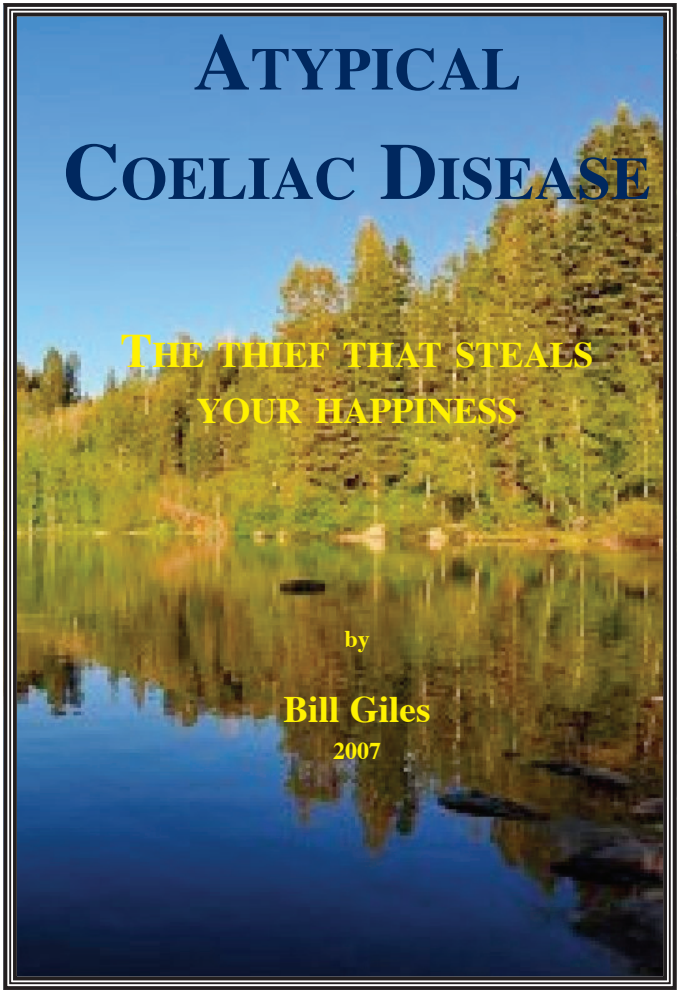
ATYPICAL
COELIAC DISEASE
THE THIEF THAT STEALS
YOUR HAPPINESS
by
Bill Giles
2007

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Chapter One

'Jenny, my name is Bill Giles, hello'. We shook hands and she glanced at me with a look that implied 'Am I wasting my time again?', but she was polite. She gathered up her lovely handbag, lightweight coat and bundle of papers. 'Would you like to come this way—down to the back room'. As I followed her down the hallway I said 'Put your bag and coat on the purple chair and you can sit on the adjacent one'.

She was a compact woman, about 45 years I guessed, with weight captured on her hips and a walk that reflected past agility. She was no fool. We entered my rather small consultation room and settled adjacent to each other. I re-focused on the question form (more than 100 questions) she had filled-in while seated in the waiting room and glanced at her written reason to consult with me. I'm a biologist in clinical practice. I use my training and experience to assist people with chronic health problems—all sorts, but find myself working mainly with immune related illnesses and their accompanying symptoms. This is partly because I have immune related problems myself and am always searching for more understanding.

'So Jenny, you've written here that what you want from this consultation is a way to turn your health around!'

'Yes, if I can find a way! I'm only 39 and should not feel this bad. Some friends have recommended I see you because you have helped them. I've tried lots of things but nothing seems to be working for me. Would you like to see my doctors reports?'

All her standard blood tests were normal—the doctors were satisfied with these but vexed with her symptoms. She did have confirmed antibodies to arthritis—rheumatoid[1]—but this was not her greatest health concern, or so she said. Over the next several minutes we discussed an array of symptoms, some that she remembered having as a youngster and others that had started a few years ago and had been with her ever since. Her main concern seemed to be just feeling like 'death warmed up'—chronically ill about life.

Anxiety, a degree of depression and a loss of enthusiasm for life were troubling her more and more. She felt her real nature was light and free, but now her head was fuggy and she had started to have headaches. She felt that she was battling with life. 'Don't get me wrong' she said 'I can do it, I can survive, but I would like to feel in my head like I did when I was younger!'.

'Why am I putting on so much weight around my hips and middle?' she asked with perplexity. She had been trying various weight-loss programs that seemed to work for others but could not get her to where she wanted to be. Her weight would go up and down in a day. She felt bloated and heavy in the tummy. 'I think at times I have irritable bowel syndrome like my

mother, but if I take some laxatives or something to slow it down I can cope with it' she sighed.

For several years now things had been happening to her. She was tired all the time. She had developed sinusitis, was constantly waking at night about 3.00 am feeling hot. She would throw off the blankets, go to the toilet and then lay for ages unable to go back to sleep. In the morning she would feel exhausted. You could read tiredness in the fine lines framing her face.

She was developing bad skin even though she used all the right creams. Then there were the aches and pains—her shoulders and arms throbbed. One doctor suggested she had fibromyalgia and left it at that. Every now and then the aches in her hips and lower back forced her to wince and look for support. Aspirin or Panadol did little to stop this. She had tried cortisone injections, which helped a little but not in the long term. Asthma which she had not experienced since her early teens had re-occurred.

She did have some growth problems around her uterus, similar to endometriosis, which showed up on X-ray/ultrasound scans and she was contemplating a partial hysterectomy sometime in the future. But this could wait.

I'm a total wreck but at least now I've got a wonderful husband who really understands and supports me, and my children are happy and healthy—except Alicia. She's my only concern'.

Chapter Two

Where would one start with this array of complaints? Going back to her lab tests gave a few clues. There was a positive indication to having had Epstein Barr virus[2]—the glandular fever virus—although she could not remember ever being sick with swollen glands. The doctor told her that sometime in the past she had had the virus—her blood tests showed this! She defined herself as a person who rarely got influenza and when the flu was around with everyone coming down with it, she only ever got mild symptoms—she simply had lots of little colds throughout the year. Her cholesterol readings varied reflecting immune activity and there was that autoimmune[3] reading for arthritis. Her blood pressure was a little high but still within limits.

Many people have a similar assortment of nagging symptoms and simply live with them believing that these things are a normal part of ageing! Well sure they can be, but with anything, if we can have a break, a holiday or time out from the things that give us stress, then we can renew ourselves. With a chronic illness however, there is no time out from the symptoms. They assault day and night and reduce every person's capacity to enjoy life. I have found from experience that the first thing to consider, which also is the easiest to test, when there are chronic health symptoms is the common foods we are eating.

