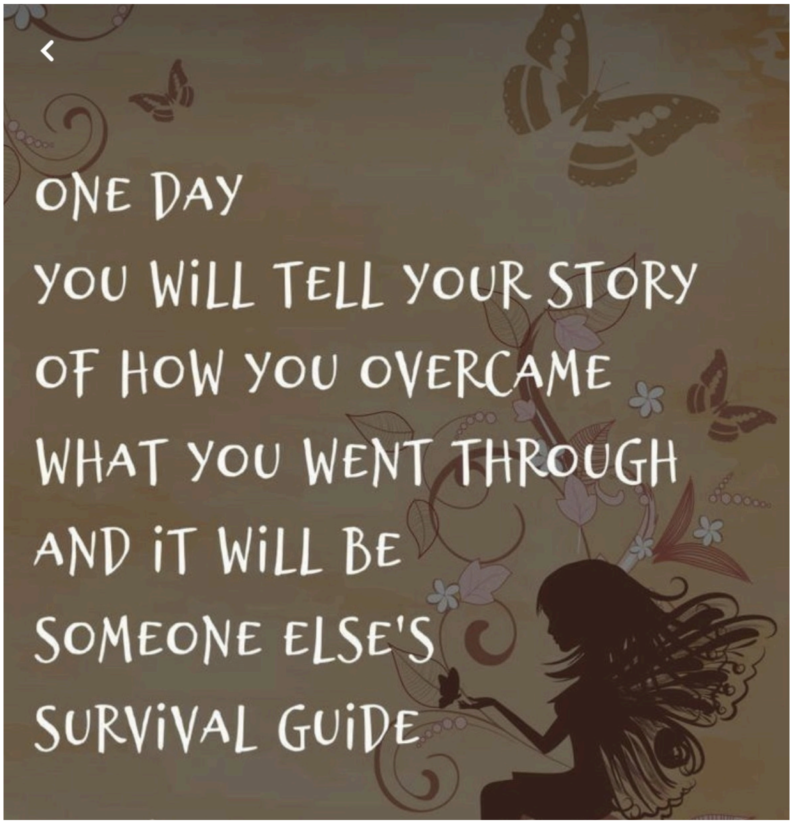
My Broken Ear - A Journey from Despair to Hope

Sudden Sensorineural Hearing Loss, Hyperacusis, and Tinnitus - My First Two Years

By: Frances Mann-Craik, May 2023



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Acknowledgments

- Deepest gratitude to my amazing husband, Jim Craik—who put his life on hold to help me hold my life together—and my family, here for me through thick and thin.

- Kaiser doctors A.K. and L.K. - my GP and ENT - were at my side during my darkest days and gave me HOPE, tools, and support to keep seeking a sustainable lifestyle.

- Dr. Martha Creek - coach, guide, earth angel, friend - helped me find my way back home.

- Jho Angeles - life crisis coach, lifted me from the depths of despair with guided me through grief toward mindful living.

"Frances, I think this happened for a reason so that you could write a story to help other people," Dr. A.K., January 2023

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My Broken Ear - Journey from Despair to Hope

I may be half-deaf, but I'm not DONE!

Introduction

My heart aches when I go to the SSHL and Hyperacusis and Tinnitus Facebook groups and see these posts:

- "I woke up deaf in one ear. I'm dizzy and can't tell where noises are coming from. I can't understand the doctors. They want to put shots through my ear drum? I'm so afraid." (Sudden Sensorineural Hearing Loss "SSHL")

- "The ringing/buzzing/whooshing noise in my ear/s is so loud I can't stand it anymore. I want to stab my ear with an ice pick to make the noise stop. When will this stop? What can I do?" (Tinnitus "T")

- "I can't stand the sound of the toilet flushing, running water, the dog barking, kitchen appliances. I am in tears during the audiology exam. It hurts so bad. I can't leave my house. Loud noises are coming at me from everywhere. I had to quit my job. They think I'm crazy. My life is over. (Hyperacusis "H")

I am ALL of the examples above.

On April 11, 2021, my life came to a screeching halt. I woke up deaf in my left ear. Surprisingly my "hearing system" hadn't become silent, rather full of new noises. I was to learn I was suffering from the triple whammy of Sudden Sensorineural Hearing Loss (SSHL), Hyperacusis (H), and 24/7 Tinnitus (T).

I am as profoundly deaf today as I was in April 2021, and I continue to have T and H. After two years, I have accepted my hearing disorder as my new normal FOR NOW while continuing to heal, research, look for solutions, and pray for a miracle. I have HOPE for me and for you. Over the last two years, I have been forced/gifted with the opportunity to completely reframe my life - from hard-charging high-tech marketing executive to humble, whole-hearted human being. Perhaps I will never regain my hearing or fully control the T & H, but I am living a happy life again most days…

This article shares my SSHL, H, and T journey. It begins with suddenly awakening with one deaf ear and the world roaring around me with noise… to living a hope-filled life. I've focused on four key areas of my journey: physical, intellectual, emotional, and spiritual growth. Not all areas are suitable for all readers -

pick what you like. My goal is to share my journey and to provide hope for my fellow travelers in the world of auditory challenges.

> Physical - my hearing condition is observed through my senses and the medical procedures used to try to cure/improve my situation.

> Intellectual - a researcher and writer by trade, my natural "go-to" is finding out. Finding out - how and why and who else and what there is to know. This was the most frustrating part of the journey, taking me deep into many scary rabbit holes. I want to know WHY this happens to people. It turns out no one knows why. For me, this finally resolved as a life-changing "gift." For some things, I may never know how or why. It's okay not to know.

> Emotional - this sudden condition brought up many emotional issues for me: from "why me" to guilt, anger, fear, and shame. I worked with skilled mental health professionals to move through my stages of grief and come to Self Acceptance and Self Compassion and a steady state of being.

> Spiritual - the most dramatic change in me has been the leaps in spiritual growth resulting from the "darkness of the soul," which came from my broken ear. I started on this growth path in 2016. The hearing incident dramatically accelerated my journey from a fear-based life to spirit-led wholeness. "All healing comes from replacing fear with truth."

I hope and pray that your hearing crisis resolves with medical care in a short amount of time and that you have no need for this article. Your path will surely be different from mine. A tip or two might help ease your journey and help you know you are not alone.

My Timeline

- Ground zero: April 11, 2021 - woke up suddenly deaf in the left ear with Tinnitus and Hyperacusis
- Phase 1: April - June 2021 - Medical healers - ENTs, audiologists, HBOT, Acupuncture, Chiropractor
- Phase 2: May 2021 - current - Mental health professionals
- Phase 3: November 2016 - present - Spiritual teachers
- Phase 4: April 11, 2022 - No more "Victim"
- Phase 5: April 2023 - Return to life - baby steps… the best is yet to come!

1. Physical

Medical Treatments

- Oral Prednisone regime: April 11 - 21
- Audiology Exams: April 12, 26; May 27; July 27
- Steroid Shots through eardrum: April 15, 22, 27
- MRI: April 26
- Acupuncture: April 21, 29; May 6, May 18
- Chiropractic: May 8
- Hyperbaric Oxygen Therapy - 20 visits from April 23 - June

Three months update: no change in my left ear, profound deafness; Hyperacusis much worse.

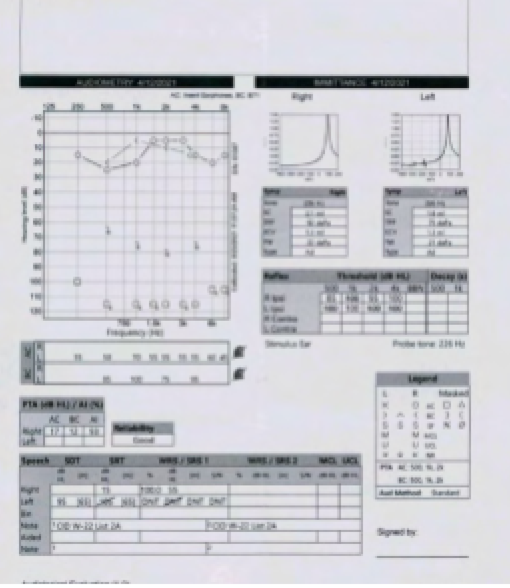
- Rest, repair, allow my brain to rewire: June 2021 - ongoing
- Ear retraining - brain habituation for Tinnitus and Hyperacusis September 2021 - ongoing(see Emotional).

