 2022 - Saturday

Speech is good and largely a normal tone of voice from fainter and higher-pitched before.

Blood sugar is now in the usual range when measured in relation to meals.

Right arm can be raised above head and held.

To bring food to mouth has now been able to use precision grip rather than power grip, but needs left hand to bring food to mouth.

The daily 3hrs total of therapy is actually reduced to 1hr on Sundays.

The food here is quite appetizing I must say even as a diabetic diet.

The social worker/discharge coordinator has been helpful in understanding the distinction between his Medicare Advantage and his Medicare, but coverage certainty by whom is a little elusive. Such is the nature of our public/private partnership.