In the womb, a baby is protected by its mother's immune system and has its

food provided through its mother's digestive system. More than any other organ system, these two have to quickly adapt following birth—or the baby is likely to die. It takes about 30 months for a baby's digestive and immune system to develop a reasonable degree of competency.

Until the baby develops teeth the advice is to restrict feeding to the breast. With the pressures of modern living this is often not practical—but if parents only knew that the colic, skin rashes, sleep disruption and other baby's symptoms could be removed if only the Mum could identify and remove all those foods she was eating that correlated with the onset of her child's symptoms. This could save both the parents, as well as their baby, a great deal of stress.

Often the medical advice to parents with children who suffer chronic immune or digestive related symptoms, is that their child will 'grow out' of their symptoms with age. This mostly does occur because the digestive and immune systems improve in efficiency, and generally peak as a young adult. After this, a variable descent in efficiency occurs depending on the person's lifestyle, genetic inheritance, infections, stress and other variables. In older age (mostly above 50 years of age) our immune and digestive systems are recognisably less efficient and need to be nurtured. In general this descent can be equated as a reverse trend to the way the immune and digestive systems developed throughout the childhood years. Most older people reasonably aware of their body's symptoms have learned through experience that they need to remove certain foods from their diet in order to

maintain reasonable health.

When ‘solid’ foods are eventually introduced into an infant’s diet care must be taken. It is well accepted in modern medicine that introducing cereals or dairy products too early into an infant’s diet can greatly increase the risk of triggering autoimmune diseases such as coeliac disease, childhood diabetes, arthritis and others. From an immunobiologist’s perspective, it would be best to introduce the major foods that our ancestors have eaten for more than 500,000 years. This *excludes* all dairy and cereal products including rice and corn. This also excludes any commercially produced foods that include these as ingredients.

The in-season freshly picked mature vegetables, as well as meats masticated by the mother, are the preferred foods to firstly introduce to an infant. A point of note is that plant foods are better tolerated by an infant’s developing digestive and immune systems if they are very well cooked and the outer skins removed. Cooking often breaks down plant defence chemicals and renders them harmless. For example, if raw fruits or vegies are given to an infant too soon, they can develop digestive colic and inappropriate bowel movements, immune related skin rashes, breathing difficulties and other symptoms. Experienced mothers know that if they cook fruits and vegetables really well, their infants will be less likely to have a reaction. The manufacturers of canned baby foods thoroughly cook their foods to get rid of bacteria and to reduce infant reactions from occurring. Salads and raw foods are best introduced much later.

Adults with chronic ill-health are well advised to investigate foods as one of the causal factors behind their symptoms. This is where it becomes harder and harder for the elderly, who are forced to buy the cheaper foods in order to conserve their money. Much of their entertainment is derived from cheap starch-based foods made from cereals and dairy products (cakes, biscuits, sweet breads, buns, ice creams, lollies and many other forms of bakery/ commercial products).

Unfortunately many elderly people attempt to address their food-caused symptoms by taking drugs, vitamins, minerals, herbal/homoeopathic medicines and undertake various therapies recommended by assisting health practitioners. Much money could be saved if the foods causing their symptoms could be eliminated from their diet! The small expense in buying meats, vegetables, organic fruits and non-grain bakery products like the Deeks range[4], would greatly offset the cost of medicines and therapies.

Chapter Three

'Jenny may I see your tongue?'
Jenny presented a delicate pale pink tongue which had a geographic pattern indicating fungal invasion inside her gastrointestinal tract. Her tongue was flattened with the indentation of her teeth on the frontal sides—common with people who have chronic low-grade fatigue. Her digestion, reflected in the colour and pattern of her tongue, was probably close to normal.

'Are your lips always this dry?' I enquired

'For years now I have to continually use lip gels to keep them right. Of course it gets worse when the dry westerlies blow, but yes my lips are generally too dry.'

The lips are the entrance for the gastrointestinal tract and like the anus, reflects some of the functions of the upper tract. It was looking more like Jenny had some sort of gastrointestinal dysfunction.

I palpated the lymph nodes under the mid-jaws (submental) and throat (cervical). She had low grade swelling of the jaw lymph nodes and none in the throat—chronic low grade immune response, probably to infection!

As she opened her mouth her jaw clicked. She had displaced jaw cartilage

causing misalignment. From experience I knew that people with occiput wedges often present with clicky jaws. An occiput wedge is a term to describe partial miss-alignment of the skull sitting on the top bone of the spine, the atlas. This was applicable to Jenny. I knew her headaches will have been worsened by this.

'Jenny you get pimples don't you?'

'Yes I get them on the side of my neck, towards the edges of my mouth and around my chin.'

In Chinese medicine this is consistent with the intestine meridian and while pimples are immune-hormonal related, the gastrointestinal tract is probably involved here to some degree.

I palpated Jenny's chest and abdomen. She winced in pain as I pushed on her liver and on her diaphragm under her sternum. Why was her liver swollen? Blood tests indicated normal function! Her diaphragm was also probably distended from the swollen liver. Sometimes a twisted diaphragm can worsen acid-reflux. She also presented with a spasmed base to her stomach which was sharply painful when pressed. Also she had extensive pain across the area of her small intestine when it was palpated!

'Jenny does your lower abdomen swell and feel heavy from time to time?'
'My tummy has been giving me more and more trouble—probably I feel it

every day now. Its not when I eat something either. It just gives me a pain when it wants to and what is worse is that my clothes get really tight around my waist and hips.'

My guess was that she was experiencing intestinal lymphodema where the first line of immune defence activates against a 'bug' or a chemical in the intestines and the result is this type of swelling. The lymph swelling could last for some time before it reduces, but if it was a food that Jenny was eating every day that was causing the problem, then a lot of her weight around the hips could be lymph swelling due to the immune reaction against the food! Where there is lymph stagnancy there usually is accompanying fat deposition (lipodema). I was becoming more inclined to focus on the intestines as a definite link to some of her symptoms.

There are several areas of concern when a person has bowel problems. There are the 'bugs' that live in the gastrointestinal tract (fungi, bacteria, parasites and viruses)—there are very effective medicines to destroy most gut 'bugs'. Then there is the environment of the gastrointestinal tract which is mostly composed of the food we eat and the digestive enzymes from the stomach, liver and pancreas. This environment can cause poisoning or it can initiate defence reactions by the immune system. Both of these make people really sick.

