# FRIDAY IS TOMORROW OR

# THE DAYENU YEAR

Chronicles from the NYC Covid-19 Oral History, Narrative and Memory Archive

BARRY JOSEPH

June, 2021

Denise,

So after all of this time, what do you think?

You and your colleagues spent over a year gathering the daily "chronicles", interviews, images and more from nearly 200 New Yorkers during the first year of the COVID-19 global pandemic. Collected into your archives at Columbia University, do they now tell a unified story of a city under siege? Have you found ways to weave together our individual voices into one choir? Is the total greater than the sum of its parts?

This book is a collection of the parts I submitted to you over the year, within my own feeble effort to exert some control over how they are interpreted. Initially I offered you an article I had written about losing my father. I wanted the act of capturing that moment to live on in a memory greater than my own. You and Columbia accepted that. But like a drug dealer in reverse, you roped me in, the addiction coming from my love of writing, and of sharing my experiences with others. That one article grew into a series of interviews, then online entries chronicling my days, all supplemented with digital ephemera I collected over the year.

Your Archives will soon open. Anyone will be able to dive into my folder and check out any of these submissions. But here is my attempt—with my own imposed structure, and only slight edits—to seek some greater meaning. And with that explanation I add this book, itself, into the folder, as my final contribution, a whole alongside its parts.

It will start with a note to the reader and then, from there, it will begin.

With more thanks than words can express, Barry Joseph

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"Obsessing over what it did to *me specifically* almost inexcusably leaves out my constant awareness of the damage to my community,... to say nothing of the half a million dead Americans."

—Nico Muhly, composer, when asked to reflect on one year of COVID.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> "75 Artists, 7 Questions, One Very Bad Year". The New York Times, March 10, 2021, Page 4, Art section.

### NOTE TO THE READER

Every child who grew up in the *School House Rock*-era of Greater Metropolitan New York was bitten by this particular earworm inserted into the pro-bono advertising space between Saturday Morning Cartoons: "The most important person in the whole wide world is you, and you hardly even know you. The most important person!"

In this book, the most important person is you, and I don't even know you. So welcome! And nice to meet you.

We already have something in common. I survived the COVID pandemic. If you are reading this, so did you.

In other ways our stories will be vastly different.

This book is less about me than it is about us, about the similarities and differences you experience as you explore my personal story. Did you also lose someone you loved to COVID? Did you also lose your job? Did you also discover things about yourself—some you wish you'd known earlier, some you wish you'd never known?

I give my story to you as an offering. You may receive it as an opportunity to reflect. Perhaps to mourn. During the pandemic we were afforded precious little space to do either. As with any traumatic experience it is going to be our responsibility—to ourselves, to our loved ones—to (as Peter Gabriel sings) "dig into the dirt".

Where our stories are similar, accept my words as my hand as we revisit it together.

Where our stories are different, accept the safety provided by our anonymous conversation. Use it like a confessional.

So come dig into the dirt with me. Then narrate your own story, if at least to yourself.

At the start of the pandemic, I read stories of people turning lemons into lemonade by committing themselves to new projects to make the most of being self-quarantined: learning how to make sourdough bread, or how to play a new musical instrument. I tried the latter but failed. Our apartment overlooks a park; when it was padlocked by New York City officials I took a photo from our apartment balcony, capturing how empty it was. The next day I did the same. Then again, day after day as spring returned and nature took over. I'd found a daily project!



A few weeks later the park re-opened. That ended that.

Meanwhile, I read an article about projects being set up to document how we experienced the social disruptions wrought by COVID-19. One was at Columbia University. I sent them an article I had recently written, about losing my dad the previous month. The story, I felt, should have a good home, and a university archive seemed as good a place as any.

Within minutes I received a response from the COVID-19 Oral History Project

Subject: Re: Any interest in this COVID-related article from me?

Date: May 7, 2020 at 10:16:57 AM EDT

Dear Barry,

Thanks so much for sharing this wonderful and heartbreaking article. I'm so sorry that you lost your father, especially in this difficult time.

Would you be interested in participating in our archive? You can choose to write chronicles if you'd like, or to participate in interviews, or just to fill out our survey. If you'd like to do any of this, here is a link to our intake questionnaire. I think your perspective would be important to have.

If you decide to fill out the questionnaire, we'll get back to you about the next steps to participation.

Hoping you stay as well as possible under the circumstances,

Denise

She asked so nicely, how could I say no? I filled out the intake questionnaire with no expectations but, based on whatever criteria they had in place, I was selected as one of two hundred people they would interview over the next year (because, surely, in a year, it would all be over, right?). All I had to agree to was two interviews. Everything else was optional. Talking on the phone twice in the next year sounded easy-peasy.

Every few weeks I would receive the following email prompt:

What are you thinking about this week? What is going on in your neighborhood? What kinds of conversations are you having? What effect have the events of this week had on your thinking about the COVID-19 pandemic? We want to hear from you. You can contribute chronicle entries to the archive any time by clicking here, or copying and pasting the link below into your browser:

Rather than click on the archive I trashed the email. Not with malice, mind you. I just did not have the bandwidth to even consider it.

Something changed after our first interview. Maybe things had lightened up, just enough. Maybe I saw the value of a daily place to record my thoughts. In any case, while I had not written a daily diary since college, I thought it seemed like a worthwhile endeavour. Columbia asked us all to share our posts, digitally, in a web-based form, which is fine with me. But I didn't want to write it on the computer. There was something freeing in the constraint of writing it by hand each day. It forced me to be concise, and to create it on the page without belaboring an idea or reworking a sentence. It just was what it was. Then I'd type it up and share with the Columbia team for their archives.

My interviews with Denise and the daily diary make up the bulk of this book, lightly edited (mostly to protect the innocent).

To fill in the gap between the start of the pandemic and my time with Columbia, I included two things. The first are articles I wrote during the spring as a way to process my life and connect with others. The second are the notes I took when my father was in the hospital, its own sort of diary, created less for processing the pandemic life than as a tool for navigating it.

I wanted to prepare this fast, as something that could be available as soon as possible, to enter our lives during the transition out of COVID. So while the contents of the book are a record of one life during COVID, the book itself is an artifact of our transition to what came next.

Finally, I'm writing this book so after a year plus of social distancing I can reconnect with the whole wide world, one person at a time, starting with you: the most important person.

## CAST OF CHARACTERS

Akiva: My son.

