inspire

The magazine of the
Tumour Foundation of BC

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Improving the lives of those
affected by neurofibromatosis

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Tumour Foundation of BC

FROM THE EDITOR

DESIRÉE SHER

When you live with neurofibromatosis (NF), it's easy to believe that no one knows what you are going through. If you live outside of an urban area, meeting someone else with NF seems impossible, only further impacting isolating thoughts.

While there are certain challenges unique to NF, when you dig a little deeper, you discover that just like NF, fear, anxiety, and pain do not discriminate. These challenges affect people from all around the world.

In this edition of Inspire, we've come together to share how both those within and outside of the NF community cope with chronic pain and anxiety and improve their mental wellbeing.

From self-hypnosis to building community connections to listening to podcasts and spending time with horses, our writers share their personal stories and strategies to live their best lives.

We focused this issue of the magazine on pain and mental health as our recent health care survey (results on pages 2&3) reflected that these are the most prevalent health concerns facing the BC NF population.

2020 has challenges us in many ways; COVID-19, wildfires, and even murder bees have forced us to learn to live in a world of uncertainty. Families affected by NF are, however, no strangers to adversity. They get up and face fear everyday with grace and courage as they navigate the challenges of having a disorder with little medical support.

I want to remind you that you do not need to walk the NF journey alone. The Tumour Foundation of BC offers support groups, virtual community events, a support line, and other programs to connect you to a larger community. Email or phone us – we are here for you!

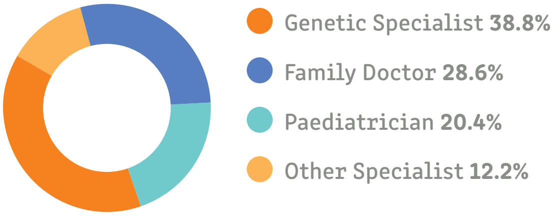
After all, we are always stronger together.

Desirée

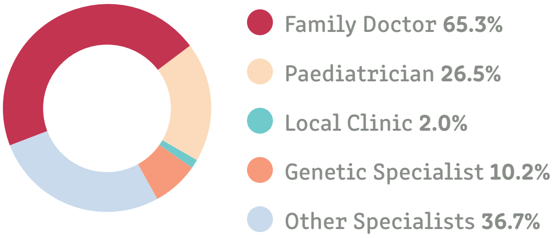
NF healthcare snapshot

In June and July of 2020, the Tumour Foundation of BC conducted an online survey of individuals affected by NF, in an effort to better understand the health care experience for NF patients. Some of the highlights are presented here, and the full survey results can be viewed at tumourfoundation.ca/health-survey

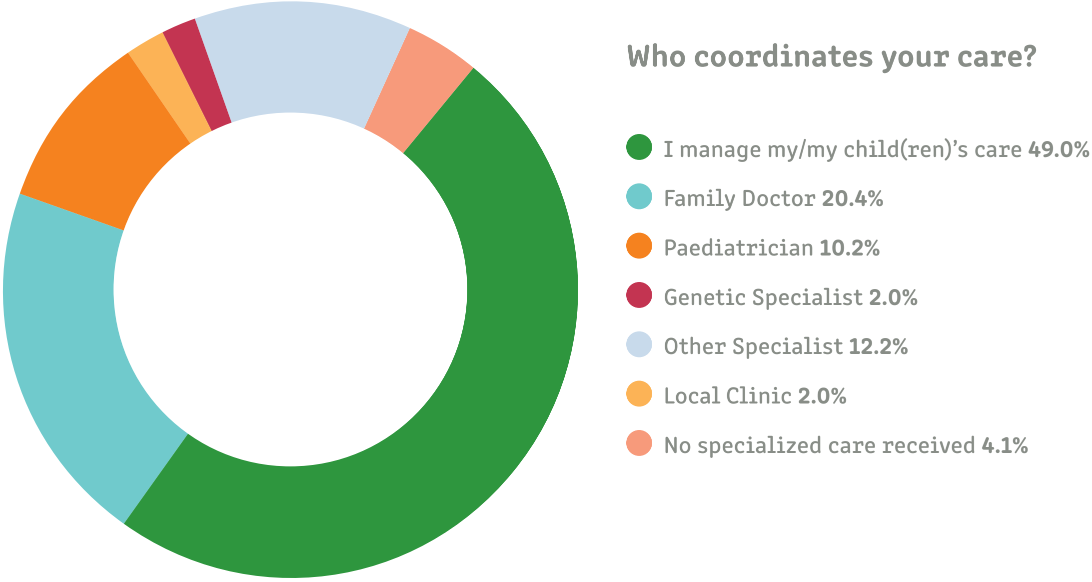
Who diagnosed your NF?