There also is the activity of the immune system around the intestinal wall which can produce inflammation and even death of intestinal wall cells—as

occurs in coeliac disease. Both of these will disrupt nutrient uptake and result in symptoms in other parts of the body. It must be remembered also that the genetic makeup of the cells lining the gastrointestinal tract can also effect the health and function of the bowel.

Lastly there are 'neuro micro-muscular' responses from holding tension in the tummy region. This occurs in some people when they are emotionally stressed. It can cause muscular spasm in the gastrointestinal tract and may contribute to constipation or diarrhoea. It can also alter digestion, nutrient uptake and detoxification efficiency. Well, could one of these be contributing to Jenny's bowel problems?

I looked at her fingernails. They take about three to four months to grow out and during their growth they often record a short history of the person's health. For example, the nails will be appropriately thick when a person is healthy and during the time they are ill, say with the flu, the nails will become thin. This will show as grooves across the nails. The time and duration of the poor health can be somewhat determined from this. Chinese medicine ascribes more comprehensive associations between illnesses and the structure of individual nails.

Jenny's fingernails had lots of recurring grooves on most. She also had some thin longitudinal ridges with occasional white spots on similar fingers of each hand. Jenny said her nails were generally soft and were cracking all the time. She buffed them regularly and she also attempted to hide the

defects with thick nail polish. I made my notes.

While these may be minor symptoms in themselves, they did reflect the bigger picture of poor health that Jenny was experiencing. 'But doesn't everybody have these minor symptoms from time to time?' Jenny queried. 'Yes, I suppose most people do from time to time, but along with some major symptoms, you have them all the time now, don't you!' I gently asked.

Chapter Four

There are many ways to define health and the causes of illness. Being trained as a biologist gives me a particular slant. A biological model of health and disease is not a bad way to conceptualise illness. I introduced it to Jenny. She had nothing to lose by considering this model. If it made sense to her and she could apply it to her chronic condition throughout the rest of her life with success, than she would be ahead.

A good place to start is with the cells of the body. All organs of the body and the immune system[5] are composed of cells. When functioning normally the majority of cells are acting in cooperation. On a day to day basis each cell in the body aims to exist in a comfort zone (homeostasis) in which they function normally, neither overactive nor underactive. When the majority of organ cells function normally there will be no symptoms of ill health. When a large enough number of organ cells temporarily function outside their comfort zone, temporary symptoms occur. For example, if a person drinks too much red wine on an occasion, later they may experience a temporary headache, they may feel sick in the stomach and experience a swollen liver for several hours until their body detoxifies. When their liver and other organs return to normal all the symptoms dissolve and normal health is regained. This is known as an acute illness and is a limited experience.

On the other hand, if symptoms of ill-health persist for weeks, months or years, one or more organs (or the immune system), cannot regain their

normal comfort zone of function. This is the chronic illness. It will only occur if certain influences continually prevent the organs from regaining their normal comfort zones. These influences will be the cause of chronic ill-health symptoms as they alter organ function on a daily, weekly or even monthly basis. Following a biology concept, there would be eight categories of causal influence that create all chronic illnesses. They include:

• Infecting pathogens that are able to continually evade or manipulate the immune system (virus, bacteria, fungi, parasites).

• Continual exposure to chemicals that continually enter the body (either industrial, natural or in our foods).

• Irreparable physical injury which results in scar tissue, loss of organs or simply 'wear and tear'.

• Geopathic stress—'geo' means 'of the earth'—earth pathology. The geography of an area in contact with the body continually influences organ function (consider hayfever/asthma occurring in Canberra which is relieved by travelling to the coast). By going to another area the dysfunction stops and the person is relieved of the associated symptoms—returning to the original area causes the symptoms to return. 'Sick Buildings' are also included in this category.

• Genetic predispositions inherited from parents—ageing tends of reduce the accuracy of cellular reproduction and increases the likelihood of activat-

ing genetic predispositions (such as the coeliac disease gene).

• Nutrient deficiency through malnutrition (vitamins, minerals, enzymes, trace elements).

• Catalytic protein imbalance due to malnutrition (trace chemicals that manipulate nutrient composition throughout the body).

• Ongoing emotional stress (exhibiting in anger, fear, anxiety, sadness etc).

From my experience in our modern world, most chronic ill-health will be associated more with genetic predispositions, the food people eat, the emotional stress they experience and human pathogens rather than physical injury, nutrient deficiency or simply as a cause of ageing.

I decided to take some fluid samples from Jenny for general testing, then photographed her irises to assist in determining a longer health history and undertook a profile of her immune system.

'Jenny, you have been battling with your health for years now, you should have some idea. What do you think is the cause of your array of illnesses?' I pointedly asked.

'Well, I have thought that my sister and I are similar to our Mum with her health, but I don't know!! Umm, I sometimes think that food makes me

worse, but I saw a naturopath who put me on a vegetarian diet for a while and it did nothing! I do work hard and would like to take more holidays—possibly that would help, but that isn't the real problem. I don't know, you're the expert, you tell me. If I knew what the answer was I wouldn't be here!'

'You have too many seemingly unrelated symptoms to attempt to give you medicines. I suppose you have tried taking various types?'

'I have been taking supplements, and herbs from a really good naturopath—they help a bit. My doctor has also given me a few drugs but I don't like taking them. He is now concerned with my increasing blood pressure and has suggested I consider medication for this. No I don't want any more medicines, thank you.'

I asked her to return in a couple of days to discuss the results of the tests I was going to undertake and possibly plan a course of action. She asked a few more questions about what I was going to test for. I said I was really not sure but hoped that something would show up. Politely she thanked me and I escorted her to the waiting room. She really was a good person.

I went back to my office. Writing up notes on this preliminary interview with Jenny I couldn't help but think that she was presenting a health profile that could have matched many of our society. I wonder if she could be one of those that come under the classification of atypical coeliac disease[6]?

She certainly had enough of the symptoms. There are no concluding tests for this and it does initiate a swag of symptoms unrelated and related to the gastrointestinal tract! Well tomorrow I should have some results from the testing and profiling and maybe this could give me more of a pattern to identify the causes behind Jenny's health problems.

Chapter Five

Later the next day I got around to assessing Jenny's test results. I started to link symptoms and signs. Within a short time I was starting to see the first signs of a pattern emerging. The good news was that most of Jenny's organs were probably functioning normally—her doctor's tests already indicated this. However her liver and stomach were having a hard time, but there appeared no infection in these organs and there was no overt immune activity. Her liver and stomach digestive enzymes were in the normal range but her somatostatin levels were borderline (somatostatin is a hormone found in the brain and the gastrointestinal tract which suppresses the release of other gastrointestinal hormones, lowers the rate of gastric emptying and reduces smooth muscle contractions along with blood flow within the intestine. It suppress the release of pancreatic hormones, inhibits the release of insulin-glucagon and suppresses the exocrine secretory action of pancreas).

