

Autoimmune Disease – My Journey

Anyone with autoimmune disease will have a tough time pinpointing the cause. Is it genetics, something we are eating or not eating a family history or are our bodies just prone to autoimmune disease? In my instance my father had an issue one time that I remember, and I remember he was given radioactive iodine.

Hopefully in sharing my personal experience with autoimmune disease you may find similarities in yourself or a loved one and find inspiration and, if needed, seek medical treatment. My journey started with Hashimoto's Thyroiditis which led to Celiac's Disease which led to Rheumatoid Arthritis and hopefully that will be the last of the autoimmune diseases I have in my life.

Hashimoto's Thyroiditis

After my first child was born, my thyroid became overactive. At the age of twenty-seven, I had not yet become a nurse and was unaware that hyperthyroidism after a first pregnancy is common among women. I should have taken my skinniness and periodic racing heartbeat and run with it, as it would have more than likely self-corrected in a brief time. But my OB-GYN wanted me to have my heartbeat returned to normal sinus rhythm. So, after a visit with a physician, I ended up in a radiologist's office getting radioactive iodine like my father. I was fine until my mid-thirties when I ballooned from five feet six inches 128-132 lbs. to 187 lbs. I was so tired all the time, all I wanted to do was sleep and I had many of the signs of hypothyroidism. I saw my first endocrinologist who drew bloodwork which was normal, said I was just obese and eating too much. I was so upset because I was not eating very much and wondered how my bloodwork was normal since I was feeling so badly, and it seemed like I gained so much weight overnight. I wondered why this doctor only treated my lab work and not my symptoms. He was a 5-star endocrinologist! Since my husband is diabetic, I made an appointment with his endocrinologist who is and was one of the best-known endocrinologists in town. This endocrinologist was nothing short of rude and said the same things to me except if my symptoms persisted, to return to his office and see his NP. I did return to see the NP.

Hashimoto's Diagnosis: The NP listened to me and my symptoms and examined me. He ran autoimmune specific blood work and examined my thyroid where he felt my enlarged thyroid (goiter). A person with thyroiditis will usually have an enlarged thyroid especially before treatment begins due to nodules on the thyroid and inflammation from lack of iodine and the autoimmune response. I was so grateful as I was having trouble swallowing. The NP did a thyroid ultrasound which was needed to rule out cancer. I returned as soon as lab results were complete. My thyroid autoimmune test was ten times higher than the upper limit of normal. The NP confirmed I had Hashimoto's Thyroiditis. By that time, my thyroid was beginning to show signs of failure. My T3, T4 and TSH were no longer in the normal ranges.

Methods of confirmation:

- **Anti-TPO antibodies** – Anti-thyroid peroxidase. Antibodies created by your immune system; target enzyme found in thyroid gland. Presence of antibodies in blood means abnormality – suggesting autoimmune disease present; not specifically Hashimoto's (Childs, 2025).
- **Anti-thyroglobulin antibodies** – Hallmark of Hashimoto's Disease if these antibodies are present; indicates inflammation. These antibodies are never present in healthy people without Hashimoto's Disease (Childs, 2025).
- **ESR** – Erythrocyte sedimentation rate - Level of inflammation. The higher the level, the greater the inflammation (Childs, 2025).
- **CRP** – C reactive protein – Measures inflammation. Typically measures the risk of heart disease. The higher the result, the greater the inflammation (Childs, 2025).
- **Vitamin D** – Close association between low levels of Vitamin D and greater likelihood of having Hashimoto's. Higher Vitamin D helps protect your immune system and decreases your risk for thyroid cancer and Graves' disease (Childs, 2025).
- **TSH** – Thyroid hormone made by brain. Tells your thyroid when to make more or less thyroid hormone based on the level. The higher your TSH, the less your thyroid is functioning. However, with Hashimoto's your TSH can be normal, and you can respond (need) to small doses of thyroid hormone (Childs, 2025).
- **Free T4** – made by thyroid. It is an important measurement in Hashimoto's. Inactive T4 converts to active T3 but this process slows down in Hashimoto's, so it needs to be monitored. (Childs, 2025).
- **Free T3** – measures the total amount of active thyroid hormone. It is the most important measure of thyroid function. Thyroid function should not just be about TSH when you have Hashimoto's. (Childs, 2025).
- **Reverse T3** – anti-thyroid metabolite when your body does not convert T4 to T3. Most doctors will not order this test, especially based on symptoms (Dr. Childs, 2025).