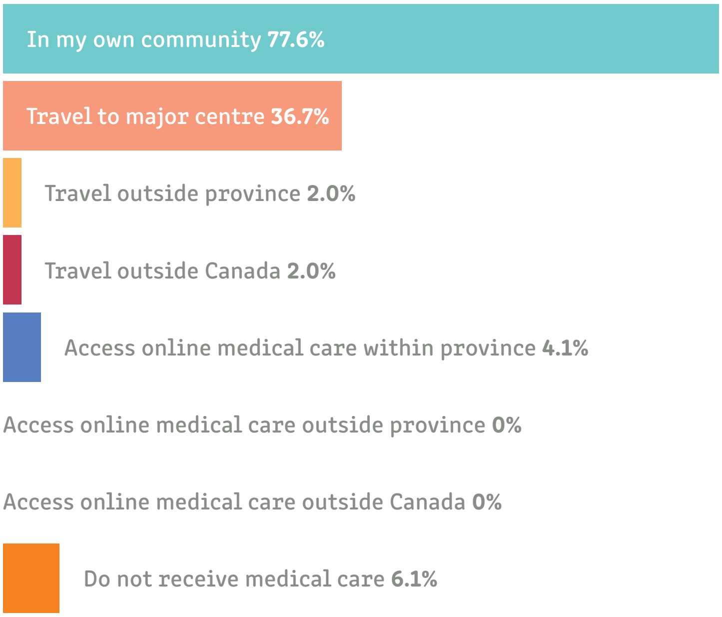
Who provides your primary care?



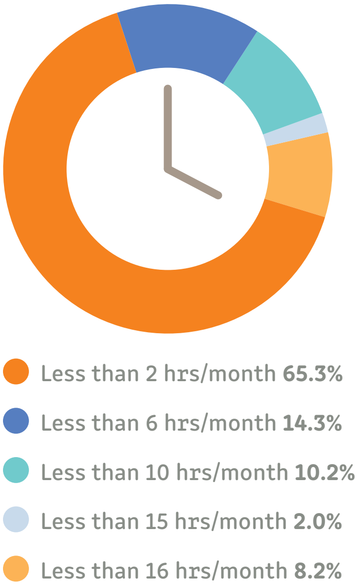
Who coordinates your care?



Where do you receive your medical care?



How much time do you spend managing care?



Top Six
Health Impacts of NF

Internal Tumours 59.2%

Learning Differences 53.1%

Skin Tumours 51%

Itching 44.9%

Headaches 42.9%

Pain 40.8%

Top Six
Biggest Challenges of Living With NF

Lack of public awareness 65.3%

Lack of professionals who understand the disorder 59.2%

Anxiety 51%

Lack of coordinated care 49%

Lack of education supports for learning differences 36.7%

Depression 36.7%

95.9%

of respondents have NF1

55.1%

Received genetic testing

89.8%

Would use a Vancouver clinic, if one existed

BUILDING COMMUNITY WHEN YOU'RE DEALING WITH CHRONIC PAIN

LINDSAY VERMEULEN

Popular culture and folklore are packed with stories of communities coming together to help people overcome challenging circumstances. But what do you do when you don't have that community in place, it feels like it is growing distant, or is not supporting you in the ways you need?

