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## LIVED EXPERIENCE

**Child Patient | Teenage and Transitional Patient | Adult Patient | Patient Safety  
Caregiving | Patient-Provider Communications | Mental Health | Insurance Navigation**

### CHILD PATIENT

#### Acute Incident: B Strep Meningitis

Ft. Wayne, IN  
February 1983 – August 1984

- ❖ Three days in a coma in the ICU. Three weeks in the hospital pediatrics ward, including 2 CT scans and a spinal tap.
- ❖ Post-incident effects: brain damage, 18 months in a wheelchair with hemiplegia, muscle atrophy in paralyzed limbs and misalignment of back muscles. Occasional seizures and migraines. Physical therapy every day for first six months, occupational three times a week. Effects temporary except for musculoskeletal issues. Chronic strep for 8 years. Developed skill to self-diagnose.

#### Development of first chronic illnesses

- ❖ Allergies, including an allergy to fish and seafood (iodine).
- ❖ Asthma, triggered by weather and exercise.

### TEENAGE PATIENT

#### Type 1 diabetes

Ft. Wayne, IN and Northampton, MA  
March 1991 – July 1997

- ❖ **Lack of access** to care – no pediatric endocrinologist. Rigid approach and my own rage led to 6 years of non-compliance, and an eating disorder, [diabulimia](#).
- ❖ **Inpatient hospital stays** an average of 1-2x/year. Averaged 40 days out of school to accommodate sickness caused by sustained high blood sugars. [A1c ranged between 12 and 15](#).
- ❖ Nearly failed out of first semester of college due to unexpected impact of loss of support system.
- ❖ First complications: developed severe peripheral retinopathy and severe retinopathy.
  - Neuropathy: **poor treatment delayed diagnosis**. Forced to undergo **unnecessary test**, an EMG, which sent electrical current down dying nerves.
  - Retinopathy: diagnosis to surgery was 6 days. Iodine allergy prevented use of dye, had to be done freehand.
- ❖ Take **expensive essential medication** and wear **Class III medical device**.
- ❖ Developed cataracts due to high doses of steroids used to treat meningitis. **Doctor failed to communicate** diagnosis. I had to overhear it from a third party (not my parent).

### TRANSITIONAL PATIENT

#### Scared into compliance

Ft. Wayne, IN and Northampton, MA  
July 1997 – May 2000

- ❖ Treated neuropathy with amitriptyline, which lowered blood sugars without my knowledge and caused grand mal seizures. During school, lost consciousness 2 days in a row because of side effects. Parents were worried enough that my mother stayed in my college town 350 miles from home for the subsequent semester.
- ❖ Saw pediatric endocrinologist until graduation because issues were more common to teenagers than adults.

### ADULT PATIENT

#### Continued Complications

Washington, DC  
May 2000 - present

- ❖ Developed hypertension and diagnosed with mid-stage kidney disease before I was 30.
- ❖ **Learned that my body does not follow traditional rules, which drives the need for providers willing to look past their own experience:** kidney disease went from stage 3 to stage 2. Reaction to amitriptyline happens in 0.3% of patients. I was never supposed to recover from meningitis, let alone paralysis. Gastroparesis does not manifest traditionally. Breast cancer scare came down to, “your body just doesn’t work/look like everyone else’s.”

- ❖ Cardiac incident due to **failure to communicate** asthma to nephrologist – asthma prohibits beta blockers.
- ❖ Built **coordination of care** network based on excellent **patient-provider communication** – providers recognize my input is as valuable as their input, and treat me as a peer.
- ❖ Developed gastroparesis, autonomic neuropathy, and trigger finger in eight fingers. Learned to balance all my conditions separately and as a whole.
- ❖ Nearly sued employer due to lack of reasonable accommodation. **Discrimination** negatively impacted kidney function.

## CAREGIVER

Ft. Wayne, IN, Hartford, CT, Washington, DC

Parent with severe Crohn's Disease and terminal pancreatic cancer

June 1987 – March 2001

- ❖ Crohn's: Cared for parent when she was unable to care for herself. Memorized medications and dosages, and made sure she took what she needed when she needed it.
- ❖ Crohn's: Went with her to doctors' appointments. Kept her company and advocated for her during multiple hospital visits.
- ❖ Cancer: Primary caregiver while other parent kept his job in another state. Pushed for diagnosis when only symptom was back pain. Took her to doctors' appointments. Helped her decide on courses of treatment.
- ❖ Cancer: Stayed in her room for two weeks of hospice care before she died.

## Grandparent with dementia

- ❖ Assisted in finding appropriate assisted living facility, including research and visits to facilities/interviews of staff.
- ❖ Assisted parent with care and nurturing of grandparent once he was in the facility.

## MENTAL HEALTH

Ft. Wayne, IN, Northampton, MA, Washington, DC

In regular treatment since 1993

September 1993 – present

With every diagnosis, you have to change your identity. One moment, you are who you thought you were, the next moment, you are forced to change that. Even if it requires no change in behavior or medication, you still know that your body is not as strong as you thought it was. Even the less serious conditions can chip away at mental health.

- ❖ Built defensive walls during meningitis recovery due to stigma of wheelchair-bound child in the early 1980s.
- ❖ Began mental health treatment at 16, but was resistant, became expert at telling therapists what they wanted to hear.
- ❖ Spent fruitless 2 weeks in locked psych ward in an attempt to address non-compliance and diabulimia.
- ❖ When I got scared enough to be receptive to mental health treatment, I began a journey of self-discovery, and now I understand the motives behind my own behavior, then and now. It worked because current therapist challenged me on a statement during first visit, and offered to find a better fit if I did not fit with her.
- ❖ Lost main source of emotional support to pancreatic cancer. Had to decide whether I would let myself drown in my medical issues (sink or swim). Strong secondary support system stepped in and helped me to swim.
- ❖ **Chose career based on which companies could pay for my health insurance.**
- ❖ Kidney disease diagnosis was the first time I directly feared for my life.
- ❖ Breast cancer scare took 10 days to resolve. It was one of the scariest periods of my whole life.

## INSURANCE NAVIGATION

Washington, DC

Learned from the inside

February 2002 – present

- ❖ Parent was in-house counsel for life and health insurance portfolios for Fortune 500 insurance company. Made sure I knew how to read and understand documents, including language, summary plan description, how, and who regulates insurance. Learned **methods of payment**, how to track bills/reimbursements, and to lodge a complaint/file an appeal.
- ❖ **Denied coverage** of Rx due to PBM's arbitrary decision to contradict medical community regarding qualification. Dealt with changes to coverage of critical supplies **without being informed** beforehand.
- ❖ Managed coverage from 3 different insurers. Bought **long-term care insurance** at 29 because I was offered a policy without an exam. Afraid no one was ever going to let someone like me have access to affordable long-term care again.