I woke on Sunday, April 11, 2021, stone-cold deaf in my left ear. I was assaulted by a strange, loud whooshing noise inside that deaf-left ear - Tinnitus (T). I was dizzy and disoriented, and a bit concerned. Then the dog barked – and searing pain entered my left ear. (Hyperacusis). Now I was terrified.

I called Kaiser Advice Line and was connected to a doctor over the phone within minutes and scheduled for an appointment that very day – a Sunday.

Usually, I would hop in my car and bop down to the hospital, but my "hopping and bopping" around days were over for a while. I couldn't stand up straight – my balance was off. I was confused – noises were coming at me from different directions. Loud noises hurt my ear – like a knife stabbing me. My husband called out to me, but I couldn't figure out where he was – my sense of direction was gone. My wonderful husband dropped everything in his life to care for me as I was struck with this sudden health crisis.

The first days and weeks of SSHL are critical for a hopeful reversal and return to hearing. I jumped into the medical dance with both feet. Within minutes of seeing me on Sunday afternoon, the urgent care doctor had a plan – start taking Prednisone now and come back tomorrow to meet with an ENT and audiologist. The following day, wearing a Covid mask, using two hiking sticks to keep my balance, and with my husband "steering me" to the doctor, I met my first ENT. She listened to my symptoms. She explained the "protocol" for treatment: Oral Prednisone, Steroid shots in my ears, Audiology exams, MRI, and Hyperbaric Oxygen Therapy.



My first ENT was young and concerned.   She arranged many procedures/tests the first days after I was struck deaf. She did a magnificent job of trying to fix me fast. After the last steroid shot in my ear, on April 27 - eighteen days and ten procedures later - she said, “We’ve followed the protocol, and that’s all I can do.” The next step was for me to work with the audiologist on hearing aids. That was it.   No additional medical interventions or tests were indicated. She was done with me. Next steps: See what happens over time… and learn to live with it.

As each day passed without improvement, I became increasingly stressed and afraid. Nothing was working. As my stress went up, my T&H got worse. For me, Hyperacusis is the most debilitating condition. Many day-to-day noises – toilet flushing, water running, dog barking, kitchen appliances, tires on the road, silverware on the table, Television, Zoom calls – were intolerably loud and painful. They caused my adrenaline to pump and me to spring into fight or flight. My nervous system was on high alert all the time. The H and T are cumulative for me, so as the day goes by, the noise gets louder and louder. At the end of six weeks, the H was so bad I had to isolate myself from the world completely. I was still deaf, and I was scared, exhausted, and felt hopeless. My busy life as a high-tech executive was no longer possible. I thought my life was over.

Over five months and 46 appointments and treatments. From oral Prednisone to Shots in the ear drum, to MRI, to long luxurious sessions in hyperbaric oxygen therapy.   Nothing worked.
It was time to listen to my intuition that told me to rest. My brain, body, and soul needed to rest from the onslaught of noise, activity, and anxiety surrounding my medical condition and all the medical procedures. I needed to give myself time to heal and give my brain the time and restful space to begin rewiring.

For me, the worst of my three conditions is Hyperacusis - the mystery ailment that the medical world can’t test, measure or fix. When I tried talking to my audiologist about the loud noises - the Hyperacusis – I got a blank stare. I felt she didn't believe me when I explained how painful the audiology exam was. The last thing I could do during the early days was fight for the legitimacy of my condition.   I knew there was more wrong with me than hearing loss and tinnitus. I knew that the pain from the audiology exam - like an ice pick stuck in my ear - was not “normal.” With tears running down my face at my final exam, I pulled off the headphones and said, “Enough!” I can’t stand this torture. I’m done.

In the research, I discovered that super-sensitive hearing issues are REAL with a REAL name and that some people, like me, really have it. That my doctors couldn't test it and wouldn't acknowledge it didn't make it any less real for me.

One of the huge benefits of Kaiser is that there are many doctors in the system, and you can review their bios. I searched the bios of all the local Kaiser ENTs and found one, just one, that mentioned "hyperacusis."

September 2021 - Enter the wonderful Dr. L.K., Kaiser ENT. When I shared my ear story with Dr. L.K., she validated that super-sensitive hearing, hyperacusis, is real and not "made up in my head." She acknowledged that it is rather rare but no less real for that. I asked her what she would tell her sister if her sister were struck with this disability. She told me, "You will get better." She continued saying my hearing may never improve again but over time I will get it figured out, and I will get better. It might take a month, a year, or years, but I would learn to make the T less bothersome and cope with the strangeness of navigating with one ear. The Hyperacusis was harder to predict - maybe not a cure, but at least relief was possible.   Dr. L.K. gave me HOPE and a new perspective. And she treated me as a whole patient, first asking about my coffee consumption, how my psoriasis was doing, and whether I was taking B vitamins, etc.   Dr. L.K. treated me like a patient to care for rather than a condition to treat via the protocol.   Dr. L.K. and I have continued our relationship over these two years. She is a constant resource of information and support and encouraged me to write about my experiences.

Lessons Learned from Medical Treatments

> **Find an advocate** to help you with the first week's appointments and treatments. In the first days, I was so full of noise and fear I just went along with whatever the medical pros said. It was hard for me to hear, and the noises inside my head were so loud I wasn't able to understand. Unfortunately, I didn't have an advocate in the room with me. This was a mistake.

> Try to find an ENT and Audiologist who will treat you as a whole person and believes H is a physical condition. If you have Hyperacusis, keep searching until you find an ENT and Audiologist who recognize Hyperacusis as real.   After six weeks of medical treatments, my original ENT said, "Well, we've finished the protocol. There's nothing more to do." I searched the bios of all the Kaiser ENTs and found one that mentioned hyperacusis - my most debilitating condition. When I moved to working with Dr. L.K., it changed everything. She offered me HOPE and encouraged me to treat my ear with the utmost love - not fear, anger, or regret… but hope and love.

- My ENT questions (note - my most debilitating problem is Hyperacusis)
    - Have you treated SSHL?
    - How many patients have you treated with SSHL?
    - What do you know about Hyperacusis?
    - How many patients have you treated with Hyperacusis?
    - If this happened to your sister, what would you say to her?
    - What should I do to help prevent this from happening to my good ear?

    - What should I do to help prevent a stroke?
    - Did my Covid vaccine cause this?

> **If the audiology exam hurts - pull off the headsets!** Another mistake I made… During my first three audiology exams, I sat in that little room with tears running down my face as the audiologist blasted sound in my right ear to see how profoundly deaf I was in my left ear. That noise got increasingly painful as time went, but being a "good" patient, I endured it. I don't know if this caused my hyperacusis or made it much worse. The end of my fourth audiology exam came when I removed the headsets and said, "I'm done." "Why?" the audiologist asked. I said, "It hurts - do you not see the tears running down my face?" She tried to convince me it couldn't hurt. Hah! My fourth audiology exam was my last. I'm still deaf - I know this - and I don't need the painful proof.

> Don't schedule an MRI on the day of an audiology exam. For my convenience, they doubled up my appointments for an audiology exam and MRI on the same day. I was already distressed, as this audiology exam had blasted my H into the stratosphere. For me, H is cumulative. The world gets louder and louder until I have to remove myself entirely. Every tiny noise hurt. The MRI waiting room was painfully loud - I could hear the noise from all the MRI machines throbbing in my head. Finally, a kind nurse took pity on me and gave me a blanket to go and sit outside in the cold to wait for my exam. No one offered me earplugs or a headset for the MRI procedure. I was blasted again in the MRI exam room. Normal MRI - phew.

> **Hearing Aids -** I was bewildered about how hearing aids could help me. As my audiologist wouldn't acknowledge my super sensitive hearing and would never even say the word "hyperacusis," I had little trust that she could help me with my condition. My left ear is profoundly deaf, and my right ear is normal. Something in my head hears noises way way too loud – wouldn't a hearing aid make this worse? How could my deaf ear hearing be so loud when I was deaf? Was it my right ear, my hearing ear, that had H? The ENT and the audiologist could not give me any answers I could understand. (My ability to process language and understand was at an all-time low at that time). Indeed, when I asked specifically about hearing too loud, I got an answer: "It's tricky." I tried and failed at hearing aids. I may try them again in the future.

> Isolation, grieving, healing - I am blessed to live on a forested mountain away from city noises. After resigning from my day-to-day life - my job, my volunteer work, my projects - I hid in my little cocoon and grieved for my old life and the vibrant post-Covid life I had planned. The medical treatments, fear, and anxiety exhausted me. Being okay with giving myself time to heal wasn't easy for me as I've "powered through" illness and brokenness my entire life. Not this time. I came to accept that it was okay to "take a day off and rest." After some months of cocooning, I accepted the medical world wasn't going to solve my problem. I needed to find a path back to the world.