She did have real problems with her small intestine. There was strong and unusual immune activity and appreciable dysfunction of that organ but Jenny had not considered this organ as any real problem. Her large intestine was also in trouble but she said her bowel movements were mostly normal. There appeared to be considerable inflammation in this organ from the profile of immune activity in the colon. The possibility of the beginnings of a cyst or growth were highly likely.
Her nervous system activity was auite normal, although there was plenty of neuropeptide concentration in the small intestine. This reflected where

Jenny held most of her emotional tension. Her hormonal system also was functioning quite normally. There appeared normal immune activity against dysplasic cells (cancer/tumour[7] cells). This was good news for it indicated that the colon cysts were probably not cancerous—yet. I made a note to get her to check this with her doctor. Her levels of blood toxicity were reasonable. Her blood nutrient profile was within the normal levels—if a little low for some. Her broad immune profile was disturbing. It was showing consistent high level activity directed at unknown pathogens.

The immune system is an organisation of cells, chemicals and molecules that have specialised roles for defending the body against infections and damaging chemicals. Consider them to be like the police and military forces while the citizens of our communities are like the normal body cells.

Organisms that infect our bodies like bacteria, viruses, fungi and parasites are known as pathogens. Most of these encountered in daily life rarely cause perceptible disease because they are detected and destroyed as soon as they enter into the body—by the first line of immune defence cells.

Immune cells have identification libraries to register the vast range of unwanted pathogens and chemicals that we will mostly come into contact with throughout our lives. These libraries evolved through our ancestors over hundreds of thousands of years and constitute the first line of defence which is known as our innate immune system. The cells are broadly called leukocytes—there are several types.

If a pathogen or chemical is able to breach this defence it will be assaulted by a more potent second line of defence that has the ability to modify its identification methods. Although this is a slower system to react, given enough time and the right conditions, this adaptive part of the immune system does have the potential to identify and deal with almost any type or pathogen new to the body. Once correct identification is complete, a minor army of specific cells are created that only focus on the new chemical or pathogen. After the infection, these cells produce a small company of memory cells that prevent subsequent infection by the same pathogen. The cells are broadly called lymphocytes—there are two broad types, T-cells and B-cells. Thus the immune system defends the body using two broad approaches based on these different cell types.

Like any system, living or otherwise, mistakes can occur in its smooth operation. When immune cells react inappropriately, we can experience illness and poor health from their actions within the body. There are three broad types of immune related illnesses: allergic reactions known as hypersensitivity, autoimmune diseases and cancers.

To expand this further: there are four types of allergic hypersensitivity of which Type 1 is the most common and occurs in body tissue like the sinus and lungs. It is caused by a chemical (IgE) released by certain immune cells (mast cells). Other allergic types of reactions occur through the production of another immune chemical (IgG) and the most complex type of allergy

Type 4, occurs from T-cell activity. Rhinitis, asthma, urticaria and contact dermatitis are typical Type 1 allergic reactions. The allergy tendency is influenced by genetic makeup, the degree of efficiency of the immune system and environmental factors.

The more serious illnesses are caused by the second line of defence involving T-cell activation. While these cells can initiate the Type 4 allergies like contact dermatitis, chronic asthma and chronic rhinitis. They can also initiate autoimmune diseases as well as complex types of autoimmune/allergy diseases. Coeliac disease, rheumatoid arthritis, multiple sclerosis[8], insulin-dependent diabetes mellitus[9], systemic lupus, autoimmune hemolytic anaemia and others are caused by these inappropriate T-cell responses. All can be related.

Pathogens that are able to overcome normal defence mechanisms or have an ability to subvert the immune cells, can continually infect the body. This often happens with viruses. When a person is ill, sometimes symptoms of illness are caused by the person's own immune response to the pathogen and are not caused by the pathogen itself.

Sometimes the pathogen uses immune activation to spread infection. This happens in influenza. Sometimes a pathogen is able to destroy important cells of the immune system and chronic disease occurs. This happens with HIV. Sometimes the immune system mistakes an innocuous chemical or 'bug' for another more lethal pathogen and initiates inappropriate responses.

This occurs in autoimmune diseases such as coeliac disease. Sometimes the T-cells lose the ability to detect and destroy particular unwanted cells. This occurs in cancer.

Evidence was accumulating that the rheumatoid arthritis response that Jenny had, was probably part of a broader immune hypersensitivity pattern. I phoned her and asked her if she had ever been tested for coeliac disease.

'Yes I have' she replied. 'Several years ago my doctor strongly considered that I could have coeliac disease and so I had some blood tests which were negative and just to be sure they did a colenoscopy and also found nothing really wrong except some low grade inflammation. My doctor was really unsure of the results and also tested me for several other bowel diseases! I've also had X-rays. It took forever and showed nothing—its in the notes I gave you. My doctor was really unsure of the results but couldn't go any further!' Hmmmm!

'Jenny you have never bled from the bowel have you?'

'No, never that I can recall'.

Jenny, could you come in soon, I have an idea to present to you. I'll make an appointment for Thursday, if this is OK?'

Chapter Six

Until the last several years, the only way to diagnose coeliac disease was through a biopsy of the small intestine—to look for death of the intestinal villi. Ulcerative colitis, coeliac disease, pernicious anaemia and Crohn's disease are probably the most common conditions associated with intestinal malabsorption—which further causes many other chronic symptoms of ill health, just like Jenny had.

The development of less invasive antibody blood tests has made initial screening for these diseases easier and has reduced the cost and time required by hospital staff to diagnose these diseases. When these blood tests are positively correlated, then biopsies are undertaken for final confirmation. Interestingly, as high as twenty percent of intestinal biopsies necessary for final confirmation of coeliac disease are rejected by insurance companies, claiming that the cost of the biopsies isn't justified because the person does not have the classical symptoms.

Most people with coeliac disease also develop other autoimmune diseases even though they remove all gluten from their diets. To remove the symptoms of these other autoimmune diseases, the individual needs to consider that other plant defence chemicals may be the trigger and test for these!

Coeliac disease tests measure the amount of autoantibody activity that is responsible for intestinal inflammation and damage to the intestinal wall.

The autoantibodies tested for coeliac disease are known as immunoglobulin A and immunoglobulin G. IgA is mostly found on surface epithelium tissue while IgG is mostly found in body fluid.