**Andy**: A best bud from high school.

Barry: Me!

Becky: Noemi's sister.

(the) Biens: Family friends with children the same age as our own.

Carol: My step-mom.

**Dad**: My father. Also known as Daddy, or **Paul**.

**Debby:** My sister (I'm older).

**Denise**: Director of the MA Program in Sociology at Columbia University and Co-Director of the NYC COVID-19 Oral History, Narrative and Memory Archive.

Lily: My step-sister. Married to Michael. Children are Eva and Delia.

Mira: My youngest child. Often called Miri.

Noemi: My wife.

**Oma**: My wife's mother (also known as Gaby).

Paul: My father. Also known as Dad.

Paul: A best bud from high school. Not my dad.

**Steven:** A best friend since elementary school.



# THE SEASON OF FEAR



# **MARCH 2020**

In which the author is introduced. As is Denise, from Columbia. The pandemic hits... the Girl Scouts pivot... schools move online... a city closes...

### COVID-19 Oral History Project: July 2020

The Reminiscences of <u>Barry Joseph</u>

Columbia Center for Oral History Columbia University 2020

The following oral history is the result of a recorded interview with Barry Joseph conducted by Denise Milstein on July 10, 2020. This interview is part of the COVID-19 Oral History Project.

The reader is asked to bear in mind that s/he is reading a verbatim transcript of the spoken word, rather than written prose.

Q: Good morning. I guess I'll just say formally for the people watching this or listening to this or reading it in the future, that I'm talking with Barry Joseph, and this is Denise Milstein. Today is July 10, 2020, Friday afternoon, 3:00 p.m.

Joseph: It's currently raining.

Q: It's also raining here, yeah. Where are you in the city?

Joseph: Forest Hills. Queens.

Q: Okay, so you're a good distance from me. I'm in Harlem right now. I think it would be great if you could start by saying a little bit about yourself. That would be useful for people encountering this interview in the future, just to frame your experiences. Who are you? How did you get to where you are today?

Joseph: I'm fifty-one years old. I grew up on Long Island, which if you aren't from the area is just east of New York City. Went to school outside the city, came back for graduate school to go to New York University in the early '90s and have been here ever since. I've spent the past twenty-five years working in ed-tech in one way or another, starting in the new media industry and then, twenty years ago, going into the after-school education space, and eight years ago, specifically, in the museum education space. For the last two years, I've been working at the headquarters of the Girl Scouts of the USA. I'm the Vice President of Digital Experience.

Q: Interesting. So you came into the pandemic already with a lot of experience with digital communication, it sounds like.

Joseph: Yeah. I've been online before the term "online" even existed, starting when I was using bulletin board systems back in the '80s to use my phone to call into other local computers to chat with other people and play games. My degree was called, in the early '90s, Integrated

Media Arts, which was all about thinking about how to integrate different forms of technology together for artistic or other reasons.

When the web hit big in '95, I was already more than a decade experienced in that space and have been leveraging it ever since, largely for educational purposes and often to create opportunities for young people who didn't have the economic advantages and the resources that came with them that I had growing up. I've helped them be empowered to use technology, in one way or another, to pursue their interests and dreams.

The pandemic forced people to figure out how to communicate online, socialize online, work online, dance online, do performances online, run Passover Seders online. I'd been doing this stuff for decades, and quite specifically working with young people. It's what I do—supporting adults to work with young people.

It's a strange moment for me that the stuff I've been trying to build the capacity for organizations to do for years is now what suddenly everybody needs.

Q: Has your work changed very much as a result of the pandemic, given that you were already doing a lot of work with online communication?

Joseph: My perspective hasn't changed, but the needs I'm filling certainly have. I work at Girl Scouts, as I mentioned. It's about 1.4 million girls around the country in troops that are organized into 111 different Councils. Within a few weeks of the pandemic starting to hit America in March, all Councils were told to stop their troops meeting in person. This was also in the middle of our cookie season, which is where the bulk of the income comes from for all of the Councils. Many people know the cookies. Those cookies aren't sold all year. They're only sold over a few months. So it was right in the middle of it for many folks.

The troops tend to be tied—not always—to the school season. We knew that if schools weren't reopening, then troops weren't going to continue in person. That meant that they all would have been interrupted in the middle. Schools were continuing online, in some capacity, but Girl Scouts had little in place to support troops to be able to run remotely, to support the girls to keep connecting.

So within a very quick period of time, within a period of days, we had to come up with a number of different strategies and approaches to support the girls at home with their families to get content, to keep doing the Girl Scout activities, to support troop leaders with tools and resources they needed to run their troops online, in order to support them to do whatever they were figuring out. And to create new ways for girls to connect with each other and with Girl Scout activities, like through live events, and selling their cookies online.

So what I do hasn't changed. What's changed is that now everybody needs someone like me, and I'm able to contribute to many more areas of our work. Of course, we're going to be back in person someday, and between now and then, there are going to be lots of pivots between in-person, not in-person, things being blended during those same periods, depending on what peoples' needs are and what the communities are doing. So we are in a period of tremendous change for the next year—maybe eighteen months, maybe two years—where we're going to be pivoting back and forth between fully online, fully in-person, and blended. The switches need to happen very fast between the two.

Like every informal learning organization, we are trying to figure out how you build for that in a sustainable way to help girls feel like their troop is not always about meeting in person. Their connections will be with their troop leaders, with the values, with the traditions of being able to pursue their interests and being able to demonstrate what they learned. We think it's better to do it in-person, but that's not what is required. So how do we figure out what that essence is?

#### FRIDAY IS TOMORROW

And whether they're doing it in-person or virtually, that it's still a constant for them during this time of change.

Q: It's pretty amazing. When did that change first begin for you?

Joseph: I actually wrote about it for the *Forward*, like an online opinion piece. I'll submit it into my file so you can have all the details...

# Article: This is Not About the Bagel, nor the Seltzer Man

An excerpt. Originally published in the Forward June 3, 2020

For me, it was a bagel—my last taste of normalcy before the "new normal" arrived, eaten mere hours before NYC effectively cancelled the school year for my children. The inevitable was fast approaching—had arrived in fact—and I was just slow to accept it.

My family was in Philly for the weekend, the only guests at my wife's sister's youngest's birthday party, the only ones brave/foolish enough to make that trip. That Friday, Philly had cancelled school. The hotel where we stayed, usually sold out, was at 10% capacity. So when we packed our bags to return home to Queens, to what was beginning to feel like the opening scene of a post-apocalyptic movie, I could not resist popping into the Montreal-style bagel shop just south of Rittenhouse Square.

