

Sick building syndrome—is it the buildings or the people who need treatment?

May 1 2018, by Shayla Love

In early September 2011, when the weather in Finland had begun to turn its back on summer and trudge towards winter, a woman prepared to leave her home in the suburbs of Helsinki. Kirsti Paasikallio emptied her refrigerator, packed some clothes, her toothbrush, toothpaste and an iron, and left the house she had lived in for 34 years – for good.

"I closed the door, turned my back, started my car and left," she says. "I had lived there since February 1977. A lot of things, carrying a lot of memories, remained behind that closed door." The hardest room to leave was her personal library. "It is funny that one can miss the books as much as I do, it's as if they were part of my blood."

In October 2017, I meet the now 73-year-old Paasikallio, a thin, regal-looking woman with glasses and silver hair. We sit in the lobby of a hotel in downtown Helsinki, a few blocks from the apartment she lives in today. When she first moved, she bought a bed, a TV and a broken sofa from the previous tenant. She didn't bother to get any chairs – she didn't think she'd be there long. It's been more than six years.

The problems with her old house started in 2008, when she began to get fevers and developed issues with her voice. A building company found high levels of mould in her basement. She says that, although she tried to get her house cleaned, the mould seeped its way into all her belongings. She began to feel so ill that she had no choice but to abandon her home.

After leaving, her symptoms persisted and her [health](#) continued to

deteriorate. She tells me she became highly sensitive to other buildings, minuscule levels of mould, and chemicals or smells. When she went to the doctor, she was told these multiple chemical sensitivities couldn't be related to her mould exposure – she had moved, there was no way she could still be sick. She gave up. "I was so tired I really hoped the next fever would kill me. I didn't try to find any help any more. In a way, life was over."

Paasikallio has [sick building syndrome](#), or SBS, a controversial condition with many definitions and symptoms and even more proposed explanations. A basic definition is that it's an illness a person gets from a building they live or work in. Speculated causes have included dust, microbes, carpets, ventilation and, like in Paasikallio's story, mould. Other researchers have claimed there are psychological forces at play, that SBS is related to anxiety, dissatisfaction at home or work, or other mental conditions. Sick building syndrome was a common term in the 1980s and 1990s. It has since faded out of use in the USA, where I live, but continues to be studied and discussed in Nordic countries like Denmark and Finland.

I came to Helsinki to meet members of an online SBS community, including Paasikallio. Another member of the group, Alex Vinska, a slim 17-year-old with dyed blond hair, tells me that he and his mum, Heli, also had to leave their home. "I was getting sick every winter and summer when the temperature dropped," he says. "I got the flu, I got headaches, my legs hurt, my head hurt, rashes on my skin, everything like that."

They found mould growing in the walls of their house and had to desert their clothes, all their furniture. "Everything," he says. Family photos were salvaged and wrapped in plastic. They are going to make photocopies of them through their coverings. Vinska says he often has reactions at school. Sometimes he has to do his classwork in the

hallways, away from other students. His visits to the doctor didn't yield any help. "Because it wasn't any sort of flu or any kind of bacteria or virus, we were all right," he says. The doctors told them there was nothing wrong.

In 2013, Paasikallio found a doctor who thought he could help, and through 'nutritional therapy' she eventually felt well enough to rejoin the world. She doesn't think her illness and sensitivity will ever go away, but within months of starting treatment, she managed to go on a skiing trip with her daughter.

Others are not so lucky. Elina Seitz, 40, says that doctors in Finland are too quick to label SBS as psychological. In 2012, she got sick from her office where she worked in child services. She would get stomach pains, infections, high blood pressure – all medical issues she had never had before. In 2014, mould was found in the building but, despite loving her work, she had already left the job. By 2015, she wasn't able to go into other buildings too. But being diagnosed with SBS in Finland does not open up access to support.

"When I got sick, there was no place for me to go," says Seitz. "I couldn't get any money. No sick pay, nothing. No rehabilitation, no retraining in a new profession, no unemployment benefit. I was being left out without any rights at all, with nothing."

Alan Hedge at the Department of Design and Environmental Analysis at Cornell University tells me SBS appeared in the 1970s when, to reduce energy use in response to the oil embargo, ventilation standards were lowered. Building-related health complaints began to rise shortly after. No study ever returned definitive results or caught a single compound red-handed making people sick. Focus turned from fleecy fabrics to allergens, and for a short time it was believed that indoor carpeting was the culprit. "The [US Environmental Protection Agency] spent a fortune

trying to establish that relationship and they couldn't," Hedge says. "But what began to happen was almost a kind of mass hysterical reaction."

