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# Bone of Contention

## One Small Boy, One Errant Salmon Bone and Boom -- How a Family Found Itself Captive on a Medical Mystery Tour

By Deborah Simons  
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It all started with a fish bone.

And it only took one emergency room doctor, two pediatricians, five otolaryngologists, two allergists, one family practitioner, one physician's assistant, one ophthalmologist, one pediatric oncologist, one pediatric gastroenterologist, one pediatric neurologist, one chiropractor, one osteopath, one physical therapist and one doctor of alternative medicine -- as well as two CT scans, a thyroid ultrasound, two allergy tests, four blood tests and an MRI -- to figure out what was going on.

On Nov. 30, 2001, we had salmon for dinner, and my son Gideon, then 7, swallowed a bone. How do I know this date so precisely? I have the insurance papers to prove it. When Gideon was still complaining about his throat at bedtime, we trekked over to the ER at Northern Virginia Community Hospital. There Gideon had his first experience with a nasopharyngeal scope, which goes up the nose and down the throat. There was no bone there, the doctor said. It must have gone on down, and it would be digested with no problem. We thought that was the end of it.

After letting Gideon sleep in the next morning, we set off for school. All of a sudden he started complaining vehemently: "My throat really hurts!" Hmmm, I thought. Maybe that doctor missed something.

So Gideon had a second throat scope that afternoon, at a pediatric otolaryngology practice near our home. This time the procedure was a bit more high-tech, as the scope had a camera attached to it. We were able to see Gideon's throat down to his larynx on a TV monitor.

Again, no bone was found. There was, however, a scratch on the back of his throat, a white line two or three inches long with swollen edges. It certainly didn't look like much of a problem. I remember the doctor's words very well: "Oh, that's what he's complaining about. And he'll keep on complaining about it for two or three more days. But then he'll

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be fine."

Here was the first missed opportunity to ask the vital question, "Where does your throat actually hurt, Gideon?" No one asked it.

I'm a pretty inquisitive mother. Some would say intrusive. It would have been characteristic for me to ask Gideon in a few days if his throat pain had gone away, but I didn't. It wasn't that I forgot about it; I made a deliberate choice.

Gideon hadn't said another word about his throat since that second doctor visit. The obvious explanation was that the pain had gone away, as the doctor had said it would. Why remind Gideon of the discomfort of having his throat scoped twice in two days?

So I kept quiet. The results of my poor decision led me to formulate one of the biggest lessons of this whole sorry affair: Always ask the obvious question.

Weeks went by. We were well into 2002 when Gideon started saying, "My throat really hurts."

Alert readers will notice that these were the exact words he had used earlier. Did that thought occur to me? No. So much time had passed that any connection in my mind with the fish bone incident had been lost.

Foolishly, I didn't ask him where his throat hurt. I had no idea that he had developed a second area of pain, down at the base of his neck, by the day after the fish bone incident. This had been what he was talking about when he complained then. The pain from the scratch, up in his actual throat, had gone away but this lower pain had not. He had assumed that this lower pain would also go away and had finally started complaining when it didn't.

Meanwhile, I assumed that he was merely talking about a normal sore throat, even though he had never had any throat problems before. (Note all of the assumptions.)

His symptoms did puzzle me, though. He had no fever, didn't feel bad, and wasn't starting a cold. He didn't say that he wanted to stay home from school. He just kept insisting that his throat hurt.

I am appalled to note from my insurance papers that it was May before I took him in to the pediatric practice where he has been going since he was 2 days old. They, of course, looked at his throat with a light and a tongue depressor. Nothing. They took a strep test. Negative. Must be a virus, they said.

### **Getting Embarrassing**

Time passed. Gideon continued to complain at intervals, and at some point I finally

caught on that he was actually saying that his throat hurt all the time, not just when he talked about it. Could this possibly have something to do with that long-ago fish bone incident, I wondered.

My reaction to that thought was a harbinger of what I would get from doctors when I finally started talking about it: I was embarrassed even to think something so silly. I could just hear myself saying to a doctor, "My son swallowed a fish bone last November and his throat still hurts." Yeah, right.