These are two of the five classes of antibodies that the immune system creates to help defend the body. The IgA tests tend to be more positive markers for coeliac disease, but the IgG tests are still important since they enhance confirmation and reduce the likelihood of false negatives. The broader the confirmation the better, because coeliac disease and other autoimmune diseases like IgA deficiency, give very similar responses to autoantibody tests.

Autoantibody blood tests for coeliac disease include:

1. *Anti-tissue (blood) Transglutaminase Antibody IgA tests:* Tissue transglutaminase is an enzyme responsible for cross-linking IgA immune reaction with proteins such as gluten. Gliadin, one of the subunits of gluten, triggers the development of transglutaminase antibody.

2. *Anti-endomysial Antibodies IgA tests:* Endomysium is the thin connective tissue layer that covers individual muscle fibres. Anti-endomysial antibodies are developed in reaction to the ongoing damage to the intestinal lining.

Almost one hundred percent of people with active coeliac disease and about seventy percent of people with dermatitis herpetiformis (another autoimmune disease that is reflected as skin eruptions) have Anti-EMA-

IgA antibodies. Anti-transglutaminase antibody and Anti-endomysium antibodies are two ways of measuring the similar small intestine tissue damage.

3. *Anti-gliadin Antibodies IgG and IgA tests:* Anti-gliadin antibodies are autoantibodies against the gliadin peptide (within gluten) created by those who develop an immune sensitivity to this peptide.

4. *Anti-reticulin Antibodies IgA tests:* Anti-reticulin antibody tests are not ordered as frequently as the others because they are not as specific or as sensitive to detecting coeliac disease as are the other autoantibodies. These particular antibodies are found in about 60% of people with coeliac disease and about 25% of people with dermatitis herpetiformis. This test is ordered along with other coeliac disease tests to add more evidence for final confirmation by a colonoscopy.

Chapter Seven

I was running a little late when I got to see Jenny on the Thursday afternoon. I was seeing her in a slightly different light and looking for signs to further confirm my suspicions. When I said hello and shook her hand I closely looked into her eyes for signs of bowel lymph activity. Hmmm, I wonder!

Once again we sat together while I ordered my notes on the desk. Partly facing Jenny and partly facing my notes I asked how she had been. 'No change, just the same. Have you got anything for me?' she pressed without any real enthusiasm.

'Well I am intending to agree with your doctor. At this point I think you have a major intestinal problem. I also think that it is definitely immune related. If you want it classified, I am thinking that you would definitely be a candidate for atypical coeliac disease'.

For several seconds Jenny thought this over. 'You mean that I have coeliac disease[10] but not the typical symptoms?'

'Well no. I think you probably have an immune reaction to a plant defence chemical similar to what occurs in coeliac disease. I trust the blood tests and the endoscope results and would bet that the chemical would not be

gluten based. Let me tell you a little about this.'

About forty percent of Australians[11] have the gene for coeliac disease although less than ten percent develop coeliac disease which is formally diagnosed. Many of the other thirty percent simply get variable low grade symptoms from time to time, in combination with a range of unrelated symptoms. This mostly gets worse when they are tired, ill or stressed.

The 'clinical definition' of coeliac disease isolates it as a partly genetically based Type 4 allergy/autoimmune response linked to wheat gluten. Although gluten also occurs in oats, rye, millet and barley, these foods are not strictly included as the triggers for coeliac disease. In addition, corn and rice, which are also grains (hard-seeded grasses) do not have gluten and are definitely not triggers for coeliac disease.

In recent years the term atypical coeliac disease has arisen to cover a range of symptoms that are linked to gluten and other plant defence chemicals that are not classified as being typical of the coeliac condition—linked mainly to gastrointestinal symptoms. I will just read from this symptoms list published from the Mayo Clinic in the USA: diarrhoea, abdominal pain and distention, gas, pale foul-smelling stools, irritable bowel syndrome, lactose intolerance, oral ulceration, calcium, vitamin and protein malabsorption, weight loss, bone-joint pain, anaemia, weakness, dermatitis, osteoporosis, amenorrhea, infertility, impotence, acne, stunted growth, alopecia, dental enamel defects, anorexia and bulimia and chronic fatigue.

You see Jenny, you do have some of these symptoms but your major concerns involve your mental fugginess, depression and lack of motivation for life. You also have a diagnosed autoimmune disease (arthritis) which is somewhat linked to other autoimmune diseases such as coeliac disease.

You do have chronic immune related symptoms that cannot be diagnosed using the known and accepted medical tests.

The broad group of atypical coeliac disease symptoms are being recognised more and more. As with classically defined coeliac disease, the diagnosis of atypical coeliac disease is tentatively established through standard coeliac disease serologic blood testing and biopsy evidence of the destruction of small intestine villi. Concurrently the diagnosis requires the elimination of symptoms when the person removes all grain products (which can include rice and corn) on a grain-free challenge diet over a number of months. There are three subclasses of atypical coeliac disease:

Silent coeliac disease occurs in people who have no coeliac symptoms but have positive serologic blood tests and villous atrophy on biopsy. This form of the disease is usually detected by screening high-risk individuals with relatives who have been previously diagnosed. The disease is also detected by endoscopy and small intestine biopsy conducted for another reason.

People with silent coeliac disease usually have unrelated low-grade chronic

symptoms of ill-health unrelated to the classical coeliac symptoms and with time will develop classical coeliac symptoms. I did not believe that Jenny had silent coeliac disease.

Latent coeliac disease is determined through having positive serologic blood tests but no evidence of villous atrophy on biopsy. These individuals usually do not have the chronic coeliac symptoms but later in life develop them as their villi eventually become destroyed by immune activity. They often experience chronic low grade coeliac symptoms for many years as children and young adults and their vitality for life generally sees them through this period.

When their immune system becomes compromised through emotional stress, a bad infection or a physical injury, the disease usually develops. With 40 percent of Australians having the gene for coeliac disease, it is probable that many will have undiagnosed silent and latent coeliac disease. I did not think that Jenny had latent coeliac disease.

Pseudocoeliac disease is the latest sub category of atypical coeliac disease. It is determined through having negative serology, little or no villous atrophy on biopsy but on a grain-free challenge all the chronic symptoms abate and re-occur on reintroduction of even small amounts of grains.

This category in many ways is quite distant from coeliac disease. There is no gluten connection but there is a positive association with chemicals

similar to gluten that occurs across all the grains, sometimes including rice and corn. These chemicals probably have similar defence roles to that of gluten. Clinical observations indicate that many autoimmune diseases can be considered pseudocoeliac and can be controlled by totally eliminating any contact with particular plant proteins!

It is possible that in the future many immune related diseases will be included in the pseudocoeliac category. This is Jenny's disease category.