There must be a psychosocial element, some research claimed. How else to explain that women are more likely to have SBS than men? Or that employees' wellbeing could be associated with floor plans and office arrangement, office noise or how much control they had over their environment? Hedge's own work examined SBS questionnaire answers from thousands of workers in various buildings. "We didn't find any evidence of an actual syndrome. In other words, no consistent pattern of all of the symptoms." In the end, he says, they "don't really know whether it's the building or it's the people."

Hedge has had a long career of tackling building-related health problems and says the 'building or people' puzzle isn't easy to solve. In one of his cases, people felt ill only in the mornings between 09.30 and 10.00. When the air was tested (later in the day), nothing unusual was detected. Hedge eventually found a cause that explained the odd timing: carbon monoxide from the morning's arriving cars was rising into the office through elevator shafts.

In another case, a man had a tiny hole in his bed – which Hedge noted was a water bed. Water was seeping under the carpet and growing mould, causing the man to become ill. "There's no question that there are a variety of [building] mechanisms by which people might get sick," Hedge says. "The problem is, they're not uniform."

An office in Montreal with 2,000 employees was on the verge of evacuation because of a bad odour. Hedge says everyone was worried it was a 'sick building' and that their health had been affected. He found only a couple of mouldy oranges left in the desk of an employee on vacation. Smelly, but not dangerous. "But the reaction," he points out, "it was a genuine reaction. You smell something, you don't know what it is."

You've heard there is a problem and pretty quickly you can feel bad."

After SBS had peaked, Hedge says he started to hear about another disorder: multiple chemical sensitivity (MCS). People who claim they have it say they can be intolerant to any chemicals or materials in any building. I ask Hedge to apply his standard line of inquiry: is it caused by the buildings or the people?

"I have no doubt that they have a problem," he says diplomatically. "The question is, how much is that problem related to their environment or how much is it related to what they think might be in the environment?"

The bigger problem, Hedge says, is that people who suffer from SBS or MCS often get lost in the medical system. They're shuttled between medical doctors who can't find anything wrong with them physically and psychiatrists who say their symptoms are imagined. Neither offer treatment. People can end up homeless, broke and feeling cynical about doctors and therapists alike, just like it has played out in Finland.

"Over time, these people will find each other," he says. "And then when they find each other, it's like the Flat Earth Society. They reinforce each other. These are people who are desperate for an explanation for what's happening to them. And in the absence of that, all they have is their imagination."

On a frigid morning at a café in downtown Helsinki, Tamara Tuuminen orders a hot chocolate. She has short sandy brown hair and is wearing a green sweater with a matching pendant. She's the coauthor of a strongly worded letter to the academic journal *NeuroToxicology* about SBS, rejecting the conclusion of a study that had recommended mindfulness-based cognitive therapy for people with SBS as a symptom of mould-related illness – people like her.

Tuuminen tells me there are thousands of people in Finland who are sick from indoor mould exposures, who have been told they are crazy, referred to psychiatrists, have lost their jobs, left vacant furnished houses and, in some cases, destroyed their homes. True to Hedge's advisory, she also belongs to the group of people with SBS and MCS from indoor mould who meet in Helsinki every few months.

Her own experience began when she started getting frequent coughs, colds and flu-like symptoms in the summer of 2014. At first, she attributed them to her grandkids, whom she was babysitting on the weekends. You know kids, she tells me – they always want to "puss," she says, puckering her lips and miming kisses in the air. But her health steadily got worse. She always felt tired, her voice would disappear and she would cough all the time.

Tuuminen is a medical doctor and a specialist in clinical microbiology, and at the time worked at Mikkeli Central Hospital. "We had occupational doctors, and I went and said, "Something strange is happening to me."" She wondered whether her immunity had somehow been compromised? Was her thyroid damaged? Did she have HIV?

"We took all the tests I suggested and everything was clear. I started to think about very unusual things. I am a doctor, but could not understand." When she went on sick leave for a week, her voice returned. Back at the hospital, it disappeared again and the coughing returned. That's when she started to think it was related to the building.

Tuuminen tells me that she had heard about mould illness before she got sick, but she didn't consider that it was happening to her. Until, that is, her technicians found a large mushroom growing in the lab next to her office.