In July, on our second visit to the pediatrician, physician Katherine Lischwe told us to take Gideon in to a pediatric ear, nose and throat practice. They'd have equipment to see down farther into Gideon's throat and be able to tell what was going on.

This was excellent advice, and we took it. Unfortunately, our appointment with another otolaryngologist at the same practice where Gideon had been seen the previous fall was simply the first of a very long and very unproductive series of visits to specialists.

The doctor we saw in July, to her credit, asked Gideon where his throat hurt.

When he pointed to the base of his neck, at the hollow of his collarbone, she said, "That's where children point when they have acid reflux." I learned later that she is the "refluxologist" at that practice. And so she put him on Zantac and later Prevacid. Not content with that, she also prescribed a 10-day course of antibiotics, in case Gideon had an infection, and Claritin, in case he had an allergy.

Three drugs. I was very uneasy about this shotgun approach but asked only a few timid questions before agreeing to her plan. After all, she was the authority, wasn't she? There is a second lesson to be learned here: Always speak up about what makes you uncomfortable.

### **The Doctors' Parade**

More weeks passed. Gideon faithfully took his medicine but was no better, (although he really enjoyed taking the antibiotic since it was in the form of chewable cherry-flavored tablets), and a follow-up visit and call to the doctor elicited no further suggestions except that I should "give it time." It seemed clear that she had nothing else to suggest.

In October, Gideon developed a chronic headache to go with what we all persisted in thinking of as his chronic sore throat, even though he had clearly pointed to the base of his neck as the area of pain.

Our visit to our pediatric practice to investigate this additional malady gained us nothing except an additional medical term: "behavioral." The doctor we saw that day said that he thought Gideon was just being "histrionic" and that his symptoms were behavioral.

What did that mean? It meant that Gideon was making the whole thing up. And nothing I could say against such an idea made any difference. There was no help to be gained there.

Time would fail me to describe the parade of doctors that followed:

- The allergist who administered a test showing sensitivities to mold and mildew.
- The nine weeks of shots, followed by a second test from a second allergist, showing no allergies.
- One otolaryngologist's immediate endorsement of the behavioral hypothesis.
- Another's theories that the neck pain might be caused by his thyroid (actually a very good idea, and one that no one else had thought of) and that the headache might be a migraine and should be evaluated by a neurologist (not such a good idea, since there is no such thing as a continuous migraine).
- The neurologist's theory, after an extremely cursory exam, that something was "bothering" Gideon, that he was "somatizing" it, and that the symptoms would probably go away on their own if I would just quit taking him to doctors.
- The utterly needless sinus CT scan.
- The upper endoscopy showing a perfectly pink and healthy esophagus.
- The second CT scan, this time of Gideon's neck.
- The blood tests.
- The useless medications.
- The long discussion with the physician's assistant in which she assured me earnestly that Gideon's symptoms were psychosomatic and that I should just drop the whole thing.
- The suggestion from a couple of sources that if the symptoms weren't interfering with Gideon's life, then there was no point in pursuing treatment.
- The three months of chiropractic treatments that seemed, for a while, to be helping the headache but which, in the end, did not.

### **In Whose Head?**

All this time Gideon went to school and church, did his homework and chores, practiced the piano, worked on his Bible club memory verses, and threw himself into his regular physical activities. How could such a healthy-looking, active child have anything wrong

with him?

On the other hand, how could someone so seemingly happy and well-adjusted be making the whole thing up or imagining it? And yet there were many mornings when he would get up saying, "I feel horrible. My head and my throat really hurt."

And I would have nothing to offer him except some children's ibuprofen and the promise that if he felt during the school day that he absolutely could not sit in class anymore he could go to the office and I would come and pick him up. He did this only once.

### **Diagnosis: Lymph Nodes?**

And then we finally got a break: We were given the name of a medical doctor who also uses some alternative therapies, including acupuncture.

This recommendation, from the fifth otolaryngologist we consulted, was very much in the form of a last resort. He had nothing to suggest in the area of conventional medicine. These things were sometimes mysterious, he said, and we would probably never know what had caused Gideon's symptoms. But perhaps an acupuncturist could do something about the pain.