For over a decade I've started each work day buying one toasted bagel with butter, which I'd devour walking between the cafe and my office, finishing before arriving at my desk. But my bagel place would close down along with other New York City non-essential businesses; as I write this, it has yet to open. So that day in Philly, I bought an everything bagel, still steaming hot, plus a bag of more that could last for days. It was my "what would you bring to a desert island" moment. It was my last grasp at the old normal. It was the last time in now two months I've bought food, let alone anything, from a store.

Back to that hotel in Philly, and how empty it was. I want to explain what I did there, after sending my wife in advance to walk to her sister's place with the kids. I needed some privacy. I needed to speak at a funeral.

That morning, back in Brooklyn, Eli Miller would be laid to rest. It had nothing to do with the pandemic. He was a Brooklyn icon, a recently retired seltzer delivery man whom I featured in my book on seltzer<sup>2</sup>. His family, fans of the book, had reached out to me to provide a eulogy. Sorry, I said with true regret, I would be in Philadelphia.

But just a few days after the call, by the time I was in Philly, Eli's funeral had moved to Zoom so that family from Pennsylvania to Israel could participate. It turned out, I could eulogize the greatest Brooklyn seltzer man. As I sat alone in my hotel room, empty of people — both in my room and throughout the hotel—staring at the panel of close-up videos revealing the exquisite intimacy of faces in mourning, I was not only taking my first steps into the Wide World of Zoom that was poised to transform my life. I was developing new skills that I would need just six weeks later when I delivered a socially-distanced eulogy for my own dad.

<sup>&</sup>lt;sup>2</sup> Seltzertopia: The Extraordinary Story of an Ordinary Drink. Available where all fine books are sold.

# **APRIL 2020**

In which Passover goes virtual... hospitals are negotiated... Dad dies... A funeral is held... mourning is re-defined... an iPad is donated....

# July Interview Continued: COVID-19 Oral History Project

...Q: I read what you wrote about the experience with your father's death, and then the subsequent experiences doing things online. I want to make some space to talk about that. If you feel comfortable talking about it, it would be really great.

Joseph: This year was the first time I hadn't been to a Passover Seder<sup>3</sup> with my dad. My dad ran them when I was a kid. And when I was an adult—well, when I was away at college, I guess I didn't do it then for a few years—but then eventually, as I became older, we were always together. And eventually I took over from him and led our Seder.

We had set it up for him to join us on Zoom. Forty minutes before it was supposed to start, Carol, my stepmom, contacted me and said that he had fallen and wasn't doing well and maybe had a fever and couldn't join.

The Seder was great and I loved it. It worked really well. We did a lot of innovative stuff that made it really meaningful for me and, I hope, for people in attendance.

The Passover Seder is a home-based meal ritualizing the story of Moses leading the Jewish people from slavery to freedom. In the U.S. it is usually repeated two nights in a row.



But the whole time, I was terrified because he wasn't there and I didn't know what was going on.

Over the next three days, it became clear that something was wrong and that he'd have to go to the hospital. Now, the context here is that he went to the hospital a month earlier—this is before the pandemic became a problem—and had other issues. He had fallen actually, clipped a piece of furniture on his way down, and lost a chunk of his ear.

### Q: He's 87?

Joseph: 87, yeah. And there was no reason to think it's COVID-related. I mean, it could be COVID, but it was just as likely that it was something else. He wasn't having COVID symptoms. It was other stuff, or so I was told.

He went to the hospital the next day...

### **Hospital Diaries**

### Day 1: Friday, April 104

**12:00 AM (midnight):** I spoke with a nurse who saw Dad. She said he's in a room, comfortable, and is very funny. He is stable and currently being evaluated. They are awaiting results in the next few hours from imaging, and from the lab test (blood work). They'll know that in the next few hours but I might not be up then. They also tested him for COVID but that will take much longer (I don't know how long) to get those results. That's the latest.

1:00 AM: Dad still in emergency room. He just went to X-ray so they can check if he has had a fracture, just because he had been falling. The initial lab blood work looks fine—nothing jumped out to them. They did a CT scan on his head, due to the falls, but those results are not yet back. When he came into the hospital his fever was at 99.1 (last I heard when he was at Atria it was around 102). They do not believe he had a stroke. I don't know when the COVID test comes back, but the earliest they've seen is 4 hours. I'm going to bed and will call them first thing in the morning.

7:47 AM: I spoke with a new nurse. She has had him since last night. She said "he has been a gentleman." He is having a hard time peeing so they gave him an antibiotic for possible urinary tract infection

Dad was transported around 10:30 pm from his place at Atria, the assisted living facility, by ambulance to the emergency room at Long Island Jewish Hospital. He'd been falling repeatedly, was physically weak, had issues urinating, wasn't totally with it, and had a fever. I took notes every time I called the hospital, to help me track my dad's condition and record whom I spoke with (when and why) so I could advocate for him. Sometimes I re-wrote them to share the highlights via text with my wife, sister, step-mom, and step-sister; other times they were my reference guide and to-do list.

(UTI). He has no fever (he's been around 99 degrees) and had no chills since arriving there (she suspects he was given some Tylenol before he arrived at the hospital and that that brought down his fever). His other vitals are good. He is breathing on his own. She suspects the falling is from the UTI, as well as the fogginess. The lab work doesn't look like COVID to her (the usual markers are not there—so it could be but it'd be a coincidence with why he needed medical care) but they did the test anyway and they are keeping him in isolation until the results come back; the results are returned to the hospital in batches and can be up to 24 hours. His CT scan came back fine (so with his 5 or so falls this week, it looks like both his brain and his bones are fine). Although he is still in the emergency room, they have admitted him to the hospital, due to the falls. She said the falling and fuzziness is common to UTI and once resolved, with some physical therapy (PT) and antibiotics over the next few days at the hospital, his balance should come back. Since he is still in the emergency room he can't yet use a phone; there are no phones there for patients—to stop the spread of COVID—so we can't reach him until he gets admitted into his own room. The hospital is not full, just busy, and they need to bleach the rooms from head to toe first. Once he's in his own room, in a few hours, he can use the phone there to call us. He has asked to speak with Carol a number of times. They explained staff are not allowed to let patients use their phones, but she will give him a message I gave her from Carol (I made some stuff up but, trust me, it sounded good). I asked about his spirits and she said "He's a sweetheart. We're buddies." So there's not much for us to do other than to wait a few hours and call back to learn if he has his own room and phone.