Her boss told her that they would renovate, and that when she returned

from sick leave she would work in a different office on a different floor, away from her bacteriology lab. When she went back in January 2015, her symptoms started up again. Doctors told her there was no logical explanation. "They said that I am afraid," she says. "That I was imagining. It was so offensive."

Her last day at work was in February 2015, when a technician pointed out how strange her breathing sounded. Tuuminen says it was a wake-up call: "I tried with all my efforts," she says. "I thought that I should overcome, I should stand it. And the technician said to me, "No, you are not breathing well." And then I looked at myself, and I thought, "This is really crazy, I will kill myself.'"

Eventually, she found herself in the position of so many people with SBS. She wanted to work, she loved her profession – but how can you have a job without being able to go into a building? Instead, she started to research mould-related illness and its after-effects and to work out her rights.

I ask her what she thinks about psychological treatment, which is often turned to in the absence of any confirmed physical cause. Even if their illness wasn't caused by mental problems, couldn't someone who has lost everything benefit from therapy? She is adamant in her answer: "Psychiatric therapy? No. They don't need it. They need new apartments. A place to stay. A place where they can breathe. They are strong people, they have overcome such difficult situations. They don't need this 'blah blah blah.' They need real help, real support."

Tuuminen doesn't strike me as an imaginative hypochondriac. She is level-headed, forceful, clear and has a seemingly perfect memory. There is no doubt in my mind not to believe her, and the debate over mould illness and SBS seems ridiculous. They found a huge mushroom in Tuuminen's office, how could there be any dispute?

I continued to think this about pretty much every mould sufferer I met: most had documentation to show me the proof of mould contamination found in their home or office. How could a real mould exposure be considered psychological? But I soon recognised that it wasn't that initial exposure being contested.

It was the continuation of symptoms – the cough and breathing problems that Tuuminen had, even after the mushroom had been removed, the lab renovated and she relocated to a 'clean' office. Those were the symptoms that were harder to explain and impossible, according to Tuuminen, for doctors and insurance companies to accept were real and deserving of 'real' help and support instead of psychiatric help.

Tuuminen says that one of the most upsetting parts of her illness was being disappointed by her own profession. "I was so perplexed because I am a medical doctor, I always wanted to help people," she tells me. "I was taught I should believe what [patients](#) tell me about their illness, I should do my best. And when I was in the position of a patient, nobody really wanted to help me. Why is that?"

Eventually, though, like others in her group, she found the one doctor who would believe her symptoms were real.

Ville Valtonen, a bald 73-year-old in a pressed coat and a dark cap, waves me over to his car. We're driving to Helsinki University Central Hospital, where he worked for over four decades. His SBS history lesson is the same as Hedge's: the energy crisis led to a change in building practices, and the patients followed. The first ones he saw came in the late 1980s. They would be previously healthy, usually early middle-aged people who had started getting repeated infections.

Valtonen's career then was centred on the link between strokes and infection. Now, in his retirement, he is returning to the mystery of those

early patients. He is one of the few doctors in Finland who is willing to give mould patients a diagnosis, which he calls Dampness and Mould Hypersensitivity Syndrome.

Valtonen defines [five stages](#) of the disease. They're based, he says, on the progression of the syndrome that he's seen in the hundreds of people he's treated. First, a history of exposure to mould in water-damaged buildings, then an increase in infections. Third comes SBS, and fourth, MCS. Finally, an enhanced scent sensitivity, meaning a person is extremely sensitive to the smell of moulds, "a hundred-fold more accurate than normal," he says.

In Valtonen's model, SBS is just one factor of the overall illness. He says there is still hope for a mould-exposed patient with only SBS, because their symptoms will stay away if they avoid any source of mould or chemical that triggers them. "But if the patient has gone forward to this mould and chemical sensitivity, it is almost impossible to cure completely," he says. "And if you have electromagnetic sensitivity, it's hopeless."

Although he tells me that many of his patients have it, I'm sceptical of this symptom, as repeated studies have shown that participants cannot tell when they're being exposed to electromagnetic fields. He says many of his mould patients can no longer use mobile phones. Some develop chronic fatigue syndrome, unable to walk even 10 metres; others develop epileptic seizures, but show normal electrical activity in the brain when tested.

That's a lot of different symptoms, I venture, so what does he think is going on? Valtonen says he can't dive into researching the mechanism as deeply as he would like. "I'm 73 and I'm too old to get any grants and do anything, so I'm only going to see those patients I have now," he tells me. His theory is that the illness involves an immunological reaction that

combines with secondary infections.