Chronic pain can feel isolating at the best of times. And in the midst of a global pandemic, people are feeling that more than ever. The good news is, you are not alone. In April of this year, an Ipsos poll found that over half of Canadians are feeling lonely or isolated. Everyone is looking for meaningful connections, and that search can bring us together to support each other.

SEEK OUT YOUR PEERS

Family and friends without NF can be wonderful resources, but they may struggle to fully understand what you are going through, and as a result, may occasionally express frustration about issues you are unable to control. Loved ones will require your patience and understanding, just as you will require theirs. And when you are working with a limited reserve of energy, it can feel overwhelming to help people understand, when what you really need is their unconditional support.

It can be helpful to build ties with people within the NF community (including others who share your diagnosis) who already know what you're going through and can sympathize. That way, you can focus on getting to know one another, without having to educate or make excuses.

TAKE YOUR TIME

Chronic pain takes up a lot of energy, as does making friends and building community. And when you add on regular daily activities such as getting dressed, preparing food, etc., you may find it all requires more energy than you have available on a given day.

Christine Miserandino, an award-winning writer and lupus advocate, came up with the "spoon theory" to help understand these limitations and explain them to others. She uses a handful of spoons to represent the total energy available to a person on a particular day. Every

Photo by James Baldwin on Unsplash

activity requires a certain number of spoons to complete, and once you've used them up, they're gone. This doesn't mean you will never have enough "spoons" to build a community – just that you need to allot them carefully and save enough for yourself.

When you are reaching out to peers and making connections, listen to your body and take breaks when you need to. Your energy for socialization may vary from day to day, and only you will know how much energy you have available. Making friends and building community is not a one-shot deal – you can pace yourself as slowly as you need, doing what feels comfortable and taking breaks.

EMBRACE THE INTERNET

The internet is an incredible tool for building community and for finding like-minded people in similar situations around the world. It's also helpful in that, unlike physical meet-ups, you can come and go anytime, and meet people from the comfort and safety of your own home. Suddenly exhausted or dealing with a wave of pain? Simply log off. Find you have a little energy to spare? Head onto social media for a bit to check in with friends.

Online communities are a great place to connect with new people. Connecting with others in the NF and chronic illness communities is one place to start:

- On **Facebook** visit the Tumour Foundation page and the BC NF Families Page
- On **Twitter**, try following hashtags like **#spoonie**, **#chronicillness**, and **#neurofibromatosis**
- Neurofibromatosis Network (**@nfnetwork** on Twitter) hosts teen game nights over Zoom

REMEMBER THAT YOU ARE ENOUGH

Building community takes time, so don't worry if you don't seem to be getting anywhere at first. In the long term, you will see results!

As you work on building relationships, remember to keep your own well-being in mind. If you find that something about a new connection or friendship isn't working, let that person know as tactfully as possible, and look together for ways to improve it. And if a relationship is draining you of energy and not offering enough in return, give yourself permission to move on.

It can feel awkward at first, but you will learn to be vocal about your needs and your abilities, and to expect the same from others. Your love and the community you offer are so, so valuable – don't let anyone tell you otherwise!

You can learn more about spoon theory on Christine Miserandino's blog:
butyoudontlooksick.com

Lindsay Vermeulen is a writer and editor based in Vancouver, BC, on the traditional, ancestral, and unceded territory of the Musqueam people. She specializes in food and travel content and enjoys finding small ways to bring beauty to each day.

FINDING MY ZONE: AN EXPERIMENT WITH SELF-HYPNOSIS

MAGGIE EASTON

I told my children the other day that I didn't want to be their mom anymore. We were in the car, and they were fighting and screaming at each other and one of them looked right at me and dumped a whole cup-full of Cheerios all over the seat because she "just felt like it." My back was aching, my hands sore, and knuckles swollen. The pain of arthritis disabled any ounce of patience and elevated my anxiety through the sunroof!