**12:40 PM:** I spoke with a new nurse. She said "He's not doing too bad." Vitals are okay. She checks up on him every :30 minutes, to make sure he's okay. No fever at all. COVID test not returned yet. Still in emergency room, just waiting for his bed. He is taking a nap right now. They can FaceTime on someone's iPad now (!!). So I gave them my number. This is something new—someone brought it in to try it out. They did a urine culture for UTI, and currently waiting

on the results. She said: "He's great. He was talking with me about his pediatric practice, then talking about the measles vaccines, and some study in Europe..." Then she held the phone while speaking to another nurse while I was listening and I heard her call him "My awesome guy there..." So: he seems in good spirits, waiting for his room and COVID results. The doctor will call me as well, at my request, just to confirm all of this. If you have messages you want me to share with him if we can FaceTime, please let me know (and Carol, what number can I give them so they can try to FaceTime with you as well?)

**8:20 PM:** Just spoke with a weird doctor. He told me nothing.

**10:23 PM:** He is in Tower 411, in a private room. The night nurse I spoke with, who has been working with him, will be there until 7a.m. She said he is sleeping now but will wake him soon for his medicine and will tell him we send our love. No COVID results yet. When I asked how he seemed she said he seemed okay, but tired (which made perfect sense). There is a phone in the room, but she didn't know how to direct us to call it; instead she said to call tomorrow and ask for "the secretary," who will be in at 8 a.m., to connect us with room 411. I will call him then. She said physical therapy won't happen on the weekend, so if he'll be receiving it that should happen on Monday. That's all folks for today. Good night!

### Day 2: Saturday, April 11

**6:30 AM:** Dad just called with the help of the night nurse. She left the room so we could speak. The volume was not loud enough so I could hear him but he could not hear me. It was very frustrating for him and he called for the nurses. We agreed to hang up and that I would call the nurses.

I called the nurses' station and reached the night nurse. She went into the room and called me from there. She could not see a way to turn the volume up any more. She said the secretary comes in at 8 and could help see if the hospital has any different phone he can use. They also just started something new with tablets for the rooms so we can video chat. The secretary can help with that as well.

Before I hung up I asked her some questions. No responses yet on the COVID-19 test. When I asked how he's doing she said "He's doing okay," which sounded conditional and when I pushed was based on his mood. With assistance they got him to the bathroom, but it was still frustrating for him. She'd spent the night frequently chatting with him to cheer him up. He currently has no TV access. She thought the TV payment process had not yet been turned on but when she checked she got it on for him; I asked her to look for tennis, but who knows if that's available. He does not have his phone (which he could use to speak with us), his glasses to read, nor anything to read if he did.

So at 8 or soon after I will speak with the secretary or day nurse to 1. see what we can do to get a phone he can use to hear us and/or the tablet and 2. explore with her if we can get him some reading materials (many options have been paused due to COVID-19). That will then lead me to 3. work with Carol to possibly get him his phone, phone charger, glasses, and a pile of *New Yorkers*.

**8:20 AM:** Spoke with the receptionist at the nurse's station (in until 3). A person is now going around with a tablet, connecting with patients' families on Zoom. About 10 AM they start, so I should call back then. She will call TV and phone services to ask about a different phone.

**9:00 AM:** Spoke with a new nurse. I got Dad's direct number in his room. The staff that manages phones not in until 1 PM. I will follow-up with them then. He has already eaten breakfast. He's currently in the bathroom, so they suggested I call his room at 9:20; I asked for an aide to be there to help him answer and to make certain there's nothing that can't be done to make it louder on his end.

**9:21 AM:** I called his room but couldn't reach him. Spoke with nurses who said he's fed, cleaned and asleep. Must be exhausted, with everything, and fell asleep. I spoke with a new nurse. His COVID results are in and she said he is positive. She couldn't tell me anything else and I can't learn more until at least noon. She said she will try to call me from his room.

**9:40 AM:** They called me 4 times from the room. They couldn't hear me any of the times. I heard nothing three of the times. One of them I heard my dad asking the nurse if she had had breakfast yet. It was frustrating. I called the nurses' station but there's no answer. When I call his room there is no answer.

**9:54 AM:** I called the nurses' station again. I asked to speak with a doctor about Dad's COVID status. The nurse says they've been trying to call me. Then she put me on hold. She came back and said they were trying to call me on the tablet; I said I wanted to speak with a doctor. The nurse said the doctor is not available but a physician's assistant (PA) is checking the patients now, and I can speak with her later, at noon. I need to call back at noon.

**10:04 AM:** The nurse was able to reach me. She figured out how to turn up the volume. Dad and I spoke for a few minutes. He feels tired but nothing hurts. He said he slept a lot last night. He'd like his glasses and a *New York Times*.

Then the physical therapist (PT) was doing her evaluation. I spoke with her to answer her basic questions and set a baseline for her. She will make a recommendation and I can ask a nurse after 4 what she advised. So, I need to call back at 4 PM.

The nurse is trying to help me call directly into the room. When I call it just rings. Turns out Dad's direct number in his room is different from what they had told me. Now, I call and it works. The PT is still there, and says he was able to do some things with him but he's tired now and wanted to stop. So I said goodbye to them both.

12:30 pm: I spoke with the new physician's assistant who just saw Dad. She said he looks good. The most important thing to her is that he is having no difficulty breathing and is well hydrated. The PT recommended he be moved when he can from the hospital to a rehab facility. Also, a new nurse said Dad looks good. She also said everything he is experiencing is due to COVID. She says it is unlikely he has UTI. So the fuzziness, his loss of balance, and that fever that came and went are all symptoms that some seniors are having connected to COVID. But right now—and that can change—all of his vitals look good. And they will watch these on a daily basis, as they can change. If things stay like this—his breathing and hydration remain good—then they can move him early next week to a rehab. There are rehabs that have COVID wings. They can provide him with the physical therapy they can't provide at the hospital, as they are strapped. When he goes, the fogginess and weakness might last, and is what the rehab will help him recover from. I will hear from a social worker who will discuss with me rehab options and I will call Forest View Center (which Atria recommended) to see if they could take him. End of report (going to eat lunch).

We discussed his DNR status.

