

# South Shore Support Group for Chronic Pain Sufferers and their Families

I'd like to thank the Municipality of the District of Shelburne for allowing me to appear before your council. I am going around the South Shore speaking about a special project very dear to my heart – launching the South Shore Support Group for Chronic Pain Sufferers and their Families. Currently the South Shore does not have an active Support Group for Chronic Pain.

Nursing taught me was not to assume anything because if you assume you may presume something that is not true. I do not want to assume we are all on the same page with respect to Chronic Pain. I want to start an open dialogue on Chronic Pain so communities within the South Shore can ask questions, share their stories, learn from one another, make sure we do not leave anyone behind and make sure that all area's of the South Shore have a voice. Until recently, I did not know we had a National Chronic Pain Awareness Week. I want to make sure that the South Shore is prepared to be part of this year celebration that are scheduled to start on Nov 3rd through to Nov 9th.

I moved to Nova Scotia in the summer of 2021. The first year I was trying to get answers to questions, trying to speak to pain clinics and letting people know details of the Support Group I was trying to launch. I did not want to start a support group when I had more questions than answers. I remember when I was told incorrect information concerning the drug assistance program that was available in Ontario. As a result, I could only afford half of the medications prescribed by my health care team. Once approved for this drug assistance, I was then able to financial afford all the medications I was prescribed. It took every ounce of physical and emotional strength I had at that time, to get back on track.

In the second year, I officially launched Sir Earl Photography. Photos taken in the South Shore are showcased in a number of avenues that highlight the magic that is right in front of us. I was very fortunate last year to have a local artist give me a framed painting of a greeting card I gave her. Also, I am running card workshops at no cost to the public with the first one being at Thomas H. Randall Library in Liverpool. I look forward to meeting and working with the Chronic Pain Community of Shelburne County.

Noted below is a section taken from the Nova Scotia Government online site under- Nova Scotia Health- Chronic Pain Services. It lists the different members of the health care team that the government feels are needed for someone suffering from Chronic Pain:

" The team may include doctors, nurses, physiotherapist. Occupational therapist, psychologists, social workers and other health care professionals that specialize in pain Management. Services vary based on facility, area of the province and level of care. "

Many residents of South Shore are without a primary physician. The closes Hospital that would have access to all these services would be in Halifax and Yarmouth. Not all Chronic Pain Sufferers

have finances and/or transportation needed to be able to travel to and from these destinations. I know from my own personal experience with Chronic Pain, I am still learning but know that each one of these medical professionals have a part in the recovery process.

At this time, I would like to read part of an e-mail I received from Provincial Lead Education and Training representative of the Canadian Mental Health Association Nova Scotia Division dated Jul 2023:

“We are deeply grateful that you have come forward and are eager to connect and support you in any way we can with this critical work. We have heard loud and clear a cry for help from Nova Scotians across the province with chronic pain and illness. There is an urgent need for this.”

I am a retired nurse and chronic pain sufferer for over 45 years. Many have asked me why I am sharing what I have gone through- my answer is how can we learn if people that are in trenches do not speak out. I openly tell people my story not to get sympathy but to have something good come out of all the pain that I have gone through and the tears that I have shed. I can say that persistence, stubbornness, finding your purpose in life and the joy of giving is what has got me through to this point.

My name is Janice MacMillan. I am the proud granddaughter of Oscar E. Smith of Shag Harbor Nova Scotia. My roots go back to the original settlers of Cape Sable Island. I was lucky as a teenager to come across a journal outlining my distant grandmother’s journey on Cape Sable Island. Her husband was not on the island when she landed with her three small children. The captain waited as long as he could but had to leave because the tide was going out. He wanted to take her off the island. She said that if my husband said he going to be here, he will come. She did not know that her husband’s sea voyage to the island was delayed due to a broken hip.

I always remembered the strength, sacrifice, courage, creativity, and perseverance my relatives needed in-order to stay alive on Cape Sable Island. I am proud of my ancestral root, what they achieved, business that they set up, positions they held in their communities, community spirit they where part of and love that I felt from relatives that I only saw a couple days a year. Going through Chronic Pain I would say over and over again – I cannot disappoint my grandparents. What I am doing right now is the best job that I have ever had. It makes me want to get up at 5:00 am to start my time at my computer. Some of the things on my to do list is start open discussions in communities on this matter, invite the health minister to come to the South Shore so that Chronic Pain Sufferers can personally voice their concerns and to have MP representing the various section of the South Shore meet with the Chronic Pain community. We need to have words turn into actions, goals be reachable and empowerment of the Chronic Pain Community, so they are part of the solution. We are not going to see the change happen overnight, but the voices must be heard, people elected by the people need to listen to of their communities and media campaign started preparing for the National Pain Awareness Week in Nov 2024 is and communities need to come together to support one another.

Growing up my grandfather in Shag Harbor taught me the values that I live by to this day especially the gift of unconditional love, service to your community, fighting for what you believe in, never mess with mother nature, what you give you get back two folds, helping out members in your community and the value of volunteer work. I lost count on the number of individuals that to this

day would tell me a story of my grandfather that I had never heard before. I remember the story of a man that as a boy would run from school to my grandfather's barn to build fish boxes. He said it was great to go home with some change in his pocket.