I've been dealing with chronic pain for over 15 years. I have tried pain relieving creams, gels, pills, and patches. I've taken medication for depression and anxiety. I've tried tinctures, herbs, capsules, and teas. But nothing helped the frustration that resulted from parenting small children while living with chronic pain. I didn't have a strategy for coping with my pain and anxiety in the moment. I needed something for the times when leaving the room to take a deep breath wasn't an option, such as being stuck in the car with screaming kids.

I thought back to a recent conversation I had with a friend and fellow mom of toddlers. She told me about a self-hypnosis practice she used when she was stressed. It was a technique she learned from *Hypnobabies.com* when she was preparing for natural childbirth. I looked up the website and was pleasantly surprised to find there were hypnosis sessions for things other than childbirth prep! Hypnobabies has self-hypnosis downloads for everything from weight loss to self-confidence to quitting smoking.

> I NEEDED SOMETHING FOR THE TIMES WHEN LEAVING THE ROOM TO TAKE A DEEP BREATH WASN'T AN OPTION, SUCH AS BEING STUCK IN THE CAR WITH SCREAMING KIDS.

According to Clinical and Medical Hypnotherapist, Scott Sandland, hypnosis "is very simply: a natural state of mind in which the body and mind are extremely relaxed and yet the mind is also highly aware and focused… we are all in states of hypnosis many times a day automatically, so hypnosis is a very normal state of being that along with it's (sic) ability to provide emotional and physical healing, has been widely and successfully used within the medical community for pain relief and hypno-anesthesia." I downloaded the Eliminate Stress and Anxiety MP3 and committed to a 5-day test run of self-hypnosis and this is how it went.

THE EXPERIMENT BEGINS

Day 1: I was away from my children since I stayed at a friend's house for the weekend. In the morning, I found an area in her yard to spread a blanket on the grass where I laid down. I put my headphones in, took a deep breath, and hit play. Having zero idea what I would be listening to, my mind was fully open. The woman's voice was soothing, and I allowed my body to relax. I felt my body become heavy and grounded with the earth beneath me. I was able to completely release all my tension despite being outside and feeling a little chilly. I was still fully aware of my surroundings, but it was separate from me and it didn't disrupt my session. I felt my body twitch a few times, as it does before I fall asleep, so I knew I was in a truly relaxed state.

After completing the first session, I was excited to go about my day and try to utilize the new skill that was suggested to me during hypnosis. I was ready to challenge the world and ready to say no to stress. I did feel anxious that day, but I was able to stop what I was doing for a moment, speak words of relaxation to myself and get centered. It might have been the pause I took that helped, or the physical release of tension in my shoulders and jaw, but after taking a deep breath, I was able to continue my day with lower levels of anxiety.

Multiple times that day, I became overwhelmed and spoke to myself as the hypnotherapy audio had instructed me to do. It seemed to be working! I hoped it would work just as well when I was around my children again.

Day 2: I returned home and was with my children all day. They were pretty active and extremely messy. I found myself taking deep breaths and stopping myself when I felt about to yell. It was a hot and humid day and my lower back (as well as several other joints) were aching badly. My patience level was fairly low, but I refrained from turning into the Incredible Hulk, who I normally felt and acted like when I was in pain.

I tried my hypnotherapy session in the evening before I went to sleep. Since I was home and inside, I figured I'd be more comfortable and hopefully able to get into a deeper state of hypnosis in my recliner. Well…I fell asleep! I woke up at the very end of the session when the narrator counted to three. I was shocked since

Photo by Motoki Tonn on Unsplash

I wasn't even tired and had things to do before bed. Listening to the session in my recliner with a blanket, definitely helped me relax. I felt multiple muscle twitches as I slipped into my deep hypnosis state. But I didn't get too far into the session before I was asleep. Or perhaps I was just hypnotized?!

Day 3: I spent the morning feeling at ease even though I had multiple time-sensitive activities to accomplish. I did feel my anxiety elevate a few times and used my calming words to relax. So far this has been a useful tool for me! Overall, I felt more at ease, happier, and less annoyed, even though I was suffering from pain in multiple areas of my body.