2. Intellectual

(See reference section at the end of article for a list of books and articles.)

"No additional medical interventions or tests are indicated. Learn to live with it."

I went to every audiology exam and appointment for five months and followed every procedure. NOTHING WORKED. The MOST frustrating part of the medical process was the lack of acknowledgment that my hyperacusis, this life-changing disorder that was driving me into isolation and despair, was REAL. I repeatedly asked questions of the audiologist about the "crazy loud noises" from running water, to kitchen appliances, to wheels on the road - and I would get a vague look in return. When I specifically asked about hyperacusis concerning hearing aids, I was told, "Let's deal with the tinnitus first."

I was exhausted. I felt hopeless, lost, and without a way forward. The audiologist and ENT had given up on me. What could I do for myself?

WHY? Why did I go deaf? What was the cause? What did I do wrong? Was it the Covid vaccine, a virus, my barking corgis, the swimmers ear I had as a child, the concussion I got going through a car window 40 years ago?

WHY? Why can't the doctors fix me? I've always healed from my problems in the past, and I've had quite a busy, accident prone life. Why can't they even talk to me about my real problem?

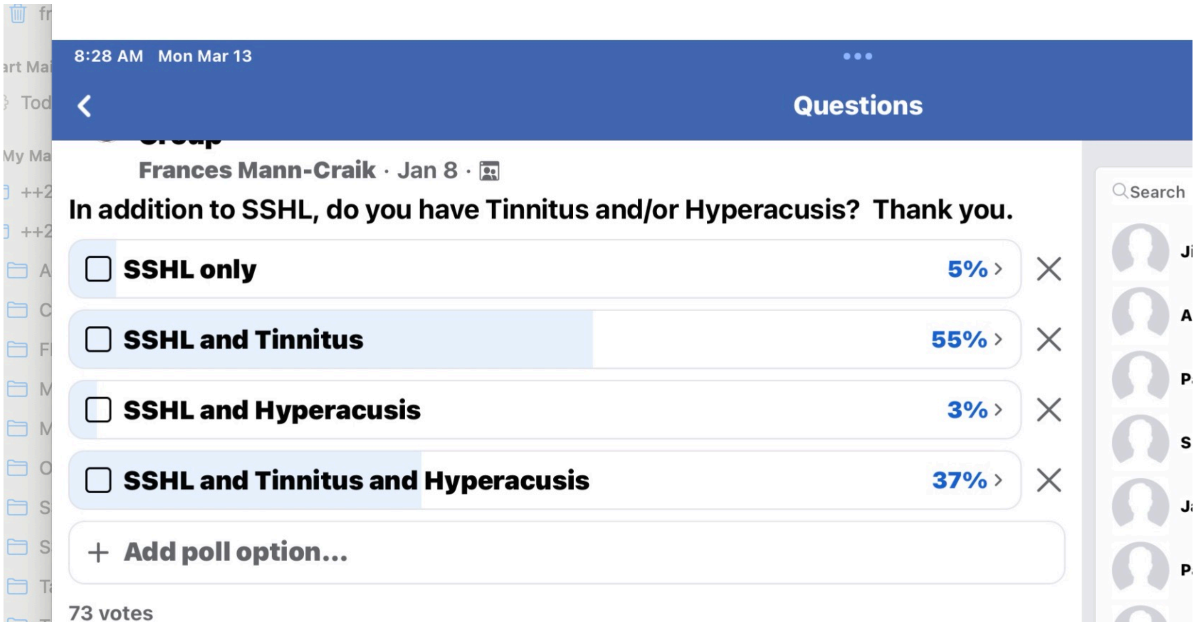
WHAT? What are these conditions? Deafness and tinnitus are fairly easy to understand if not accept, but what is this Hyperacusis thing that NO ONE WANTS TO TALK ABOUT? This is the condition that forces me into isolation and despair and yet my initial ENT and Audiologist won't even talk about it.

WHAT? Can be done - is there a cure? In the meantime, what can be done to make living with my hearing disorder more tolerable?

WHEN? When will this end? When will the noises stop? When will my world be "quiet" again?

I researched. I buried myself in research on hearing issues, particularly super-sensitive hearing. I got lost for hours – chasing down rabbit-holes on the Internet searching for a miracle cure for my ear. Computer work is quiet and is one thing I AM still able to comfortably do. My research took me from the world of the medical pros to the world of the mental health professionals and ultimately to spiritual guides. This is where I found relief and a way forward. I'm happy to share the highlights of what I've learned.

My friends on the SSHL Facebook page shared their conditions with me. SSHL has a name, a tool for diagnosis, and a protocol for treatment. But many of us with SSHL ALSO have Tinnitus, and many of us have all three. For me, the T&H are a far worse problem than deafness. It wasn't the deafness, rather, it was the T&H drove me to isolation and despair



Frances Mann-Craik · Jan 8 ·

In addition to SSHL, do you have Tinnitus and/or Hyperacusis? Thank you.

- ☐ SSHL only 5%
- ☐ SSHL and Tinnitus 55%
- ☐ SSHL and Hyperacusis 3%
- ☐ SSHL and Tinnitus and Hyperacusis 37%

+ Add poll option...

73 votes

Sudden Sensorineural Hearing Loss

Sudden sensorineural hearing loss (SSHL) is an acute-onset hearing loss (less than 72 hours) that involves the inner ear and hearing nerves. Unlike other causes of hearing loss, this is not related to ear wax, fluid behind the ears, problems with the eardrum, or disruption of the bones of the middle ear. Only a formal hearing test (audiogram) can tell the difference.

Sudden sensorineural hearing loss is an uncommon disorder that is estimated to occur in 2 to 20 per 100,000 people per year. It can be associated with vertigo in some patients. Most patients experience Tinnitus (ringing or buzzing sounds) as well as a sensation of the ear being “blocked,” “plugged,” “full,” or “muffled.”

From Kaiser: Some patients improve without any treatment at all. About 1/3 of patients will have complete resolution of their hearing loss. About 1/3 will see some or partial improvement, and about 1/3 will see no improvement in hearing, even with the recommended treatments. The more severe the hearing loss is initially, the worse the prognosis is.

Tinnitus - please make the noise stop!

Had I ever thought about it, I would have thought deafness = no sound. Fooled me, my world has never been so loud. Tinnitus is not a disease. It is a symptom that something is wrong in the auditory system, which includes the ear, the auditory nerve that connects the inner ear to the brain, and the parts of the brain that process sound. There is a great deal of information and support for Tinnitus from audiologists and hearing aids and programs to help people cope. There is no cure yet. The medical solution is a combination of sound therapy and cognitive behavioral therapy to learn to cope.

My tinnitus is a loud whooshing sound in my dead-left-ear. It reminds me of the high-wind sound on a stormy day. It has not changed from the first day I was struck, but two years later, with sound sensitivity and coping training, is no longer my main life focus.

Dr. Gans “Mindfulness-Based Tinnitus Stress Reduction” class and the Oto App combined have helped me move my Tinnitus from front and center into the “bother” section of life, most of the time. I’ve reviewed these two helpful approaches in the section on “Mental Health.”

Hyperacusis - Hypersensitivity to Sound

“Is Hyperacusis a hearing disability? A Mental Health Condition? All in my head?”

“Hyperacusis is a hearing disorder commonly associated with mental health conditions, including anxiety and depression. Living with the excessive loudness characteristic of hyperacusis can affect your mental health.”

Hyperacusis is experienced when ears become unusually sensitive to loud noises. It is often accompanied by tinnitus and sometimes occurs with SSHL. A “noise sensitivity disorder,” people with Hyperacusis find normal noises - ice falling into a glass, flushing toilets, vacuum cleaner, silverware clattering - so loud they are uncomfortable to “knife stab in the ear” intolerable. For me, a surprise dog bark, or a motorcycle driving by can literally bring me to my knees.

I was reassured that Hyperacusis is very real in Neil G. Bauman, Ph.D.’s book, *Hypersensitive to Sound?* Dr. Bauman discusses Hyperacusis types and discusses treatments for working with each of them. The two main types:

Recruitment Hyperacusis is a predictable outcome of SSHL – abnormally-steep loudness growth PERCEPTION (recruitment) and occurs only in the ear with hearing loss.