I ask him if he thinks psychology plays any part, and to my surprise he doesn't have the defensive knee-jerk reaction that Tuuminen does. "I'm quite sure that supportive psychotherapy will help to some degree these patients, but now it's the opposite," he says. "If you go to a doctor and you say, "I have mould disease," [the response is], "Oh, are you crazy?" If you say that you have electromagnetic hypersensitivity, it's quite sure that you'll be sent to psychiatrists. These patients, they hate to go to the doctor, because they know if they tell the truth they'll get poor treatment."

Many of his SBS patients describe Valtonen as the doctor they were lucky to find. He was a turning point in their illness, a moment when they could finally get better, because he gave them a diagnosis. But as we talk, I'm struck by how he doesn't really offer treatment – his advice is simply to avoid any and all triggering exposures. The most valuable thing he provides, I think, is his acceptance of the biological nature of their symptoms.

"I can't be a doctor who doesn't believe, what is that?" he says as we leave the hospital. "In my 45-year clinical career I've very seldom, very seldom seen patients who lied to me."

But as I would soon find, it's not always as simple as being lied to or told the truth. When I meet Kirsi Vaali, Merja Lindström and Christer Häggqvist, they excitedly tell me something that I want to believe: Häggqvist is a mould patient they have cured.

Lindström is a homeopath and Vaali is a biomedical researcher at the University of Helsinki. Before researching mould, Vaali studied food allergies and chronic fatigue syndrome – she has an interest in diseases that others cast off as psychological, she says. She emphatically tells me

that mould illness is actually related to mitochondrial damage, and that she has a candidate gene that could predict susceptibility.

This is the moment when doubts begin to surface in my mind. It was easier to offer my belief, as Valtonen does, to the patients. Their stories weren't focused so much on medicine or mechanism, but on life, and the ways it was taken from them when they started to feel sick.

Now, faced with the 'science' of this disease, I find my faith wavering. In 48 short hours, I've been told this illness is an innate immune system problem, an inflammation problem, an autoimmune disorder, a blood–brain barrier issue, an oxidative stress problem, and now down to mitochondrial damage and a genetic disorder? I have yet to see any data and I want details. Has Vaali taken blood samples from patients? Could they see or measure mitochondrial damage in people with SBS? What, I ask, is the connection between immune system function and mitochondria?

Vaali and Häggqvist start laughing, and I worry I've asked a stupid question. In fact, I've asked a fundamental one that they have no idea how to answer. Vaali shrugs: "That question is impossible to answer."

In the course of our conversation, Vaali adds to a growing list of putative mechanisms and symptoms, telling me that women are more susceptible because of their hormones, because toxins go into fat stores and because of a lack of liver enzymes, and that mould patients have altered sleep rhythms.

Instead of going into scientific detail on these topics, Vaali and Lindström mostly want to talk about how patients could be helped. Using Häggqvist as a case study, they tell me that through homeopathy and natural supplements, these people can be "rescued."

What are these miracle supplements? Vaali won't tell me straight away, and neither will Lindström. I ask no less than four times over two hours, tolerating digressions and caveats that for each person it is a little different, or that I probably don't have the same supplements abroad. At last, Vaali shows me Häggqvist's regimen, made up of very basic vitamins and nutrients. Most are supplements that I also currently take. B vitamins, iron, omega-3, curcumin (the active ingredient in turmeric) and a few blends of fatty lipids. Vaali also advises against eating gluten, and Lindström says only organic food is allowed. Cheese and other mouldy foods are bad, because those can be triggers. Wine is OK, but only organic wines with no additives.

I begin to have a gnawing feeling, one I'd suppressed when I heard that Valtonen makes patients better without doing much of anything, or that 'nutritional therapy' had turned Paasikallio's life around. I haven't yet doubted the illness or its symptoms, but its alleged treatment is stirring up suspicions. If SBS is purely a physiological disease, caused by something as serious as an immune disorder or mitochondrial damage, how can it be "rescued" with B vitamins?

Lindström shows me her homeopathic pills that she takes for mould illness, which I look over with raised eyebrows. I try to keep an open mind, but I know that homeopathic medicines have such low concentrations of active ingredients they can't possibly have any biological effect.

I do think that healthy eating and lifestyle can help overall mental and physical health – and the treatment of chronic disease. What I question is their application as a fix-it for a specific pathology, especially one that's unknown. We have a link between saturated fat and heart disease, but what is the link between gluten-free organic food and decreased sensitivity to chemicals? Biodynamic wine and electrical sensitivity? Homeopathic arsenic tablets and mycotoxins?

