

*The societies in which we live influence the forms of psychosomatic illnesses people may manifest, neurologist **Suzanne O'Sullivan** explains to **Denise Winn**.*

## The social elephant in the room

# CONVERSATIONS

**WINN:** Suzanne, *The Sleeping Beauties* is your third masterly and exquisitely written book, drawing on your experience as a neurologist. This one is full of examples of what seem to be mysterious, highly contagious, manifestations of non-organic illnesses – so-called mass psychogenic disorders – which, when you actually unpack them, aren't so incomprehensible at all. Your thesis is that society and culture matter a lot in shaping psychosomatic illness and you mean by that something much wider than family and peer influences.

**O'SULLIVAN:** Psychosomatic illness is also shaped, for instance, by our educational system, the health service we use, and who we go to for help – is it a doctor, spiritual leader or traditional healer? Society shapes how we interpret what is happening to our bodies. So, our health service, what we see on the internet, or read in newspapers defines illness for us (and, in our case, that is based on classification systems such as the *Diagnostic and Statistical Manual of Mental Disorders*, the *DSM*). They determine how we interpret and respond to changes in our own bodies or moods. One person may decide their sadness is depression, while somebody from a different culture might say that this exact same amount of sadness is appropriate for the life they are living at that moment.

**WINN:** You comment on the switch in terminology from psychosomatic to functional disorders, saying, "It leaves open the possibility that emotional trauma is not the only means by which psychological processes can affect the functioning of the brain to lead to disability", but you also don't think it is all good.

**O'SULLIVAN:** For a long time, as a junior doctor, I had only one formulation for working with people who had functional or psychosomatic disabilities – my only question was, "What's the hidden stress in your life?" It was a very Freudian sort of approach. But now neurology has expanded its view to there being so many more mechanisms that create functional disability. Not everything is due to a specific stressor. It could be that someone has had an injury which caused them to pay too much attention to their body or to worry about recovery. The functional disability develops not from any psychosocial problem but from a maladaptive response to injury. In those cases, I think it is really helpful to use terms like 'functional' because that stops doctors getting into the 'you are hiding something' conversation.

But I also have extreme reservations about terms like functional because there is absolutely no doubt that lots of psychosomatic conditions do arise because of psychological distress or trauma, and 'functional' is a real cleansing of the mind out of this conversation, which is just a whole other way of stigmatising this disorder.

**WINN:** Because now it implies that it is all in the biology?

**O'SULLIVAN:** Exactly. Another negative side to the term functional neurological disorder is that it seems to have become a distinct disease in itself, like multiple sclerosis or motor neurone disease. Because it has been given a scientific-sounding name and because it is presented as a purely biological problem, people begin to identify with it as a chronic disease in its own right. Again, it is cleansed of whatever caused it.

**WINN:** Indeed, this is happening for people suffering from severe and long-lasting withdrawal effects of antidepressants – they have seemingly inexplicable symptoms and get given this label as if they have a condition totally apart from what actually caused it. What they actually need is acknowledgement that they are suffering from antidepressant withdrawal effects, as so many don't even know that, and help with dealing with those effects.

In your book, you refer to the social elephant in the room, as you term it, and how you felt a need to connect the societal and the biological aspects of these illnesses because, "if you can't say what is happening in the brain, no one will care". Do you still feel that way now?

**O'SULLIVAN:** As a doctor and as a person, I don't feel the need to bring them together, but I feel that need in others. Talking about how society can create illness may make it seem to some as if I am trying to blame a person for their illness. Or that I am saying that the symptoms are not real. So I thought it would be helpful if I could say, "When society does this to you, it shapes your brain in this way to create this behaviour". Until you start talking about the brain, people who are less psychologically minded just think pretence. For instance, the doctor I met in Sweden, who was looking after the resignation-syndrome children, didn't want me to say anything about psychology or the social events that had led to that manifestation of illness. She only wanted to know about the biology. The world respects biology.

