

Chronically Their Mom.....



Renee Swope, RN-Chronic Fatigue Clinic Nurse

- I graduated from Burge School of Nursing in Springfield, MO in 1993.
- I worked in a pediatric step-down unit and the NICU at Cardinal Glennon Children's Hospital in St. Louis, Mo in my early years as a nurse.
- I got married and moved to Baltimore, MD in 1998 and was a stay at home mom for 13 years until my youngest was in elementary school.
- Worked as a school nurse in our county in Maryland for 10 years as my kids progressed through school.
- Came to Johns Hopkins as the Chronic Fatigue Clinic Nurse working alongside Dr. Peter Rowe after all 3 of my children had become patients of Dr. Rowe- all of them with POTS and ME/CFS.

Mothers of children with health challenges pour themselves dry. They do this because they must, because they know that no one else will fill their child's well of need, and because their hearts break for their ill children. As hard as it is to be the parent of an ill child, they know full well that it is even harder to be that child.

The Immeasurable things like fatigue and brain fog are "invisible" to most people. These kids don't always look sick.

Before ME/CFS



After ME/CFS



Having an invisible chronic illness is hard enough. Being doubted, judged or dismissed is heartbreaking.

Meghan: 24 year old

- Had an acute onset viral illness at 12 years of age, in the ER x 2, tested negative for the common things like mono, EBV, strep.
- Received her 2nd dose of the HPV vaccine just prior to the viral illness.
- She had an immediate intolerance of upright posture.
- Standing test showed a supine heart rate in the 60's rising to the 120's within the first 2 minutes of standing (60 beat increase) with worsening symptoms of brain fog, sweating, lightheadedness, fatigue and acrocyanosis.
- She has food intolerances of gluten, dairy and egg that were not present prior to onset.
- Insomnia, gut dysmotility, hyperhidrosis, endometriosis, thoracic outlet syndrome, POTS, anxiety and depression all not present prior to her ME/CFS diagnosis.



- Meghan was quiet, but social in school and she danced 4 days a week and played the piano prior to the onset of her illness.
- Very bright and eager learner with no difficulties in school prior to her illness.
- Dismissed by the cardiologist saying that they didn't think ME/CFS was a real illness.
- Graduated from high school on time via on-line school, then managed PT esthetician school graduating on time with her class with the help of some major compression garments and stools to sit on during clinical sessions.
- She is now a certified medical assistant working as a research assistant in the Chronic Fatigue Clinic and is taking classes to enter into the nursing program.

Me: I need to do a thing.
Body: You did a thing yesterday, that's enough things.

Treatment: midodrine and floriene initially and more recently with ivabradine, Ritalin, OCP's, desmopressin, cromolyn, wt B12, and an antidepressant.

Jack: 20 year old

- Diagnosed at 15 y/o after his brother became ill, but did not have an acute illness trigger, (started showing symptoms at 12-13 y/o)
- Jack developed a 52 bpm increment between his lowest supine and peak standing heart rates, along with provocation of **fatigue**, **lightheadedness** and **leg acrocyanosis** on his standing test
- Frequent episodes of **syncope** with postural provocation began in year 4-5 of the illness
- **Insomnia** is a nightly problem
- **Hyperhidrosis** (shows 2-3 x daily) and changes clothes a LOT.
- **Depression/Anxiety**



- Always an introvert, but not antisocial and did not struggle in school until the 7th grade when he started to show what we thought at the time was executive dysfunction (AD/HD)
- We had a full psychoeducational evaluation done at that time, but no medications aimed at focus were helping. He was c/o some of the same things as his sister, but I just thought he was trying to avoid school because he had some anxiety after dealing with some bullying in middle school
- Visited the school nurse frequently to try and go home (before he was diagnosed) when I thought he just didn't want to be in school he was likely feeling pretty badly and pushing through.
- After his diagnosis, Jack chose to move to on-line school like his sister had done and graduated on time. He is currently taking on-line computer cyber-security classes.

Can I order a replacement body please, this one is constantly malfunctioning

Treatment: salt, fluids, atenolol, Latuda and vitamins B and D, along with melatonin and Benadryl for sleep.

Schaefer: 17 year old



- Diagnosed in the 7th grade at 12 y/o after an acute onset viral illness like his older sister.
- Schaefer had an impressive **76 bpm increase in HR** with standing, and had to terminate his standing test prematurely due to increased symptoms of **lightheadedness** with profound **acrocyanosis** of his legs.
- **Fatigue** that he described as a "heaviness" that would not lift, had him in bed for 2-3 months at the onset after the viral trigger.
- **Insomnia** is a nightly problem that was not present prior to the illness.
- **Hyperhidrosis** has been present since early childhood.