**1:25 PM:** The nurse at Atria told me which rehabs to request and in what order.

**3:30 PM:** Chatted with Dad for :25 minutes. They got him a speaker phone. Mostly he listened as I told him things. His responses were a word or two. I checked after every few sentences to see if he was following. He said he was. I explained his condition to him. He asked and I told him Carol was well.

#### **FACEBOOK POST:**

My dad went into the hospital late Thur night, April 9th. It was confirmed today he has COVID. He is NOT (at least for now) suffering from some of the worst symptoms we tend to hear about—

his breathing and hydration is perfectly normal—but he has other COVID-related symptoms—lack of balance, a fuzzy headedness, and being tired. He is in a great hospital in Great Neck, in a private room (after 24 hours waiting in the emergency ward). If he remains stable over the next few days he'll be moved into a rehab to get the physical therapy he will need. Carol is managing well and, while remaining at Atria, will act, and be treated, like she is positive as well (no reason not to, and no need for her to leave Atria to get the test). I'll try to post updates once a day and, while I will read and appreciate any notes below, won't be planning to respond to any as I'm overwhelmed with managing and balancing my current load of family and work responsibilities, but know I love you and we here appreciate all your support (which is why I am sharing this with you).

**4:30 PM:** Carol has a 102 temperature and has been taken to the emergency room of Long Island Jewish Hospital. Lily says: "Atria says if she tests positive but no other symptoms they will let her come back."

### Day 3: Sunday, April 12

10:30 AM: Spoke with a new nurse. She said his confusion comes and goes, and she did not attribute that to the COVID. Otherwise she had nothing else to report. I chatted with her about Dad's phone situation. It turns out it was not a speaker phone they brought into his room yesterday. The phone by his bed, which is very hard for him to use to hear anything, is still there. When I chatted with him for :25 yesterday I had thought they had brought a speaker phone into his room. It turns out they brought a type of Amazon Echo device into his room, and that is what I was using to speak with him. It's so new most of them don't know how to use it or what to call it. I now just spoke with Raj (maybe a floor manager) and she said tomorrow they will see what can be done to get him a speaker phone. So until then 1. it will be hard for us to speak with him, 2. we will probably need to be very patient and work with the nurses to speak with him,

and remind them not to hand him the phone receiver but instead to use the Amazon Echo, 3. follow-up on Monday with their TV and phone dept to see if there's a speakerphone available and 4. Carol, should we consider getting his cellphone today, as that might be something that can be used for him to speak with us (or does he not know how to turn that to speakerphone as well?). If anyone has any other thoughts, please let me know.

11:00 AM: I just spoke with Dad for 10 minutes. His responses were words and phrases, not always clear (in part because he's not able to project). So mostly I just spoke to him about the banalities of my life —I think he just wanted to hear a familiar voice—and then he said he was tired so we ended the call and I said I'd call him later. I asked if he had spoken with Carol yet today and he said yes (but I wasn't sure I believed him).

7:30 PM: Chatted with Dad for :20 minutes. He can hear me fine over the Alexa device, but I can only follow 1/3 of what he says—in part because he is having a hard time projecting and enunciating, and in part because the Alexa device muffles everything (it's hard for me to speak to the nurse over it as well). He mostly just wants to hear me talk, about anything. He has no awareness of the COVID pandemic, at all, and I have to remind him each time.

I then spoke with the nurse assistant who tells me how much she likes him, (same person who got Dad that 1/2 sandwich last night and told me that he had got mad about Trump). She said he has had a loss of appetite, which is common for COVID. He is asking for PB&J; they will look but that can be hard to find. She will look for turkey as well. He is shaking a lot too, she said. I explained he might not be getting all the regular medications he takes. She said she will contact a nurse to talk with me more about his medical condition, and to learn what medication he needs to be taking.

She also told me I need to ask the PA if there are underlying conditions they need to address. To say: He is not the same as how we

left him last week. So a PA—physician assistant—can get me more in-depth information.

Finally, she told me when it gets dark he gets more forgetful. They call it sundowning. It's a thing with elderly individuals. Once it gets dark they act differently.



### Day 4: Monday, April 13

7:15 AM: I called to check on Dad and to speak with a doctor. They said, Change of shift. Check in at 8.

I called back to see if there was someone there from last night who was about to leave who could track the night for me—and I named the nurse I last spoke with. That seemed to work.

Didn't work. No one knew who she was. They said they are in the transition now and I should call after 8.

**8:00 AM:** A nurse answered, who told me I had reached the wrong nurses' station. I did not know that was even possible. I asked who can give me an update on my dad and said I need someone's help to speak with him. She sent me to the other nurses' station, no one answered, and it went back to her. I asked her instead to connect me with a doctor. She said she would give them my number.

I called again and spoke with a nurse. She said 8:30 am is the general recommended time to call. Staff has transitioned and rounds are over by then. She told me the name of the nurse I should ask for. And I should ask her to call the PA.

**8:40 AM:** I called and asked for the recommended nurse. I waited :25 minutes on hold then hung up.

**9:05 AM:** A nurse answered. Wrong side of the floor again. She transferred me to the other side's nurses' station. A new nurse answered. Said she had spoken with me earlier. I said I did everything she told me. She said they are busy. I said, So am I. She will try to get to me through the Tablet. But she doesn't know how to use it. But she will try.

9:35 AM: Still no call. Still waiting.

**9:36 AM:** That last nurse called, from Dad's room, on the Tablet! Then she unplugged it and then called me back. I chatted with Dad for 19 minutes. He said he slept so-so, and was fine physically. "I am mixed-up. I want to see you," he told me. "Appetite is not good. I'm ready to go home," he said, and asked "When will you call me?" I told him dinner and he said all right.

**11:12 AM:** I spoke with his day nurse. "He's okay," she said. He ate some food, but not everything. She has seen patients getting confused like this, when they are low on oxygen, but his oxygen is fine. I am thinking he could be missing his regular meds. She will pass

Debby's<sup>5</sup> phone number to the doctor to get the updated list. Debby should ask that person who calls what their assessment is for his next steps, if vitals stay the same—would he be moved to a rehab for physical therapy?

**12:14 PM:** I just spoke with his social worker at the hospital. They say Dad is close to being medically stable for discharge to a rehab. Perhaps as early as tomorrow. The goal is to get him "closer to his baseline" where he can get 90 minutes of physical therapy a day. We discussed facilities and she will call me later when she has more information about their availability. I have her number if anyone needs to speak with her directly.

