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Senior Correspondent

Ms Bertilla Wong was in Secondary 3 in 2005 when she suddenly developed rashes on her feet.

She would also get breathless after climbing two flights of stairs when she usually had no problems walking up four storeys to her classroom at Nanyang Girls' High School.

She sought help from a general practitioner who found that she was anaemic. Then just 15 years old, she was diagnosed with systemic lupus erythematosus, commonly referred to as lupus, which affected her heart and lungs, and required two weeks of hospitalisation. Lupus' symptoms include joint pain, fatigue and a butterfly rash that appears across the cheeks and nose.

"I think what triggered my lupus was stress because I was juggling many things. I was in the student council, I played table tennis, and I had dance and piano lessons and third-language classes," says Ms Wong, 35, co-founder of home-grown fashion brand The Closet Lover.

She dropped all her co-curricular activities and focused on recuperating. In the two decades she has been a lupus patient, she has had one or two major flare-ups requiring a higher dose of medication and more rest. She is on several types of medicines, most of which she has taken for 20 years.

"If I get a small flare-up, like joint pain, then I'll rest. I'm really quite lucky," says Ms Wong, who has two sons aged three and four.

She is one of many women here suffering from autoimmune conditions, where the body's immune system, which is supposed to protect, attacks healthy cells instead.

One in 10 people have autoimmune disorders and women make up the majority of such patients. Scientists suspect that sex hormones play a part.

Women are two to three times more likely to develop rheumatoid arthritis, which makes joints inflamed and painful, and nine times more likely to develop lupus than men, says Dr Anindita Santosa, a rheumatologist and medical director of Aaria Rheumatology, a private rheumatological practice.

Globally, autoimmune conditions rank among the top 10 causes of death for women under 65, she adds.

Scientists have discovered over 100 autoimmune disorders, but the common ones that doctors here see include rheumatoid arthritis, characterised by joint pain; lupus; systemic sclerosis, which causes large patches of thickened skin; and anti-phospholipid syndrome, where patients are prone to pregnancy losses and blood clots.

Dr Cho Jiacai, a consultant from the division of rheumatology and allergy in the department of medicine at National University Hospital (NUH), has also seen a spike in Covid-19-associated autoimmune conditions, such as inflammatory arthritis and anti-phospholipid syndrome, since the pandemic. While rheumatologists report more patients seeking treatment, thanks to better awareness and more sophisticated tests, diagnosing autoimmune diseases is often challenging because symptoms are not specific to any disease and may ebb and wane, says Dr Sue-Ann Ng, a senior consultant from the department of rheumatology and immunology at the Singapore General Hospital.

Different individuals can also have different manifestations of the same disease.

Patients with multiple syndromes may also "fall in between the cracks" when they see different specialists for their various symptoms, Dr Cho says.

"Undiagnosed autoimmune conditions in women and men can lead to devastating consequences, including irreversible organ failure, seizures, strokes, blood clots and miscarriages," adds Dr Cho, who says he has seen women seek help late because they dismiss chronic symptoms or turn to alternative therapy.

**Common autoimmune disorders doctors here see include rheumatoid arthritis, characterised by joint pain; lupus; systemic sclerosis, which causes large patches of thickened skin; and anti-phospholipid syndrome, where patients are prone to pregnancy losses and blood clots.**



Ms Bertilla Wong, co-founder of fashion brand The Closet Lover, with her husband Glen Yeo and their sons Caden, four, and Caleb, three. Diagnosed with lupus at 15, she is one of many women here suffering from autoimmune conditions, where the immune system attacks healthy cells. PHOTO: THE LOVE STUDIOS

# Living with an invisible disease

Women with autoimmune conditions face a host of challenging symptoms, even judgment from outsiders as their suffering is not obvious to others

Most children of mothers with autoimmune diseases will not develop the same condition, he says.