Häggqvist senses my scepticism. He tells me he doesn't believe in this stuff either. He's a general practitioner and a child psychiatrist, and let the supplements sit in his closet for nine months before trying them. He rejected the homeopathic pills and affectionately calls Lindström a "witch doctor." But he does believe that the supplements helped make him feel better.

Häggqvist bought a new house in 2003, and his symptoms began in 2007. By the autumn, he was living in a campervan on the street. He says that when all his symptoms – itching, headache, nausea, throat and nose irritation, and eczema – hit at once, it was like "burning in a hell." He suffered for five years before finding relief with Vaali and Lindström's treatment. He says it took one or two months to improve; at the same time, the ventilation in his house was being cleaned. He attributes his recovery to the combination of both.

Häggqvist has been in psychotherapy for years. He tells me he knows himself very well and is sure this isn't a psychological disease. "I think different kinds of psychotherapy can help people to stand the hell that they are living," he says. "But not to cure them from the biological disease that they have."

Later, I get Kirsti Paasikallio's list of nutritional therapies. She too is being 'cured' with supplements, and I want to compare her regimen. It's a lot of the same: fatty acids, high doses of B and other vitamins, curcumin, etc. It's broken down into parts of the day: before breakfast, breakfast, after breakfast, before lunch, lunch, after lunch, before dinner... and at least three or four pills each time. Whenever you finish taking your last supplement, you begin gearing up to take the next one.

Part of me feels glad she has a solution that works for her, and the same with Häggqvist. But it also feels like they're being chained to something else. Whereas the sickness used to control their lives, now it's the

diagnosis and the cure.

I take a break for lunch, appreciating the brisk air on my face. As I walk, I think about how much my attitude has changed since I arrived. I'm upset because I feel close to the mould sufferers for reasons I haven't disclosed to them. That feeling of knowing you're sick, but being told by doctors that you're not – I know that feeling.

Throughout my life, I've regularly gone to the doctor for unexplained symptoms. I've gotten scans and painful tests for which, over and over, the results would come back normal. I've had three doctors, in different specialties, try to prescribe me antidepressants for physical symptoms. Recently, I struggled with idiopathic dysphagia, meaning I was having trouble swallowing – even choking at times – but there was no reasonable explanation. I had been diagnosed a few years earlier with laryngopharyngeal reflux, a version of acid reflux some gastroenterologists aren't sure exists because there often isn't any measurable acid in the throat.

I have fallen into natural remedy black holes too, hoping to find the magical supplement that cures me. I go beyond what Vaali and Lindström offer, though never to homeopathy. I add super greens powders to my smoothies, powdered liquorice to help with digestion, digestive enzymes and L-glutamine to help my stomach lining.

As a science writer and the child of scientists, I justify a lot of my actions by consulting research. Deep down though, I know that my relationship with my body and the way it feels comes both from how it 'really' feels and how I've been taught to react to it. In my childhood home, food was labelled for when it would go bad and each person had a hand towel just for them, to control the spread of germs. Going to the doctor, requesting unusual medical tests, searching for something in the body gone wrong – this was the environment I grew up in, a kind of 'sick

building' in itself.

A specialist who observed my swallowing, and saw nothing wrong, warned me that if I kept treating my body as if my swallowing was broken, I could, in fact, break it. By not using the muscles in my throat, I could create a weakness and then have a real problem. "No need to create a real issue out of nothing," she said.

Her advice frightened me into eating solid foods again. But I remember thinking: isn't my issue already 'real'?"

I have always looked at my body as a potential battleground; Tuuminen and the others in Helsinki have not. Something clearly happened to them. Could the very real exposure to a toxic mould have pushed them into seeing their body through new eyes? Shown them that this is all it takes for your health to be taken away? That it could be something invisible, growing in the walls, in the air you breathe? It's such a violation, perhaps other walls start to break down. The wall between emotions and body, thoughts and physical feeling. Perhaps that wall was never there, but they thought it was – and that exposure, that violation, broke the illusion.

Risto Vataja, head of the neuropsychiatric clinic at Helsinki University Central Hospital, believes SBS in Finland to be a contagion of ideas rather than a disease. He tells me SBS is so well-known here that it's common to believe that houses are dangerous, schools and hospitals are dangerous, that any place you go, your health is at risk. He says the media plays a big role in disseminating fear, and he scrutinises my intentions with this story. Later, he will email me to say, "Good luck with your article, and don't make people sick, you journalists have the power..."