Loudness Hyperacusis is an abnormal acuteness of hearing due to increased irritability of the sensory neural mechanism; characterized by intolerance for ordinary sound levels.

Current “treatment” for Hyperacusis mirrors that suggested for Tinnitus - coping strategies.
From ChatOpenAI.com: Some common treatments for hyperacusis include:

1. Sound therapy: This involves the use of white noise or other soothing sounds to help desensitize the individual to the sounds that trigger their hyperacusis. This can help the brain to relearn how to process sound more effectively.

2. Counseling or cognitive-behavioral therapy: This type of therapy can help individuals with hyperacusis to understand and manage their condition, as well as address any underlying anxiety or depression that may be exacerbating their symptoms.

3. Medications: Certain medications, such as anti-anxiety medications or muscle relaxants, may be used to help alleviate the symptoms of hyperacusis.

4. Hearing aids: In some cases, hearing aids may be used to help amplify sounds that are difficult to hear, while also reducing the volume of sounds that trigger hyperacusis.

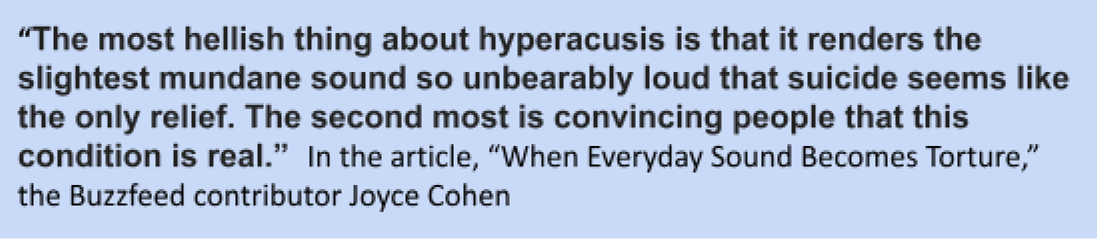
5. Tinnitus retraining therapy: This type of therapy is designed to help individuals with hyperacusis to habituate to the sounds that trigger their symptoms, and learn how to perceive them as less threatening

Hyperacusis is “commonly associated with mental health conditions.” In my opinion, this is because Hyperacusis is the CAUSE of mental health conditions, NOT because mental health conditions cause hyperacusis. It’s NOT that it’s “all in my head.” Well, literally, it IS all in my head because that’s where my auditory system is, but it’s not “made up” or imaginary. Rather, there are no medical interventions that can do anything for me to “fix” it. As with Tinnitus, the medical solution is a combination of sound therapy and cognitive behavioral therapy to learn to cope with this hearing disorder in the best way possible. To learn to live my best life possible WITH a horrible hearing disorder was going to require more than research and medical help. It was time to call on the Mental Health Professionals.

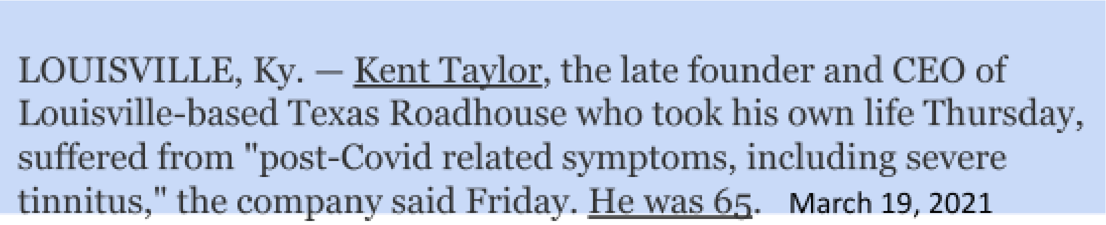
Hyperacusis - September 2021: I sat outside and watched
the beautiful wedding reception - through the window

3. Emotional

After three months of rigorous medical activity, I was exhausted, in complete despair, and full of self-pity. I had no choice but to cancel everything - my work, my volunteering, my family commitments. Everything. I curled up into a little ball of despair and thought my life was over. Was suicide the only solution?



"The most hellish thing about hyperacusis is that it renders the slightest mundane sound so unbearably loud that suicide seems like the only relief. The second most is convincing people that this condition is real." In the article, "When Everyday Sound Becomes Torture," the Buzzfeed contributor Joyce Cohen



LOUISVILLE, Ky. — Kent Taylor, the late founder and CEO of Louisville-based Texas Roadhouse who took his own life Thursday, suffered from "post-Covid related symptoms, including severe tinnitus," the company said Friday. He was 65. March 19, 2021

Guilt - What did I do wrong?

- Was it the Covid vaccination, a virus, my barking corgis, the swimmer's ear I had as a child, or the concussion I got going through a car window 40 years ago?
- Was it stress from my 40+ years of work in high-tech marketing?
- Was it karma? For many years my new year's resolution was "listen more,"... but I didn't?
- How would the world go on without me?
- How would I go on without the world?

I resigned from most of my business and volunteer life:

  - CEO of Addison Marketing - a high-tech marketing agency
  - Fractional CMO for a Berlin-based tech firm
  - Contributor Silicon Valley Startup Incubator
  - Menlo College Supporter: Student internships, mentorships, speaking
  - Neighborhood "First Arrivers Workshop" development and delivery
  - South Skyline Association Contributing writer
  - Allied Arts Guild Gift Shop Volunteer (support of Lucille Packard Hospital)
  - Unity Palo Alto – leader of the Elves (women's auxiliary)

What value do I have when I can't DO?

Canceling my life and curling up into a little ball worked for a while. I was in despair. I read, "Hyperacusis. You need mental health help." In my stressed-out condition, I interpreted this as meaning, "It's all in your head… you need a shrink." And I resisted. YES, it IS in my head - that's where my auditory system lives. But, no, I'm not making it up. The loud noises that drive me to my knees, with a pain like a knife stabbing into my deaf ear. This is very REAL. I've had to cancel my whole life.

It took me some time, and the help of Dr. L.K., to understand that the issue was NOT that they didn't believe I had H and was in pain, but rather that there was nothing **medically** they could do to help me. The solution was finding tools and techniques to help me **live with this catastrophic illness.**

My goal was more than not to end up a suicide statistic – while I completely understand this path for people with my condition – I wanted to figure out a way to have a life again. I learned through experience that the "noises in my head" both the H and T are extremely sensitive to stress. The more stress, the louder the noise. So how could I – a stress-addicted high-tech executive – learn to manage stress to save my very life?

HOPE changed everything!

Dr. L.K., and the HOPE she offered changed everything. I began the journey to acceptance and self-compassion, and I am getting better with the help of mental health professionals and coaches.

I began my Mental Health journey with a wonderful mental health professional at Kaiser who guided me with CBT – Cognitive Behavioral Therapy. This was the right approach for me, and I could see how much it could help me, but access was limited to one session a month (high demand during Covid for the Mental Health pros). Desperate, I went outside to find additional coaches to supplement the work. Some of this work was more general, whole-hearted living work, and some of it was very specific to my hearing issues. All of them, combined, have helped me learn to adapt and have a life again. Here were the most helpful resources.

- **My husband and family.** My wonderful husband, Jim, has been my rock throughout this experience. When I woke up deaf on April 11, 2021, I was also fall-over dizzy. My left ear was deaf, but there were loud noises everywhere and a constant loud whooshing in my ear. I was so afraid, and I couldn't walk straight! Jim was preparing to go on a driving trip for a week. He dropped everything. He canceled it. He took me to the hospital and walked me through the process - I was fall-over wobbly. I felt guilty about inconveniencing him. About his needing to cancel his plans. About me being so needy. I had always been a self-reliant, hard-working businesswoman. I hated this neediness in me and felt terrible about how sad Jim looked. I thought he was mad at me because he missed his planned fun. It turns out his look wasn't anger. It was fear. He was so afraid FOR me.

  We sat down and had a good deep conversation about our health and aging and that we might each "break" occasionally. We remembered that we'd signed up decades ago for the "in sickness and in health," and we've mostly enjoyed great health all along, but that now has changed. THIS conversation has made the rest of the journey a sharing one. Together we have worked on changing our lives around in a way that works for us both. I am blessed.

  When the ENT asked whether anyone in my family had hearing problems, I realized I didn't know. It turns out each of my three siblings all have various degrees of tinnitus. Unlike me, they NEVER complain about it. Over time, they have all learned to live their lives successfully, and this, plus their outpouring of support, gave me hope that I, too, could cope. My 38-year-old daughter, it turns out, has extensive experience with hearing issues. She was able to help me sort through the diagnosis, think through the hearing aid challenges, and provide support and practical advice for dealing with day-to-day and ear-health professionals.

