

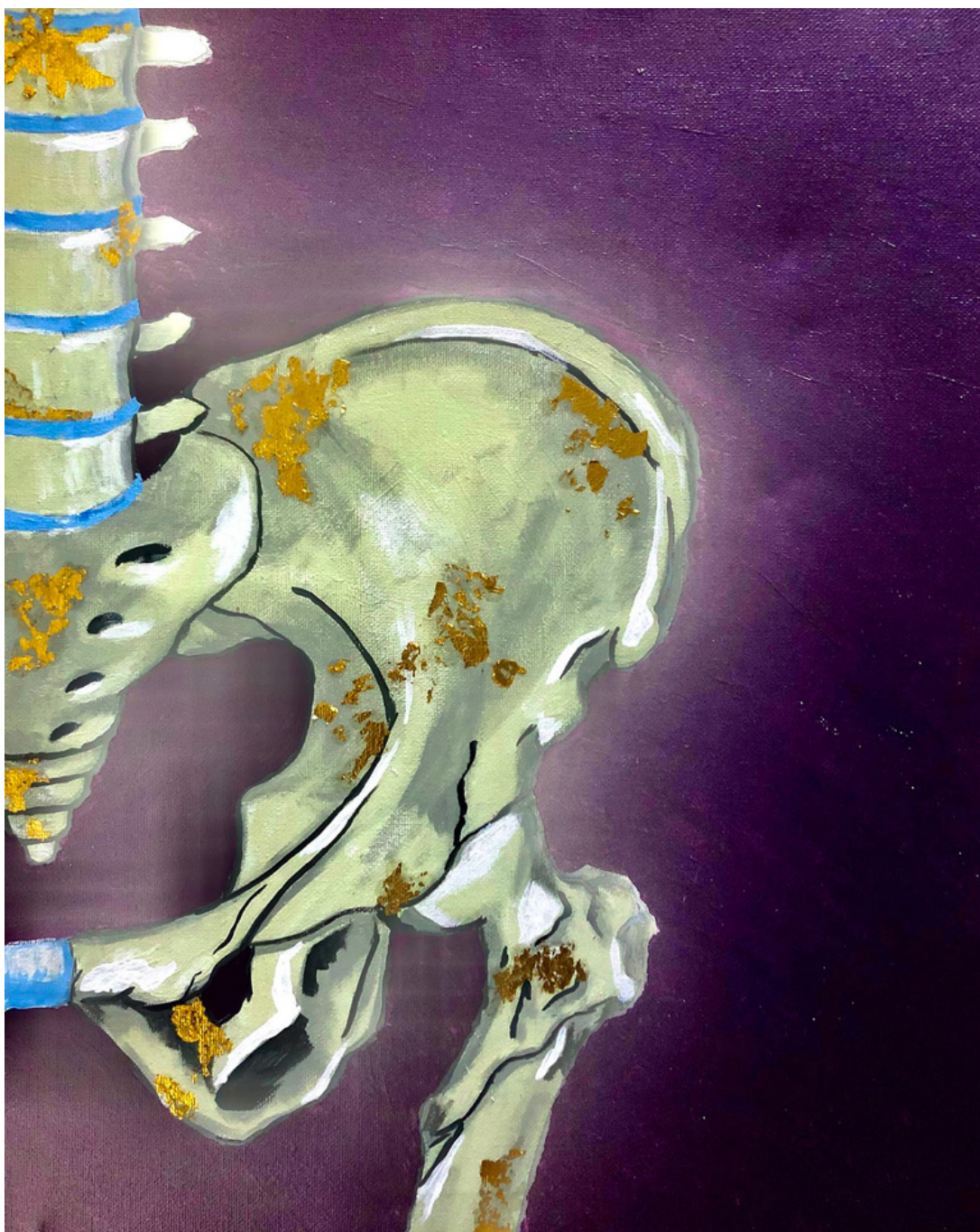
# HOW TO BE MYSTERIOUSLY ILL

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When the pain returns, you will be completely surprised and entirely expecting it. It will feel both foreign and familiar at the time. First the subtle discomfort, the beginnings of a cramp, then the sharp stabbing (in a location you will be able to pinpoint to the millimeter, but that no doctor can seem to find), off and on for a day or two, and then it will spread slowly, stabbing and burning as it moves from place to place. You will find yourself wondering: what has it come to disrupt and destroy this time? What lessons has it come to teach? But you did not invite it in, and you did not ask it to come visit now. You may want to scream, to cry, to resist it with all your might (or you may not). It will feel like a small creature has entered your pelvis, grabbing the organs there and squeezing as hard as it can, repeatedly, off and on, for days. You will be afraid. You will be calm. You will lie on the couch for hours, and then you will rally your energy and take care of your son and do your work and go about the normal routines of family life. People who see you out and about will comment on your weight loss. You will explain that it's a side effect of a health issue. After a long awkward pause, they will tell you: "Well, keep it up! You look GREAT!" You will not speak of the pain publicly again.