**2:00 PM:** Dad called. He said he wanted to talk. But when he reached me he didn't say anything. A nurse said she doesn't know why. I used the opportunity to have her tell him the hospital said he'll be able to leave in a day or two, and remind him I will call him after work today.

# Day 5: Tuesday, April 14

7:24 AM: Nurse said to call back after 10. In 3 hours! "It's a shift change, and then they have to do an assessment." I said I just need someone for one minute to call me from his room, as I start work at 9, will be in meetings all day, and it would make a difference for his spirit. She blew me off, I think she sent me to the phone in his room, which he can't answer.

**9:10 AM:** Got nurse to call me from the room so I can talk with Dad while they fed him and gave him medicine. On for 17 minutes. Couldn't communicate much at all with Dad.

<sup>&</sup>lt;sup>5</sup> Debby is my sister. She is younger and lives in Manhattan.

**3:50 PM:** I spoke with the social worker. She said they don't have clearance yet from the hospital to release him. They had wanted to monitor his white blood count for a little longer. She did send referrals to rehabs but can't ask for space until he is cleared to leave. She will follow-up with the medical team, hoping she will hear back before she leaves at 5 today, and once she does she said she'd be back in touch with an update.

**4:10 PM:** Spoke with Dad's nurse. She shared what Deb heard earlier, that his white blood cell count increased. It was 8.19. It is now 19.53. They will check again tomorrow. Today he is more restless and agitated. I should call and ask the attending doctor how he is tomorrow morning, and if it doesn't go down ask why not discharge him, and what the concern is? I told her he likes classical music, and she said she will try to get some to play in the room.

**6:55 PM:** I called at 6 and asked to speak with Dad. At 6:55 they called me back from the room. For a half hour I stayed on the phone with Dad—I don't want to say we chatted, as mostly I was just keeping him company—and then his nurse came, gave him some water, and he promptly fell asleep. When he was up he said he wasn't in any pain, just exhausted. Tomorrow morning they will check his white blood cell count, and compare with today's and yesterday's. My understanding is we're hoping it goes down, if he's going to be discharged soon.

# Day 6: Wednesday, April 15

**7:00 AM:** Called to speak with Dad, or nurse. They said they'd call me back.

**10:00 AM:** No one called me. I called again. They moved Dad to a new room, 422B, to get him closer to the nurses' station. Tablets are down right now. IT is working on them.

I spoke with a new nurse. His white blood count was not done for a reason she does not know. I asked her to get it done, as we understand it's the only reason he is in the hospital at this point. She will ask the provider if they want to do it and I can call after noon to ask her for the results.

She said otherwise he is okay. Stable. Keeps taking his clothes off because he is hot. So they moved him closer to the nurses' station.

**10:30 AM:** I asked the social worker to call the provider, and escalate it. She will do that. But she recommended I do the same. She taught me new language to use when advocating for him: he is "deconditioning" and we want to get him back to baseline.

**10:48 AM:** The Rehab called to check in. She gave me more recommendations on which ones to avoid.

12:38 PM: No one called me so I called and asked to speak with a doctor. They gave me the PA; he will ask Dr. J. the plan for next steps, as he is the attending doctor. Only Dr. J. can speak to the treatment plan. The PA said Dad's white blood count went down to 10.7 (from 19—he was at a healthy 8.9 two days ago). I told him that the social worker said Dad needs to be medically cleared for discharge. Doctor J. will decide if Dad needs to be held an extra day to see if count holds or if he can be discharged. Dr. J. will call me but, if he does not, then I will call the PA at 5 (he is on today until 7).

**12:50 PM:** The social worker has coverage for social work tonight when she is out. So a rehab ask can still be made tonight if Dad is cleared. But she also needs nurse's paperwork as well, to be updated, if a nurse is available, and won't know until tonight (if a case manager is available). And then it depends on what time the facilities will take new people. The social worker will leave my contact information for the new social worker coverage (starting at 4:00).

**2:30 PM:** They called me with the roving iPad and I got to FaceTime with Dad for ten minutes, and see what he sees. That was really nice.

**5:00 PM:** I called to speak with PA. Got a new nurse instead. She will call the PA and ask him to call me.

**5:08 PM:** The PA called me back. He spoke with Dr. J. He said the doctor will call me back. I told him I was about to give a public talk from 5:30 - 7. The PA said he will ask the doctor to call between 7 and 8. I asked what to do if I don't hear by 7:45. He said call the nurse on the floor and ask them to call him, insist, saying "expecting update today."

**7:50 PM:** Called to speak with Dr. J. They put me on hold then said Dr. J., the provider, would be calling me.

**8:24 PM:** Dr. J. called. (He'd had my wrong number.) Dad is doing okay, when it comes to COVID. He was ready to discharge him this morning, but then someone recorded him with a fever of 102.8, so he decided to wait. They took his temperature multiple times over the day and the fever never returned. So tomorrow he'll check on his white blood cell count and make sure there's no fever. And if that's the case, then he will discharge him. He said I should call back between 11-12 tomorrow morning, and ask for the PA, to learn the decision.

**8:45 PM:** The nurse tried to connect me with Dad but the Alexa didn't work. So she called me on the phone. He was super weak, but probably late in day so tired. And hard to hear him. But he said "Hi Bar" and I told him I loved him, said they are almost ready to release him, and said good night.

#### FACEBOOK POST

Day 6: Today Dad was set to be discharged, as his white blood count returned to normal, but then he had a fever—for just an hour or so—so they decided to keep him in. He's been fine all day and if

they can say the same in 12 hours from now then they SHOULD discharge him tomorrow (once they can find a rehab to take him). Fingers crossed!

# Day 7: Thursday, April 16

7:00 AM: Called nurses' station. No answer

**7:20 AM:** I received an email this morning, from the social worker. "I just wanted to let you know that I will not be in the building today. I don't know which social worker will be covering today. Any questions, please call the unit."

**8:13 AM:** I called and asked for the PA, but he is busy. I spoke with his new nurse. There was no fever overnight. Dad is on "room air"—he was on oxygen but no longer needs it. He is calm, but fidgety.

**8:20 AM:** Called for social worker to check on getting him to a rehab. Left message.

**11:13 AM:** I asked to speak with the PA to learn if Dr. J. has made a discharge decision. They said they will give him my message.