**WINN:** You have brought us on to resignation syndrome, after which your book is named.



Photo by Jonathan Green

This is the tragic affliction that has affected hundreds of children in Sweden at different times over the last 20 years. It starts with a child becoming anxious and depressed, then withdrawing from their usual activities and then eventually taking to their bed, no longer responsive in any way, not eating, not opening their eyes. It can happen to children as young as three and can persist for many years, well into adolescence. They seem unconscious but their brainwaves show all the normal cycles. What is clearly so significant is that this doesn't happen just to any Swedish child but only to those in specific communities – mainly Yazidis from Iraq, Syria or Turkey and Uyghurs – who experienced extreme persecution in their former home countries, were granted temporary permission to stay in Sweden and had been turned down, often after years, for permanent asylum there.

After reading your highly moving account of the plight of four of these girls, calling this resignation syndrome seems rather a misnomer because you talk about the high heart rate in one of the girls, Nola, which is evidence of extreme stress. It seems more like complete terror syndrome.

**O'SULLIVAN:** It was much more disturbing when I saw it than when I read about it – although reading about it was disturbing enough – and for precisely the reason you mention. I expected the children to be in an apathetic sleep, with no sign whatsoever of distress. But I saw signs of distress everywhere. Nola's jaw was clenched and her eyes were really tightly closed. In patients with functional paralysis, some physical signs are mistaken for evidence of intent. Tightly closed eyes might be misinterpreted in that way. In clinics, doctors sometimes keep an eye on patients in their quiet moments, looking for evidence of pretence; if doctors see their paralysed patient moving in a relaxed moment, they can interpret that to mean the person is not 'really' paralysed. That isn't the case. Functional disabilities are variable – so the signs can be misleading. The paralysis may come and go because it needs attention and anxiety to sustain it. This is a completely unconscious process.

**WINN:** Yet it can be mistaken for malingering?

**O'SULLIVAN:** Yes. Psychosomatic disorders have a psychological mechanism, so the normal neurological pathways are intact and that means disability does not necessarily obey the rules of disease. So I agree. I think in resignation syndrome the signs are more closely linked to something like a refusal syndrome than apathy. Words fail these disorders.

**WINN:** In the context of the sickness experience of people in Krasnogorsk in Kazakhstan, which involved a variety of symptoms including sleeping, you make the point that it is dangerous or

misleading to blame such symptoms on stress. It affected people who were resisting leaving the town they had once thought of as paradise, even though now it was in complete decay. But surely it is stressful to have to leave the home you love, one that means everything to you?

**O'SULLIVAN:** I don't think stress was absent but people have a simplistic understanding of how stress affects the body. They can understand the autonomic nervous system and the immediacy of that – the increased heart rate, etc. What they don't understand are the more complex interactions between our psychological and physical wellbeing. People in Krasnogorsk were indeed going through terrible hardship, living in unheated apartments with no running water. But when I listened to the whole story, I learned that there was so much more to the illness than just stress. The people had an incredible link to this town. I felt they expected the town to bloom again. They knew that they had to leave and they could hardly bear to do so. The sleeping sickness gave them the push that they needed to move forward with their lives. The complexity of that is lost in the way we usually think about a stress-induced illness.

**WINN:** Our human givens understandings are that, for good mental health, we have essential emotional needs which must be met, and innate mental resources to help us meet them. Therefore, all mental ill health, however it is manifested, comes from the fact that needs are not being met, or not in a healthy way. That is what causes the stress and that would apply very much here, wouldn't it?

**O'SULLIVAN:** I agree with that 100 per cent.

**WINN:** When we work with people, we are trying to help them widen their perspectives as well as teach them new skills and understandings, and that means working with their beliefs and telling them different, more empowering stories. You say, "For many people, the development of symptoms is not about a specific traumatic event but rather is related to embodied expectations, beliefs and stories." So I am particularly interested in hearing your own interpretation of that.

**O'SULLIVAN:** A literal example would be Tara, from the book, who, like so many people I see, suffered a small medical illness from which she could potentially have recovered quite easily – but instead she got worse because of a story she built around her symptoms. Tara believed that she had a slipped disc pressing on her spine and this belief was so vivid for her that she

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progressively developed the symptoms that represented her idea of a spinal cord problem – she ended up with three paralysed limbs. It flew completely in the face of what the doctors were telling her. Knowing her scans were clear didn't help her. She needed her story to be unpicked and properly understood in order for her to feel reassured enough to trust her body to recover.