I graduated from George Brown College Nursing Program in 1983. Nursing taught me that pain was a sign that something was wrong. I worked in downtown Toronto hospitals in cardiovascular surgery, ICU and Dialysis. I would go to work and treat my patient's pain but when I was the patient, I was told they could not do anything for me. I lost hope, not sure I wanted to keep living, been homeless, not able to financially afford some of medications my health team prescribed and face many other challenges to get to this point.

I was diagnosed with Fibromyalgia in my twenties. You never knew when the pain was going to start, when it was going to stop, how bad the pain would be, can you make it home and/or if you were going to make it through to the end of day. I was originally told that I had Fibromyalgia for life, and they could do nothing for the pain. I was given the Fibromyalgia diagnosis once I was seen by seven specialists. At that time, the medical community would say it was a diagnosis of exclusion. Many Doctors did not take this condition seriously – it took quite a number of years before this condition was part of curriculum for medical students. Many physicians blamed my pain on my profession as a nurse, it was due to stress and/or due to being overweight. Sometimes when I was driving home from work, I would wonder what it would be like not to be in pain. Many times, I would think about driving off the road because I could not see the point in living if this was what my future would be.

Chronic Pain sufferers do not have any scars to show but the pain is real. I would not tell people when I was in pain because I did not want to be labeled, excluded from events, be stereotyped and/or be judged by society as being inadequate. I came across an article that stated that the physical reaction your body goes through when you are in chronic pain would be similar to what the body goes through when running a marathon. Now, I do not believe marathons are meant to be for an indefinite period of time- at some point they get to stop. Chronic Pain Sufferers can not pick and choose when they want to be in pain- none of us want to be pain.

Nursing also taught me not to put your personal feelings into the equation when you are dealing with chronic pain. It does not matter how you think the person should feel but you go by how painful it is for your patient. One day when I was a volunteer at Coastal Queen, a woman with chronic pain sat down beside my desk in tears. She had chronic pain but what brought her to tears was the reaction she was getting from her daughter. Her daughter would say hurtful words to her because she really did not understand what her mother was going through. Even with medical professionals in my family, that did not help them understand what I was going through.

Chronic pain sufferers are not given a choice of whether they want this life- it is out of their hands. Everyone has different opinions on how the pain should affect a loved one. Unless you are walking in their shoes, you truly did not know what they are going through. You need to keep an open mind because even if you would deal with pain differently, it does not mean that the feelings of others are not valid.

He referred me to a pain specialist that was actively working with the chronic pain community. I would talk to her about my family's reaction to me taking pain medications. When we started talking about my family, she would say they do not give you a break. My mother's opinion on this

matter never changed no matter how many letters my pain specialist wrote. I know I would not be where I am now if I did not have a family physician and pain specialist as my guardian angels. You cannot have chronic pain treated in the Emergency department. You need to have a medical team supporting you all the way through this process.

I will not forget the day my pain specialist said to me, Janice I cannot believe I am saying this to my patients but the best treatment for chronic pain is cannabis. Due to lack of financial resources and reduced availability of cannabis, I was not able to use this as a treatment mode. To my family every action and reaction was viewed from the perspective of an addict. When does being tired mean you have taken too many pain pills and if you are upset be labeled as being stoned. We need to be careful not to jump to conclusions and/or label someone that is not backed up by their medical professionals.

During one of my appointments with the pain specialist I asked if I could go through a detox program. Her answer was that I was not taking enough medication to qualify for the detox program. Neither my pain specialist or my pharmacist could tell me which medication I should reduce first or how I should taper down my medications. The whole time this was happening, my pain levels were increasing in severity, frequency, duration and physically limiting my mobility. I was tapering the second medication when I had to tell my boyfriend that I could not handle it anymore- the pain was too much.

In 2017 I was hit when a truck reversed into my stationary car. It took me over a year to recover from the brain damage suffered from this accident. At times I could not express my words, I could not say the word but could try to draw a picture of what I was trying to say, had to relearn using my computer, if my mind thinks of something else I would forget what I was talking about and goes through a grieving process for what I had to accept I could not do anymore.

After the accident I came to realize that I could not use my professional camera anymore. I could not remember how to operate the camera no matter how many refreshers class I took. I started taking pictures with my phone. At first, I was trying to solve a personal mystery – are all snowflakes the same. I have come to conclusion that all snowflakes are different just like each of us are different in our own special way. No matter what your background may be, who your ancestors may be, how bright you shine and where you may live- the common link is Chronic Pain. The symbol for the group is a snowflake.

I picked the name of the snowflake to be Krystal because I want the snowflake to shine like a diamond the rough. I want all the negative feelings about chronic pain turn into positive energy. I have a fine tremor when I am taking my pictures. As a rule, I will pick out what I want to take a picture of, take about 50 pictures of the same item and if I am lucky, I get one photo that I liked. Currently I have close to 20,000 pictures on my camera.

I want to thank you all for listening to my journey. I hope anyone who has questions, has suggestions, has contacts that could be helpful in our goals, ideas for support groups and/or marketing companies, please reach out to me.

I want to leave you with one rule my grandfather said to me. If something is wrong do not just talk about it but do something about it. Let's work together to change the future of Chronic Pain in the South Shore.

Sincerely

Janice MacMillan

Sir Earl Photography

South Shore Support Group for Chronic Pain Sufferers