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After the Endoscopy, in Which You Looked into My Guts and Found Nothing

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After the Endoscopy, in Which You Looked into My Guts and Found Nothing

Cover Page Footnote

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After the endoscopy, in which, you looked into my guts and found nothing, July 2017

In the summer of 2016, I began to notice that my body had stopped digesting food in the usual way. Pain and pressure and the tremendous sense that my guts were paralyzed began to dominate my life. My food seemed stuck, and my belly blew up like a balloon in increasing levels of severity. I blamed it on stress and stayed away from the doctor. Previous experience told me there would be no help there, as stress causes illnesses that the system cannot see, hear or touch.

I thought I'd never again be well.

When I finally sat myself in my PCP's office, the burning epigastric pain pointed to ulcers as the likely culprit. But proton pump inhibitors and stomach-coating Carafate did not help in the least.

On the day of my endoscopy, I waited nearly an hour for Dr. Gastro, laid out in a gown in an endoscopy suite, while the anxious RN (who sensed the growing wait time) chatted with me about his career and family. I thought the oxygen mask and tubing, along with the plastic mouth piece, would all choke me to death. Prior to entering the endo suite, Dr. Gastro had visited with me in a curtained room and spent a total of 45 seconds before the procedure, performing a perfunctory prep consisting of rapid-fire questions about my symptoms, while allowing me no time to answer. She proclaimed that my ascending colon was likely filling with gas, advised me to cut out gluten and dairy altogether and immediately. I sensed she had no idea of the weight of my pain. And how could she? She was managing truly "sick" patients out on the floors that day.

Versed takes over quickly. I wished they would just send me home with it, and I could live outside of myself for the remainder of my life. At that point, I would have given anything for safety and relief.

The endoscopy was normal. I should have been delighted that my esophagus and stomach were so pink and perfect on the inside. And no sprue from celiac or ulcers or acid damage to be found. I was sent home with instructions to cut out dairy and gluten, no gum, no bubbles, no apples or beans or FODMAP's. [See the handout.]

I remained overwhelmed with the sense that my guts weren't moving, but now believed I would have to live with it for the rest of my life. There were no answers for me, and I didn't know how I would come to live with the pain. I recalled the words of my family doc, who had exclaimed when I pointed to my upper right hand side, "That's your gallbladder! You're young and healthy for stones, but I can order an ultrasound." I had tried to follow the most likely route by proceeding with the endoscopy first (with special consideration for my out of pocket costs and a little bit of disbelief). Turns out my attempt at prudence backfired in the end and only added delays.

July 22
Betrayal of my

Body

Forged in stone

over eons (years or
months) Eons

Left me to sit in a
Disaster

Sudden comes sedative in the
form of mock

mockingbird delighted
from one to eternity

The wings of Doves
Betrayal of Self
Formed in mud
I would never choose
umbrella over Rain

until now

July 23
Stillness walks all over me.

I send out my Blood, coursing
into the Stillness, and decide

I can Hang Handle it

I aim for Stillness and Bubbles rise

can't help themselves

reminders

Choking on the serpent's tail

After a year of payments, my financial ordeal did come to a close. Patients become familiar with the barrage of statements in the mailbox, notices and questionnaires from the insurance carrier, bills from the hospital – for the nursing and endo suite time, from the clinic – for the gastro doc and the surgeon care, the radiologist, for the interpretation of the ultrasound, the surgery center, for the anesthesia and from pathology and lab for taking a specimen and writing a story about it.

After the endoscopy... while living in limbo, every attempt to eat led to unbearable burning and the inevitable blowing up of the balloon on my right side. I drifted in and out of waking dream-state such that dreams became nightmares and shifted back into dreams of fantastic sweetness. Trauma brain took over, and I sat out back by the stream behind my house and wept. By then I couldn't even pull on a pair of pants because the waistband seared my abdomen, and I resorted to dresses at work, ate little bites of oatmeal and sucked on popsicles to maintain my blood sugar.

Refer back to list of low FODMAP foods, said the institution. These fermentable oligo-, di-, mono-saccharides and polyols are wreaking havoc for you. After a few weeks, you will feel well, after you cut out fructose, garlic, wheat, milk, soybeans, lima beans, asparagus and stone fruits. It's Irritable Bowel Syndrome or some sort of food intolerance, nothing more.

"Did you not hear me? I can't eat anything!" I cried. "Something is terribly wrong." (But no one was listening...)

I seemed to be so close to answers, and then came to recall again and again that my guts were frozen in time. The pain took over my sense of self, and when the burning became so hot I could barely feel anything anymore except the oblivion of the other side (death?), then my belly turned to ice.

Eventually, Dr. Surgeon reached in for my gallbladder but it didn't come willingly. She had to increase the size of the incision during the procedure, for the stone had nestled and grown and the organ was grotesque with yellow-green swelling (when bile is static, it melds and hardens).

tongue slides back in my
mouth
Bile will rise

I never write pleasantries
Lately
How did I become So Heavy

There is a list
of things I cannot tolerate

List
grows
longer,

When will I reject everything?

Every last lovely bit that makes this world
whole?
Will I be safe then

Would
will
that I build
up Fortitude
instead

Fucking Fortitude

Again, the castle Burns
like salted candy
Formed in the shape
of Cinderella
and Beset to the side with
coals
Taffy scars,
pull away
Right side out

The castle, slides
in and out vision
In and out of
Belly-Self – slicing
its way through

the Right Hand Side

I had described the Stuck feeling, multiple times, and to multiple sets of shaking heads (kindly though they were). My story didn't fit the textbook. When vindication finally came, starting with an ultrasound revealing a stone, leading to a HIDA scan demonstrating that the biliary fluid could not escape, the trapped feeling came to make sense to me. This is the way I experience my body, in flashes and metaphor, rather than in collections of symptoms. This is, however, not the way physicians are taught to diagnose – or to understand.

Today, I find myself catching my breath sharply in memory of the horizon of pain, with no end in sight.

But now it seems obvious. As a clinic manager, I'd watched patients (also known as human beings) wait months to see a doc, weeks for the next test, days for the results, more lag between, waiting for schedulers and staff and processes geared around systems of production. And patients were caught in the gaps of that system, which was never designed for them. I'd reassured them and encouraged my staff to follow up, facilitate, make repeat phone calls, or sometimes to even recommend to wait and be "patient". Radiology is backed up right now. So is the specialist.

Of being not-heard, I'm in good company. But I can't blame anyone.

Eventually, the surgical report dated August 22, 2017 told the story: "Received labeled 'gallbladder'. . . . The cystic duct is stenosed. . . . Opening reveals a single stone, yellow-green, measuring 2.1 cm in greatest dimension." But that revelation was a long time coming.

The lesson here must be that
The System
Has a mind of its own.

and sinks again
Blackwater fishes
gape and gaze up through
ice

That's fortitude

but no Healing
to be Found

Inside of a coasted
Searoom, Lighting
flashes

you might have seen it
or missed it
or known it

spring-side misted ponies
lap at pools on the
sidelines

Undetectable weather patterns
you think
you see Answers

your approach is one with the times
I'm never Secure
Deep from the recesses
of a screen Life – which is
to say, Falsely certain
and surface-driven

Uncertainty expands, barren
Transaction
Transaction
No-fault
the system