Still, he hesitates to call SBS a psychiatric or psychosomatic disorder,

instead preferring the word "functional," which is also used to describe conditions like fibromyalgia, chronic fatigue syndrome and irritable bowel syndrome. "Functional means that they are not psychiatric," he emphasises. "Psychology is probably involved in the mechanism, and we know that in patients with functional disorders. So, they are real symptoms, but we just cannot identify any good physiological explanation."

Vataja is an advocate for psychological help, like cognitive behavioural therapy. That advocacy probably explains the trouble he's had reaching patient groups, who tend to reject any psychological component. "We agree that we are not able to help them enough," he says. "We agree that the healthcare system has not thought enough about these problems, and that we don't have enough research. We have lots of common things that we agree on and we should try to build on those."

Vataja thinks that telling patients to avoid all buildings that make them feel sick only furthers the illness. "Some colleagues of mine can increase the burden of these patients," he says.

I had seen Ville Valtonen's unwavering belief as a source of relief for his patients, but was he at the same time perpetuating the disease? Did they have mould illness before they went to see him, or only after? Valtonen remains convinced that avoidance is the best available treatment – although he accepts that controlled studies to prove this theory would be beneficial.

I turn to Juha Pekkanen, head of the Department of Public Health at the University of Helsinki and a researcher at the National Institute for Health and Welfare. He tells me that, according to studies they've done comparing European countries, Nordic countries should be less prone to dampness and mould. There's less humidity and very dry air during their cold winters. There might be a slight chance of more exposure because

people spend more time inside, or that dry winter air could add irritation to respiratory systems, but there's no solid reason why there is more mould illness – except for the fact that people know about it. "We know worry causes symptoms and causes disease," he says, "so we want to build trust and reduce worry."

He is one of the researchers assigned to set up a governmental programme to provide aid to people with SBS. How? "It's not obvious yet, but of course we need to help these people. There are people who are living in tents and bad situations. Anybody within a bad situation we should somehow extend a hand and try to help them."

It was encouraging to hear someone affiliated with the government saying this, because some patients had suggested there was little care for their outcomes. Pekkanen says that's not true, but he thinks a focus on mechanism and diagnosis has clouded the issue. He hopes that whatever they design to help people will be more practical.

"I think we should try to get them back to the society, and not build separate communities somewhere in the woods with no electricity, no chemicals, no nothing. There's no end to that," he says. "That's not going to help these people. If you just focus on making it cleaner and cleaner and cleaner, it stops never."

He doesn't think they're "playing sick" though. Why would you pretend to have an illness that is not approved for compensation? He thinks that once a person encounters an issue with indoor air, they get real irritation and respiratory symptoms. But once they have these symptoms, some people begin to expect something more, something more sinister.

"For many people, it is likely due to some kind of nocebo effect. You've heard about the nocebo effect?" he asks me. "Basically, expectation. I don't like this categorisation between physical and psychological, I think

it's been shown we're one whole, our psyche and self are intertwined, inseparable."

The placebo effect pervades much of the history of medicine, and explains why in the past some remedies, surgeries and treatments appeared to work despite our now knowing they are inert. More recently, attention has turned to nocebo, the reverse effect.

The two aspects of nocebo effects are negative expectations and conditioning. Negative expectations are when you assume an outcome will be bad and then perceive it to be so. This has been shown in studies where patients experience side-effects to sham treatments only because they were warned about those side-effects in advance. Conditioning can occur when you associate a certain activity, place, drug (or anything) with a feeling or symptom. Studies of positive conditioning have shown that patients can [find relief from allergic rhinitis symptoms](#) through conditioning with a flavoured drink, can have conditioned immunosuppression and conditioned [growth hormone increase](#). It's [been speculated](#) that some of the negative side-effects of chemotherapy can be attributed to negative conditioning.

But calling something placebo or nocebo doesn't mean it's not real or physical. "Neuroscientific investigations from the last 15 years have shown that the placebo effect is in fact a real biological phenomenon due to the psychosocial context of the patient and the therapy," authors of a [2013 review](#) wrote. Nocebo effects are associated with changes in several brain areas, neurotransmitters and hormones.

Keith Petrie, a professor of health psychology at the University of Auckland, has studied how nocebo effects can stem from the idea that the environment, medicine, architecture and technological advances in food are causes of poor health. In 2001, the New Zealand Ministry of Agriculture and Forestry had announced they would be spraying

insecticide to eradicate an invasive moth species, the painted apple moth. Petrie surveyed 292 residents about their current health symptoms and any health worries they had, then followed up after spraying. Higher levels of worry were associated with a higher number of symptoms attributed to the spray programme.