I think that is largely the case for all the people's stories that I look at in the book. Imagine being an American diplomat in the embassy in Cuba. History tells you there is a valid reason to be worried about enemy attacks. Somebody gets sick and is certain they have been attacked. You are told to hide behind walls to protect yourself. You are told to search your own body for signs you have also been attacked. That fear could make anybody sick, because when you search you find. Doctors take symptoms literally and direct scans at them – when sometimes the solution lies in unpicking a person's story and understanding what symptoms mean to them.

**WINN:** We find something similar with depression. People may think it is an illness that they are unlucky to get when, in fact, their experience reflects that something isn't working in their lives. And when you know what that is, you can work with them to start changing it.

**O'SULLIVAN:** Many people who come to neurologists are not willing to accept that at all. They come to me looking for a neurological disease and are resistant to other explanations.

**WINN:** That came across very much in your first book, that people didn't want to let go of their suspected diagnoses and had often built their lives around them, with partners as carers.

You talk about predictive coding, a concept which will be familiar to our readers through the work of neuroscientist Lisa Feldman Barrett on prediction. Predictive coding, as you term it, explains how such expectations get translated into physical symptoms, without brain disease.

**O'SULLIVAN:** Again, we are back to the kinds of stories we tell ourselves. I wanted to talk about predictive coding in the book because I wanted to take away any sense that what is happening to us is imaginary. We have a cultural expectation about everything that happens to us, and where it will lead, due to brain programming. Every event of importance that happens to us, how we are educated, the stories our society tells us, code our expectations of health and ill health. For example, experience tells a person how to interpret a headache – so, if I had a family member who had a brain tumour, a headache may raise that concern for me. Then predictive coding may influence how my

symptoms play out. I will look for the symptoms they had and possibly find some of them. If I have a regular experience of migraine, then my coded expectations will be different.

Expectations matter because they decide what we will look out for next and can lead us to search our bodies in a particular way to get to another symptom. And that may overwhelm the nervous system to fulfil the expectation. That is very often what happens in patients with dissociative seizures whose cascade of seizures actually started with a faint. Imagine someone feels dizzy on the London underground, faints, and wakes up on the platform surrounded by strangers. That is a terrifying experience. They are bound to worry the next time they feel dizzy.

**WINN:** Or that it will happen the next time they get on the London underground.

**O'SULLIVAN:** Exactly. And then it just gets worse and worse. Our predictive coding and our coding templates tell us what to expect of our bodies in certain situations and how one symptom will lead to another. It's a top-down processing effect.

**WINN:** That fits with what Feldman Barrett says. For instance, if there is a certain person you had a bad experience with and you see someone who looks like them, your brain will send down messages to the body to prepare in particular ways for another bad experience. It all happens outside conscious awareness. For me, what you say about predictive coding explains, more than anything, how what appear to be mysterious, strangely contagious illnesses physically come to happen.

I would like to move on to the wonderfully named *grisi siknis* experienced only by Miskitos, an indigenous tribe living on the Mosquito coast – and only by those who still live there. You found out that the name is their phonetic version of 'crazy sickness'. Sufferers have hallucinations, maybe of attractive men or women, that lead them to start screaming and run off blindly, putting themselves in danger. In one case you describe, the hallucination was of a baby and that was experienced by a girl who had helped with an illegal abortion. Having *grisi siknis* enabled her to act out how she felt about that. It is seen as an acceptable illness, not dismissed as a psychological one. Do you think it is about licence to express difficult or taboo feelings?

**O'SULLIVAN:** I do. Of all the people I met, these were the people about whom I thought, "Wow, we can learn a lot from them!" They have an elegant way of working through social problems. First of all, when individuals develop this disorder, it speaks to the community of a particular

*"Of all the people I met, these were the ones about whom I thought, 'Wow, we can learn a lot from them!'"*

type of conflict, without the girls having to be too explicit. A lot of it is about sexual tension. Older men sexualise younger girls. Meanwhile, the young girls are expected to hold a certain moral standard. They are able to express the feelings brought on by this sort of conflict through *grisi siknis* without feeling overly uncomfortable or embarrassed. In response to the seizures the whole town rallies around the girls, which is wonderful. *Grisi siknis* attracts community support, whereas the exact opposite would happen in the UK. *Grisi siknis* is a wonderful way of expressing a certain type of distress and attracting a non-judgemental form of support.

