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'IT'S NOT IN OUR HEADS'

A diagnostic test is a crucial first step in understanding CFS, writes **Janelle Miles**

KETRA Wooding lives in aged care on the Gold Coast. She's an articulate, intelligent young woman who once enjoyed the carefree life of a sailor, working on luxury yachts and travelling to exotic places, such as the Galapagos Islands and the Caribbean.

She spent the first half of her twenties on the world's oceans, but for the past five years the 32-year-old has resided among dementia patients. However, it's not living with the elderly she finds confronting.

Wooding has been diagnosed with the controversial medical condition chronic fatigue syndrome, also known as myalgic encephalomyelitis, or CFS-ME – an illness which cannot be confirmed by a simple blood test, but is estimated to affect 240,000 Australians to varying degrees.

Scientific evidence shows the complex condition, once derided as “yuppie flu” and its sufferers labelled malingerers or hypochondriacs, is biologically based and not psychosomatic.

But the medical profession

is divided on how best to treat the mystery disorder.

Some insist on adhering to Australia's 2002 CFS-ME guidelines by prescribing graded exercise therapy – encouraging patients to slowly increase their physical output – despite suggestions this may be making them worse.

Wooding fell ill in 2010 after developing flu-like symptoms she was unable to shake. At the time she was looking forward to sailing the yacht she was working on back to Europe and had been researching the best ways to get through the Malacca Straits and the Red Sea without being attacked by pirates. But she was too sick to make the trip.

By 2013, she was incapable of working and had deteriorated to the point where she spent three months bedridden in the Gold Coast's Robina Hospital.

She was no longer able to tolerate bright lights, loud noises or common chemicals such as those found in perfumes and laundry detergents.

“I couldn't get to the bathroom by myself, I could barely roll over in bed. I couldn't chop my own food up,” she recalls. “My body was shutting down. I

felt like I was dying. My mum was completely burnt-out from looking after me.”

Although she found many of the hospital staff supportive, her mother was accused of “making me sick”, despite Wooding living independently after finishing high school until just before her 25th birthday, when she reluctantly gave up her job, too unwell to continue.

“My experiences in hospital were really traumatic and I don't want anyone else to go through that,” Wooding says.

“I was told I had no problems and that I was fine. Mum couldn't get any support which is why she wouldn't bring me home after being in hospital. It was pretty horrific.”

She was discharged into a nursing home, unable to care for herself. “It was really, really bad,” she says. “I was on a dementia ward. I remember the first room I went into. I thought: ‘Oh well, this is the room I'm going to die in’.”

Wooding lies on her back, recounting her story via Skype. Sitting “makes me a lot sicker”, she explains. At times she loses



her train of thought – brain fog is another common symptom.

But even with her obvious fragility, she's become a crusader, determined to help

other CFS-ME patients avoid her plight. She wants more research into CFS-ME, better treatment and diagnostic guidelines for doctors and greater understanding for its sufferers.

"It's not in our heads," she says adamantly.

Dr Heidi Nicholl, CEO of the CFS-ME patient support group Emerge Australia, says more awareness of the condition is desperately needed among doctors.

"While I absolutely believe that doctors are trying to do their best for patients, we also know that the average general practitioner is not fully across the issues and potential harms surrounding graded exercise therapy," she says. "With the extremely limited time for many consultations, and the lack of knowledgeable qualified specialists to refer patients to, it can be extremely tough for doctors to get it right."

The illness is so contentious, questions and interview requests from *The Sunday Mail* to the Royal Australian and New Zealand College of General Practitioners went unanswered.

Despite the urgency for more treatment options and diagnostic tools for CFS-ME, the National Health and Medical Research Council (NHMRC), Australia's peak funding body for medical research, has spent just \$1.63 million on the illness since 2000.

But in October last year, an NHMRC committee was set up to advise on the research and clinical guidance needs of CFS-ME in Australia. The committee includes doctors, researchers and consumer representatives, including two people with the condition.

The prospect of new guidelines is welcomed by patients such as Wooding.

When she was first diagnosed with CFS-ME in 2010 she consulted the 2002 Royal Australasian College of Physicians' guidelines, using them as the basis for her decision to keep pushing herself at work for another nine months before becoming too ill.

"They strongly implied that it was important to keep as active as possible in order to avoid depression and further decline," Wooding says.

"This was what I wanted to hear, as I wanted to keep working and doing things. However, it was the wrong advice.

"It still makes my blood boil that those guidelines were written. The harm they've

done me and other patients – and the cost to taxpayers – is obscene."

Among those on the NHMRC committee is Griffith University researcher Professor Sonya Marshall-Gradisnik.

The immunologist, who specialises in CFS-ME studies, is also the scientific co-director of the National Centre for Neuroimmunology and Emerging Diseases (NCNED).

Together with public health physician Professor Don Staines, her co-director on the NCNED, she's working on developing a diagnostic blood test for the condition. They are also hopeful of finding medications to treat the debilitating disease, which can leave patients so fatigued they are unable to work or study.

Those with the condition also complain of extreme muscle pain, difficulties with concentration and memory, sleep disturbances, gastrointestinal problems and cardiac abnormalities which can see their heart rate spike significantly with little exertion.

Comparing the blood of

CFS-ME patients with that of healthy volunteers, Marshall-Gradisnik and Staines have identified malfunctioning in the immune cells of people with the condition.