Treatment: salt and fluids along with melatonin and Benadryl for sleep as needed. He uses weight training to help maintain muscle for improving vasoconstriction.

- Very social and athletic kid who also had no difficulty with school prior to diagnosis.
- Had played travel soccer continuously since 2nd grade and generally never stopped moving.
- Made a vow that he would never visit the school nurse (unless he was forced to take medicine at school) because he says "just because I can't stand up for 5 minutes, doesn't mean I'm sick."
- Currently a junior in high school, but quit playing soccer so that he could try to remain in public HS. He has a 504 plan with accommodations in place, but rarely uses them.

Anyone can fake being sick. It takes real talent to fake being well!

~ In chronic illness ~

When the medical encounter consists of curiosity, empathy, validation and a willingness to problem solve, there are fewer distressed patients.

- Dr. Ingela Thuné-Boyle

What educational challenges arise for those with ME/CFS?

ME/CFS educational challenges:

- Individuals feel worse in the mornings, when blood volume is lowest, and do better in the afternoons
- Insomnia and disrupted sleep schedule common
- Symptoms wax and wane, often unpredictably, making planning and attendance a challenge
- Symptoms persist longer after common viral illnesses
- Symptoms are often worse after vigorous exercise
- Cognitive problems can mimic ADD/ADHD
- Orthostatic symptoms are often worse with prolonged standing or longer periods of sitting (block classes)

Educational Accommodations-Any of the following can be recommended, depending on the student's physical condition:

In the school:

- A person designated as a single point of contact for both teachers and the family.
- A shortened day/shortened week; the student might arrive late, leave early, attend school for only part of the day and/or only 2 or 3 days a week; students with sleep reversal might not be able to manage morning classes.
- A reduction in course load and flexible scheduling where only classes in selected subjects are attended.
- A quiet place to rest if fatigue is evident to the student or the teacher.
- Use of the elevator to access different floors.
- Exemption from or modification of, the physical education program.
- Provide homebound instruction or Distance Education for students who are partly or completely homebound.

In the classroom:

- Provide two sets of textbooks—one for school and one for home.
- Use the buddy system, so that someone can take notes in class, allow taping of classes, and/or give the student an outline of material taught.
- Permit the use of electronic devices such as a laptop or tablet and allow work to be completed and submitted online.
- Permit a student with orthostatic intolerance to move around during classes.
- Allow salty snacks and a water bottle for use in the classroom and especially during long tests.
- Provide tutorial or homebound instruction for work missed or if the student is too ill to attend school.

Assessments/Testing:

- Allow flexibility with assignments and deadlines as well as modifications of the number of problems and/or assignments to be completed.

What can school nurses/counselors do to help these students and families?

- **BELIEVE** that the child is as sick as they describe themselves being. It is heartbreaking when they are dismissed and it has been the toughest part of chronic illness for my own kids. Not feeling seen and/or heard is very demoralizing.
- **CARE** about them like you would any child that is diagnosed with an acute illness, theirs is chronic, but not any different to them.
- **GIVE** them a place to take respite when they are having a bad day (without making them feel badly about feeling badly), while also setting boundaries to avoid over use of the nurses office. (come at the end of class when work is done or lecture is finished if possible and always check in with the teacher first so they know where you are).
- **COORDINATE** with teachers, counselors and administration and encourage a 504 plan and letting them know they have a back-up plan.
- **COMMUNICATE** with the parents when there are concerns. Usually the parent can easily validate if they thought the day would be a rough one that their child was trying to power through or if there was some stressor that the student might be avoiding.
- **UNDERSTAND** that they will have good days along with the bad days and never make them feel badly for feeling well enough to have fun and participate in the activities that can sometimes give them trouble. Also understand that these kids can power through almost anything that they want to do badly enough, but it can come with the high price of a debt of fatigue that can last for hours, days or weeks after.
- **LEARN** as much as you can from them, they are usually willing to share their own knowledge and experiences that might help someone else down the road. (except Schaefer, because he's not sick!)



SHE BELIEVED SHE COULD, but she was tired.

(So she rested and you know what? The world went on and it was ok. She knew she could try again tomorrow)

one day at a time

Chronic Quotes

"But you don't look sick"
Are you accusing me of faking my disability or are you asking what concealer I use...

DAILY REMINDER:
Not everyday has to count. Some days are about just making it to the next one. That counts, too.

"It's like swimming upstream every moment that you're awake"

"Yes, hello, I'd like a refund on my body. It's kinda defective and really expensive."
— anyone with a chronic illness

