

# UNDER ATTACK

Scientists are beginning to unlock the mystery of why the immune system goes rogue and attacks healthy cells in the body, causing a potentially fatal autoimmune disease.

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What would you do if you were told you had just six months left to live?

For Indie Lee, mother of two young children at the time, there had long been signs that something was amiss, including an autoimmune diagnosis (rheumatoid arthritis), early menopause at 36, and a sudden loss of peripheral vision in her left eye. But that life-changing call from her doctor came while she was in the car on an everyday errand: Her MRI had revealed a fatal brain tumour.

“That drive was the most impactful 15 minutes of my life,” says Indie. “I realised I had spent the entirety of my adult life as a passenger and not the driver. I was going through the motions, doing what I thought was expected of me. It was in that 15-minute drive that I created the three Ps of how I would live each day forward – with purpose, passion, and being fully present.”

Miraculously, that was 15 years ago. Having found a surgeon who was willing to operate (the odds were not in Indie’s favour), she not only survived but thrived, going on to conceive and create a highly successful global skincare line, Indie Lee. Curiously, her tumour wasn’t cancerous – her doctors believe it is autoimmune related, meaning her immune system had attacked healthy cells in her body.

“Autoimmune diseases have no boundaries to who they hit and when, but 80 per cent of those living with them are women,” says Indie, now a board member of the Autoimmune Association in the US (autoimmune.org). “My doctors will never definitively know the cause.”

Although some autoimmune conditions are well known – type 1 diabetes, multiple sclerosis, psoriasis

and rheumatoid arthritis, for example – many we know very little about.

“There are over 100 different autoimmune diseases with weird and wonderful names. The number’s a bit slippery but we believe they affect one in eight Australians,” says Professor Chris Goodnow, Head of the Immunogenomics Laboratory at the Garvan Institute of Medical Research. “A lot of these diseases were known, but we’ve only subsequently worked out they were autoimmune conditions. Previously they were just weird.”

He means weird in the sense that they are often characterised by non-specific symptoms (think fatigue, joint pain, fever and gut issues) that doctors find tricky to nail down as a specific condition and thus have no treatment plan for.

“Like many biological problems, it turns out to be like an onion: when you peel back one layer there’s another layer beneath you never anticipated,” says Professor Goodnow, who acknowledges the frustration this process brings both patient and doctor. It’s something he experienced as a child in the 1960s when his mother was diagnosed with systemic lupus (where the immune system goes to war on its own tissue and organs).

“It was a new disease then and only the extreme end of it was known so

my mother was told her kidneys would fail, her brain would fail, and that she would need to think about who will look after her children. But she muddled through it and figured out some of the things that triggered it.”

For many sufferers, those triggers are lifestyle related – experts say sleep, stress, nutrition and exercise are key in managing the inflammatory symptoms.

“A plant-centred diet comprising of whole or minimally processed foods and including a variety of fruits, vegetables, nuts and seeds, whole grains, legumes, herbs and spices is the best diet for reducing inflammation,” says Robyn Chuter, Lifestyle Medicine Practitioner at Empower Total Health, though she does caution that even anti-inflammatory foods, specifically citrus, tomatoes, pineapple and bananas, can still

be a trigger for some people.

“Evidence also suggests that people with autoimmune thyroid disease, rheumatological diseases, psoriasis and inflammatory bowel disease may be better off avoiding gluten.”

According to Robyn, a disturbed gut microbiome is common with autoimmune diseases. While probiotics can help boost good gut bacteria, that alone isn’t enough. “Exposure to a wide variety of

#### Common CONDITIONS

## Did you know?

Common types of autoimmune disease include:

- **Type 1 diabetes:** Insulin-producing cells in the pancreas are destroyed
- **Rheumatoid arthritis:** Redness, stiffness and deformity in joints
- **Psoriasis:** Inflammation of the skin
- **Multiple sclerosis:** Damage to the nervous system
- **Systemic lupus:** The immune system attacks tissue in many parts of the body, commonly the kidneys
- **Crohn’s disease and ulcerative colitis:** Inflammation in the digestive tract
- **Graves’ disease and Hashimoto’s:** Affects the thyroid gland, causing it to become under- or overactive.

*“A lot of what makes us different is the way we respond to inflammation and infection. That makes it all the harder to come to grips with autoimmune diseases.”* – **Professor Goodnow**



## Going rogue

microbes from other people, garden soil, forests and animals, particularly dogs and farm animals, helps encourage a healthy and diverse gut microbiota,” says Robyn, adding that extensive research shows a varied high-fibre diet is also optimal.