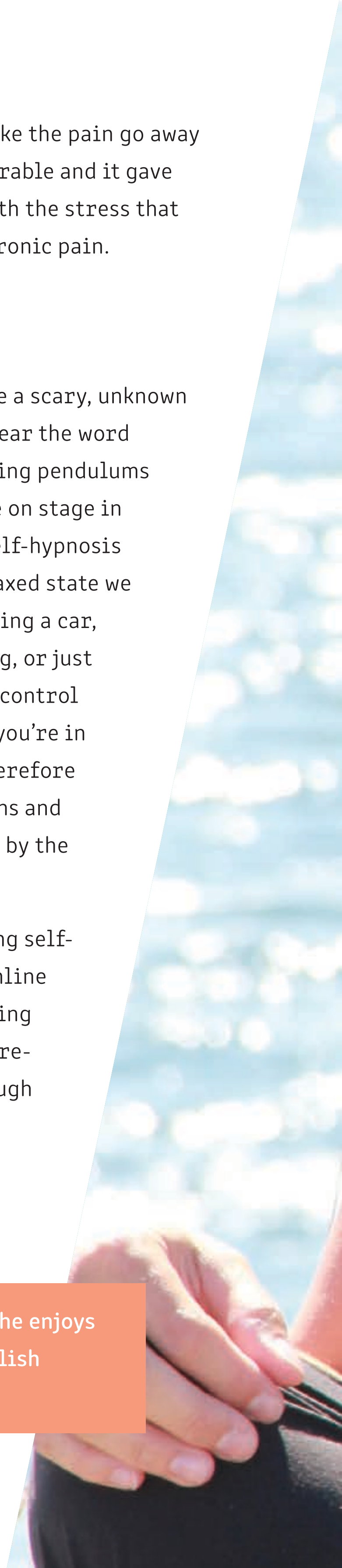
Day 4: It was a busy day. My hands were swollen and painful and my rings didn't fit. I did my hypnosis session in the late afternoon. It immediately put me more at ease and I did something I normally want to do but never have the energy for: I took my kids to the park after dinner! I felt relaxed and happy and I was able to ignore my pain even while pushing my kids on the swings!

Day 5: Today was the last day of my self-hypnosis experiment but it won't be my last day of self-hypnosis! I felt the program was working for me overall. I will benefit even more from it as I continue. It didn't make the pain go away but it did make it more tolerable and it gave me a coping skill to deal with the stress that results from living with chronic pain.

WHERE TO NEXT?

Hypnotherapy may seem like a scary, unknown practice. Usually when we hear the word hypnosis, we think of swinging pendulums and mind control, or people on stage in a trance and acting silly. Self-hypnosis though is much like the relaxed state we find ourselves in while driving a car, watching television, praying, or just zoning out. You are in total control of your mind and body, but you're in a fully relaxed state and therefore more open to the suggestions and visual imagery given to you by the narrator.

If you're interested in trying self-hypnosis, there are many online resources available, including the free stress and anxiety release program I found through Hypnobabies.



Maggie Eason lives on Whidbey Island with her husband and two daughters. She enjoys writing, home improvement, and exploring the outdoors. She has a BA in English Literature and is working on her first novel.

BECOME YOUR OWN EXPERT

MAYA KENNEDY

Anxiety stems from uncertainty. It is what we feel when the present feels too overwhelming to face, the future too unknown to contemplate.

So how can we combat some of this worry? By becoming experts in our own anxiety and developing tools to soothe our stress. We've compiled a list of podcasts, books, television shows, social media accounts, and activities that will either help you conquer your anxiety through the power of knowledge or provide a blissful escape from everyday worries.

PODCASTS

Oprah's SuperSoul Conversations

Just as the title suggests, Oprah's weekly podcasts are a chance to nourish your soul. Through conversations with actors, authors, and Fortune-500 executives, this podcast is the perfect way to sit back and enjoy a lazy Sunday.