A friend will suggest you should call the doctor. But you will wonder, why? To be, yet again, poked and prodded, invaded and opened up, all so that they can once again tell you that they can't find anything, that there is nothing wrong, that whatever small thing they find couldn't possibly explain the type of pain you are describing. You might try to explain to this friend that you have been sick now, off and on, for over 20 years, with a wide range of symptoms that you can describe in detail, but that no doctor can explain. You might add that you have been tentatively diagnosed with nearly a dozen different conditions, and then been un-diagnosed with most of them, that you have spent months, or occasionally years, learning about and making peace with and making plans for, a particular diagnosis, only to learn - when a doctor finally agreed to more invasive diagnostic practices, or when new tests became available - that you did not actually have these conditions. You will try, but be unable, to count how many specialists you have seen during these years; how many blood tests, scans, and procedures you have had; how many different kinds of complementary therapies, new diets, herbs and supplements, forms of bodywork, and emotional and spiritual remedies have been recommended. (Even without counting, you will cringe at how much money you have spent on these beacons of hope, and how much income has been lost during these flare-ups).



## OS COXA

Kirstin Hope Peters

*Acrylic on canvas with gold leaf*

Point of Connection, To carry the weight of life, Then crumble with age.

If you get this far in telling the story, you might mention that, by default, you have been diagnosed with one of those mysterious, misunderstood, and maligned syndromes that have become catch-all's for women complaining of certain persistent and unmeasurable symptoms (or, you might not mention this, remembering the multiple doctors who told you: "Don't tell people you have that. It's stigmatized, and they'll think you're crazy or you're just trying to get pain meds." If you do share this, you will laugh, minimizing the shock and anger and confusion you felt each time you were told this, as you wondered how you were supposed to get proper care if you couldn't tell anyone what was wrong with you). You might remember the doctors who told you that you look too good, or are too high-achieving, to have these conditions.

You will recall also the other doctors, who gently, caringly, told you: "I know what you have, I have other patients who have the same thing. But I don't know what it is, and I don't know how to treat it." You will think about the doctors who told you that you might not be able to have children, and others who said that this condition would have no impact on your fertility, and those who, later – as your body gestated a child – advised that it could not affect your experience of pregnancy, childbirth, and breastfeeding despite the fact that you were in their clinics seeking help for those effects (you will wonder, often, over the years, how they could each have been so certain of these things, when none of them knew what was wrong).

You will remember how the first doctor to give you this diagnosis was clear that it was a diagnosis of last resort, that he didn't actually know what it meant, but that it was what they told women like you, with your symptoms, when everything else was ruled out. You will be ashamed to say out loud that for so many years, you internalized this stigma and this lack of clarity, and kept this diagnosis secret. Because you understood that it simply meant you were another, more modern, woman with hysteria.

At different times, over those 20 years, you will be told that certain foods are causing all of your symptoms, while others will know with complete certainty that diet is not a factor. You will be told to exercise more, and you will be told that exercise will make you worse. You will suffer from mood swings and be diagnosed occasionally with depressive tendencies (thus confirming that you are in fact a hysterical woman). You will also learn that these mood swings often coincide with pain flare-ups, but no one, including you, will be able to say whether one or the other comes first, whether they are linked physiologically, or whether simply being mysteriously sick makes one depressed.

You will be told that your symptoms are repressed trauma, that you need to think more positively, or be more true to yourself, and that if you only do these things, you will get better (and while it's true that your body is holding stress and emotions and intergenerational trauma deep within its tissues, and that acknowledging and expressing these will be healing to your soul, doing so will not magically reset your dysfunctional neurological system). There are days when you will think that this is all your fault, and that you have the power to change it, and days when you will know that you are powerless and helpless. You will feel defeated and you will feel empowered. You will rage at and resist both the medical system and the experiences of your body; you will have times of acceptance and peace and gratitude, for the ways that this illness will shift the directions of your life and break you open emotionally and spiritually and even professionally.