- **Kaiser Mental Health Professionals (June 2021 - present)** and Cognitive Behavioral Therapy (CBT) - not to be confused with CBD (a medicinal part of cannabis).

  "We've followed the protocol; learn to live with it." This pronouncement put me into a deep depression and despair about my future. The associated fear and anxiety made my T and H worse. I needed to find a sense of safety and security and be able to live again.

  The Kaiser therapist helped me in several concrete ways. We devised a number system so that I could share the volume of noise in my head on a real-time basis with my world. (see "Daily Life Tips") We focused on present-moment awareness/mindfulness and the danger of "future-casting," where I create many possible, often negative, outcomes. We worked on coping strategies and thoughts about gradually re-engaging with life. We focused on my need for self-compassion and self-acceptance as I reframe my life for this new phase.

- **Dr. L.K., Kaiser ENT (September 2021 - present):** HOPE. I searched the Kaiser MD database for the most experienced ENT. Someone I hoped would understand the extreme challenges I was having with the combination of SSHL, H & T. I discovered Kaiser ENT Dr. L.K., and during our very first call, she changed my world. I went from my first ENT, who said, "Learn to live with it," to "I will help you on your road to recovery." Dr. L.K. also shared ideas about our brain's amazing ability to re-wire (neuroplasticity), which involves adaptive structural and functional changes to the brain. HOPE. There was HOPE for me to adapt and have a life again. My telemedicine calls with Dr. L.K. are joyful exchanges of tips and ideas and tiny successes.

- **Coach Martha Creek (July 2019 - present):** Speaker, minister, leader, coach, earth angel, and friend. I have studied with Martha for three years, starting before my ear broke. Martha's classes gave me tools and ideas for coping, growing, and surviving. First, a nine-month class and coaching around the book *Loving What Is*, by Bryon Katie, doing "The Work" on innumerable "Judge Your Neighbor" worksheets. Followed by a two-year study of the works of Dr. David Hawkins and his guidebook: *Letting Go, The Pathway to Surrender,* focusing on mindfulness, surrender, and spiritual growth.

  There are not enough words in heaven or on earth to express my gratitude for the marvelous Martha Creek, who has held my hand for my two-year journey through the dark night of my soul. Martha is helping me learn to live in victory - in a constant state of surrender. She is helping me learn to balance:
    - What is "doable" for me;
    - What is "good" for me;
    - What makes my "tail wag?"

  I didn't think I could ever be happy again. I am happy today.

- ***Radical Acceptance*** **and** ***Radical Compassion*** by Tara Brach (**July - August 2021)** Books: focus on **self-compassion** and **self-acceptance**. These have been essential for my survival. They have helped me accept and acknowledge what "IS." I accept reality and work through the pain to no longer live with the suffering. I have read MANY other books in the last two years - see reference list - but these two helped me the most with accepting my new life.

- **Coach Jho Angeles (September 2021 - January 2022):** "Guiding Mindful Change" was a fellow "sojourner" in the evolving chapter of my life. She helped pull me out of despair and work through the "stages of grief" around my hearing loss and lifestyle loss: denial, anger, bargaining, depression, and finally, acceptance. I learned to accept my new health situation and let go of much of the life I knew. Jho helped me reframe my ear challenge in the context of my life; overall, helping me find a new "lens" to look through.
  We focused on three main themes: 1) Self-compassion and my growing compassion for those of us coping with "hidden" issues every single day. 2) Rest - life, despair, and the "medical dance" had wiped me out. I needed to give myself permission to rest. 3) Play. Play? Me? Play? I've been working nonstop since I was 14 years old - that's now 55 years. There has been very little time to play. What an opportunity! Jho helped me refine my values and helped me create a roadmap for my life now. Frances 2.0 is a slower, quieter, kinder version.

- **"Mindfulness Based Tinnitus Stress Reduction**" (**October - November 2021)** – an eight-week class by Jennifer Gans, PsyD, a clinical psychologist from UCSF specializing in the psychological impact of deafness and hearing on well-being. Based on John Kabat-Zinn's *Full Catastrophe Living, her online course is* 100% focused on learning to live with T & H as a "bother," rather than a central focus of life. This approach has worked for me. The online, self-paced course costs $225.

- ***Oto App*** **(January 2022)**– an App that provides Tinnitus Retraining Therapy TRT - similar to Dr. Gans's classes. Had I not just finished Dr. Gans' class, I might have found this App provides similar results. "Get your life back from tinnitus. Let Oto help you feel calmer, find control, and sleep better with its expertly designed tinnitus program. Oto has helped thousands of people learn to live with tinnitus. 86% report feeling better and have less stress after just 1 month."

- ***Hypersensitive to Sound*** by Neil G. Bauman – this book gave me concrete VALIDATION that this loud noise is REAL in me and has a real cause that can be understood if not healed.

- **My hairdresser.** Believe it or not, my hairdresser, a woman in her 30s, has SSHL (without H.) She, too, gave me hope as I observed her living her full life.

Emotional Milestones:

Year 1 - Acceptance and Compassion

I did the medical dance and, after a full year, accepted that "What is… Is," and it's not likely to change. Living with it as best I can. I wear earplugs and headsets and avoid loud noises - no more concerts or car races for me!

I have learned an important life lesson about "hidden disabilities." Most disabilities are hidden. In my quest for healing, I have developed a deep compassion for every other human being on the planet - we all have "something."

Year 2: No longer a Victim - a CHOICE

On April 11, 2022 – one year after my ear went whacky - and with no changes to my physical condition, I made the choice to stop being a victim of my condition and get on with making the best life I can. Over the course of the year, I have reframed my life into one that works with my whacky ears. Frances 2.0 is a bit slower, much quieter, and able to have a life – a very different life than in the past. Not as great in some ways, and much better in others.

I've now spent year two creating a sustainable new lifestyle. Because the level of H & T are DIRECTLY related to stress and anxiety, learning to live with the H&T, rather than fighting them, has been essential.

With the coaching of the marvelous Martha Creek, I've shifted from: "I'm deaf in one ear" to "I have a hearing impairment" and from "Noises are loud, and I have to protect myself," to "I have to reduce the outside noises at times."

Year 3: My "broken ear" is no longer my "design center"

I am now re-entering life in baby steps. I'm learning what I can and cannot comfortably do. I know how to protect myself - earplugs and headset. My thinking has shifted from "I have a broken ear, I can't do XYZ, and I need to hide from noise" to "I have a hearing disorder" where I sometimes need to reduce the noise around me. So much less drama!

Emotional Lessons Being Learned

- **What did I do wrong?** Maybe something… maybe nothing. It's a mystery. But it's not my FAULT. I didn't purposely CAUSE this. I let go of the guilt.

- **Shift - Victim to Survivor** - it is a choice.

- **Grief >> Resistance >> Acceptance.** Treating my hearing loss as a "death" that needed to be grieved helped me accept my hearing disorders. After months of no improvement, I got over the notion of getting better fast and accepted that this is my life for now. Once I found acceptance and stopped fighting, my road widened, my anxiety lessened, and I began to learn to cope.

- **Reduce anxiety -** I MUST control anxiety and stress for my very survival. The more anxiety, the more noise in my head, and then I shut down.

    - Carefully manage my time with people - I can now, two years into this, manage about two hours with people, with headsets on, and not need an extended recovery after. It is glorious!

    - Build in Recovery days - I know that after a gathering, even if I stay within my two-hour limit, I may need a day for the noise to go down in my head before I do again.

    - Be ready for “ear lapses'' - setbacks happen. I had a bad one just as I went to craft this article. I spent five hours volunteering, and then the dog barked in my ear. Two months of isolation to recover. I am getting better.

- **Mindfulness training - Learn to Live in the Present Moment** - Learning to live in the present moment isn’t easy, but it’s the only way for me to survive. Not pining for the “perfect” past or ‘future casting” about how difficult life will be with a hearing disorder. With special awareness of the present moment, I can shape activity in my nervous system to promote integration and well-being into my life. Meditation, contemplation, and hiking in the woods are all helping me with this.

- **Live my more balanced life -** Lessons from “Whole-hearted Living” work by Berne Brown: I no longer “hustle for my worthiness by performing and producing” and have “let go of exhaustion as a status symbol and productivity as a yardstick for self-worth.” Workaholics like me will know these lessons are a huge change from a high-stress, high-tech life.

