

## Rare disease banishes Manitoba artist to real life ‘Nomad land’

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Marie in front of her van, broken down and stranded, in  
Alberta last month. Photo provided

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By **Sean Ledwich, Local Journalism Initiative Reporter**

Artist Marie Leblanc picked up the 1991 Dodge B-250 Road Trek van in 2017 and got right to work on it. She sprayed and rubbed all surfaces with baking soda, hydrogen peroxide, isopropyl alcohol, ozone, coffee grounds and vodka. Then she gutted it—out came the toilet, stove, sink and passenger seats. The steering wheel, driver’s seat and dashboard she covered with Mylar and Reflectix—a bubble wrap with a reflective foil coating—and the air vents she stuffed with charcoal filters.

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*From Overdressed: Marie standing in a doorway at Two Guns, a Route 66 ghost town in Arizona.*

Leblanc, 57, was diagnosed with multiple chemical sensitivity (MCS) and electromagnetic hypersensitivity ten years ago.

It's a condition she's battled her whole life, and in 2019 she decided she could no longer tolerate the pain and discomfort of indoor living options.

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"I was too sick, and I couldn't find any place to live," said Leblanc, on the phone from Alberta, where an irreparable axle and suspension on her van stranded her outside a small town since May.

For the past three years Leblanc's been driving her oft-broken down van from Alberta to Arizona each winter in search of warmth and toxin-free environments.

She crosses the border armed with notes from a medical doctor.

"Due to the severity of her chemical sensitivities, I have recommended Marie to spend the winter months in the desertic areas of the USA," says one note.

The doctor also included an instruction for any border agent suspicious of her modified van.

"If her van is to be inspected or work done on it, the agent involved should be unscented and use gloves as much as possible."

When in Arizona, Leblanc spends much of her time on survival activities—finding water, finding a safe place to park, finding and cooking food. Campgrounds with

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campfires and parking lots with other vehicles are too toxic, so she often depends on the kindness of strangers who allow her to stay on their land. She avoids stores, where the electricity and fragrances can be toxic to her, by giving people money to make her purchases. When COVID-19 made people reluctant to touch her money she risked, and suffered, more exposures from entering buildings. It felt ironic that MCS had quarantined her from the world, and then a pandemic caused the world to quarantine from her.

An exposure can cause Leblanc myriad symptoms including severe migraine, muscle and joint pain, poor cognition, abdominal swelling, extreme fatigue, hyperactivity and anxiety. Chronic conditions she attributes to exposures include fibromyalgia, rheumatoid arthritis and interstitial cystitis, which almost led to her bladder being removed. The cognitive symptoms can lead to people thinking she's drunk or on drugs, and unable to understand what people are saying to her.

"I can't even tell you how embarrassing it is."

Being on the road, avoiding most toxins, has reduced her symptoms and allowed her

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to stop taking powerful painkillers like fentanyl.

“I can do more. It varies throughout the day, and I still feel like crap, but I can do more. At least I’m not bedridden.”

She says she fights off despair. She knows of MCS sufferers who have felt they could not go on and chose medical assistance in dying.

“It’s an option I don’t ever want to have to take. It’s there, but I don’t ever want to have to take it. I’m doing everything I can to survive.”

Making art helps her survive, she says.

“It’s what keeps me going now. I have purpose.”

Leblanc is a visual artist. She takes photographs and she has produced several virtual art shows, including photography and video, with the help of Arts AccessAbility Network Manitoba (AANM), an artist-run not-for-profit that assists artists with disabilities. She has also included her work in several show and sales put on in the West End by Art from the Heart—an organization that supports the

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development of inner-city and low income artists.

Her recently created short film, *The End of the End of Time*, features photographs from her travels. The images, set to music and sometimes translucent and layered, are organized to explore themes of ecological injury, and healing.

Last year Leblanc produced *Overdressed*, an exhibition featuring images of her day-to-day survival and encounters on the road. She appears in most of the photos herself wearing a frilly blue ball gown symbolizing how small acts of survival—like doing laundry or bathing in a Rubbermaid tub (she mostly takes bird baths)—are special occasions.

In spite of battling pain and the logistics of a solitary nomadic life in a stripped-down van, Leblanc remains upbeat. It is a characteristic that her doctor also saw fit to address in one of the notes he supplied her.

“Please note as well, that Marie’s physical appearance does not reflect the severity of her condition. Otherwise stated, do not be misled by her positive demeanor,” the doctor warned.

“Under this ‘mask’ remain exceptionally severe and disabling symptoms.”

Leblanc’s photographs are for sale through AANM. Go to [aanm.ca](http://aanm.ca) and search for Marie Leblanc to find a listing of her online exhibitions. To help her repair her van, or buy a new one, with a donation go to [gofundme.com/f/help-marie-leblanc](http://gofundme.com/f/help-marie-leblanc)

### **MCS: stigma and controversy**

Marie Leblanc says multiple chemical sensitivity is difficult for people to understand. The symptoms come and go with exposures, and she often appears normal, so she has been accused of faking or imagining it. It has also strained relationships.

“Some people will go to the ‘nth degree to try and prove it’s in my head, or some people think it’s funny.

I know that I have this condition. I don’t have to prove it to anybody.”

The Canadian Human Rights Commission considers environmental sensitivity to be a medical condition and a disability which affords people protection from

discrimination under the Canadian Human Rights Act.

A 2021 report by Quebec's public health agency concluded that MCS symptoms were not caused by chemicals but were rather a type of anxiety disorder, though it also said MCS sufferers experience very real and debilitating physical symptoms.

Marg Friesen, director of the Environmental Health Association of Manitoba, says doctors who work with MCS patients were critical of the Quebec report.

"There's a lot of science indicating that this is not just an anxiety issue, that it is physiologically-based," says Friesen.

"I think that if somebody has this condition it's not too surprising that they would develop anxiety, so what came first, the chicken or the egg?"

To learn more about MCS and environmental sensitivities, Leblanc suggests the websites [seriouslysensitivetopollution.org](http://seriouslysensitivetopollution.org) and [mcs-aware.org](http://mcs-aware.org)



*Marie's photography art includes translucent superimposed imagery.*



*From Overdressed: Leblanc taking a bath in a Rubbermaid tub on a farm in Saskatchewan.*

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