'Why didn't my doctor let me know about this'?

'I can't answer that, but possibly pseudocoeliac disease is too new a disease to be well known in medical circles and since there are no defining tests for this disease, and because it is too wide open in its variety of symptoms, it is hard to recognise'. Jenny had sat upright and was definitely focused now on what I was saying and she was asking searching questions.

'How long could I have had this disease?'

'Well Jenny how long ago did you feel really healthy?'

'Probably 10 years ago I remember having good health.'

'Can you recall any illness or really bad flu about this time?'
'Well that was a really stressful time of my life. I went through a marriage

breakup and it went on for nearly 18 months. I remember not feeling well during that time and it is possible that I have never felt well since. Not that I haven't moved on from that experience—that's Ok—but life has really been tiring for me since then.'

'Do you think you could have contracted glandular fever around that time?'

'It is possible, but I don't really know. That wasn't a good time. The blood tests were only done a few years ago.'

'Have you ever removed gluten from your diet?'

'Well yes a few years ago I did for a month or so on my doctors advice and although I felt sort of better overall, my tiredness and mental dullness along with many other symptoms continued.'

'I presume you didn't remove rice nor corn products.'

'No, they didn't have gluten and were safe.'

'True enough if all you had was coeliac disease, but they could have something to do with your present illnesses and I think there could be some benefit for you to do a controlled trial removing all grain products for at least six weeks and see what happens. You would have to graph your symptoms. I can give you all the information on how to do that and get someone to

help you when you need it—if you wanted to do a trial.'

'I don't know. What can I eat then, if I do this trial?'

'You can eat all flesh foods (meats, fish, lamb, chicken etc), vegetables, fruits, nuts, seeds and any bakery products that are totally free of grains.'

'I know there are gluten free breads but are there any grain-free breads?'

'Yes the Deeks Health Food Bakeries provide these and a range of bakery products totally grain free.'

'Would it be OK if I just cut down on the grains?'

'Unfortunately Jenny this trial, like a coeliac trial requires that you cut them out 100 percent. If you take an occasional biscuit or something that has grains as a filler like Baked Beans, you would be required to start the trial over again. You see, it appears from thousands of case studies that even a single mouthful can trigger the symptoms, sometimes for weeks—it is not volume controlled like a poison. You would probably not get the best out of your trial time by simply cutting down on grain-based foods and I don't think the majority of your symptoms would go. On the other hand, if you undertook the trial rigorously, within six weeks you should be back to normal or close to it.'

'Why would I have to do the trial for six weeks and not one or two weeks?'

'From my understanding, after stopping all contact with the grains, people like yourself are likely to have continuing symptoms for days or even several weeks or more. A six weeks trial would give you an eighty percent evaluation of any connection between your symptoms and grains.'

'If this trial showed that my symptoms were related to grains, would I have to stop eating them for the rest of my life?'

'Yes and no. If all your symptoms went away then you would know that there is a trigger associated with grains—but which grains ...? Because pseudocoeliac disease is not triggered by gluten, you may be able to eat some of the gluten carrying grains like wheat. On the other hand the triggering chemicals could occur in all grains including wheat, rice or corn. I don't know. Only you can determine this by having a go at another set of trials—but use some controls this time. We can help you with this also.'

'I don't know if I want to do this. I love my bread and pasta and from my gluten-free trial I found that wheat is in all sorts of processed foods. That would mean I would have to stop eating lots of things like sauces, chocolates, lollies, health bars. What about alcohol—would I have to stop having an occasional drink?'

'Well yes drinks like beer and possibly whisky would be out, but wine, gin, rum and others would be OK. Actually Jenny the trial would only indicate

that the trigger for your symptoms would be in the grains. What you do after that is your business. I have known people who have done the trials and then found ways to greatly increase their health so they create a buffer to the occasional grain meal. By using all the good health advice that is available today (exercise, vitamin-mineral supplements, herbal products, yoga, meditation) you should be able to create a health buffer which would allow you to eat some grains and suffer only minor symptoms. Some people do this quite successfully, but I know others who cannot take even small amounts of grains because of the intense responses they get. It appears to be an individual thing.'

'What if the trials do not give any change—what then?'

'Hmmm, that really presents another challenge. You could undertake an Immunocompromised Trial, but that is really hard work so lets try this first? I know you have tried medicines both mainstream and complementary without success, so ...'

'Let me think about it for a bit.'

'That's fine. But a word of advice, to do a trial by yourself if you were half-hearted about it or if you did not graph your symptoms on a daily basis could confuse you. Just contact us when you want to have a go and we will give you the tools and instruct you on the problems that we know about.'
'Oh one more thing you could consider that you may have to follow up

on after the trial. You won't like this either—most don't. You will have to challenge the effects of all dairy cow's products[12]—milk, butter, cheese, yoghurt and those commercial products that include dairy.'

Jenny just looked at me in disbelief. This was really too much for her. 'And what has dairy got to do with grains? Where would I get my calcium?'

'Cows mostly eat grasses. The grains are part of the grass family (Poaceae) and are described as the hard seeded grasses. Just like the chemicals in foods that a breast-feeding mother eats eventually end up in her baby, the chemicals in grasses that a cow eats eventually end up in humans who consume the cow's milk. The defence chemicals in many plants, including grasses, are often not broken down by digestion. Some of the defence chemicals occurring in the grains also occur in other grasses. There is a small possibility that some of your symptoms could be attributed to cow's milk. With the condition of your small intestine, it is also possible that you could be caseine or lactose intolerant, but I don't think so.'

I think I had gone too far now. There was an air of disbelief flittering across Jenny's face.

On the way out to the waiting room I gave Jenny a small booklet on coeliac disease and some websites for her to look up. She shook my hand, she appeared a little lost, not really happy, but there was the smallest spark, a dawning of possibility, that I hoped would grow. I hoped she would just

have a go at a grain-free trial. It really would cost her nothing but a bit of discipline.

Something like atypical coeliac disease is a difficult thing for many of us to accept—that one of the main foods we have been eating since childhood could now be giving us all this grief—and it's a plant. Isn't the vegetarian diet supposed to be the most healthy diet? Sure, pesticides and fungicides that are added to plants can make us unwell and we also know that the added taste enhancers and preservatives can also give us a little grief, but the plant's own defence chemicals ...? Well I suppose out of the millions of plants in this world, only a handful are eaten by humans—and many of these have to be cooked to make them edible!