- **Your friends sort themselves out** - it’s pretty fascinating what happens when you stop working and stop volunteering and have to say to folks, “I can’t right now.” I learned much about my friends at a deeper level. Some offer unending support; some send you every whack-a-doodle article about a miracle cure; some - Poof - disappear from your life! My favorite, my friend Cheri sent me a text, “I will learn American Sign Language. We will be okay.”

- **Share your story - shame loves secrecy.** Curling into a little ball and hiding from the world was so tempting. I was ashamed that, successful together, Frances couldn’t DO anything. I was ashamed of my diminished capability. And I couldn’t just hide. I had to tell my boss, colleagues, and the groups I had to “unvolunteer” from. I was ashamed that I wasn’t strong or capable anymore. Sharing my story helped lift my shame. There was NOTHING to be ashamed of.

- **Be as good a friend to yourself as you are to others** - While I was wallowing in shame, coach Martha Creek told me, “Frances, if this happened to your best friend, what would you say to her? Would you think she should be in shame?” I never would. I would offer support and love and a box of chocolates. I am learning to be as kind to myself as I would be to a friend.

- “**Argue for your limitations, and they will be yours**” was a lesson I learned years ago. For years I said, “I’m not a writer; I’m a numbers person.” Indeed, at the time, I was an accountant. A good friend challenged me to write an article - and his faith in me gave me the courage. Now, writing is the thing I do with the most joy. I am now applying this adage to my hearing disorder. There are many, many things I still CAN do. I focus on these.

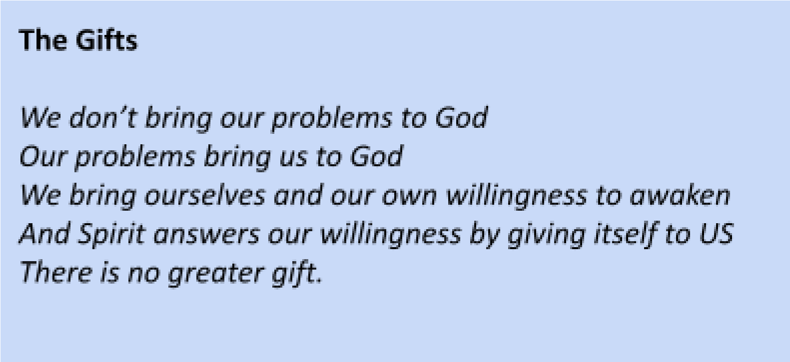
- **Back into the world - baby steps:** Now, in the context of my new physical setup, I am easing back into a more “normal” life. Trying things out, suffering ear-lapses, recovering, trying again.

Mental Health professionals offered support, profound thinking opportunities, and tools to help me learn to accept and cope with life. Mental Health pros come in many flavors and styles - psychiatrists, psychologists, coaches, and gurus. At Kaiser, they are so swamped that one time a month was all the help they could provide me. I found affordable resources outside the medical system. There are many “life coaches” and many offer “first-time free,” so you can see if there is a good style match. Finding a good match, you can trust is essential, as this work will take you deep and possibly set you free.

4. Spiritual

“What punishments of God are not Gifts?” J.R. Tolkien

Spiritual paths and lessons are deeply personal. For me, spiritual development has been essential in recreating my happy life. If even one more person can find relief by forming their own bond with the Universe, for me, this is worth the risk of personal disclosure. So I’m sharing.



The Gifts

We don’t bring our problems to God
Our problems bring us to God
We bring ourselves and our own willingness to awaken
And Spirit answers our willingness by giving itself to US
There is no greater gift.

On October 8, 2020, I received a Divine message, “This year, I’m going to send you things. I want you to be at ease and in grace so you can welcome them with joy, not stress. Study more. Listen more. Go deeper. Spend more time on the Divine side. Be on both sides simultaneously.”

Perhaps I wasn’t listening? Six months later, the Universe gave me a chance to reframe my entire life. My goal: “Transmute suffering into consciousness and disaster into enlightenment,” as Michael Singer discusses in *The Surrender Experiment*.

Broken ear - a sacred wound? God uses suffering and pain to bring us to a more significant identity. Because of my broken ear, I had “permission” to be self-aware and put all of my energy into healing and Divine unfoldment.

The gifts are still emerging, and they are HUGE:

- Less doing, more being
- Time for deep study and contemplation
- Reprioritization of my life - doing out of love rather than duty
- Permission to live my life just as I choose
- Every day I awake is another gift

Both Jesus and Buddha state that “pain” is the foundational teacher of transformation, leading to compassion and love. My spiritual growth has been profound during the past two years. My life approach has shifted from an always-on-the-go and reflexive reaction to a compassionate, intentional response. From hard work, integrity, and doing doing doing… to acceptance and compassion (with plenty of self compassion). I believe I am a better human today.

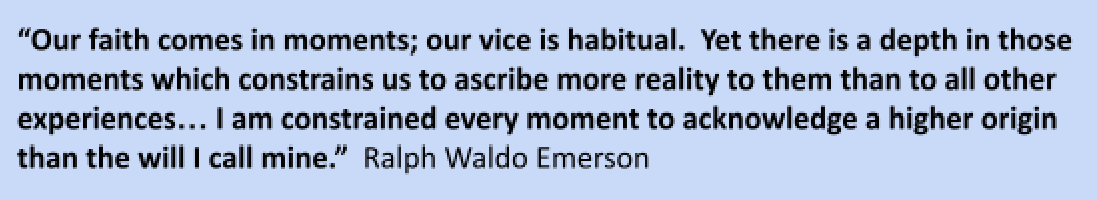
Frances 1.0 was a high-tech marketing executive running a marketing agency for 20+ years, built on top of 20 years of work for high-tech giants. Frances 1.0 was a CEO, a founder, an entrepreneur, and a creator. Frances 1.0's design center was ego-driven-striving, stress, and fear. Frances 1.0 ran hot and fast and did EVERYTHING life had to offer - traveled the world, built businesses, created events, organized teams, created joy, helped, and shared. No regrets.

Frances 2.0 is a "spun down" version - quieter, slower, kinder, more compassionate, wiser, and a bit sad sometimes, but working on improving daily. Frances 2.0 is a co-creator, a friend, and a Fairy Godmother - centered on sharing, gratitude, and love.

"What you are is God's gift to you. What you make of yourself is your gift to God."

Even before my ear broke, I had started earnestly on my Spiritual path. My world crashed on November 9, 2016, the day Donald Trump was elected president. I have been a feminist and activist since my high school days of marching and protesting in the '60s. When Donald Trump was elected, my dreams of women taking the reins and a world of kindness and peace crashed, and I was filled with dread for our future. My professional life felt empty. My activism had failed. The work I did now felt meaningless.

I found Unity Palo Alto on November 13, 2016, and began on a life-transforming journey into the mysteries – My "magical metaphysical mystery tour."



> **"Our faith comes in moments; our vice is habitual. Yet there is a depth in those moments which constrains us to ascribe more reality to them than to all other experiences… I am constrained every moment to acknowledge a higher origin than the will I call mine."** Ralph Waldo Emerson

And then my ear broke, and I fell into despair. My spiritual light, slowly growing over the last four years from a flicker to a flame, went out. My broken ear gave me a desperate "need." I deepened my study into metaphysics and worked to transform my consciousness.

Spiritual Lessons - Overt Soul Journey

My lessons are profoundly personal, and we each have our personal paths. I'll share a few things that helped me.

- My life is a Divine unfoldment - this is why I came here. It is full of gifts that bring me closer to enlightenment. I am on a Divine path to enlightenment.

- **Time:** Remove time from illness. Don't give it a past or a future, rather let it force me into intense present-moment awareness. "Transmute suffering into Consciousness and disaster into enlightenment." I have had many bumps and bruises in life, including an adventure through a car window. As broken as I've been, I always got better in time. But it never took this long. Getting over the frustration of life not running to "my time" has been a big lesson.

"Be present to the sound your heart makes as it heals.
Don't rush through the verses."

- **Living beyond fear:** a hard life lesson and an essential life choice. My first days were a solid block of pain and fear. Fear is the base rock of the humanness of things. I needed to learn to be with fear differently - to come not from fear but from love.

- **Acceptance and self-acceptance:** I accept that I can't control my illness and I can't control the actions of the many people in the world. This is actual and factual. My power, creativity, and happiness depend on my including reality. The world doesn't change - my relationship to the world has changed.