**WINN:** You make the telling point that, when we get a diagnosis in the West, it tends to stick. Whereas *grisi siknis* is dramatic, sudden, expressive and responds to traditional healing. It has a beginning, a middle and an end.

**O'SULLIVAN:** That is the thing I love most about it. It is not what happens here. Dissociative seizures are medicalised, which can create chronic illness. People wait a year for cognitive-behavioural therapy, which may or may not work. Whereas the Miskito people say, "This person is distressed. Now we are all going to come together and support them, and here is the cure." They get better. A lot of people in similar circumstances in the UK do not get better.

**WINN:** Not only is *grisi siknis* highly contagious but it is shaped, you say, by suggestion and expectation – of what?

**O'SULLIVAN:** First, this condition has been around long enough for everyone to have a very definite idea about what the features are. I find a lot of functional disorders are highly fluid; the symptoms keep changing and every person adds something new. Whereas *grisi siknis* had a definite narrative within the community and, although it is changeable, everyone knows what its main features are. Once one person gets it, they know that the girl who lives in the house with them or the girl who sits beside them at school will get it next. I can't remember if I put this in the book but I was told that sometimes a girl calls out the name of another girl, and that girl will then be the next one to catch it.

**WINN:** A strong nocebo effect.

**O'SULLIVAN:** So it spreads like a highly choreographed dance. And knowing what to expect is part of what makes it curable, because they also know it has an ending.

**WINN:** It reminded me a bit of the Korean condition *hwa-byung*, which you describe, whereby certain symptoms in women communicate the highly specific stress of marital conflict and their husband's infidelity.

**O'SULLIVAN:** The symptoms of *hwa-byung* are symptoms that we neurologists in the UK see all the time. They are not terribly specific symptoms and we deal badly with them because they don't indicate an immediately treatable problem

– for instance, burning sensations all over the body. In the UK, these sorts of complaints often lead to a raft of medical tests but no ultimate diagnosis or treatment.

**WINN:** As a neurologist, would you be able to ask the kind of questions which might reveal whether there are difficulties in the patient's relationship or life generally?

**O'SULLIVAN:** No. In the UK, it doesn't work that way. I feel almost that I am not allowed to ask those questions.

**WINN:** But from the rich content of your books, with so much detail about your patients' lives, it is clear that you do!

**O'SULLIVAN:** A junior doctor once remarked that people tell me things that they don't tell anybody else. But I don't ask my patients direct, personally probing questions because it is not what patients expect from me, as a neurologist. I often allude to the sort of social circumstances or psychological stressors that can lead to psychosomatic disorders (like abuse) but I do not probe too directly – because patients come to me to have their brains examined and too many personal questions make them feel I am neglecting my role as a neurologist looking for disease. But what is most useful is that I do ultimately have long-term relationships with my patients, so things come out in time.

**WINN:** As you have said, what we pay attention to may result in spread of symptoms, as in the case of paralysed Tara. You say she still needed physiotherapy to retrain her brain to enable her to walk again. When we are working with someone with, say, pain that has no organic explanation, we would enlist the person's imagination – get them to imagine walking comfortably and so on. Would that be enough for your patients or would there always be a need for physiotherapy as well?

**O'SULLIVAN:** I think our patients also need actual physical rehabilitation. I used to play tennis a lot and then I switched to squash, which makes you use your arm completely differently. And when I went back to playing tennis, it was as if I had unlearned something from my muscle memory. I didn't know how to hold my arm anymore. Like this, my patients may be so deconditioned to normal movement that they need physical rehabilitation to teach them how to do ordinary things again. That does depend on how long a person has been disabled – and it is years for many of my patients. Their problem may have started with ideas, stories and imagination but in the end they have trained their bodies in such a way that they need the physical input as well as the psychological to overcome that training.

**WINN:** I suppose, in those cases, our type of help would be most useful in encouraging them to focus on the end they are trying to achieve, motivating them to continue by experiencing, in their imaginations, being in that place they are trying



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to get back to, making movements, and feeling comfortable and free, and so on. We have to be willing to take on board, at every level, that this is a genuine possibility. And that brings me on to asking you about the powerful role of cognitive dissonance in creating or perpetuating mass psychogenic disorders.