“Hugh Trowell, a doctor who worked in Africa for over 30 years, observed that when rural people moved to urban areas, they ate fewer plant foods and more refined carbohydrates such as sugar and white flour, and animal products and oils. And their rates of autoimmune disease went up.”

The rates are rising in Australia too but getting a proper diagnosis, let alone an effective treatment, can be a painful process.

“I have rheumatoid arthritis, yet I didn’t test positive for years,” says Indie. “Further complicating diagnosis is that once you have one, you’re more apt to have multiple autoimmune diseases. It wasn’t until years later that my ovarian failure was diagnosed as part of an autoimmune issue. We had to go through many tests and medications to figure it out.”

That figuring out process is an ongoing challenge for our medical system – if doctors sent every patient who feels fatigued or has an ache for MRIs and intestinal biopsies, the system would collapse. In addition, patients find it challenging to communicate exactly what’s wrong to a GP in the

first place, so it’s usually shrugged off as stress or a lifestyle factor.

“Often symptoms come and go, especially when the disease is in its early states,” says Robyn. “So, a person who has rheumatoid arthritis may think their sudden onset of joint pain and swelling is a gym injury, or a person with multiple sclerosis may think that their transient numbness and tingling is from a pinched nerve.”

While medication and lifestyle changes can help with symptoms, what sufferers really want to know is, what’s the cure? “I was winning awards and prizes and getting papers in top journals for research discoveries and I would go and visit

Mum and tell her how great the research was going,” says Professor Goodnow. “She’d be excited but then say, ‘Well, Chris, when it is it actually going to help me? I’m still on steroids!’”

Even now, Professor Goodnow doesn’t have a definitive answer, but his Hope Research team recently made a breakthrough, identifying ‘rogue’ immune cells that drive the immune system to attack healthy cells. They also found evidence of the correlation between stress and autoimmune damage.

“Progress is happening. By pinpointing chinks in the armour of these rogue cells, we can make them susceptible to new drugs and immunotherapy,” he says. Advances in

## Where the chips fall

According to Professor Goodnow, our bodies are designed to function with incredible accuracy: Every time a cell divides only one error creeps in for every 100 million letters of DNA. “But as you age, you’ve accumulated what I think of as ‘chipped crockery in the cupboard’ – serviceable but not quite right.” When mutations fall on those ‘chips’, problems occur. “Even then there are back-up mechanisms so it’s only when several things behave badly you end up at the rheumatologist or endocrinologist.”

technology means a speedier initial diagnosis could become a reality too.

Professor Goodnow and his team are working towards a future where the health of a patient’s immune system can be determined by a simple blood test, something he thinks is achievable in the next decade or so. “It seems like science fiction now but we just need more technological advances in how we read the immune system. If we can design aircraft as complex as those flying today, we can solve immune malfunctions too.”

In the meantime, sufferers have to contend with a trial-and-error approach to managing their condition, usually with immune-suppressant drugs and lifestyle changes. “Once the autoimmune disease genie is out of the bottle, it can’t be stuffed back in,” says Robyn. “You can achieve long-lasting remission, but there’s always the risk of relapsing.”

In real terms that means watching what you eat and taking time out when there’s a flare-up. “I still have autoimmune issues I need to manage daily,” says Indie, revealing a second brain tumour appeared a year after the first was removed. “I believe the first tumour was so I’d wake up to my life’s purpose and this tumour reminds me never to get complacent.

“Since my diagnosis, I see life in technicolour. It’s completely changed my perception of the world and my role in it.” Surprisingly, a recent scan showed her second brain tumour had reduced in size. “The doctors are still amazed and have no explanation,” says Indie. “I plan to live a long and incredible life.” **AWW**

### Action plan

*Indie Lee’s top tips for living with an autoimmune disease:*

- 1 Advocate for yourself: You know your body better than anyone else.**
- 2 Collate medical notes: Bring the binder to every appointment. You never know when a doctor may make a connection between various test results.**
- 3 Create a ‘board of health’: It is a long road and you’ll need friends and family to raise you up when you are feeling low.**
- 4 Community connection: Autoimmune diseases can be lonely. I’ve met incredible friends through social media who understand what you are going through firsthand.**
- 5 Be kind to your body: Eat a healthy diet, get the proper amount of sleep and find outlets to manage your stress levels.**