

“Pandemic Disabled”: The New Disability that was Always There **By W.K. Sheldrake**

The A.D.A needs a new classification of “disabled”: *Pandemic Disabled*.

Pop Quiz! What’s the most common prosthetic in the world? Immediately you think of devices for lost limbs, athlete’s sprinting with spring customized legs, or perhaps a mastectomy bra. None are the answer.

Answer: prosthetic heart valves.

182,000 prosthetic heart valves are implanted per year in the U.S. ¹ My prosthetic aortic valve was implanted in 1993, to replace the defective valve I was born with. The math suggests that there may be as many as 4, 419, 000 Americans walking around with man-made heart valves since then. It could be more, since these valves have been around since the 50’s. Pick any realistic number, high or low, this means that, as a minority, the number of prosthetic heart valve recipients in the U.S. could be more than 1.3% of the population. If we were considered A.D.A disabled, it would make us about 6% of disabled Americans. ²

Me disabled? Handicapped? You’d never know. I was an athlete. I used to make leaps as tall as tall buildings in a single bound, and even after open heart surgery I participated in a National Championship.

But, yes, me. I’m coming out of the closet. I’m disabled. And everyone with a prosthetic heart valve is, too. It’s important that it’s not my secret anymore because people with mechanical valves are among the highest of “high risk” during the COVID-19 pandemic.

A mechanical valve is not just a clever assisting mobility device. It literally makes my life possible. Without it, I’m dead. That said, beat for beat, a heart with a mechanical valve simply doesn’t function as efficiently as a

¹ (<https://idataresearch.com/over-182000-heart-valve-replacements-per-year-in-the-united-states/>)

² (<https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#:~:text=61%20million%20adults%20in%20the,Graphic%20of%20the%20United%20States.>)

normal heart. And, the disability of the valve itself is piggy-backed by another because proper function of the valve requires a dangerous life-long drug therapy. This second disability is also a secret. Even in a swimsuit, the passerby would never know I have it.

The Valve is a small piece of hardware, 25mm in diameter, titanium and plastic plumbing, implanted via open heart surgery. The Drug is an anticoagulant, warfarin, a “blood thinner.”

Why a blood thinner? Similar to a cut caused by a splinter, my system interprets the valve as an intruder. The blood wants to attack the invasion, rushing to the spot to repel possible infection, contain the damage and seal off the area by coagulating, by clotting. Without the “thinning” anti-clotting effect of warfarin, the heart--constantly and powerfully ejecting blood--would throw a barrage of constant blood clots into the bloodstream, streaking directly to the brain via the aorta and carotid arteries, causing debilitating if not deadly strokes. With warfarin, the clotting properties of the blood are muted, slowed down. Before blood clots form unnecessarily the blood moves along.

The proper dosage of warfarin is difficult to maintain and can change dangerously and quickly. Even at recommended dosages, those like me live an adapted lifestyle, limited from many “normal” activities and practicing an onerous watch-dog like responsibility to our health (We also have a shorter life span. Try to get real Life Insurance if you have a prosthetic valve. Forgetaboutit.)

Here’s the danger: we bleed almost three times faster than normal and three times as long. Meaning, any activity or event that might cause bleeding of any kind is off limits. Simple things like shaving with a bladed razor are discouraged. Everyday activities that might cause any kind of internal bleeding are taboo, too, including activities that might cause injuries from impacts, falls, collisions. No bruises, broken bones, pulled muscles, torn ligaments, please. Chef’s knives, power tools, any sharp objects, working on ladders are no-nos. So much for the fencing lessons. Ice skating, roller skating, skateboarding, bike, surfing, skiing--anything where you might hit your head--you better think about it.

Bleeding three times faster means I also bruise three times as easily and three times more severely than a normal person. No sliding into second base in the softball league; no backyard soccer. Simple pulled muscles for a

normal person can become serious hematomas for me--large, angry, painful. Deeper arterial bruising is life threatening, because the clots can travel to the heart and lungs.

With a mechanical valve and on warfarin you're in for a life-long run through the gauntlet of infections and inflammatory conditions and diseases, avoiding flu, strep, pneumonia, etc. Remember, inflammation is bleeding. We get three times the inflammation. Asthma, diabetes, autoimmune diseases are complex complications.

With a virus like COVID-19, a prosthetic heart valve and blood thinners are now comorbidities. Add on any of the above ailments (and a host of others) and you're stacking potentially deadly risks like a pile of pancakes with coronavirus for the syrup. I also happen to have asthma, and an aortic aneurysm, along with a history of stroke and cerebral hemorrhage. I'm a House of Pancakes "High Risk" Special.

Put it into perspective this way. A normal person has a fender bender, bumps his head on a window or the steering wheel--or has his head punched by an airbag. Ouch, for a normal person. That kind of blow can kill a patient on warfarin. It happened to my father; walked into an emergency room, never walked out. The warfarin assisted bleeding in his brain happened so fast it couldn't be stopped before he was already in a COMA. He had turned his airbag off, because that's what you do if you are on warfarin, because that punch in the face is risky, too.