**11:20 AM:** I was told Dr. J. is seeing patients. He will call me afterwards.

**2:10 PM:** Never heard from Dr. J. Calling for him again. The nurse took the call. She said she will page him, or call me back.

**2:36 PM:** The nurse has not received any update. Doesn't see anything in Dad's charts about the discharge.

**3:30 PM:** I spoke with the nurse. She will reach out to the PA again. Their new Alexa system is no longer connecting to their wifi. They don't know why. By 3:50 we decided I will try the phone. Dad and

I spoke for 5 minutes, using the regular phone— he mostly could not communicate but if held to his ear he could hear me—and was able to start and end the conversation (I love you, bye, etc.). He eats fruits, pureed; avoids pureed proteins.

**4:00 PM:** I called the social work office and left a message that I had never heard back.

**5:00 PM:** The PA called me back. Dad medically cleared to go. He spoke to social worker mid-day, around 12 or 1. Paper work is done at his end. So we are just waiting for social worker to find a space. Once a location made, the social worker will call me. They will not send him outside the hospital without calling me. And if it doesn't happen in the next hour or two it most likely won't happen until tomorrow. He told me typically they have 300 patients in the hospital; today they have 500, and they are spread all over the hospital.

**5:00 PM:** Called Social workers again, as they never called. Left third message.

#### FACEBOOK POST

Day 7: In one hour it will be exactly one week since Dad entered the hospital. The hospital approved him for discharge today—the challenge now is finding a rehab that has a space for him. No luck today. Maybe tomorrow.

### Day 8: Friday, April 17

**7:30 AM:** I called the Social Work Dept. Left a message. It's been 24 hours since I called yesterday and have yet to hear back.

**9:43 AM:** I spoke with someone at Forest View. They have accepted him, medically and financially. They will hold bed. He could be transferred this afternoon.

**9:45 AM:** I called the social worker. She will check in now and catch-up with me in an hour.

**10:52 AM:** The social worker, called. All's good. Dad is stable for discharge. Forest View will accept Dad as well, which is preferred. They are scheduling 1:00 for transportation.

**12:00 PM:** Spoke with Forest View. Dad will be on the 4th floor. I got the case manager's name. Once paperwork is distributed, and once they meet with him, then they will call me this afternoon around 2-3. They have video chat. We'll set times.

**2:00 PM** A nurse called from the hospital to let us know Dad just left to go to the rehab, to Forest View.

### **FACEBOOK POST**

Day 8: Dad is being discharged and if all goes as planned will leave in a few hours to go to the rehab right by his home (and mine—and our preferred choice). This is great news! Once he is there I can speak with them more about his treatment plan and their assessment on getting him back on his feet and returning him back to Carol at the assisted living facility. Can't thank you all enough for your support over this past week. It's not over yet, but this was a hard hill to get over.

3:00 PM: I called the case manager at Forest View. Left a message.

**5:20 PM:** After two hang-ups, I was sent to 4th floor nurses desk (x134). He doesn't have a phone in his room. Dad was admitted at 2:14 today.

4th call - A nurse is looking for someone for me.

5th call - Social worker's answering machine answered for some reason

6th call - Same nurse answered again. She was finally able to connect me with Dad's case manager. Notes to self:

- 1. Monday we can go over the intake questions—we set up a time for noon.
- 2. Ask afterwards if I can speak with nurse to learn his health.
- 3. COVID isolation—when does that change—ask doctor. Save for next week.
- 4. He needs clothing. 2 weeks worth. I will collect from Carol and leave at front desk. Housekeeping will label and they will do laundry. They said they will also work with me to get our iPad connected. Just put his name on it and say what room.
- 5. Video calls are available—they are using a tablet. Maybe Skype or google hangout. They do it once a week, for 20 minutes, and can do it as a group call.
- 6. There is no phone in his room. We can set up a phone in his room through Verizon. They can ask about open rooms on 2nd floor on Monday so he can have a phone. They will take an iPad from us and will work with us so we can speak with him. We would coordinate with the nurses, who will ask a supervisor and then call later to ask for a nurse or supervisor; and Dad's case manager can help during the week (once a day).
- 7. He is isolated now, due to COVID, so all of his activities are in his room.
- 8. I need to speak with Dad's case manager next week about his treatment plan, discharge plan, and progress. She will work with his therapist. Atria will send a nurse to evaluate before he can return.
- 9. I learned the name of the nurse during the week, in from 7-3. The supervisor changes every day.
- 10. In two weeks, they'd have a care plan meeting if he's still there, to do the discharge planning. And invite me to the meeting. If he can be discharged before it they will be in contact.

Then I tried to speak with a nurse. I met the Nurse Supervisor. She had just assessed my dad (6:07). He is stable. He is now on oxygen. I mentioned his eyeglasses. He was responsive but she couldn't understand his words. He didn't touch his food. She will ask Director if short term room is available, then that might be possible for the phone. She said over the weekend I should call after lunch to get his health status.

For the family: I finally got a hold of folks at Forest View. To be honest, it was much harder than I anticipated (it was easier at the hospital). I spoke with Dad's case manager (X110). She will do a formal intake (asking me questions) on monday. I asked her a lot of questions to get the lay of the land; I won't write it all here but ask me what you want to know and I'll answer if I can. He needs clothing for two weeks. Due to availability, they put him in a long term care section; the implication of this is there's no phone in his room. And because he's in isolation they can't take him out TO a phone; so I will bring over with his clothes tomorrow an iPad, which they said they would manage for us so we can speak with him. I have not yet been able to speak with a nurse, but will keep trying.

I then spoke with the nurse supervisor. She said he was stable, and is now on oxygen (from what I saw at the hospital his need for it comes and goes, and it is COVID-related). He's not eating much, communication is hard, and of course he's tired. There wasn't much more she could share with me.

Carol, Are you able to prepare clothing for my dad, and/or work with Atria staff to do that, and then have staff bring to the front desk (as I am not allowed in the building)? I can then get from the front desk tomorrow morning once you let me know they took it from your room. And is there anything else you'd like to have go over to him?

#### FACEBOOK POST

Day 8: Dad is now out of the hospital, but he is not out of the COVID-woods yet, and the rehab ain't home. So this is MUCH

better, for sure, but he still has a way to go. There is no phone in his room and since he is in isolation he can't leave to get one. Tomorrow I'll try to get him a tablet they can use for us to contact him.