In a world-first, they linked CFS-ME to a faulty receptor on immune cells, providing scientists, doctors and patients with further understanding of the disorder's pathology throughout the body.

Their findings are enabling NCNED researchers to test potential drug treatments for CFS-ME.

In healthy people, the receptor – known as transient receptor potential melastatin 3 (TRPM3) – is responsible for bringing calcium inside the cell. Calcium is vital in helping



the immune system destroy infections.

The Griffith University team found people with CFS-ME had “significant reductions” in the number of functioning TRPM3 receptors on their immune cells compared with healthy volunteers, and greatly reduced amounts of calcium inside their cells.

TRPM3 receptors are found on virtually all cells in the body, not just immune cells, which may explain the wide range of symptoms experienced by people with CFS-ME.

The involvement of the TRPM3 receptors – also known as threat receptors because they increase when the body is under siege from an infection or a trauma – may also explain why patients are frequently diagnosed with CFS-ME after an infection, as in Wooding’s case, or a traumatic event.

“It’s not the infection itself, but rather it seems to act as a trigger for getting this abnormal and severe immune response that we then describe as CFS,” Staines says.

Given their findings of the disorder’s underlying pathology, Marshall-Gradisnik says graded exercise therapy is “contraindicated and potentially harmful” for patients with CFS-ME.

“The pathology we have identified in this illness specifically involves disruption to the physiological responses to adverse stimuli, including physical activity. It is negligent to subject patients wilfully to exercise and other stimuli when they are already in physiological compromise.”

Marshall-Gradisnik and Staines are optimistic of using their research as the basis for the development of a blood test for CFS-ME “in the not too distant future”.

“This is definitely a biologically-based illness,” Staines

says. “We are looking to a future where the science of this illness is much better understood and better described and will form the basis of a diagnostic test. That news, I think, is being very warmly welcomed by patients whatever has happened in the past.”

A definitive, “legitimising” blood test cannot come too soon for patients, such as Bond University business management graduate Josh Roberts, 23, who is struggling to access a disability support pension after being diagnosed with CFS-ME.

Exertion leaves him so fatigued he needed a wheelchair for a trip to Sea World with his family a couple of months ago.

“I only use a wheelchair when I’m out of the house,” he says. “I’m able to walk a few thousands steps a day if I need to. The most I’ll get up to is 2000 to 4000.

“For me, 4000 steps is a lot and I’ll have to rest for multiple days or more after that.”

Roberts first started becoming ill towards the end of Year 11 at Trinity Lutheran College, on the Gold Coast.

“Mum remembers me getting a virus in about July/August,” he says.

“I was just whacked and things were getting more and more challenging.

“At the time I was doing interviews to go for school captain and the first thing I noticed was lack of memory. I couldn’t remember things as well as I usually could.”

The previously active young man, who was successful in his bid to become school captain, slowly recovered through rest.

But after starting to push his body again – running the 2015 Gold Coast half-marathon “in a good time” – he relapsed towards the end of his university degree.

“The last few months, I just struggled over the line,” Roberts says. But CFS-ME has so far robbed him of being able to follow his dream of starting his own business, as he battles the twin maladies of brain fog and perpetual exhaustion.

“I’m quite interested in technology,” he says. “I’ve had an idea for the last year or two but I haven’t had the energy to execute it.”

Roberts, who runs a social group on the Gold Coast for young people with chronic illnesses, believes CFS-ME has a genetic basis. His father, Matthew, now 46, experienced similar symptoms from age 23 for about five years.

“He’s mostly recovered,” Roberts says. “He’s able to live a pretty normal life.”

Ketra Wooding laughs often despite living with an illness that has robbed her of the joys most young people take for granted.

“I think you have a base level of positivity or negativity in your attitude and eventually, you kind of drift to wherever it is no matter what your circumstances,” she says.

“If you win a million dollars and you’re a sad person, you’re still going to be a sad person with a million dollars.”

After five years of living in a nursing home, she hasn’t given up on the idea of one day being well enough to leave.

“I hope so,” she says. “I’ll need a lot of support.”

- Wooding has made a short documentary on her life. It can be viewed on the ME-CFS Health Page on Facebook.
- Roberts’ support group, Gold Coast Social Group for Young People with Long Term Conditions 18-40Y/O, can be found on Facebook.
- For more information see emerge.org.au



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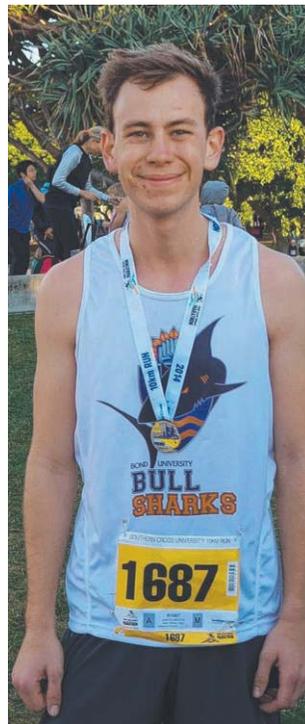
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My experiences in hospital were traumatic. I was told I had no problems

Ketra Wooding



MAKING PROGRESS: (From left) Ketra Wooding in her sailing days; after being diagnosed with the controversial medical condition chronic fatigue syndrome, Wooding now lives in a nursing home; researchers Professor Sonya Marshall-Gradisnik and Professor Don Staines; Josh Roberts first started to see the signs of chronic fatigue during high school. Roberts now runs a social group for young people with chronic illnesses.



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