

FROM C1



Ms Michelle Mak had regular fevers and rashes as a child, but things became worse when she took up her first job in 1997 as a bank teller. ST PHOTO: CHONG JUN LIANG

More pain when it rains

Rare genetic disorder made her hypersensitive to the cold

Akshita Nanda
Correspondent

Ms Michelle Mak used to be hypersensitive to the cold. For most of her life, she hated rainy days, cool weather and air-conditioning. Dips in the external temperature set off fevers, rashes all over her body and joint stiffness.

"I would wear two pairs of pants, three shirts and a jacket and still feel discomfort," recalls Ms Mak, who turns 46 in 2025.

In 2023, she learnt that she had a rare genetic disorder called Muckle-Wells syndrome.

Medical treatment has helped manage her hypersensitivity to the cold and ended her frequent fevers, rashes and joint pains. It has given her the confidence to complete a diploma in design and visual communications from Singapore Polytechnic.

Rheumatologist Anindita Santosa, who treated Ms Mak in 2023, says that fewer than one or two in a million people have Muckle-Wells syndrome.

"Many doctors may go their entire careers without seeing a single case," adds Dr Santosa, who is the medical director of private practice Aaria Rheumatology.

The doctor says an error in a gene called NLRP3 causes Ms Mak's immune system to be overactive and flare up even when she does not have an infection.

Triggers such as cold or stress cause inflammation, leading to rashes, fever and joint stiffness. Some people may lose their hearing or develop kidney problems.

Ms Mak had regular fevers and rashes as a child, but says things became worse when she took up her first job in 1997 as a bank teller. "That was the first time I had encountered such discomfort," she recalls. "I felt a lot of pain because the bank was extremely cold."

After some time in a cold environment, she would feel fatigued and later suffer fever and rashes. This affected her ability to work.

RACKED WITH PAIN

Some days, she was in so much pain that she would cry in the bus or train on the way home.

She tried various jobs, including as an assistant to a hairstylist. Until 2020, she worked in customer service and administrative support. Then her hearing deteriorated, making it difficult to answer calls. "I lost a lot of confidence," she says.

She now uses hearing aids, and can take and make phone calls on devices that allow her to connect to these aids.

Over the years, she sought help for her condition. General practitioners she consulted merely suggested that she avoid the cold.

She tried public hospitals in the mid-2000s, thinking that she might have lupus, but the tests were negative.

"I could depend only on painkillers and drinking warm water," she says.

In 2023, she developed rashes after her Covid-19 vaccination and was eventually referred to a dermatologist and then a rheumatologist at Changi General Hospital.

Genetic testing revealed that she had Muckle-Wells syndrome. She started regular injections of Anakinra, a biologic drug that stops inflammation.

Dr Santosa says the inflammation in Muckle-Wells syndrome is driven largely by excessive production of a signalling molecule called interleukin-1 (IL-1).

"Anakinra works by blocking the receptor for IL-1, thereby reducing the inflammatory cascade. This helps in controlling the symptoms and preventing the long-term damage associated with ongoing inflammation," she adds.

Ms Mak was on daily injections at first, but now gives herself the injection in her thigh twice a week. She currently sees a specialist at Sengkang General Hospital.

The cost of treatment would be at least \$30,000 annually, but with assistance from MediFund and the National Arthritis Foundation, which is a charitable body, Ms Mak does not pay a cent.

I would wear two pairs of pants, three shirts and a jacket and still feel discomfort.

MS MICHELLE MAK on how she tried to stay warm during rainy days, cool weather and air-conditioning

INBORN ERRORS OF IMMUNITY

Dr Santosa is deputy chairman of the National Arthritis Foundation, which helps subsidise medication and medically advised genetic testing for people with inborn errors of immunity, such as Muckle-Wells syndrome.

Inborn errors of immunity is the name given to a group of over 500 rare genetic conditions, where the immune system does not function properly.

It is important to raise awareness of such conditions because the symptoms are often misunderstood, says the doctor.

"People may be treated repeatedly for infections or allergies without realising an underlying immune disorder is the root cause."

Early treatment can be life-changing and help patients avoid long-term damage, she adds.

Ms Mak has seen her life improve dramatically since starting treatment.

She no longer suffers inflammation or fevers or rashes on rainy days, or after being in air-conditioned rooms.

She has completed a course on baking, as well as her diploma in design and visual communication. She is looking for a new job.

She also engages in regular light exercise, since moving around has always helped her feel better. She sometimes goes on nature walks, or stretches and marches on the spot for 45 minutes, three to five times a week.

"In 2020, I was demoralised," she says. "Now, I've regained my confidence."

