

Flew to south carolina to be able to bring my mom home from the hospital after a dizzy spell. Was home nurse/companion for her for 17 days after. Was a wonderful time to get 1:1 time with her, and she got better every day until I was comfortable she was good on her own.

Exposed a lot of unmet needs for me for seniors like her.

She is 87. She has a primary care doc, and a set of 5 specialist docs who help with her kidneys, gyno, heart, lungs, eyes. No group text messaging for them to talk to each other. No shared EMR. Each is operating independently. No way for us, her kids, to easily talk to her docs, the nurse who comes by once a week, or the physical therapy person who comes once a week. So one of her kids has to advocate for her with all of them over the phone individually.

Hospitals now use "hospitalists", different doctors than my mom's regular doctors. Seems it is to make more money. Creates a lot of confusion. No group text messaging for them or the nurses to communicate with my mom's 6 regular doctors. No communication by them to my mom's regular doctors. She goes to the hospital and they aren't informed during or after unless my mom does it.

If I hadn't been there to pick her up from the hospital, they would have sent her to a nursing home/rehab center. The nurse at the hospital was aggressively trying to convince me that she should be in a nursing home. But a few days after the hospital exit she was doing great at home. It is way cheaper for the healthcare system if she can be at home, and it is what she prefers. But she was being pushed to be in a facility.

My mom's primary issue is her lungs, as she now needs oxygen assistance. Turns out medicare pays a company \$4k every 5 years to handle my mom's oxygen needs. My mom is using Rotech, a group that seems to have 100+ locations in the US.. 18 months ago the doc put her on nighttime oxygen and Rotech delivered a machine that costs \$700 on the internet to her. They charge medicare \$110 a month for 36 months for that. When the doctor wanted her to also get daytime oxygen, Rotech is supposed to offer her a portable oxygen concentrator under the same \$110/mo. They didn't seem eager to do it as they wouldn't make any more money. They delivered to the hospital really kludgy oxygen tanks to use on discharge day. The tank only lasted 30 minutes, was heavy, and required a wrench to turn the valve on and off. No way my mom could have handled them on her own if I wasn't there. We used them to get home and then I started researching options. I figured out all the medicare rules over a week of research and started asking the right questions of Rotech and then suddenly 12 hours later they showed up with the oxygen concentrator device we asked for on day one. Mom on her own would have been stuck in the house and not been able to go out to her doctor appointments without me there advocating for her. Rotech delivered an oxygen concentrator that was functional, but big and heavy. We paid out of pocket for a \$2500 unit that she could handle much better.

Mom is in that position where she wants to live at home, and can live at home. Hardest is she has 6 different doctors that want to see her about once a quarter, and they are all in different

places and the visits aren't coordinated. She'd love to have someone be able to take her to those, hasn't been able to have that during covid. Found a woman at church now who will help her as she has had her 2nd vaccine shot. There is a site seniorhelpers.com, which is like a rover for seniors at \$20-30 an hour as a backup. I showed mom how to use lyft and uber as a 2nd backup to get to appointments.

She takes 14 different medications. Each doctor has her on a few. They don't coordinate between each other. Every doctor visit she has to carry a printed out spreadsheet of her medications so each doctors office nurse can reenter her updated medications. She ended up in the hospital as her heart doctor was prescribing meds to optimize for fluid around the heart which caused dehydration and thus other problems elsewhere. The doc also had no followup to see what her blood pressure was between visits after doubling her blood pressure meds. It got too low, which with her oxygen issues caused her to pass out when she stood, which caused her to fall and end up in the hospital. After three times in the hospital over four months, and lots of her son advocating for her and calling her doctors, we have her meds balanced and she feels great.

Most every round of doctor visits results in changes to one or more prescriptions. Any change upsets all of her work to order and manage and take her prescriptions. She has to get pills that have been prescribed for over 90 days via mail order at Optum. The other recently prescribed ones she can get at her Publix pharmacy at higher cost to her and medicare. Optum is very slow and disorganized. We tried to use their app to reorder a prior prescription and they sent the prescription request to a doctor she has never had so they rejected it. The customer service agent at Optum said their system messes up all the time. She'd love to use Pillpack, but there are medicare rules she doesn't fully understand, and each time she goes to a doctor appointment she often gets changes in her prescription lineup so she can't get a 90 day supply of all and then have one change. Since pillpack isn't an option, every two weeks she lays out all her different pills on the table with a cheatsheet my brother made by gluing a sample of each pill to a laminated card, and loads up a pill tray for each morning and night set of pills for the next two weeks. If optum is too slow on one of the deliveries, she can't do the two week process. If a doc changes a prescription, she has to go back through her two week pill kit and change it.

On electronics, she uses an ipad and an iphone. We changed her cell number as it was ringing 20+ times a day with spam calls. The home phone gets 15 calls a day from spammers, so we are going to have to change that number too. She signed up online somewhere for a political one newsletter, and I had to remove 100+ of them from her email that were far right wing newsletters. She kept asking me questions that she had clearly read from all these fake news sources. One said obama had passed a law that was going to take all her money and that worried her. She just wants to relax and enjoy life and have her phone and ipad as communications devices to her healthcare providers and loved ones.

She was having trouble hearing so my brother was able to find a great audiologist and get her hearing aids that work well for her. \$6k out of pocket for those but they are a game changer. Also have bluetooth so she can now hear on her cellphone which is directly connected.

During covid she doesn't feel safe going to the grocery store, so walmart+ is a game changer. She tells me what she wants over the phone and i order it on walmart+ for delivery. Biggest challenge for her is moving the heavy stuff from the doorstep to the kitchen.

Her finances are pretty simple. Another brother handles it. Hardest part are the weird ira and 401k required distribution rules she has to pay attention to. She gets social security and my dads pension so doesn't spend all of what comes in monthly except for times when she has to dip into savings for hearing aids or oxygen concentrators. If she didn't have the pension, it would be much harder as that allows her to fund medicare advantage part F which covers her 20% copay on medicare and makes all hospital visits free. So few have pensions in the next generation and so few have savings that a single trip to the hospital will bankrupt them.

Mom is pretty close to needing to be in a place close to one of her kids. We've been researching and found [Storypoint](#) near my sister. Awesome place. 3600 a month baseline for a small functional apartment, then they get to bill medicare for lots of services they can deliver on top of that. Storypoint is owned by one family and has many locations...a great service to customers, and a great business model it would appear.

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My sister passed away a few years ago from cancer. She went through years of experimentation where doctors were treating her with a variety of medications and radiation. Was very clear the doctors didn't really know what to do. She was a human guinea pig.

But unfortunately, very little of her data survived when she passed. She would have been happy to share her 23&me report, her daily health journal, etc to help the scientists use that data to find better solutions.

While alive, she would have been happy to contribute her EMR data too, and hear about potential new clinical studies that might be a fit for her.

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My father in law has pancreatic cancer. They have kaiser with a shared emr, and still they don't communicate well between doctors. My wife has to be his advocate.

A family who goes through it figures it out, then would be up for helping others through it. Part technical help advocating. Part emotional support by being willing to journey with you.

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- Is there a plaid for electronic medical records, so it is easy to pull emr data together

- Use cass.ai's 211 call/text triage system and ai engines to help triage patients with volunteer advocates
- Use platform feed engine to build a social net for patients/caregivers/docs so everyone can walk together

Unit economics

- \$ for sourcing data and clinical trial participants
- Maybe a monthly fee
- Do insurers cover it as it lowers their costs?