However, autoimmune diseases such as lupus and multiple sclerosis have been found to run in families. Ms Wong's older sister, 39, also has lupus, and aunts from both her mother and father's side have various autoimmune disorders.

## REBUILDING THEIR LIVES

Women with autoimmune diseases face an increased risk of developing depression and anxiety because of the chronic pain, fatigue and disability their conditions bring on, Dr Ng says.

Dr Cho adds: "As these conditions are often diagnosed in the economically productive years, they translate into significant economic losses and loss of time, opportunities and energy for women to fulfil their personal and professional goals."

Ms Deborah Yap, 35, did not

know that the frequent headaches she used to suffer from in secondary school were a sign that something was wrong.

In November 2011, during the final year of her undergraduate business degree, she had a seizure and slumped over her desk while taking a test.

She had another seizure a month later and was hospitalised for three weeks, but doctors were unable to diagnose her condition then.

Her symptoms changed in mid-January 2012, and she developed "bizarre behaviours" such as hallucinations, confusion and psychosis. She was also stricken by "movement disorders" that affected her cognitive ability. Some of her relatives thought she was possessed, she says.

Her condition worsened and she was hospitalised again for about two weeks.

Ms Yap was diagnosed with anti-NMDA receptor encephalitis, a rare autoimmune disease that affects one in 1.5 million people. The NMDA or N-methyl-D-aspartate receptor is the brain's primary excitatory neurotransmitter. She went on immunotherapy for 2½ years.

One year after her diagnosis, however, she suffered a relapse even though she had halved her study load. She eventually dropped out of her degree programme at the University of London which she was pursuing via the Singapore Institute of Management.

She then trained as a pastry chef



Ms Diana Ng (left) and Ms Maggie Mok, who have different autoimmune disorders, became fast friends when they met in a support group. ST PHOTO: AZMI ATHNI



Ms Sherry Soon founded support group Autoimmune Diseases Singapore in 2013 to connect with others like her. It now has over 300 members. ST PHOTO: DESMOND WEE

and worked for five years at various cafes and restaurants before taking up an operations role in a non-profit organisation in 2019.

She is now in remission, has not been on medication since 2015 and sells her baked goods on Instagram (@debbakes\_).

"I do get a bit afraid when I get headaches because they were the first thing I experienced before the seizures. I'll drink water or take a quick nap, and if I'm at work, I'll just take a short break," says Ms Yap, who adds that she is managing well now.

Societal pressures to look a certain way also present challenges to women with autoimmune conditions, says Dr Santosa. Steroids, which are frequently prescribed for such conditions, lead to weight gain and a "moon face", where the sides of the face swell up, and other drugs can cause gum swelling and excessive hair growth, which lead some women to skip their medication.

Ms Sherry Soon, who was diagnosed at age 19 with vasculitis, a condition where the blood vessels become inflamed, recalls feeling depressed because she could not recognise her bloated face in the mirror.

Sometimes, the side effects of her immunosuppressant medications led to frequent bathroom needs, affecting her social life. She also had bruises on her arms, which led some of her classmates at the Nanyang Technological University's engineering faculty to ask: "Did someone beat you up?"

Ms Wong says she sometimes gets messages on social media from new lupus patients who are unhappy with their bloated faces

and have stopped taking their medication.

"I have also been there – not taking my medication because I don't want to look so bloated. But it's a vicious circle because when you don't take it, your condition flares up and you have to take more meds. So, I always tell them to take the medication," she says.

Ms Lim Yan Shan was 21 in 2007 when diagnosed with lupus. Her condition stabilised quickly and, over the years, she became complacent and stopped taking her medication regularly.

Eleven years later, she had a major relapse when she took up a new job as a programme manager at an educational institution and overworked herself, not knowing her condition could worsen. Half her hair fell out, she had broken skin and "awful scars" on her body, as well as extreme fatigue and weight gain.

She could no longer do simple chores like washing the dishes, which her husband took over, and had to switch from a full-time to part-time role.

