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Title: Disabled (due to Long Covid and ME/CFS) MN Worker

Greetings Legislators, Staff and others present at the MN Health Finance and Policy Committee. My name is Andrew (Andy) Flosdorf and I have Long Covid and ME/CFS.

There is so much I would like to share with you about my journey prior to and since having contracted COVID almost exactly three years ago. Some of that story has been documented here (<https://www.startribune.com/some-covid-19-long-haulers-in-minnesota-still-lack-diagnosis/600042154/>) in a Star Tribune article from spring of 2021.

In March of 2020, metaphorically, I was hit by a bus – which then shifted into park and stayed with the wheels still on me keeping me trapped and unable to move. The “bus” was Covid-19 and Long COVID. It is also ME/CFS.

There is so much that is not yet known about the two conditions – Long COVID and ME/CFS. What is known is that COVID itself is a multi-systemic disease that can affect body systems as diverse as heart, lungs, brain, kidneys, skin, liver, circulatory and nervous systems. My theory, formed through both my own experiences as well as trying to keep abreast of current research into the disease is that Long COVID can vary for EVERY person that has it because any permutation and combination of the systems above can sustain and retain damage from the COVID virus. In addition, however, there is the further complication of the ME/CFS condition. Does everyone who has Long COVID also get ME/CFS? I don't believe so. Do many? I think a large percentage do.

What makes me qualified to make that assessment? In my career, prior to being knocked out of it by Long Covid and ME/CFS, I spent 30+ years in the medical industry. While not a medical practitioner myself, I have worked closely with them for more than 20 of those years, including reviewing, writing, and editing medical protocols and creating new protocols under the supervision of Medical Directors and Directors of Nursing. I have a Master of Public Health in Management and Policy and worked for organizations as large as the largest health care providers and insurers in the State of Minnesota as well as tiny Medical Startup organizations, but always with the goal of trying to improve care and access to care for all Minnesotans, often for those with the fewest resources such as elders in Nursing Homes or those with disability.

My own experience with COVID, Long Covid, and ME/CFS has been traumatic and fortuitous.

It has been fortuitous because I have family, friends, professional experiences, and resources such that I have been able to find and leverage most of the help and support I need. This support network of family, friends and other resources have helped to keep me afloat. I have been fortunate because after about 31 months, Social Security finally agreed that I am in fact disabled and I'm now able to receive disability benefits from Social Security – a notoriously difficult thing to do. Had I not had all of these supports, my situation would have been much more dire.

It is currently estimated that between 10 – 20% of people who get COVID also get Long COVID. How many of them do not have the good fortune to be able to find and retain the assistance they need? How many do not have friends and relatives close enough to be able to continue helping them, sometimes for years as their symptoms linger for no one knows how long.

It has been traumatic, because for me, Long COVID and ME/CFS has meant the following:

- I am currently and for the foreseeable future, unable to work due to fatigue and brain fog.
- In the early days of the pandemic, I was gas-lighted by many Minnesota Doctors who did not even believe I'd had COVID, let alone that I could possibly still be experiencing symptoms 3, 6, 9, 12, or 24 months later. Now, at 36 months since the start of symptoms all agree that it was almost certainly COVID and that it is ME/CFS. It has been a long struggle to get those providers to that consensus and one I believe that I was only able to achieve because of both my persistence and my experience and connections in the medical industry, which helped me to find Doctors who were qualified to make those kinds of judgments.
- I have been fighting (so far unsuccessfully) with my long-term disability insurer, who has not provided any benefits under a long-term disability policy because they have chosen to cherry pick medical records from the first 3-6 months of that gaslighting period.
- I have little ability to do some of the most basic functions such as run errands, maintain my residence or even keep up with personal hygiene.
- If you were to see me in the community, I would not look disabled. That's because if I'm out in the community, it means that the prior day I took the one shower I'm generally able to take in a week and that I scheduled my entire week around the excursion so that my energy for that excursion was present. In the days before and after the excursion I slept extra and limited almost other activities.

Prior to having this condition I was a normal, healthy 50 year old male. I went to the gym four times a week. I shoveled my driveway. I mowed my lawn. I worked full time and was able to do all the errands, socializing, and other activities considered "normal" for fully functioning adults. Now. Simply. I am not able to do any of those things. Gym? No. Shoveling? No. Lawn? What used to be a 45-minute job is now an hour and a half over three days. Many times, much to my embarrassment and shame, it's been my 78 year old mother, who is fortunately in fine health, that has done that chore. How mortifying. I should be helping her do those sorts of things, not the other way around.

It is often said by many high functioning people that there are not enough hours in a 24-hour day. With Long Covid and ME/CFS (for me) rather than being 24 hours, it's a two-hour day and even at that, I'm working at 1/3 capacity.

When my Doctor, Doctor Ruby Tam of St Louis Park, Minnesota confirmed an ME/CFS diagnosis she said two things that really stuck in my head.

1. She said, "I'd have been better off if I'd had a heart attack. At least something can be done about that."

2. She also said that with the condition, I'm "like an old cell phone battery. I can only take a 10% charge, it takes an extra long time to charge, and the new operating system runs the battery down much more quickly."

With regard to what Minnesota can do to support and assist people with Long COVID, I have many ideas about how to assist. They all start with support for MN HF2930 (Liebling): Department of Health Budget Bill which provides funding to assess and evaluate the impact of Long Covid and ME/CFS in the State of Minnesota. This funding addresses a critical need and I hope that it will move forward to the benefit of all Minnesotans.

- The funding proposed in the Governor's budget will fund activities to proactively support COVID survivors whose lives are disrupted by long COVID symptoms and complications.
- The funding will raise awareness of long COVID; develop and implement up-to-date statewide consensus guidance for long COVID diagnosis, treatment, and care coordination; co-design tools and resources to support long COVID survivors, their families, primary care providers, public health practitioners, schools, employers, and local communities; contract with local media and communications, community surveyors, health care systems, and data partners to increase awareness and monitor impacts of long COVID; and provide grants to community and nonprofit organizations, long COVID survivor groups, and local and tribal public health to support those most impacted.
- Supporting this funding is the right thing to do. It is critical that these dollars be made available to support and expand the Minnesota Department of Health's work around Long COVID as well as making sure that funding funneled into community groups providing services to those impacted by Long COVID.

If there is anything else that I can do, or any other testimony that I can provide to assist with these efforts, I would be happy to do so.

Respectfully Submitted,
Andrew (Andy) Flosdorf
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