And so finally Gideon and I went to see Marie Steinmetz in Alexandria, and things began to happen. Within two months of our initial -- indeed, our only -- visit to her, the cause of Gideon's symptoms had been diagnosed and he was well on the road to recovery.

So what was wrong with him? It was very simple: He had enlarged lymph nodes in his neck and behind one ear and a buildup of lymphatic fluid. The pain apparently was being caused by the pressure of this fluid on nerves in his neck.

Once we got hold of that idea, things began to click into place. For instance, I had noticed, without realizing its significance, that Gideon's face looked "heavy" around his jaw; indeed, his jaw line and chin line had disappeared. This puffiness was caused by fluid. I had also noticed a hard, painful knot behind his right ear and been told it was a lymph node.

Steinmetz pursued several options in Gideon's treatment before settling on the lymphatic idea: a thyroid ultrasound, an acupuncture treatment and two visits to an osteopath. None of these resulted in any answers or improvement, but she was undeterred.

We then had an MRI done of Gideon's neck to be sure that we weren't missing anything. "God, please show us the truth," I prayed during the 45 minutes that this procedure took. And indeed the results of this test supplied the clue we needed: The radiologist included "swollen lymph nodes" in his report.

I was frankly astounded at Steinmetz's level of involvement. She called and discussed the

results with the radiologist. She called and e-mailed me several times. She talked with the osteopath. She called a pediatric oncologist and had him evaluate the MRI films to be sure that the swollen nodes weren't malignant. She left nothing to chance.

### **Drain It**

And once she was sure that Gideon's problem was lymphatic, she wasted no time in referring us to a physical therapist, Pamela Wood of Hand-n-Hand Therapy in Arlington, who specializes in something called "lymphatic drainage therapy."

It sounded pretty strange to me, but at this point I was willing to try just about anything, especially if Steinmetz recommended it.

The first session, which took place on April 7, was well-nigh conclusive. Wood, an ebullient woman who won Gideon's heart by offering him jelly beans, said right away that she had seen a number of lymphatic cases with pain in the front of the neck. Her treatment, which consists of very gentle massage at various points of the lymph system, brought about immediate and dramatic results. Gideon said that same evening that his headache was quite a bit better. The puffiness in his face went away, and the knot behind his ear softened. And each succeeding treatment produced more positive results.

Wood, who has been a licensed physical therapist for 25 years and has also studied intensively with Bruno Chikly, the founder of a school of lymphatic therapy, was willing to invest a great deal of effort not only in the treatments themselves but also in distracting Gideon enough from his areas of sensitivity so that she could work on them. Mr. Potato Head made an appearance, as did a take-apart model of the skull. Wood was the first health professional we saw who actually got Gideon to talk to her.

Of course, she spent a lot of time with him: Sessions usually lasted over an hour. And two weeks after his sixth treatment, Gideon was able to say that both areas of pain were gone. It was fitting that he could make this official announcement on Memorial Day, May 31. That date marked exactly 2 1/2 years since the beginning of his symptoms.

### **Back to the Bone**

While we can't say with absolute certainty what caused this lymphatic problem, the timing of its onset strongly suggests a connection with the fish bone incident.

Jay Greenberg, the oncologist we consulted, had provided a final clue during our visit with him when he mentioned that infections or other immune reactions can sometimes be triggered by a child's swallowing a foreign object and sustaining an injury from it. The infection can run its course but leave the lymph nodes inflamed and swollen.

If Gideon's treatments from Wood had not been effective, a biopsy of one of his lymph nodes would have been the next logical step and might have provided further information

about what exactly caused the swelling.

An obvious question arises: Since Gideon's ailment was not especially unusual, why did none of the five otolaryngologists we consulted mention this possibility? Beats me.

The word that best describes this whole process that we went through in dealing with Gideon's problems is waste: the waste of time spent in useless doctor's visits and procedures, the waste of money spent by us and by our insurance companies and, most important, the waste of a child's needless suffering.