  Martha Creek said, "Acceptance is the great healer. Part of your soul's evolution is to accept that you will not understand the occurrences of your life. It's all okay. Acceptance is the great healer of strife and corrects the imbalance of perception. Acceptance is not passivity; it is non-positionality. All is OK."

  Accepting life empowers me to shift perspective and make new choices - a new life frame. My full hearing life might be over. I don't know what it is going to do next. Force of will does nothing but make it worse. I choose to align, accept, and allow for my miracle!

- **Compassion and self compassion:** My suffering has served to awaken compassion in me for all those with "hidden" disabilities. And we ALL have hidden things. Self-compassion comes hard for me, being a self-reliant woman. I remind myself, "What would you say to Frances if she were your best friend?" I strive to be as nice to myself as I am to my friends.

- **Shift: Integrity to Compassion:** During my business career "integrity" was my watch word. "Do what you say you will do," has turned out to be a big advantage in the business world. My ear experience has shifted this strongly held belief. I now realize integrity isn't always a choice - life happens.

- **Surrender:** Surrender is the end of the mind as your master. All judgment and all negativity dissolve and the unfathomable presence of peace and great joy. The purpose of surrender is to move us to courage. And with courage, we move to acceptance.

- **Living beyond fear:** a hard life lesson and an essential choice. A choice between getting my way or freeing myself from being bound by wanting to get my way. Life wins. I am completely open to what life brings me. I turn to the Divine within me and realize I have the power to cope, learn, and grow. I begin again.

- **Reframing my life and reforming my heart**: I am moving from an ego-centered to spirit-centered life, where devotion to the Divine replaces devotion to the ego. I am working to integrate my human and spiritual experience to become a "whole-hearted" person.

- **Accepting the Mystery:** A life-long learner, I always dive into research when I'm troubled or tickled. My broken ear experience has opened many doors I never would have chosen, but so it is. During the last two years, I have learned to relinquish my need to know. I have gained a strong tolerance for ambiguity and a willingness to not understand and never need to know.

- **Grace and Gratitude**: I am grateful for the state of grace and vibration that replaces the pride of accomplishment. LET MY LIGHT SHINE THROUGH my grace-filled words.

Living a spirit-led life is the only path that works for me now. I begin my day in meditation and do what I can do each day to help make our world a happier, healthier, and more peaceful place for all. I happily continue my “magical metaphysical mystery tour,” and I am at peace with my life.

5. Daily Life - Accommodations and Tips

Over the past two years, I have developed a great deal of sound tolerance and have learned to cope. I do about half of what I did before my ear blew up. I know the environments to avoid and to be careful in. I would love to have my old life back, but this new one is OK for now. Perhaps there is a tip or two here that will be helpful to you.

- **Daily Communications around the house:**

    - **A number system for the noise level in my head:** We devised a number system so that I could share the volume of noise in my head on a real-time basis. I use a 0 to 10 system to share how loud the noise in my head is at a particular time. When I wake up, it's usually around 3 or 4 (if I've had a good sleep). By the end of the day, it rises to 6 or 7, depending on activity. When it gets to 8, I need to isolate myself. This system helps the people in my world understand what it's like inside my noisy head.

    - **Where are you???** With SSHL, I lost my ability to determine where noises come from - my sonar is broken. Solution: we now add what room we are in when we call out to each other. "Hey there - I'm in the kitchen."

    - **Listening harder:** I've lived at super speed all my life. Part of running hard and fast is that I've missed things and run over people along the way. Now that I have only one ear to listen with, I need to listen "harder" - focus, pay attention, and read lips and expressions. Consequently, I'm "hearing" deeper.

- **Ear plugs** - many choices. Essential for living with H. The waxy ones work best for me as I seem to have large ear holes, and the little foamy ones fall out. I wear them whenever I go into a noisy environment and always have them with me "just in case." Every pocket, every purse, everywhere. I wear them in the house for showers and working with kitchen appliances. Yes, I've read all about the dangers of over-dependence… the people who wrote that have never felt the knife stab in their ear when a car backfires, a dog barks, or a baby cries. I am prepared for reality.

- **Headphones** - I use Bose Noise Canceling Headphones 700. I use these often - riding in the car (the noise of wheels on the asphalt gets me) and eating in restaurants (I can only manage outside seating at a few restaurants, but it's a start); With the noise canceling feature, ambient noise is reduced, and I can still hear someone next to me. It's not perfect, but it's much better than staying home.

  I also have a set of heavy-duty aircraft headphones from the surplus store. They block out almost all sounds but push hard on my head, so I can't wear them for long.

- **Earbuds** - my best tinnitus relief is listening to audiobooks with audio Earbuds. I also use these for my at-home hearing checks.

- **Home Hearing Checks:**

I will not take another audiology exam - too much pain with no good "why." However, I am curious about my condition. I have "home hearing" checks that help me gauge how I'm doing.

  - **TV Volume** - For several months, watching TV meant watching with the sound off and closed captions on. Recently I noticed I wasn't reading but was listening to the TV again - with the volume at my pre-broken-ear level. After a setback, I had to turn the sound off again, but I'm slowly improving. I use the game show Jeopardy as a home hearing test, as it seems to stay at a constant volume without too many spikes.

  - **Earbud test** - I put the earbud in my good ear to mark the "normal" volume. Then I put it in my bad ear and see how loud I crank the volume up before I can hear anything. Never to the point of pain. Slowly, slowly the dial is moving up. I am healing!

- **Apple Airpods** - have some cool hearing-aid-like features. They can amplify sound in the deaf ear and cancel out some noise. I am playing with a pair now.

- **Audiobooks** - a lifesaver for me. I am deaf and have tinnitus in my left ear only. When I stream in audiobooks, I don't hear the tinnitus. This is my only physical relief from tinnitus.

- **Meditation** - brings me to present-moment awareness and dramatically reduces the anxiety that triggers the noise in my head. I struggle with sitting still, but I'm working on it.

- **Hiking** - I live in the mountains and find the quiet and peace of hiking in the woods to be the #1 relief for me. I have discovered that my tinnitus noise exactly matches the whooshing noise of the very high wind in the upper parts of the trees. It's like TRT on the hoof!

- **Cars, planes, and boats**
  - Car rides are hard for me - the noise of the tires on the asphalt, the noise of the car engine, the noise of the other cars. I can manage these by wearing my headset. I now have a backup headset in the car in case I forget mine.
  - Airplanes - I flew from California to Alabama to visit my sister! A combination of my headphones and earplugs did the trick. The challenge - after several hours, the pressure of the headphones on the sides of my head becomes bothersome. So far, I've limited my flights to inside the US. My colleagues in Europe want me to come over. I'm not sure.
  - Boats - I am embarking on a great adventure next month - a cruise! I have zero notion of how this will go. In my "baby steps" mode, I chose a ship that leaves LA, and my first stop is in San Francisco. If it's too bad, I can exit the ship in SF, and I'm home. Fingers crossed, it will be wonderful!

- **Time management - Pacing** - one day on, one day off – build-in recovery time. For me, the more anxiety, the more noise in my head, and then I shut down. I've learned to "stop in the name of love" and carefully manage my time with people. I can now manage about two hours with headsets on and not need an extended recovery. For longer adventures, I plan for days off, after the adventure, as recovery time.

- **Managing Expectations:** I am no longer ashamed of my condition. It is what it is, and I make the best of it. I let people know in advance of my limits. I can only stay for two hours. If it gets too loud, I will quietly leave.

- **Zoom with Closed Captions** - has allowed me to return to meaningful work. I turn the volume off and read the conversation. In addition to Closed Captions, Zoom has a “Transcript” feature so we can capture and read the whole meeting. This is a huge benefit to helping me return to a bit more “normal” life.

- **Food**: My doctor recommended plant-based eating to prevent stroke. As my ear situation could be considered an “ear stroke,” improving my diet became an important element of my get-well program. I signed up for “My Fitness Pal” and began tracking my nutrients. I’ve had great success in reducing inflammatory foods, which I believe is helping with my getting better.

- **Coffee:** Oh, the pain of going from 4 cups of coffee a day to one. My solution is ¼ caffeine ¾ decaf. Not the best solution, but needs must!

- **Changed sides of the bed** - after more than 30 years, we’ve changed sides of the bed so that I can hear my husband when he talks. This has been the most difficult and amusing accommodation. SSHL Bonus - when the bedroom gets loud, a dog and four cats, I turn my good ear to the pillow and hear none of it!