Consider a plant like a strawberry. When the seasonal conditions are right for the plant to grow seeds it starts to grow a pulp and the germs of the seeds. It protects the seeds not with a hard woody cover or with spikes like some plants do, but with defence chemicals. These chemicals prevent fungi, moulds, insects, bacteria and animals like ourselves from eating the seeds before they have matured. Imagine a large green unripe strawberry. Green strawberrys all appear perfect. Very few living things can get away with eating a green strawberry and not feel sick or worse.

When the seeds have matured, the plant releases chemical enzymes to denature the defence chemicals. The strawberry changes colour to orange then brilliant red and all sorts of animals and bugs can start eating the fruit.

In fact the plant encourages the fruit to be eaten by providing sugars in the pulp as an inducement. In this way the plant seeds can be distributed by birds and other animals.

Now if you picked a perfectly dark green strawberry and put it in your kitchen to ripen—if you pick it too early—you may find it never ripens and when you taste it, it tastes bitter and may give you a reaction in your mouth. If you swallow the green fruit you may get an upset tummy for a while, or even worse. If a strawberry goes orange in colour you may be able to stomach it a lot better, but the taste will still reflect the defence chemicals because again you will have picked it too early.

Now many of the commercially available fruits and vegetables are picked far too early and we tend to have some problems with these also—they can be tasteless, cardboardy, tart and unwholesome—and yet, if fruits and vegetables become over ripe, they can can have moulds and insect infestation and again the food is not good for us. In a similar manner the grains such as wheat also use defence chemicals to protect the growing seeds on the stalk. Harvesting grains too early allows too many defence chemicals like gluten to remain intact.

Chapter Eight

After a week, Jenny had not called to let us know if she wanted to do the trial. Oh well, that was not surprising. The atypical coeliac diseases were new to modern medicine and most people have a tendency to be conservative about change until a critical mass of people endorse a new concept.

Two more weeks passed and then Jenny made contact with the clinic. She had removed all the grains including all rice and corn products for two weeks and noticed one change that swayed her into phoning. Her head cleared for the first time in several years. She felt renewed enthusiasm for life, a cloud had lifted. She just wanted to let us know that she was going to continue with the trial. We advised her to come in to the clinic and pick up the graphs and controls. She said she thought she could do it without them.

When people do these trials there are a lot of traps that only become obvious after observing the results of hundreds or even thousands of trials by different people. Some symptoms linked to autoimmune responses do not change for several weeks but most should notice some lessening of symptoms within the first two weeks, especially if the symptoms are secondary. Some symptoms parallel others while some lag behind. Some are independent and some respond in an opposite nature.

Some people with particular immunohormonal diseases[13] will experience

withdrawal symptoms for up to a month, much like the alcoholic going off alcohol or the heroin addict going off heroin. It is very confusing if all the symptoms get worse when by simply removing a food from one's diet. This is when the question should be asked 'Why should I get worse when I simply remove a food from my diet?' Healthy people should be able to eat any of the recognised foods, in normally considered amounts, in any combination, at any time of the day and not suffer any symptoms.

Some people gradually improve but find difficulty knowing this if they are not graphing symptoms on a daily basis. Many people try for a few weeks, feel a little better but are not dramatically freed of their symptoms and then reject the concept. Because of a lack of discipline this type of person could do themselves a great dis-service and possibly put themselves into a mindset that would prevent them ever finding the pathway to good health.

People on medication to reduce symptoms such as blood pressure are advised to take daily readings. If the blood pressure is a by product of an autoimmune response, then as this abates, the blood pressure will fall. The person may find themselves experiencing the symptoms of low blood pressure and get confused. People must be prepared to reduce and even eliminate their medications when undertaking these types of trials.

Rarely will any new symptoms occur, unless the trial is undertaken during the influenza season and the person concurrently gets the flu, and then gets confused by feeling worse instead of better. Some people become confused

about what to eat and end up not eating very much at all. Then they start to feel tired and run down and their symptoms get worse. When they eventually reintroduce the high starch diet of the grains, they often get an initial energy lift which also adds to confusion.

There are dietary confusions as well. If the stomach is not efficient with digestion, shifting the diet from predominantly starchy grains to emphasise proteins/fats can cause other symptoms that can confuse the results. The first problem appears to be the volume of saturated fats taken in each meal. With efficient stomach digestion four or five eggs would be no problem. With inefficient stomach digestion this may give stomach pains, increased urination, waking around 3.00 am, headaches, left sided aches and pains.

Secondly, if the person compensates by eating more fruit in their diet for entertainment, their liver may become overloaded (the fruit sugar, fructose, is metabolised by the liver, unlike other types of sugars) and the digestion of fats may be compromised. In Jenny's case, with her liver already exhibiting pain and spasm, she would be best advised to balance her protein-fat meals with non-starchy vegetables and greatly restrict fructose sugars while on the grain-free challenge. Later, with the improvement of her digestion, she could introduce more sugars for entertainment.

Any of these could confuse Jenny if she was not graphing her symptoms and did not have a system-control in place to stabilise her graph results.

Chapter Nine

A month or more passed before we heard from Jenny. She made a call and booked her daughter Alicia for a consultation.

When I again saw Jenny she was different. There was something in her eyes that had not been there in the past. She initiated a smile and introduced her daughter—a carbon copy of Mum. It transpired that Jenny had still not gone off all grains and had simply cut down—but she was positive something was happening. There was some sort of connection between rice/corn as well as some other grains, and her many symptoms. She was well enough now to be worried about her daughter.

'You said this atypical coeliac disease had a genetic component. Do you think Alicia could have it, because she is always feeling out of sorts and not a happy kid?'

'It's possible. Atypical coeliac disease has a genetic link just like coeliac disease. Alicia let me have a look at you.'

Alicia was a fragile 13 year old with menstrual and emotional issues. She was thinner than normal and had *always* had problems with foods! She had some symptoms similar to her Mum. Jenny considered her other children healthy and normal.

‘Could you do those same tests on Alicia please. I want to know if she has the same profile as me. If it is the same, then we will do one of your trials together. I mean we will do them properly, no cheating—won’t we Alicia?’

‘Isn’t this good to see’ I mused to myself, Jenny’s body language and tone of voice told me that she was now serious about testing for a food connection and her health. It would be so satisfying for Jenny if she could help her youngest daughter. Together I think they could do this.

Jenny interrupted ‘Before you start can I ask one more question? Why should my emotional state change just because I cut down on grains?’

‘I can’t accurately answer that one Jenny. However if small amounts of chemicals like medicinal drugs, herbs like St. John’s Wort or street drugs like heroin can change a person’s mental state, why couldn’t a chemical in a food act similarly? You aren’t the first person I know who feels better emotionally by changing their diet. There is a strong connection between mental health and atypical coeliac disease. You can look that up on the internet.’