I felt, most of the time, as if my husband and I were completely on our own in trying to figure out what was wrong. Until we discovered Steinmetz, there was no one in charge of Gideon's overall treatment: just us, bumbling our way from one doctor to another.

I began to feel after a while as if Gideon and I were on trial whenever we went in to see someone new. How should I present his symptoms? How much should I tell? How could I be sure that this doctor would take us seriously and not dismiss me as hysterical and Gideon as manipulative or psychologically troubled?

I remember during one appointment hoping the doctor wouldn't notice that I had put on my navy blue pants instead of my black ones and therefore my outfit didn't match. If I couldn't even put my clothes together properly, how could I possibly be a valid witness about my child's symptoms? That's how paranoid I became.

Well, Gideon is fine now. He is what he always was: a bright, normal, active, happy child. He's not harboring some deep, dark secret that his father and I know nothing about but is horrible enough to keep him in pain for more than two years. He's not a malicious little imp putting one over on us and his doctors just so he can have the joy of shots, medications and long stretches in waiting rooms.

His problem was, in the end, simple to fix. We were fortunate. Gideon's condition wasn't progressive or life-threatening, and he doesn't seem to have any lasting effects from it. We have good medical insurance and so didn't have to deplete our savings to pay for all these treatments.

But it shouldn't have had to be this way. It's tempting for me to just blame myself for not asking the right questions or noticing the right things, and I'm sure that there would be some justification for that. But it would have been nice if we could have found a doctor sooner who was, in my husband's words, "willing to do doctoring." If the problem couldn't be solved within a 10-minute appointment, most doctors we consulted seemed to have little interest in pursuing the matter.

Is this attitude the fault of our health care system, or our medical schools, or what? I don't know. Of course, it's likely that none of this would have happened if I'd done what I

should have done in the first place. Which leads to one last lesson from all this: Always take the bones out of the salmon.

*Deborah Simons is a writer living in Falls Church.*

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# Lymph Notes

Tuesday, July 20, 2004; Page HE05

The lymphatic system can be thought of as a secondary circulatory system, with its fluid carrying immune cells throughout the body. When the lymph nodes, which act as filters, are removed, damaged or infected, the flow can be disrupted. This disruption can cause swelling, called lymphedema, as fluid builds up in the circulatory vessels and tissues.

Lymph drainage therapy (LDT), or manual lymphatic drainage, is a recognized medical therapy in at least one area of conventional medicine: for treatment of the swelling that can occur in an arm or leg after surgery, especially for breast or prostate cancer. There is an insurance code for LDT, and when the treatment was used for our son Gideon, we had no problem being reimbursed at the normal out-of-network rate by our insurance carrier. Although the medical community generally shuns LDT except for post-surgical conditions, there are a few MDs, including Marie Steinmetz, who prescribe it in other cases.

Ioana Razi, a pediatrician in the District, often refers patients with lymphatic and other special needs to either Pamela Wood, the physical therapist who treated my son, or an osteopath, a physician with additional training in manipulative therapy.

Like other physical therapists, Wood cannot perform LDT for a specific medical condition without a doctor's prescription. There is no national standard of certification for physical therapists performing LDT.

Wood has consulted and shared treatment of lymphatic patients with several osteopaths in this area.

Some LDT advocates say even laypeople can perform simple treatments on patients with minor lymphatic problems -- for example, a child with an ear infection or a cold. Osteopath Mary Ann Block outlines the procedure in her book "No More Amoxicillin" (Kensington Books, 1998); Razi distributes relevant pages to her patients.

There is no single nationally recognized credential for a lymph drainage therapist.

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However, the Lymphology Association of North America ([www.clt-lana.org](http://www.clt-lana.org)) certifies lymphedema therapists. This association and the Upledger Institute ([www.upledger.com](http://www.upledger.com)), home of LPT authority Bruno Chikly, who developed the techniques used by Wood, maintain directories of therapists who have been qualified through their programs.

As with any medical treatment, a willingness to ask questions, check references and scrutinize credentials is the patient's best defense.

-- Deborah R. Simons

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