"If people believe that they're sensitive about a particular stimulus and then they're exposed to it, then they report symptoms," he says.

When I ask him how Finland's mould patients could possibly feel better from natural supplements, or from seeing a doctor who doesn't give them medicine, Petrie says: "The good thing about treatment, any kind of treatment, is it shifts your perceptions. You go to somebody with a problem and say you've got the flu or a cold – you're focused on how terrible you feel and your headache and your cough. You go and see someone and they give you a treatment and the way you're viewing your illness shifts immediately. Instead of looking at how sick you are, you look for signs of recovery."

But it can go the other way too. Research has shown that placebo and nocebo effects can also be triggered by interactions with a doctor, even if your doctor tries to empathise with you.

A [2015 review](#) concluded that "reassuring patients that there is nothing physically wrong with them, when they are in a great deal of pain, can leave them feeling misunderstood and delegitimised." Another study looked at doctor–patient interactions in patients who complained of symptoms but had no diagnosis. They were assigned to two groups, one where the doctor said they didn't know what was wrong and another where the patient was given a firm diagnosis and reassured they would be better in a few days. After two weeks, 64 per cent of the patients in the group with a diagnosis reported getting better while only 39 per cent of those in the group without did.

If there's one thing common to all the mould patients, it's being dismissed by doctors and being told their symptoms were unexplained. After reading these findings, I wonder if their true toxic exposure was to this uncertainty. It seems it can be harmful to your health to hear that what's taking place in your body is a mystery.

There are researchers who haven't given up on this mystery and are hunting for a biological explanation. Thomas Dantoft, at the Center for Clinical Research and Prevention in Denmark, is looking for biomarkers: differences somewhere in the body between people with MCS or other functional disorders and those without. He is also project coordinator for the [Danish study of Functional Disorders \(DanFunD\)](#), the first large, coordinated epidemiological study focusing exclusively on functional disorders.

The cohort includes 9,656 men and women who were surveyed for fibromyalgia, whiplash-associated disorder, MCS, irritable bowel syndrome, [chronic fatigue syndrome](#) and bodily distress syndrome. The study includes interviews and personality tests and collects plasma, DNA, urine, gut bacteria and more. Participants will be followed until 2020 and hopefully will provide some much-needed epidemiological information.

Because it isn't just the sufferers who have numerous conflicting hypotheses about the cause of their illness. I spent weeks reading different papers – spanning decades of research – on biological causes of MCS. Several implicated the immune system, validating one of the theories I was told in Helsinki, but other work contradicted them. One of Valtonen's stages of the disease is an increased sense of smell, but Dantoft says that his and other studies have shown that isn't true.

What about psychological factors? Dantoft says he isn't sure either way. He says functional disorder patients live in dire conditions and it would

be incredible if they didn't get depressed. "All studies working with MCS and other sorts of disorders, whatever you want to call them, show that there is higher risk of anxiety and depression," he says. "But we don't really know what comes first, and that also doesn't mean that they are making it up. Maybe people who are at higher risk of getting depressed also have a higher risk of getting MCS? But that doesn't mean you can cure MCS by treating the depression, necessarily."

Dantoft thinks mental help could be offered not as a fix, but as a stand-in until more is known. "The big issue is that the patients and the clinicians aren't being honest with each other," he says. "Because the fact is we have absolutely no efficient treatment to offer these people."

Is the building sick, or are the people? I'm frustrated that I'm no closer to answering this question. I also feel guilt. Guilt that my reporting led me to question the experiences of the people I met in Helsinki, and for my nagging intuition that there is more going on than just mould exposure. Faced with the option of building or people, real or not real, I still can't settle on one.

When I ask Linus Andersson, a cognitive scientist at Umeå University in Sweden, he tells me why: it's been the wrong question all along. He is collaborating with chemist Anna-Sara Claeson, and together they are doing the most comprehensive work that I could find on mould and toxin exposure in people who report that they have MCS. "I have felt pushed toward choosing whether or not I would follow psychological or medical/biological lines of work," he says. "But I came to the conclusion that it's not even a real question. Or, there is an answer: it is always both."

For the past decade, Claeson and Andersson have been exposing people to different compounds and measuring any effects on blood flow using brain scans, inflammatory markers in the mucus from the upper airways

and, recently, gene expression.