Jenny glanced at Alicia. I couldn’t read the complexity of her expression which stayed for several seconds. I started my examination of Alicia.

Two days later I faxed my report to Jenny and we talked for a little bit over the phone. They were going to start the trial in less than a week. She had

already bundled up all the foods in the house with any connection to grains and had given them to her neighbour who laughingly took the goodies, told Jenny was a little balmy and retreated. She and Alicia sat down together and planned what they were going to eat for the next couple of months. There had been the normal resistance, but Jenny's enthusiasm was now rolling over the slight obstacles. She really must have been feeling better.

The handouts we gave her on shopping had lots of tips. She went on the internet and contacted Deeks Bakeries website (www.deeks.com.au) for deliveries to a store in her area, or to directly post to her. She bought bulk meat and ventured down to the local fruit and vegie market to see what was available. She was going to make her own chocolate for entertainment, she bought the CSIRO Cookbook and Janette Nard's 'Grain Free Cooking' (www.grainfreecooking.com, to help out.

School lunches for Alicia were solved by using Deeks breads which she found were nothing like the gluten-free, stale tasting, heavy and hard breads that she had tried in the past. The dried pasta also tasted great, but she had to be really careful with the pasta sauces from the supermarket. She bought three dozen eggs each week. They bluetacked their graphs with pencils dangling from a length of string, on to the fridge. An evening ritual was put in place—each were going to rate their individual symptoms from one to ten.

They decided that Alicia was to say to her friends that she may have an allergy to grains and was keeping away from them for a while. Most people

understand and accept avoidance of foods that cause allergies. They would have a go at baking a cake and some biscuits. If these weren't successful then they could always get some from Deeks—and they started.

Jenny told me later that it was quite manageable, especially because of the Deeks products. She had tried some red wine which gave her a headache the next morning but she eventually found a good white wine without too many preservatives which she tolerated quite well. During the trial Jenny got the whole family to take some worming tablets (liquid Combantrin), including Jasper the cat. She did spend more on food during the two months, but now she thinks that it was an extra expense that was well worth it—she saved money on panadol.

Chapter Ten

It would be good to write about a happy ending for Jenny and her daughter. This could be done. I have conducted almost 6000 case studies from my clinic in Canberra around chronic immune related illnesses and the majority of these are success stories. However they also require hard work and a reasonable degree of understanding by those who undertake their own trials. There is huge cultural resistance to newly recognised health conditions like atypical coeliac disease—just like there was resistance to the original idea by Dr. William Dicke in 1951 that bread was the cause of coeliac sprue. Coeliac sprue had debilitated and killed untold numbers of people throughout European and Middle Eastern history.

Until 1950, the scene of people dying of coeliac disease in hospital, is one in which patients would be fed a bowel of soup and a piece of toast and they would die. However from 1952 under the same circumstances in those hospitals with doctors aware of the connection between wheat and coeliac sprue, they would be fed a bowel of soup only—and they would live.

Coeliac disease was untreatable until the 1950s. For decades, some of the public had been suggesting that bread was connected with coeliac disease however it took Dr. Dicke (a Dutch pediatrician) to link bread with the symptoms of coeliac disease. He had observed that there was a significant reduction in the occurrence and severity of this disease in Holland when

bread and other bakery products were not obtainable during the latter stages of World War Two. He advocated the removal of all wheat containing foods to remove the symptoms of coeliac disease.

The introduction of the small bowel biopsy in the late 1950s confirmed his theories that the small intestine was the organ involved with coeliac disease. Subsequent research isolated gluten as the protein compound linked to coeliac disease and the triggering chemical as a subunit of gluten (an alpha-gliadin 33 mer peptide).

Since the early 1960s the advice given to coeliac patients to remove their symptoms, has been to totally exclude all gluten food products from their diet for life. This does not cure the disease however the person can live a symptom free life by not triggering the genetic predisposition through removal of their body's contact with gluten.

I do not believe that the number of people with atypical coeliac disease is very large in our communities. However if you or your family have this disease, you will simply not be healthy. Medicines will have to be taken consistently to buffer symptoms. You will age prematurely. Weight will become a problem—overweight with liphodystrophy and lymphodema—and underweight compounded with nutritional deficiencies as well as many other chronic symptoms.

One of the saddest things to observe is the mental changes that occur in

people with pseudocoeliac disease. I generalise here—men tend to be more inappropriately aggressive, with a short fuse and irrationality. Women tend to gravitate to degrees of depression. All people with this disease tend to lose the love, appreciation and wonder of life and search here and there for happiness which originally was there birthright and occurs naturally in people with normal brain neurochemistry.

If you feel that you could have one of the forms of atypical coeliac disease, or if one of your parents or some of your siblings or offspring have low-grade chronic health issues, then consider undertaking a total grain-free challenge trial. Construct a graph for at least two months. For the first six weeks remove all grains including corn and rice and rate several symptoms on a daily basis from 1 to 10. After the six weeks, reintroduce the grain foods for at least 10 days, have your normal diet and still continue to graph your symptoms. Decide from the results of your graphs whether or not grains have an effect on your symptoms.

If there is a correlation between grains and your symptoms, you can then determine which grains are the link. You can cut down on your medicines (with your doctors assistance) and you will find that you will need fewer supplements and complementary medicines to assist with your health.

Good luck.

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For those people who prefer to look up scientific peer-reviewed references about the subject matter in this book I have included the following as a start. However, if you purchase the booklet (72 pages) 'Coeliac Disease - a broader perspective' 2007, written for the first Coeliac Awareness Day in the Australian Capital Territory, you will find hundreds of references across the full range of issues associated with coeliac disease. Phone the Canberra Medical Ecology Centre 02 6282 6800 for this small booklet.

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11. *For information about the genetic occurrence of coeliac disease throughout the world start with:*

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O'Grady J. et. al.: **Intestinal lactase, sucrase, and alkaline phosphatase in 373 patients with coeliac disease.** J Clin Pathol 1984. 37:298.

13. *Such as Grave's disease, Hashimoto's disease etc.*

Bill Giles is a biologist specialising in immune related illnesses. With three degrees in science from the University of Queensland and the Australian National University, he has been using his biological knowledge to assist thousands of people with immune related disorders for nearly 25 years.

Because he has suffered chronic fatigue and from immune related diseases, Bill has taken a personal interest in helping others who also suffer with similar chronic health problems.

He has conducted nearly 7000 case studies on immune related disorders during which clients have undertaken their own trials. In this way they are able to take control of their illnesses and determine the best lifestyle changes to free themselves of their symptoms.

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