

A case history – The relationship of Thyroid and Coeliac Disease

A functional, dysfunctional, genetically connected family – Sue Black's familiar story.

I feel particularly pleased with myself today! I've just visited the doctor to get my six month blood results and, without bragging too much, have come away with a clean bill of health. My cholesterol and sugar levels have both declined since the last test, mid 2009 and my TSH (thyroid stimulating hormone) was in the normal range.

I wish to tell you my story, as I find more and more people are not just diagnosed with one but often two autoimmune diseases – thyroid and coeliac disease seem to be very common.

Chapter 1

IN THE BEGINNING

In 1990, I had visited my family doctor for something quite minor when he discovered my thyroid condition. The man who told me of the three pregnancies with my beautiful girls, gave them their first vaccines, tending to cuts, warts and infections, noticed the lump at the front of my neck when I laughed one day in his surgery. He examined and prodded and sent me off for the thyroid blood tests and a visit to an endocrinologist. So from then on, I had the autoimmune condition called Hashimoto's Thyroiditis (related to an underactive thyroid). This is where the white blood cells invade the thyroid gland and attack the tissue. The immune system produces antibodies which interfere with the production of the thyroid hormones. (There will be a parallel to this later on).

Thyroid disease like coeliac disease can produce a multitude of symptoms. It is not always cut and dry.

With having thyroid disease it was suggested I have a six monthly blood test to keep on track and, believe me, my thyroid levels can fluctuate as much as the stock market. I have battled the fluctuations of my hormones for

ten years now and know, without hypochondriac tendencies, when the levels are wrong. With six-monthly check ups, the roller coaster ride of feeling well and energetic for a couple of months then hitting the trough with emotions running riot with anxiety attacks of feelings that I was going to die (which I wasn't), being breathless (which I was) and having a fluttering heart beat (which thankfully only lasted a few seconds). I didn't feel it at the time, but I gather from reading and talking to many friends with thyroid problems, I really am one of the lucky ones with my symptoms.

Over the years, I have discovered that my father had hyperthyroidism, an overactive thyroid. As a young child I remember stories of him having radioactive iodine treatment and of his mood swings which all now make sense. Dad had three brothers, one had hyperthyroidism and Alzheimer's Disease, and another had Parkinson's disease. My aunt on my mother's side has a thyroid condition along with my sister and brother both getting late onset hypothyroidism, an underactive thyroid and thoughtfully, I have passed it on to my youngest daughter, who needed an operation at the age of 12 to 'trim' her thyroid growing around her windpipe. She also has Hashimoto's thyroiditis and is on hormone replacement, especially to rest her thyroid over her growing years.

Chapter 2

YOU KNOW WHEN SOMETHING JUST ISN'T RIGHT?

In 2000, I went to the doctor with symptoms of shortness of breath and a feeling of pressure on the windpipe. After many months, being told it was 'nothing to worry about', or 'lose some weight' and worse, 'it was all in my head', I insisted on being sent for a CT scan on my neck. Results showed that the 'burnt out' thyroid was slightly enlarged and showed significant compression on the trachea. December 2000, I had my thyroid removed.

I'm hoping that my thyroid gland is in a specimen jar in a research lab. It ended up being quite fibrous and had lost total function – no use to me now! So for the rest of my life I was going to



be on Thyroxine, a thyroid replacement hormone.

There was only one slight problem with the operation. With the thyroid being so fibrous, it left scar tissue fused to the side of the trachea.

Over the months ahead, I noticed a distinct change in my voice, usually hoarse and gravelly especially with overuse. Many husbands would say that there was a good cure for that and luckily for mine, an ENT specialist suggested I give my voice a rest. This did not really help my symptoms.

You are made aware of the .09% chance of laryngeal nerve damage during the procedure. Even though the nerves were identified and preserved during surgery, it was suggested that the nerve had been caught up in some scar tissue resulting in palsy of the right vocal cord. So, of course, I booked an appointment to see a speech therapist who helped train my left vocal cord to work harder. An absolute nightmare for a singer (for me it was only in the shower and the National Anthem at school assemblies) – no longer could I reach the high notes where the vocal cords come together quite tightly to get those high octaves.

I would like to make it clear that I am the 1 in 100 for this to happen to.

Please be aware that there is a very minimal chance of this happening.

Chapter 3

WHAT CAN I BLAME MY COELIAC DISEASE ON?

Once again, I need to give thanks to my doctor I mentioned earlier who has always looked outside the square and knew the tests to be done. After many months of iron deficiency nothing was working – dietary intake was good, menstruation was normal – what was next? After coeliac serology was taken and a visit to the gastroenterologist for a biopsy, I was diagnosed with coeliac disease in 2001.

When I read up on coeliac disease I recognised some familiar words – ‘Autoimmune is where the body mistakenly produces antibodies that damage its own tissues.’

On reading The Coeliac Society’s ‘What is it?’ brochure, the first thing I noticed was that ‘the immune system reacts abnormally to gluten, causing small bowel inflammation and damage.’ Are you seeing a parallel here?

Reading on, it mentions ‘Environmental factors also play an important role in the development of coeliac disease.’ What could I blame it on? The stress of building of a house and dealing with council, eating pasta for six months around the USA because that was all we could afford; could it have been having the flu or just wonderfully inherited genes! Who knows?

I have been following a gluten free diet since being diagnosed. Accepting that the days of fresh bread, light puff pastry and Tim Tams were over – however there are some gluten free breads out there getting very close! It’s something you do get over and I don’t miss them anymore.

Since cutting out gluten, I also feel the family has benefitted as well. We

follow a relaxed high protein and low carbohydrate plan, especially at night. Rarely do we have pastries, fried food and pasta. Don’t get me wrong, we aren’t saints. We still enjoy dessert.

Chapter 4 incomplete

SO, LET ME CONTINUE THE FAMILY TREE

My sister was diagnosed with Multiple Sclerosis (also involving an autoimmune process – an abnormal immune response directed against the central nervous system). Her daughter was the first to be diagnosed with coeliac disease in the following generation. Another niece was diagnosed with coeliac disease whilst living in London and her father, my brother, after a year of feeling unwell finally found out why his Thyroxine wasn’t taking effect and was diagnosed with coeliac disease. (Medications, as do nutrients, have trouble being absorbed.) Once again, I passed an autoimmune disease to one of my other daughters who was diagnosed with coeliac disease last year. Hence, our Christmas dinner consisted of gluten free pudding, no stuffing in the turkey and no stout-glazed ham. Thank

goodness champagne wasn’t off the menu.

There you have it – a functional, dysfunctional, genetically connected family.

I’m sure there are many of you who are nodding and starting to see connections in your own family. Maybe there are symptoms that need to be looked into. Your job now is to get family members to seek proper diagnosis, ruling out thyroid disease, coeliac disease or other autoimmune diseases. One theory is that the genes for coeliac disease and other autoimmune diseases are likely to be inherited together. If my family isn’t proof of this I don’t know what is.

Autoimmune conditions can occur in clusters so a thyroid patient can get other autoimmune diseases such as type 1 diabetes, coeliac disease or pernicious anaemia (vitamin B12 deficiency). However these latter conditions are less common than thyroid disease and most thyroid patients don’t get additional autoimmune diseases.

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