## RENEWED

Jenna Clare Kay

*Watercolor*

This piece is a reflection on how our environment is woven into our identity. What we surround ourselves with will shape who we become and will influence our state of mind constantly.

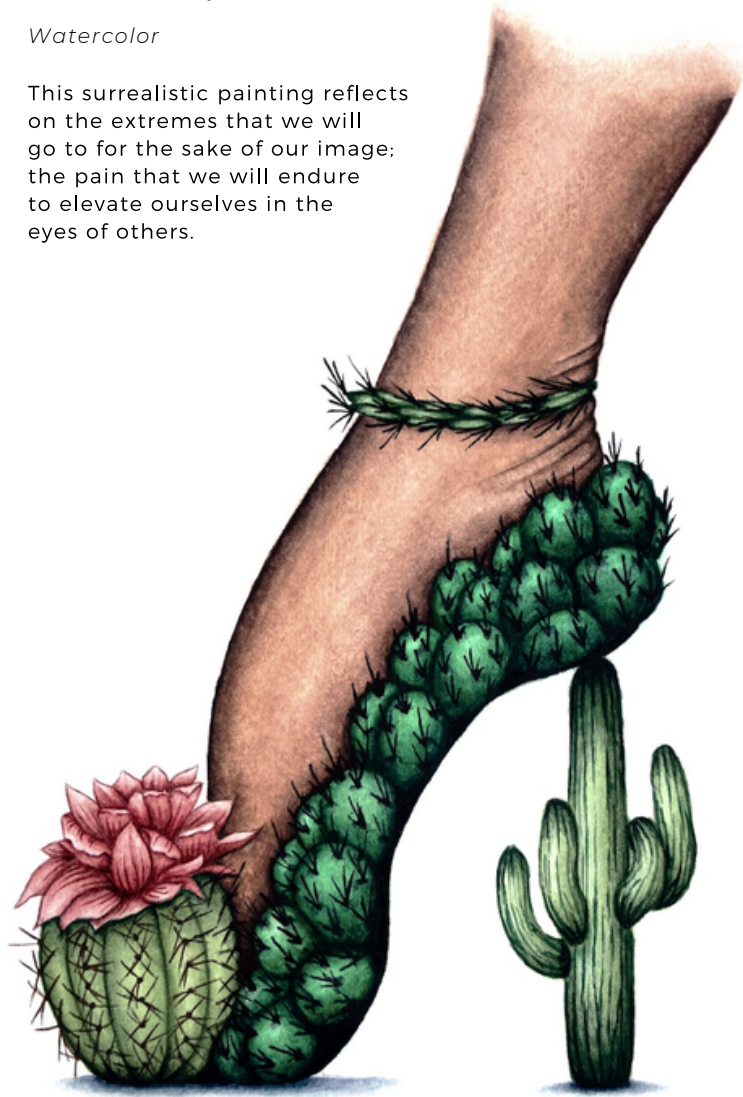
You will follow your friend's advice, and go to the doctor. They will poke and prod and rule out the scarier possibilities, but will yet again find no explanation for the pain; they will not be able to identify the creature that is squeezing you from within. This will be consistent with the only thing that has remained true all these years: the illness keeps coming back, and the medical system doesn't understand it. At some point, a still, small voice will quietly and slowly emerge from the cacophony of fear and pain inside you, and you will listen to that voice and remember that the doctors do not know how to heal you, but you do. Gently, the voice will remind you that only you know best what will help and what will hurt. You are the only one who will be able to connect the dots in your body's strange and mysterious collection of reactions.

## ELEVATED

Jenna Clare Kay

*Watercolor*

This surrealistic painting reflects on the extremes that we will go to for the sake of our image; the pain that we will endure to elevate ourselves in the eyes of others.



You will stop taking the medication and supplements that are supposed to help (and stop listening to the doctors who say they can't possibly be causing this trouble), and gradually, the acute pain will subside. You will start listening to your yoga teacher, who prescribes "radical self-care," and to your body-worker, who tells you to feel into the pain, as she stretches and opens and calms the inflamed fascia constricting your entire body. As your panic eases, you will shift your diet, and meditate, and do yoga, and try to sleep and rest, and wait (patiently and not) as your body finds its equilibrium again. And it will. You will slowly start over, as you return to the quieter, chronic, aches and pains and fatigue that you know so well. You will almost forget the intensity of the pain and the fear and the confusion and the rage. Almost, but not quite. Because now, these too have become part of the tissues and cells of your body.