

What we learn from T-Bro

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When I was 11 years old my grandfather had both his legs amputated. When I was 27 years old my grandmother had one leg amputated. When I was 30 years old my father had both his legs amputated. On May 4, 2009, my mother's leg was amputated and on August 18 she had a heart attack and double by-pass. On June 18, 2009 my twin brother had a heart attack. He had by-pass surgery on July 11 and his second leg amputated two days later. On September 24, 2009, my older brother had his leg amputated. They were or are all diabetic. In my family of origin, I am the sole surviving member that is neither diabetic, has heart disease, nor any amputations. I am healthy.

The opening paragraph is part of a thank you letter sent to professionals who work in the medical field. My older brother and I are the surviving members today. My twin brother (T-Bro) is a poster boy for what works and what doesn't work in managing disease. Upon his passing in 2016, he was a triple amputee who was on dialysis with excessive comorbidities his Diabetes created including CHF (Congestive Heart Failure). Despite the severity, he managed to walk the streets of Manhattan unassisted even at night on rain soaked streets till a year before his passing. What T-Bro teaches us is what works and what **don't** about what we do every day to treat disease and govern care in the United States.

Diagnosed at ten years old with pre-diabetes, T-Bro was placed on a sugar free diet to resolve the problem. His first serious episode occurred at the age of thirty-eight when he experienced his first heart attack. The last three years of his life were spent in many hospital beds. Fifty-percent of his hospital stays had more to do with getting

consensus about care involving numerous doctors. Thirty-five percent of his out-patient time was spent attempting to coordinate his care after discharge. I stopped counting how many discharges he had after fifteen. Care management was a luxury which T-Bro could not afford and his insurance plan did not provide.

Population health and chronic care management are buzz phrases we use to refer the **effort to support** patients that live with disease proactively since 2008 when *Obamacare* redirected our economic thinking. While some things are better, we have further to go. Silos still exist. Fragmentation still exists. Communication failures still exist. Despite technological advances for care, data collection, and remote communication, it is still segmented. The costs are enormous for everyone with a sizeable portion that is never reimbursed giving the professional collection agencies works by default and tax payers a greater burden.

Diabetes is at epidemic levels globally claiming an average of eight percent of the population and growing. Public health experts focus on the things patients can do while they work through the greater complexities all chronic disease presents. As someone who lives the diabetic life as a non-diabetic working in the health industry for over thirty years, I have valuable wisdom to offer despite the lack of a medical degree. A lifetime degree suffices.

Taking cues from business and medical science about mapping the chronic disease journey, I recommend that we start with pre-diabetic confirmation. Primary care physicians have improved diagnosing it and directing patients to educational programs. Winthrop University Hospital, located in Mineola, New York has

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an excellent diabetic educational program to teach patients and their primary care givers about Diabetes. They also follow through with attendees to assist with adaptation.

Such programs exist all over the United States. But it is not always open for pre-diabetes only newly diagnosed diabetics. After the educational program and adaptation portion is complete what happens from there depends upon patient lifestyles, mindsets, culture, age, economics and the severity of the disease.

At the point of pre-diabetic or diabetic confirmation there are several steps that can be accomplished that will prove economically and socially invaluable long term. The first is to assign a care manager or care team at point of diagnosis that stays in contact with the patient and family more frequently during transition or disease eruption and then quarterly or half yearly thereafter. A phone call, video chat, or if necessary a home-visit are options. Part of the care manager's responsibility should include ensuring that patients have all the providers they need as part of the coordination of care at every stage of life.

Recognizing that insurance plays a role and life changes occur with every patient, it should be standard operating procedure and standard coverage that a care manager be part of every patient diagnosed with chronic disease. If patient records can transfer from one doctor to another so can patient data from one care manager to another. Monitoring and coordination easily identifies and eliminates the gaps that occur episodically that contribute to disease escalation. The upfront costs have already been proven and documented as worthwhile downstream.

The second step is to connect patients to remote methods that allow them to better manage their disease and their time collaborating with numerous doctors. Auto-office visits causes non-compliance. Stable patients may only need an office visit once or twice a year in tandem with quarterly communication that care managers provide. Disease active patients will have opportunities to better communication with care professionals to determine if an office visit is appropriate or another direction needs to be taken to which care managers would be informed about.

The third step is to include pharmacy as part of the care team responsible for medication management and monitoring able to report back

to providers and care managers with a click of a button. Non-compliance happens. Pharmacy has become sophisticated enough that text reminders up to four times a day can be sent to patients and/or caregivers to monitor, measure, and encourage compliance. The technology is available cost effectively. Care managers and providers can be alerted when patterns occur necessitating investigation as to why. Monthly reports and medication reconciliation is now a pharmacy requirement.

These are three very small examples that exist in health care now. They are segmented and it is up to the patient to learn about them, coordinate them, and most of the time; pay for them. In T-Bro's case, that was not an option not because there wasn't a lack of desire but because it was too complicated and too overwhelming for him and his family.

In fairness, some of what is suggested didn't exist ten years ago. But care management did. It was standard procedure in managed care fifteen years ago to control costs specific to managing provider and procedural costs. When it was determined to not be effective it was eliminated. Fifteen years later it has shifted to managing chronic disease and a sub industry now exists for that purpose.

Mapping chronic disease is an effective tool. I use the visual box and circle method for every step of the process. The picture demonstrates where the gaps are. It is an excellent project for a college intern or class to perform.

At T-Bro's worst, there were at least twenty-two entities involved in some manner of his care. They included two health insurance companies; one for care as an out-patient and one for an in-patient. None spoke to the other. Discharge planning failed most of the time because no one was there to ensure it would happen upon entering back home. Frantic calls were common and stressful. Hospital discharge responsibilities end when the patient is wheeled to the curb where transport is found.

There were numerous office visits with different doctors in addition to dialysis three times a week but T-Bro still had an accounting practice to run in order to support his family which suffered with every lengthy hospitalization.

Clients would see T-Bro at the rehabilitation center during tax season so he could complete their taxes after part of his left hand was amputated. They kept his spirits going as he kept them out of tax jail. The rehab facility was

partly chosen because they had strong internet connectivity.

As an industry insider, I recognized what worked and why. I recognized what didn't work and why. My insights have the power to change what we do with the existing tools we have and the technological capabilities first becoming main stream. I understand it is complicated but sometimes we are so caught up in the minutia we can't see.

There is nothing complicated about a patient needing a haircut just to feel better. Go find a barber or hair dresser willing to come to a patient's bedside. That is the challenge I have with my older brother now. While not our problem as health practitioners in the grander

schematic, it is part of the ecosystem of patient life like internet connectivity.

I invite you to learn about T-Bro not because his story is any different or better than many other worthy stories. T-Bro represents what we can do with one disease based upon one case we can map. In doing so; we then have an algorithm that is adaptive and able to replicate. Adaptation is necessary because chronic disease manifest differently for everyone. We then use existing solutions that are logically and intuitively assigned, measured, and monitored. It evolves into best practices. It drives down costs. It reduces human suffering. Most of all it lets a twelve-year-old; thirteen-year-old and eighteen-year-old have their father longer than they did.