Over Skype, they show me their exposure chamber, which looks a bit like a phone booth – only with no phone. In this tiny room is where most of their experiments take place. In an experiment published in 2015, they exposed participants with MCS (along with controls) to a compound called n-butanol, which they chose because people find it hard to decide whether it smells good or bad. For the first ten minutes there was nothing, then the n-butanol increased to a set level and plateaued. MCS participants, compared with controls, reported greater perceived odour intensities, more unpleasantness from the exposure, and increasing symptoms over time.

The MCS group also reported more symptoms in the ten minutes before they were exposed to anything. Andersson thinks this could be associated with nocebo-like expectations, but he also says that to him, expectations producing symptoms doesn't mean that an illness is imagined.

He tells me that people often have [allergic reactions without a 'real' exposure](#). In a [2007 study](#) on food allergies, it was found that children could have reactions to placebos: more than one in ten of the food challenges produced false positives. The symptoms were real: intense bodily responses like rashes, hives, diarrhoea and vomiting. Claeson and Andersson say this shows that the body is very good at predicting and defending itself from what it thinks will be damaging, which should make researchers cautious when interpreting nocebo and placebo results.

In a [2017 paper](#), Claeson and Andersson describe exposing people with chemical intolerance (along with controls) to the chemical acrolein. Chemicals are detected in the upper airways by the olfactory and trigeminal nerves. The olfactory nerves are involved in smell, while the trigeminal nerves can evoke irritation or pain. They found that people with MCS reported greater irritation to the eyes, nose and throat, even

when acrolein's smell was masked. Because their aggravated symptoms didn't require them to be smelling the chemical, Andersson and Claeson think perhaps people with MCS could have altered trigeminal reactivity, and will continue to look into that.

No study they've done yet has offered the mechanism of MCS on a silver platter. Andersson says their goal is to find some kind of exposure that separates an MCS sufferer from a control. It doesn't matter what it is; if they can find it, he thinks it would lead to a better understanding of how and why these patients respond differently.

What does he think about natural supplements or homeopathy 'curing' MCS? "My answer to this question is basically the same as for that pertaining to explanatory theories – the claims need to be backed up with data," he replies. "When, or if, homeopathic treatment regimens would actually fulfil scientific criteria, then I would not be against it per se. I have yet to see such studies, however. So, my question for everyone who makes theories and statements of how MCS can be treated is – where's the structured data?"

I asked Vaali and Lindström so many times to tell me about their supplements, and their lack of data pushed me away from their cause rather than towards it. But while Andersson and Claeson's mindset and careful research are refreshing, it's all still exploratory. Unlike Vaali and Lindström, their work doesn't offer an easy solution someone can take today, right now. It doesn't allow patients to move from the world of the sick to the world of the well.

What Andersson and Claeson can provide now is relief from all those dichotomies: building or person; sick or well; organic or made up. I can't tell you if SBS or MCS or mould [illness](#) is 'real,' but I know now that our definition of real is flawed. The split between psychological and physical is flawed; the idea that psychological isn't real is flawed; the notion that

psychological is not inherently physiological is flawed. These divisions are what led to this health crisis in Finland, not abnormal levels of mould.

I went to Helsinki and was asked to believe. And I do. I believe that Tuuminen's symptoms are real. I believe that Seitz was mistreated by [doctors](#) and by her employers, that Alex and Heli Vinska felt alone, and that Paasikallio was neglected by her housing company. I believe that they should be helped.

But I have one belief that I worry disqualifies all the others. I also believe that, after an initial mould exposure has been resolved, understanding the continuation of any [symptoms](#) must include a consideration of the mind.

It pains me to know that the people I interviewed in Helsinki, who so graciously shared their stories, time and vulnerability with me, will probably be displeased with my version of their story. This is not the exposé they were hoping for, not a condemnation of the Finnish government nor the uncovering of a plot to keep mould patients quiet to avoid the costs of rebuilding and social security. People at the hospitals and National Institute for Health and Welfare sounded seriously concerned and are implementing programmes like the one Pekkanen mentioned to try and bridge the gap between officials and patient groups who feel wronged.

Claeson says that while researchers can't yet give people a cure, they can do their best to keep looking, keep trying to help. That in itself is a kind of belief. It's not exactly like Valtonen's, but it's belief all the same.

"I think it's important to take the [people](#) that are suffering, to take them seriously," she says. "I think that if we do research, that means that it's a 'real' problem. And I think that is something that we can offer."

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