Symptoms	Symptoms	Symptoms
Obesity	Decreased appetite	UTIs
Cold hands; cold feet	Intolerance to heat/cold	Shivering
Excessive/decreased sweating	Epstein Barr Virus	Weight gain; inability to lose weight
Alopecia	Celiac's Disease	Pernicious Anemia
Psoriasis	Scleroderma	Sjogren's Syndrome
Vertigo	Dizziness	Itchy ears
Dry eyes	Hair loss	Dry, flaky, itchy scalp
Loss of eyelashes	Body hair loss	Slow nail growth – thick, dry, cracked brittle nails
Longitudinal ridges on nails	Fatigue	Insomnia
Brain Fog	Bloating	High Cholesterol

Muscle weakness, body aches	Migraines	Anxiety, depression, mood swings
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(a.u., 2022, Hashimoto's disease)

Special Note:

The NP prescribed Levothyroxine (treats hypothyroid) and Liothyronine (treats conversion of T4 to T3). Many doctors do not recognize the importance of the need for monitoring and treating the T4 to T3 conversion in Hashimoto's. Be aware of signs of difficulty conversion like fatigue, low energy, brain fog, dry skin, hair loss and brittleness (Dr. Hagmeyer, 2024). Maintaining a healthy balanced diet, stress management and maintaining levels of Selenium, Zinc, and Iron will also assist in supporting T4 to T3 conversion naturally. If you get a chance to read Dr. Hagmeyer's article, it is highly informative on this topic. I have found that the best endocrinologists at that time knew little about Hashimoto's Thyroiditis. Hopefully, more providers, particularly endocrinologists, are aware today.

Celiac's Disease

When I was forty-seven, I had heartburn daily, so I went to a GI doctor to find out the cause. The cause turned out to be from a diaphragmatic hernia in need of immediate surgery. I had surgery the next week. The surgery turned out to be traumatic as I awoke to multiple pulmonary emboli. Recovery from this surgery was slower than expected with a stay in IMC on BiPAP (positive pressure Oxygen) and a heparin drip for the pulmonary emboli. This traumatic event caused my body to have an immune response, and I began having symptoms of Celiac's Disease. Celiac's disease was a steep learning curve because it happened overnight. So, I had to reset my digestive system by not eating and then introducing one food at a time to find out what I was able to eat and not able to eat. Since I was a nurse at this time and I already had Hashimoto's Thyroiditis, and how I was reacting with food and terrible diarrhea and vomiting, it did not take long to figure out that I was gluten intolerant. I have been on a gluten free diet since that time. My GI doctor attempted Celiac's confirmation of the antrum about six months after my recovery, but I had been on the gluten free diet too long to get confirmation in this manner. He still confirmed my diagnosis through my symptoms and the state of my colon during my colonoscopy. When you have Celiac's disease you lose intestinal villi that never fully recovers even on a strict gluten free diet. Development of MAS is also a clear diagnosis for autoimmune disease(s) and will save you from the discomfort of a small intestine biopsy.

Methods of confirmation:

- [Dermatitis herpetiformis](#) – Dermatitis is a sore that forms a blister and then begins to fade to a scab. Also, dermatitis herpetiformis are uncomfortable, itchy, pop easily, sting when they pop and can become infected. I know because I get them after I have a bad gluten episode. The fluid can be biopsied if the sores are present and in the blister stage. Getting the appointment without delay while the blister(s) is/are still present is the difficult part (u.n. 2022).

- [Duodenal Biopsy](#) – Duodenal biopsy is the “gold standard” for diagnosis. This result will likely be a false negative if you are already on a gluten free diet. Afterwards, you will have soreness (u.n. 2018).
- [Small intestine biopsy](#) – will show density of intra-epithelial lymphocytes (white blood cells in immune system); villi/crypt ratio grooves between the villi will be decreased. The villi promote nutrient absorption and line the intestine. In celiac's they will be smaller and flattened due to exposure with epithelial changes (u.n. 2018)
- [Blood test](#) – to obtain anti-endomysial and anti-tissue transglutaminase antibodies. However, this will only work after you have had a terrible exposure to gluten. Exposure to gluten is very harmful to your health if you have a true gluten allergy. A gluten exposure will strip your body of electrolytes needed and will strip your small intestine of its villi causing you months to recover. The villi never return to that of a person who does not have Celiac's disease. The goal of a person with Celiac's disease is to not have any exposure to gluten to stay as healthy as possible (u.n 2017).