With help from her family and company, it took her about two years to get her condition under control again, which delayed her plans to have a baby.

"I got quite emotional seeing friends my age starting to get pregnant and have kids," says Ms Lim, 38, who is now in a marketing role in the same industry.

The first gynaecologist she saw dismissed her desire to start a family and told her to adopt. Shocked, she told her rheumatologist, Dr Cho, who recommended a gynaecologist at NUH instead. Ms Lim gave birth to her son in December 2021.

"Be positive, work well with your doctor and live your life to the fullest. Don't get bogged down thinking you have a lot of limitations, that you cannot live a full life," she says.

Women with autoimmune conditions such as lupus and anti-phospholipid syndrome have an increased risk of miscarriage, stillbirth and pregnancy complications that may affect the unborn baby's growth, Dr Cho says. However, with careful medical monitoring, most mothers can go on to have successful deliveries.

As autoimmune conditions are often invisible to the casual onlooker, women often find themselves judged when they need accommodations at work or in public.

Ms Maggie Mok, 51, who has multiple sclerosis, a chronic disease of the central nervous system, as well as rheumatoid arthritis, uses the "May I have a seat please?" card to indicate that she needs a seat on public transport. Such cards are available from passenger service centres at MRT stations, bus interchanges and TransitLink ticket offices.

Still, she says, "people will give you that kind of expression, like, 'Are you trying to be funny?' They don't understand that with invisible diseases, we look fine outside, but we are not good inside".

She also sometimes fears being in a crowd as she may have a flare-up and fall because the nerves in her leg give way.

Dr Santosa says some of her patients have also reported being passed over for promotions or have bosses who do not believe they have fatigue and brain fog.

## FINDING JOY IN THE JOURNEY

After a decade of living with vasculitis, Ms Soon still had not met a single person with the disease. So, in 2013, she formed a group called Autoimmune Diseases Singapore on the Meetup social media platform.

The group (autoimmunedisases.sg) now has over 300 members who interact via a closed Facebook group of the same name.

In 2024, it held six events and activities, which included sessions where members taught one another skills such as playing the guitar and watercolour painting.

"They don't want to be defined by their disease," Ms Soon, 44, says of the members' willingness to reach out and share.

Ms Yap, who previously blogged about her disease, found the courage to share her story with the group's members at an event in March 2024.

"It's nice to know that others out there support me. I don't feel alone in this," she says.

The group has also brought individuals with very different autoimmune diseases closer together.

"It's because of the support group that people got to know one another and form meaningful friendships that they otherwise wouldn't have outside of their own circle," Ms Soon adds.

Ms Mok, who juggles part-time jobs in a yoga studio and an educational book firm, hit it off with Ms Diana Ng, 42, during the pandemic as they both speak Teochew. The instant best friends often catch up over ad-hoc cafe meals.

Ms Mok sends Ms Ng a custom blend of essential oils if the latter is travelling or has to be hospitalised for anti-synthetase syndrome, a rare condition which causes inflammation and other symptoms in the muscles, joints and lungs. Ms Ng also has arthritis.

An avid kite-flier, Ms Mok also collaborated with Ms Ng, a freelance designer, art teacher and art workshop trainer, on the palette for a Merlion mascot kite.

"I call her my sister in pain," says Ms Ng, who suffered from eight months of coughs before she was diagnosed with dermatomyositis in 2020. The rare disease causes muscle weakness and skin rash. She also has interstitial lung disease, which causes her to be breathless.

Both conditions are related to anti-synthetase syndrome. She was hospitalised three times in 2024 when her condition worsened.

She adds: "This journey is life-long and it can be quite lonely at times. Having someone who understands what I am experiencing is heart-warming because you need people to listen and guide you while you're navigating this."

She urges women who have been newly diagnosed with autoimmune disorders to practise self-compassion.

"Hopefully, they can find joy in the journey, share their story and remember that their strength lies in how they fight this battle on a daily basis."