**O’SULLIVAN:** In the groups of people I met, it was interesting to see how many leaps of logic they often had to make so as to continue to hold onto their beliefs. In Krasnogorsk, people affected by the sleeping sickness had their nails and hair tested for poison, the water, the plants in the town, everything was analysed. People had as many as 10 normal brain scans and still couldn’t believe their brains were normal! No matter how many doctors said there was no disease, people and other scientists believed there was. I think that people make big leaps of logic and cling to false illness beliefs, because the alternative – being caught up in a mass hysteria outbreak or having a psychosomatic disorder – is so unpalatable. Unfortunately, the belief in a disease keeps people sick.

**WINN:** You referred earlier to the tendency, in many of these mass psychogenic illnesses, for individuals to add their own stamp, their own symptoms – recognised by philosopher Ian Hacking as a concept he called ‘looping’.

**O’SULLIVAN:** I was interested in his work because I see it in my patients all the time – looping physiologically within one’s own body but also the reinforcing factors within the community. A condition is defined with one set of symptoms and then two things happen: within an individual, we have the reinforcing effect of looking for other symptoms once we have noticed the first ones, leading to physiological activation. So a person’s ideas and the reaction of their body create more symptoms to feed the ideas, creating a looping accelerating effect within them. Then, in the community, you have something else going on. One person has got a condition with certain symptoms and, once that gets known, a second person wonders if they have the same condition. And so they take the symptoms of the first person and raise them: “Yes, I have a stomach upset but I have a headache as well; could that also be a feature of this condition?”

So the symptomatology grows both through the physiological effects and psychological effects, and then within the community. We see this a lot. There are so many medical problems that started off with one symptom and now have 50 symptoms, because new people bring new features to illness.

**WINN:** Do you think this could explain any of long covid symptoms?

**O’SULLIVAN:** It certainly could. One has to

wonder about a disorder that began with limited symptoms, including cough and shortness of breath, but which has now had more than 200 symptoms attached to it. I have looked at various online support groups – one listed 72 symptoms of long covid one day and, on the next, there were 100. Now there are twice that. Some of the symptoms aren’t even symptoms – they include feelings of loneliness, feelings of isolation. So I think that long covid is growing as a result of the looping effects and classification of effects, as it spreads from person to person, with each new person adding their own experience to it, making it something new. I do think it is problematic. Everyone must have at least one of the symptoms now associated with long covid, which means everyone could think they have the disorder. What I am hoping is that vaccinations and the world opening up will provide their own antidote, and it won’t turn into a chronic problem for too many people.

**WINN:** Cognitive dissonance aside, why do you think mass hysteria, which you identify as sociogenic rather than as something with psychological trauma at its root, isn’t more widely recognised for what it is?

**O’SULLIVAN:** My experience of meeting these communities with mass hysteria was that it was commonly presented as a frailty of the individual. A particularly good example was the girls in the high school in LeRoy in upstate New York. When a dozen or so schoolgirls all started having odd tics, a *New York Times* article pointed out that one girl’s mother had had multiple brain operations, which actually turned out to be ablations for trigeminal neuralgia – a condition that is not pleasant but not life threatening. Another was identified as having had a serious fight with her father. Everything in the girls’ lives was made to sound dramatic. But, if you pick through anybody’s life, you are going to find something there.

Onlookers were intent on finding personal psychological problems in these girls. Yet, obviously, if you have got a roomful of people with symptoms, you should be

looking at something outside of those people, in their shared environment, not inside their heads, for the cause.

**WINN:** And then, of course, it is telling that this psychological spotlight wasn’t shone on everyone. As you drily point out, nobody asked the male diplomats in Cuba about their personal circumstances – the cause of the symptoms had to be an attack by a hostile government.

**O’SULLIVAN:** So frustrating. And even the older women in Krasnogorsk weren’t subjected to the same scrutiny, either. You could absolutely have torn their lives apart for trauma, because they had been through so much, but that sim-

“ A less judgemental world would help a lot ”

ply didn't happen. Whereas the young women were all treated terribly in this regard. I found it quite shocking.