Or put it into perspective this way. It is not uncommon for women on warfarin to experience heavy menstrual bleeding (HMB), abdominal bleeding (AUB). These bleeding complications can lead to iron deficiency anemia, as well as complications with contraceptive, which is complexly complicated by the fact that women on anticoagulants also cannot bear and deliver a child. Aside from the risks of anticoagulants to the fetus to deliver the child is to risk bleeding to death.

If this isn't a disability, I don't know what is. It's a disability that affects every minute of the day, even the penultimately normal repeated activity of eating. Diet profoundly affects warfarin's blood "thinning" levels. There's no food, beverage, flavoring or spice that doesn't affect the blood's coagulation one way or the other. Some do profoundly. Eat the wrong thing (liver) and your blood "thickens" increasing the risk of stroke. Or on the

opposite end of the spectrum, eat the wrong thing (oatmeal) that “thins” the blood and you increase the risk of uncontrollable bleeding.

Routine health is affected. Just like foods, there is almost no drug or supplement that doesn't either enhance or inhibit anticoagulation. The list of drugs a warfarin patient can't take is pages and pages long, including common over the counter medicines and many vitamins. No decongestants, no aspirin. No ibuprofen. (No ibuprofen? What?) No Naproxen. No vitamin E. No chondroitin/glucosamine. Vitamin K is the devil.

So, here's your life, constant monitoring of your diet, shielding from infections of any kind, deprived of many useful drug therapies and vitamins, hyper-vigilance of potentially dangerous activities, prohibition from dozens and dozens of sports, games and events normal people take for granted.

No wonder you can't get a Life Insurance Policy. You can't even get a Bucket List!

I can say from experience your mental and social health are affected, too. Occasion after occasion, I must pass on what everyone else is eating and watch while everyone else participates. Boiled onions in a soup (or any recipe) thin the blood. A volleyball bump bruises both my forearms.

Fast forward to COVID-19. My wife now can't hold her newborn granddaughter because there's a pandemic, because if I get infected there's no mild case, no waiting for a fever or not. The complex and confounding effects of this disease on inflammation (that is, bleeding) are more likely to leave me with yet more life-long comorbidities, or just dead. She can't touch that baby because an infection innocently passed to her then passed to me means a long hospital stay, if not a pine box.

And no matter how much we explain again and again, those of us with prosthetic heart valves--the most common prosthetic in the world--can't expect anyone to really understand. Even loved ones and close friends--normal people--tend to see our still vigilant isolation as a phobia, hypochondria, or a political statement. No travel? No birthdays? No funerals? No Thanksgiving? No Christmas? Are you nuts? “I had it,” they say. “It's not that bad.”

A phobia is irrational. Not getting a deadly virus, especially if it is specially deadly for you, seems extremely rational to me. Staying alive isn't a political statement. (Or is it these days?)

Conclusion: I don't feel irrational. I feel disabled, as limited in my mobility and access and as excluded as ever. And I believe the facts bear me out. People with prosthetics of any kind are not normal. True, I've selectively beaten the odds in some specific cases, selectively taken some risks that were risky. But, like anyone with a prosthetic, I am exponentially dependent on the health care system (and inordinately impacted by its expense).

To wit: during a highly infectious pandemic people like me are forced to decide whether to make appointments for weekly, monthly monitoring of the anticoagulant, forced to choose between missing important annual testing and consults with specialists or visiting the pandemic crossroads of a hospital or clinic. A harrowing gamble, akin to "mandatory air" for an extreme skier.

People like me have been forced out of public view (except in wide open spaces) by our own sensible choice to avoid erratically followed or widely ignored "voluntary," "self-monitoring" of pandemic health protocols, orders and restrictions. Every inconsistency is a threat. Every outing is an exercise in combat-like contingencies of risk management.

How to avoid infection on the paintballs course of the virus? Just ask us. Avoiding all chances of infection is the necessity of avoiding some.

I'm not asking for better parking spot at Wal-Mart. I can't even go to Wal-Mart. I won't be coy. I want people to be on my side. I want everyone to behave in ways that make my world, and everyone else's (including theirs BTW!), safer. I want people to make it a goal that they will not be responsible, directly or indirectly, for the anonymous death of any anonymous "high risk" person, including me. I want everyone to understand that from the perspective of those like me the threat of their casualness and/or militant normalness is direct.

I'm also asking for acceptance, acceptance for people like me in the form of active support, moral support. Because morale is going to go a long

way for people like me over the next few months. Every normal person knows at least one “Pandemic Disabled” family member or friend.

Attention must be paid. Make a call, send a text, an email, a post. Say, “I support you. I support what you are doing.” Think of all the lives saved by those like me staying home, really home--those unequivocally refusing to become a host for the virus. Avoiding the subject is nullifying the disability, and the person.

Whether the A.D.A recognizes the disability or not, say to your “Pandemic Disabled” friends and loved ones: “You, and people like you, matter.”

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