# Day 9: Saturday, April 18

**8:50 AM:** Called to speak with Nurse to learn how Dad is doing and tell them I am bringing over clothing and iPad. I cycled 5 times with the nurses' station not answering. Then the receptionist at the front answered and said he'd send me to the nurses' station—we tried 4 times. I reached the nurse supervisor. White blood count is stable. His blood pressure is stable. No fever. Very restless. Still on oxygen (at 94). She said 10-10:30 is a better time to call. Lunch is at 12, so that is a bad time. Evening after 7 is also better.

**11:30 AM:** Picked up clothing from Carol, stood outside Forest View and used their wifi to connect our iPad from the street, and dropped both off at the reception desk.

**2:00 PM:** Calling nurses to ask if he needs pull-ups and if we can use the iPad to speak with my dad. They have them, and we don't need to supply them! Said they were short-staffed with only two people working, but if I called back in 15 minutes they could help me then.

**2:25 PM:** Called iPad. No answer. Called nurses' station. I was told she asked her supervisor if she can help. So I will just sit and wait for them to call me. So now I wait.

**2:30 PM:** The supervisor called me. It worked for she and I. But the signal dropped each time she went into Dad's room. She will call me at 11 tomorrow with her own phone, so we can talk, and Monday we can speak with the IT staff. She said Dad is very confused.

**-4:30 PM:** Long story short. Around 4:30 they called to say Dad looked bad and since he had no DNR (do not resuscitate) or DNI

(do not intubate) they would send him back to the hospital. I told him I would sign the DNR and DNI but they wouldn't arrange it. There was no doctor to sign-off. I realized I was not going to get anywhere with them on the phone. I realized if I got there in time I could see him, in PERSON, if I drove over in time, as he would be transferred from the facility into the ambulance. I got in my car and sped over, collected his clothing and tablet from the reception desk as I waited, worked with both Atria and the very supportive EMTs to see if anyone could do anything to keep him from going back to the hospital (nope). I prepared for my 10 seconds with him during the transfer to the ambulance. When he was wheeled out on the gurney his eyes were closed and he was breathing through something pushing him extra air, so he couldn't speak. But he didn't look much worse than our last video conference. He was breathing very fast. I had my gloves on and I asked the EMTs if I could touch him. They suggested that was up to me, not them. I found his hand under the cloth that was locked around him to secure him on the gurney. I told him "Hi Dad. It's Barry. I love you. You are being moved to the hospital to give you better care. If you think it's your time, go in peace. But if you want to fight you fight. You have had the virus now for at least 1 week, and you are actually doing really well, and for most people it passes on two weeks. So if you can hang in for a few more days you can defeat it." He moved his leg, which was strapped in, and he tried to say something, which he couldn't due to the oxygen. The rehab had been telling me he was unresponsive, which was part of the problem and why they wanted to send him to the hospital—which is why I said they needed to figure out how I could speak with himand this suggested to me I had been right. He needed contact from people he knew. The EMTs were patient and did not rush me. I gave them his clothing and the iPad. I was upset but grateful I could see him, and touch him, and talk to him in person. As I prepared to leave one of the EMTs said I could follow them to the hospital. Before long, with lights blaring, we went through red lights and took the twenty minute or so drive on the highway to the hospital. I parked and ran around to the back of the ambulance to meet Dad exiting the back. I told him all the same things again, and that I loved him,

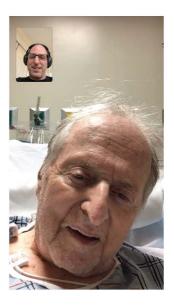
and watched him go into the emergency room. The EMTs were so patient, so amazing. They said they'd make sure the iPad was passed over. They also said I could go with them into the emergency room. I was taken aback— I guess that's a normal place for them and they don't know about the hospital's rules that keep all family out—and had to decline.

~7:30 PM: I got back to my car, allowed myself to collapse for a few moments, then called the hospital to see if they could move him to his own wing (no luck) and to make sure the DNR and DNI was in place (and they called later to arrange it). I also told them about the iPad.

**8:30 PM:** An emergency room nurse got our iPad onto the hospital wifi on her own initiative, went to FaceTime, found my name, and called me, hoping I might help Dad respond. It was late now, maybe 8:30, and he didn't respond. But I got to tell him I love him, good night, and that I'd call the next day.

### **FACEBOOK POST**

Day 9: Dad is back in the hospital. The rehab felt they couldn't give him the care he needed. Maybe, maybe not. In any case, he's made it through emergency room triage and the attending doctor said he's "hanging in there." Soon they'll admit him, and I can talk with the nurses tomorrow morning. And THIS time I got them to take the iPad I set up, so we can call him and see him. Oh, the silver lining is as soon as I heard the rehab had called the hospital I ran over in my car and made sure I could hold his hand and speak with him both when he was entering the ambulance and disembarking at Long Island Jewish Hospital.



# Day 10: Sunday, April 19

**8:30 AM:** I called and am now waiting for a nurse to call me back, and someone else to arrange for me to speak with Dad.

**10:00 AM:** Called again to speak with the nurse. On hold for :15. When they returned they said she was "in a code." I asked to speak with another nurse. Given to a new nurse. He is doing okay, she said. His breathing is fast, so she notified the doctor. In a bit they will do a chest PT to loosen up chest secretions. He is on oxygen now, with mask (at 89/90). They will evaluate at the time for swallowing. No fever. I asked to speak to Dad. She said to call back in 2 hours. I said how about right now?

They got him on—his eyes were closed, his breathing with an oxygen assist. The nurse said he moved his hand, so she thought that meant he was responding to me. I told him what was going on, to rest, and to fight.

**2:00 PM:** Driving to Floyd Bennett Field, the former airport, to kite fly with the family (and just to get outside of our apartment while being far far away from others) the hospital called. Over the car speakerphone, the doctor said his liver is close to failing. They wanted to know if we wanted dialysis or not. They recommended not, given his age and condition. We all agreed. She recommended we call right away to say our farewells. I was driving, and still 10 minutes away from our destination, so Noemi texted my sister so she could call first. The kids were in the car, included in all of this, but what choice did we have?

Having arrived at Floyd Bennett Field, I heard from the nurse. On the derelict runway, in the wind, we walked as I spoke over FaceTime on my iPhone through the iPad with Dad—with oxygen he couldn't speak—hoping he was hearing us and understanding—and Miri cried, and Akiva with bowed head, and Noemi at my side, I said all the "right things" I could think of.