**WINN:** As if they didn't need to be taken seriously and their experience was suspect. I was extremely interested to learn from your book that the *DSM* identifies culture-bound syndromes only in communities without English as a first language. But we do have it, too, and, in fact, *DSM* is giving it to us. When Western medicine introduces new classifications to the world – which, in my field, we feel very unhappy about, because it pathologises sadness or shyness, etc. – it has the same damaging effect: the expectation of having an illness, rather than a life situation, is created.

**O'SULLIVAN:** Absolutely. I, too, have issues with calling sadness depression because a label is supposed to help with making one better, but I'm not sure that this sort of labelling does make people better. It is more likely to create chronicity, in my mind. The label doesn't give you an opportunity for recovery but rather gives you an 'explanation' for the thing you now have to live with. I think that it happens not just within *DSM*. Medical doctors outside of psychiatry do it as well.

**WINN:** Quite! You give the instance of widening the criteria for diagnosis of conditions such as osteoporosis and pre-diabetes, so more people fall into their net. And, troublingly, all this affects millions, not the relatively few, like Havana syndrome and resignation syndrome.

In therapy, we often see symptoms which reflect that the life course a person has embarked on isn't the right one for them. You give the sad example of Sienna who clings to her belief that she has epilepsy (even though she has been told this is not so), and treasures her (questioned) diagnosis of postural tachycardia syndrome, where the heart rate soars on sitting up or standing. You suspected that what seemed to be at the root of it all was going into academic study that wasn't right for her.

**O'SULLIVAN:** I think that society makes failure hard for some people to accept, so they must find something that is not too personal to explain it. Some young people do well in school but then go to university and find they are not seen as clever among that new highly selected group. Some families don't allow young people to re-evaluate themselves when faced with that reality. Failure challenges our view of ourselves. I don't think society or family necessarily make it easy for a young person to admit they are failing or to admit defeat. There is a prevailing atmosphere that suggests failing means you just haven't tried hard enough. So some people need illness to explain why things are not as they believed they were.

**WINN:** There are also, of course, the young people who go into a certain field to please their parents

– they might have the message drummed into them that they are expected to be a scientist like their mother or father, whereas they themselves are much more artistically inclined.

**O'SULLIVAN:** Illness seems to solve the problem of letting others down.

**WINN:** When you started out on this book, you hoped that more knowledge could better protect against these cultural functional neurological disorders, but now, it seems, you feel that such conditions serve a purpose. As you put it, "There are simply not enough words to express everything a person feels". We need these conditions to bring attention to what is wrong.

**O'SULLIVAN:** I totally did not expect to feel that way. I think I had a pretty naive and also a very medical way of looking at these situations, believing that, if people understood how their bodies might respond to social and psychological issues, they would feel relieved. But I have come to realise that, sometimes, people are going through an extremely sophisticated, complex, unconscious form of problem solving. If this is how they need to do it, then we should allow them to do that.

**WINN:** What about at a societal level? As your examples show, people can be seriously unwell. Do you think we just have to let them get on with it? Because many are really impaired, aren't they, and their lives profoundly impacted?

**O'SULLIVAN:** The difficulty here is that the bigger problems – such as about disinformation campaigns about vaccines, or political wars between the US and Cuba – are outside the reach of the likes of you and me, and I think that is why we all psychologise and biologise, because we can't, for instance, change the hostility between the American and Cuban governments. We need a better appreciation of how powerful those external forces are.

**WINN:** And it is others' reaction to whatever symptoms have manifested that determine whether there is recovery or descent into chronic illness.

**O'SULLIVAN:** You must know this in your practice. I often discuss with a patient the psychosomatic formulation for their symptoms and they are receptive. But if then they go home and their parents say, "Well, that doctor is obviously talking rubbish," it can completely undermine my diagnosis and change the course of the person's illness. Or people get support from their families but read a newspaper article that refers to people with psychosomatic disorders in a disparaging manner and that makes them want to distance themselves from the diagnosis. Then the person is pushed into a corner. Either they are this person who deserves this disparaging label or they have to prove that they are sick, and that only strengthens scaffolding against recovery. A person who has to prove they are sick will struggle to get better. A less judgemental world would help a lot. ■