- **Social Media Sites** - I struggle with the Facebook groups around SSHL, H & T. My heart breaks whenever I see, “I woke up deaf…” In fact, these posts were my motivation for writing this article. I plan to share this article with the Facebook communities. (It’s exhausting to answer each sad post, so I’m doing it all in one HUGE post.)

- **“Ear lapse”** - relapses and setbacks - As I began writing this article in February, I was brimming with hopeful ideas as my H had finally calmed down and my T had become a “bother” and no longer my central focus. I was so improved that I could volunteer to help with a project - ushering and cleaning up for an event. It was five hours with my headphones on. It was too much. My H returned to its high level, and I returned to isolation. However, this time, I am not engaging in fear, anger, stress, denial, or grief. I’m just giving myself time to rest and heal and begin again. After two months, I am back to my pre-ear-lapse condition and hopefully engaging with life again.

Communicating About My Ears

Because of my Hyperacusis, I can only go out in public with earplugs and a noise-canceling headset. The good news is that it's not unusual to see people wearing headsets these days. The bad news is people think I’m listening to a book or music and not to them! So I simply say:

“I have a whacky hearing condition that makes normal noises very loud. I wear noise-canceling headsets to tamp down the noise to tolerable. I can hear you speak; the headset just knocks out the background noise.”

If they seem to care, I explain:

I have a hearing issue that makes some normal level noises - like running water, doors closing, music on speakers - sound very loud to me, and sudden loud noises - like dogs barking - are traumatic - like a knife stab in the ear. I manage it with noise-canceling headsets and earplugs and avoiding noisy environments. (It's called Hyperacusis - super sensitive hearing and is a Neurodiversity and Auditory Sensory Issue.)

Letter explaining my early meeting departure to members of Volunteer Board

Nov 2022

Dear SSEPO board friends (after leaving a party early):

I don't normally go into this, but you are my friends, and some of you asked about my hearing situation. It was hard to explain in person - so here's a not-so-quick run down.

When I woke up deaf in one ear (Sudden Sensorineural Hearing loss - no one knows WHY) on April 11, 2021, I also woke up with loud Tinnitus and a condition called Hyperacusis. The deafness and constant loud tinnitus are awful but manageable, and I could have a pretty normal life with hearing aids, etc. However, the Hyperacusis not so much - it makes normal noises very loud, and loud noises intolerable. Motorcycles, GT40s, blenders, garage door openers, tires on the road, and barking dogs are so loud it feels like a knife stabbing me in the ear.

It has been 18 months. I decided at my first anniversary, in April 2022, that I may never get better, and it was time to stop being a victim and figure out how to have the best life possible. Part of the challenge is that the noise level in my head is cumulative - so as I go about my day, the noise gets louder until I just have to shut down. Last night the noise in my head was already pretty loud when we arrived - returning from travel a week ago, a long day, stress… and I had limited capacity for the joyful noise. The headset I was wearing is noise canceling - it cuts out some of the surrounding loud noise, and I can typically understand the person I'm speaking with while wearing them - I can adjust the level of canceling 0, 5, 10 - I am becoming a good lip reader.

It breaks my heart to leave a party! But needs must. This has been a most interesting chapter in my life. I'm developing a new framework - Frances 2.0 - a bit slower, quieter, and less dramatic but very much still alive. Thank you for understanding.

Frances

There is a good Blog about sharing your hearing challenges with workmates. *"I wish I had disclosed my hearing loss sooner."* Check the reference section for the link.

6. Summary

Rest, recover, reframe. No one can see it, nobody knows, but something inside of me broke on April 11, 2021. I haven't bounced back up with my usual zeal.

Taking time, so much time, to reset and recover is a new experience for me. My brain is reprogramming its neural pathways to help me live a safe and happy life. Brain reprogramming is a slow and steady activity.

I am slowly, carefully, reengaging with the best parts of life. Life goes on and I made the choice - to lament what I've lost or be grateful for what remains. I seek a balance of physical, emotional, intellectual, and spiritual working together harmoniously to find fulfillment as a human being. I am deeply grateful to the many, many people who are helping me navigate this journey. Thank you.

7. About

Frances is a mother, wife, grandmother, sister, fairy godmother, mentor, advisor, volunteer, and friend. She has also been a hard-charging businesswoman working in the invigorating high-tech arena for over 40 years. In 2019, Frances founded ThankU.io – a global gratitude platform that enables and encourages "lighting up" the world with acts of appreciation.

Frances is a computer industry pioneer with decades of Silicon Valley marketing and sales contribution. In her early career, Frances helped market the first technical computers in the world, working with Bill Hewlett and Dave Packard at HP. From there, she worked with other tech multinationals, then, during the Dot.Com era, switched to the fun, excitement, and non-stop stress of working with global startups. In 2002, Frances launched Addison Marketing - a boutique marketing agency with a key focus on very early days marketing and helping international companies move into the US market. Frances has worked with more than 40 startups, helping build their marketing programs and teams.

Frances's hearing system broke in 2021; since then, she has reframed her life. Alison Harris, Frances's daughter, is now managing Addison Marketing. Frances is focusing on organically growing ThankU.io and supporting research and education on hearing health. You can reach Frances at: Frances@thanku.io.

8. References

Articles:

- “From a Hyperacusis Patient to Audiologist : My Advice for Better Patient Care” https://canadianaudiologist.ca/hypercacusis-better-patient-care-feature/

- *“Living with Hearing Loss - Disclosing your hearing loss at work in three simple steps” https://livingwithhearingloss.com/2022/07/19/disclosing-your-hearing-loss-at-work-in-three-simple-steps/*

- *Treatments for Hyperacusis:* **https://hearinghealthfoundation.org/hyperacusis-learn?gclid=CjwKCAjwrdmhBhBBEiwA4Hx5g32Qr95n8KbvD9A0J_EunU85ZfnX6UhbSHRgX-d_qkA-yb-NnjOxURoCu2gQAvD_BwE**

- “Why do some sounds hurt - with and without hearing loss” https://www.signia.net/en-us/blog/global/2020-02-18-why-do-some-sounds-hurt-with-and-without-hearing-loss/#:~:text=In%20cases%20of%20hyperacusis%2C%20however,treated%20by%20wearing%20hearing%20aids.

- “When Everyday Sound Becomes Torture,” Joyce Cohen, Buzzfeed, 3/14/13 https://www.buzzfeed.com/joycecohen/noise-kills-when-everyday-sound-becomes-torture

Books:

Neil G. Bauman	*Hypersensitive to Sound? Successfully Deal with your Hyperacusis Recruitment Other Sound Sensitivities*
Tara Brach	*Radical Compassion, Radical Acceptance, True Refuge*
Berne Brown	*Rising Strong, Gifts of Imperfection, Braving the Wilderness*
Pema Chadron	*When things Fall Apart, Perfect Just as you are, The Wisdom of No Escape, Welcoming the Unwelcome*
Martha Creek	*Martha’s Pearls*
David Hawkins	*Letting Go – The Pathway to Surrender*
Jon Kabat-Zinn	*Full Catastrophe Living, The Mindful Way Through Depression*

Pawel, Jastreboff and Jonathan Hazell	*Tinnitus Retraining Therapy*
Richard Rohr	*The Naked Now — Learning to See as the Mystics, Yes, And…*
Paul Selig	*I am the Word, Mastery Trilogy, Beyond the Known Trilogy*
Tami Simon	*The Self-Acceptance Project*
Michael Singer	*The Surrender Experiment*
Eckhart Tolle	*Practicing the Power of Now*

Websites:

- **Dr. Gans' MBTSR - Mindfulness Based Tinnitus Stress Reduction**- online program https://mindfultinnitusrelief.com/

- **Living with Hearing Loss -** https://livingwithhearingloss.com blog site Living With Hearing Loss is a blog and online community for people living with hearing loss. Founder Shari Eberts has an adult-onset genetic hearing loss and hopes that by sharing her story, she will help others to live more comfortably with their own hearing issue

- **Oto App** "Oto will show you how to push tinnitus into the background, so you can get back to what matters. So whether it's ringing in the ears, whooshing, buzzing, or a range of sounds, in just a few minutes a day, Oto will help you get your life back from tinnitus."

- **Rev. Dr. Martha Creek www.MarthaCreek.com** –Widely known in New Thought, Martha's training approaches deep inner work as an adventure with a sense of curiosity and wonder. A master of the art of right questioning, she calls forth the most stubborn and self-defeating patterns to create a **new** way of being, literally.

I'm in a place where,
I'm in my own lane. Minding
my business, making moves
privately, protecting my peace
and being unavailable to people
that mean me no good.
I love it here.