What happens to your brain when you retire

Mohana Ravindranath

For the millions of Americans who retire each year, stopping work might seem like a well-deserved break. But it can also precipitate big changes in brain health, including an increased risk of cognitive decline and depression.

Before retiring, you are getting up in the morning, socialising with co-workers and dealing with the mental challenges of your job, said Dr Ross Andel, a professor at Arizona State University who studies cognitive ageing and retirement. "All of a sudden, after 50 years, you lose that routine."

There is this idea that the body and brain adapt when they are "no longer needed", he added. "That's when you see the deterioration and its natural response to inactivity."

But retirement can also be a chance to improve cognitive and mental health, with newfound time to socialise and take on hobbies.

And even if you have started to experience some decline, there is evidence your brain can bounce back from periods of inactivity, even in older age, said professor of econometrics Giacomo Pasini at Ca' Foscari University of Venice, who studies the impact of economic policy on seniors' mental health.

One analysis of more than 8,000 retirees in Europe found that people's verbal memory – the ability to recall a set of words after a certain amount of time – generally declined faster once they retired, compared with when they were working. Another survey conducted in England showed a steep decline in verbal memory after retirement, though other skills, like abstract reasoning, were not affected.

"There's some evidence that retirement may be bad for cognition, because when you retire, you don't challenge your brain as much," said professor of econometrics Guglielmo Weber at the University of Padova in Italy who worked on the Europe study.

Research has also found a link between retirement and the onset of depression.

Suddenly going from a "busy work life to a lack of engagement can exacerbate feelings of worthlessness, low mood, sadness" and "severe depressive symptoms and memory loss", said associate professor of public health Xi Chen at Yale University who studies ageing.

The nature of your work – and how you view that work – seem to affect the risk of decline.

For example, researchers think that those who worked in higher-ranking jobs may show a steeper decline than others, possibly because their identities were more strongly tied to their careers, Prof Chen said.

The study in Europe also found that people who stopped working earlier than the standard retirement age where they lived showed less of a decline than those who stopped working later, Prof Weber said. That could be because the people who retired earlier may not have had as mentally demanding jobs, resulting in a more gradual decline once they retired.

People who are forced to retire "due to health issues or blatant ageism", or who face financial challenges in retirement, can see more severe effects, said Dr Emily Fessler, an assistant professor at Weill Cornell Medicine who specialises in geriatric care.

And women may be less likely to experience a steep mental or cognitive decline, potentially because

they are more likely than men to continue to socialise and spend time with family after they retire, Prof Weber said.

Retirement can be an occasion for growth instead of decline, the experts said. The key is to lay some groundwork ahead of time.

DON'T WAIT FOR RETIREMENT TO PLAN FOR RETIREMENT

Ideally, you should introduce new mentally and physically engaging routines a couple of years before you stop working, said Dr Alison Moore, chief of the geriatrics, gerontology and palliative care division at the University of California, San Diego.

Even if you do not start them right away, you should make the plan ahead of time. Delaying those decisions – like whether to spend half the year travelling – until after you have retired makes it harder to take the plunge, she said.

The goal is to "pivot from one type of daily life to another", she said. "Being open to new experiences before you make this big life change can kind of prep you."

FIND A NEW SENSE OF PURPOSE

"People may have felt their purpose was contributing through work, and when that's taken away, they have to invent something else to take its place," said Dr John Beard, a professor of productive ageing at Columbia University Medical Centre. Studies suggest that people with a sense of purpose tend to experience less age-related cognitive decline.

Volunteer work, in particular, can help, Prof Chen said. Research has found that people who regularly volunteer in retirement show slower rates of biological ageing, and that they can head off cognitive decline by staying active and engaged.

COMMIT TO STAYING SOCIAL

It is common for people to lose social connections during retirement, said Prof David Richter, a professor of survey research in the department of educational science and psychology at Freie Universitat Berlin. "We have rather solid proof that first social contacts are reduced, and then cognition declines," he added.

To stave off the depression, cognitive decline and early mortality that can come with social isolation, Prof Richter recommended that retirees replace workplace socialising with routine in-person or virtual gatherings.

TRY NEW THINGS

Doing something creative and novel can give you a sense of purpose and keep your brain agile. Research suggests you can practise creativity just like any other skill, said distinguished professor of psychological and brain sciences Jonathan Schooler at the University of California, Santa Barbara.

That could mean writing for a few minutes every day or attempting an adventurous new recipe for dinner. Regular exercise is critical for brain health as you age, so you could also consider trying a new type of fitness class.

Creativity can also boost a person's sense of "meaning", Prof Schooler added. "There is great evidence that finding meaning in life gives one a great personal satisfaction." NYTIMES

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