Special Note:

Doctors are usually not focused on testing confirmation. They are more focused on symptoms, management and avoiding exposure to gluten. Repeated exposure to gluten with reactions is critical to your health and life expectancy. Each reaction destroys the critical lining in your gut allowing bacteria and cancer as well as destroying your electrolytes. Besides that, the testing or blood work may not be covered by your insurance. After a recent very harsh exposure to gluten, I asked my Primary Care office if they would order the bloodwork which is very time restrictive after exposure. The MA was upset about the exposure as well as why I felt a need for this bloodwork. She denied my request; said I had been diagnosed a long time ago with Celiac's by five of my providers and I did not need to put myself through anymore.

Rheumatoid Arthritis

When I was in my sixties, I was diagnosed with breast cancer. It was detected early as stage one. My treatment was lumpectomy of one breast, removal of the sentinel lymph node, radiation therapy for three months, and an aromatase inhibitor medication for two of the five-years planned due to the side effects. Radiation therapy and lumpectomy were traumatic enough for any person. I do not know how the friends I have developed during this journey have endured the treatments, medications they have had to take and chemotherapy. All those things were medications with worse side effects (and longer), longer treatments and chemotherapy. Two of my friends are the most positive warriors for sure in their processes. I am incredibly lucky and sometimes feel guilty for having survived five years. I am incredibly grateful and humbled.

According to a study of the most common autoimmune diseases SLE, psoriasis and RA, there is a 26.6% increased risk of developing breast cancer (Dedousis, 2022). Of course, my breast cancer happened before I knew I had RA, but a provider I had in my late thirties knew “something was

wrong.” I did too; I just thought it was cancer. My bones hurt too badly for my age, I was stiff often and I could not step up high with my right leg. I walked four miles four days a week at that time. So... something was wrong.

Although I was treated for breast cancer with Anastrozole an aromatase inhibitor, there was no increase in risk of RA than in women treated differently (Wadstrom, 2019). It is a possibility that radiation therapy induced activation of Rheumatoid Arthritis with the high dose of radiation by activating my immune response since I had Celiac’s and signs of RA.

Rheumatoid arthritis is a difficult disease requiring self-management and the medications are not friendly. It can also cause a domino effect if you keep having flares while your doctors are increasing your doses to get your RA under control. The alternative of not taking any medications is far worse in my mind. I know of a woman with RA who does not take any medication and has not been to a rheumatologist. I would not be able to live without medication; the pain would be too great, and I would likely no longer be here. Since I have been diagnosed with Rheumatoid Arthritis approximately eighteen months ago, I have had more flares than I can count, and I have had three deep vein thrombosis (DVT) events. RA flares increase your odds of having DVTs, so your goal is to get your RA completely under control with medication and no stress. DVTs are blood clots which are quite a common part of Rheumatoid Arthritis. Therefore, I am now on Eliquis for the rest of my life. My pulmonary embolism mentioned above may have been an early indicator of Rheumatoid Arthritis.

One of the things about Rheumatoid Arthritis is often people confuse it with Osteoarthritis and dismiss it as mild or moderately painful. When I have a flare, it is far beyond the most pain tolerable to any person. I am not prescribed any pain medication beyond Tylenol and not Tylenol arthritis because of the prescribed medications I take to avoid the flares.

Multiple Autoimmune Syndrome (MAS)

I cannot stress enough that when you have an autoimmune disease you need to be aware that you are at risk of developing a second and a third autoimmune disease in your lifetime. If you have at least three autoimmune diseases (with one being a dermatologic condition), this is known as multiple autoimmune syndrome (MAS) which happens to about one fourth of autoimmune patients (Cojocaru, 2010).

Methods of Confirmation:

6 Blood tests:

Blood Test Name (Goodwin, 2021)	Explanation
Erythrocyte sedimentation rate (ESR)	evaluates inflammation in your body. The higher this level, the more inflammation
C-reactive protein (CRP)	protein produced by liver; shows presence of infection. High level = inflammation

Blood Count (CBC)	evaluates blood cells; RA may cause abnormalities
Rheumatoid factor	measures rheumatoid factor proteins in blood; high levels may indicate rheumatoid or other autoimmune conditions
Cyclic citrullinated peptide antibodies (CCP antibodies)	immune system protein – autoantibody found in about 60-80% of those with RA
Antinuclear antibody (ANA)	autoantibody produced in immune system that attack healthy cells/tissues. Presence in blood can mean autoimmune condition
Joint scan	shows any inflammation
Imaging test: X-rays/MRIs	shows details of muscles, joints, and bones
Physical assessment	pain, deformities in joints, range of motion and any limitations in walking, standing, balance, grip

Summing it all Up:

For me, I feel the best (and believe me, there are times when I have cheated) when I adhere to what my doctors advise me to do. I take the medications they prescribe, sometimes kicking, because I am a ‘natural girl,’ and I eat the diet they recommend 99.9% of the time with an occasional gf cookie or two. If you overdue cheating, you will pay for it. My doctors have all recommended a vegetarian diet. So now I am on a gluten-free, vegetarian diet without any chemicals or preservatives. It took effort, but I am enjoying it now. There are impressive recipes and cookbooks for gluten free vegetarian diets. I have not tried autoimmune diets, but I consume berries for their anti-inflammatory benefits.

The most important takeaway is to take the best care of yourself possible with each autoimmune disease and educate yourself. Remain positive and meet your autoimmune disease(s) head. I have a friend who has had Multiple Sclerosis for at least thirty years. She has always been a strong and positive woman and on the go, raised three children (one special needs). She was an office manager for years and took care of everything at her home as well. She is and was one of the most positive women I have ever been around. She falls now but still refuses to give in or give up. She laughs at herself when she falls or forgets the rest of her sentence and says things like “silly me.” She has never felt sorry for herself. She is an example of how we should all be in the face of any disease. It is best to become a soldier; accept it and continue one day at a time with a smile and a great presence and attitude. In a movie I saw not too long ago, one of the characters had been through so much and had not let on to those around her. Someone close said something to her about her cheerful outlook and she said, “no one wants to be around a sad sack.” It is always good to look for your blessings and find gratefulness, especially in the face of adversity.

In my next post I will talk about Sjogren’s, Potts, and Multiple Sclerosis hopefully with interviews.

Sharon DeLellis, MSN, RN

References:

(u.n. 2017-2018) Diagnosis. *Celiac Disease Foundation*. [Diagnosis of Celiac Disease | Celiac Disease Foundation](#); [Celiac Disease Screening | Celiac Disease Foundation](#)

Childs, Westin, Dr. (February 8, 2025). Hashimoto's Blood Tests (Which Test You NEED & What they mean). *DR. CHILDS*. [Hashimoto's Blood Tests \(Which Test You NEED & What they mean\)](#)

Cojocaru M, Cojocaru IM, Silosi I. Multiple autoimmune syndrome. *Maedica (Bucur)*. 2010 Apr;5(2):132-4. PMID: 21977137; PMCID: PMC3150011. [Multiple autoimmune syndrome - PMC](#)

Dedousis, D, Zhang, A, et al. (June 2, 2022). Survival in patients with breast cancer and history of autoimmune disease. *Journal of Clinical Oncology*, Vol 40, #16 suppl. <https://doi.org/10.1200/JCO.2022.40.16> suppl.1020 [Survival in patients with breast cancer and history of autoimmune disease. | Journal of Clinical Oncology](#)

(u.n. December 02, 2022). Dermatitis Herpetiformis. *Cleveland Clinic*. [Dermatitis Herpetiformis: Celiac Disease, Symptoms & Treatment](#)

Goodwin, M. (October 25, 2021) 6 Blood Tests Used to Diagnose Rheumatoid Arthritis. Healthline. [6 Rheumatoid Arthritis Blood Tests, Plus Other Diagnostic Tools](#)

Hagmeyer, Dr. (January 10, 2024). Thyroid Conversion Issues – Everything You Ever Wanted to Know. Dr. Hagmeyer. [Thyroid Conversion Issues-Everything You Ever Wanted To Know | Dr. Hagmeyer](#)

(a.u., Jan 15, 2022) Hashimoto's disease. Mayo Clinic. [Hashimoto's disease - Diagnosis & treatment - Mayo Clinic](#)

Wadström H, Pettersson A, Smedby KE, Askling J. Risk of breast cancer before and after rheumatoid arthritis, and the impact of hormonal factors. *Ann Rheum Dis*. 2020 May;79(5):581-586. doi: 10.1136/annrheumdis-2019-216756. Epub 2020 Mar 11. PMID: 32161056; PMCID: PMC7213316.