Ten Percent Happier with Dan Harris

Harris knows anxiety better than maybe any other podcaster – after all, he did have a panic attack live on *Good Morning America*. Harris' podcast explores mindfulness through his personal experiences and interviews with physicians and leaders in meditation. This podcast is perfect for those wanting to dip their toe into the world of inner peace.

I Weigh with Jameela Jamil

While there's no prescription yet for the needed confidence to banish anxiety, this podcast is as close as you can get. Each week, Jamil sparks meaningful conversations with well-known actors and creators about what it means to wholly accept yourself and how to leave self-hatred in the past.

How Did This Get Made?

On the days when anxiety seems overwhelming and you just need a little laughter, check out this podcast lead by three critically-acclaimed comedians who re-watch your favourite, awful movies. From *Space Jam* to *Valerian and the City of a Thousand Planets*, check out this podcast if you're looking for a healthy dose of nostalgia and humorous criticism to kill an hour or two.

Not Another Anxiety Show

Hosted by registered nurse Kelli Walker, *Not Another Anxiety Show* breaks down anxiety from a scientific perspective. This podcast is great for people wanting to learn about anxiety, so they can conquer their own.

BOOKS

Breathwork

by Nathalia Westmacott-Brown

A simple, aesthetically pleasing book about how to connect to your breath to overcome anxiety. With minimal text yet maximum impact, *Breathwork* is perfect for those interested in practicing mindfulness.

Year of Yes

by Shonda Rhimes

Ever find that your anxiety makes everything seem so hard? Or that's it's just easier to stay inside your comfort zone forever and ever? Executive producer Rhimes used to think the same thing. Through a year of saying yes to everything (yup, everything), Rhimes chronicles her exciting yet daunting year of agreeability. *Year of Yes* is a great read for those who are ready to conquer their fears to live their best lives yet.

How to Make Peace with Your Mind

by Mark Coleman

You know that inner critic that lives within all of us? The one who sparks anxiety and doubt? Ever wish you could banish it for good? Coleman's novel describes how we can take control of our thoughts and hold greater compassion for ourselves. This book is perfect for individuals wanting to live happier, kinder lives.

Shift Happens

by Robert Holden

A little rescue boat here to save you on the days when it feels like you're drowning in anxiety. Holden details how we can let go of anxiety to live happier, fulfilling lives and how to view change as an opportunity for growth.

TV SERIES

This is Us

This is Us will not only spark warmth into the coldest of hearts, but the critically acclaimed series illuminates what anxiety really looks like. You'll check it out for the heartwarming stories of romantic and familial love and stay for the realistic insights on mental health. Available for streaming on Netflix and Hulu.

The Great British Baking Show

All the humour of reality tv without any of the anxiety that comes from rooting for your favourite contestants. The perfect mix of excitement and wholesomeness, this TV show is great for soothing stress. Available to stream on CBC.

One Day at a Time (2017)

The reimagined sitcom of the 80's series of the same name follows a Cuban-American family as they deal with mental health, family dynamics, and racism. Each episode is both light-hearted and impactful. Check this series out if you're looking for a relatable yet humourous experience. Available for streaming on Netflix.

SOCIAL MEDIA PAGES

The Instagram page of **@thelatestkate** is just as cute as it is encouraging. Her animal and nature art are the perfect way to receive a little dose of optimism. Kate experiences anxiety herself, so her messages will hit home for anyone facing the same struggles.

Looking for a gentle introduction into mindfulness? Amber Rae's (**@heyamberrae**) posts will invite you to reflect on your thoughts and change them for the better. Perfect for someone who wants a small dose of inspiration to start their day.

ACTIVITIES

For the days when no TV show nor podcast can soothe a worried mind, there's still hope. The Tumour Foundation is ready to support you, no matter the help you need. Check out our support line for one-to-one help or our Facebook page to connect with a community who knows your challenges better than anyone else. If you want to share positivity and help others, get involved! The Foundation is always looking for volunteers. If you are a passionate, motivated individual who wants to share what you've learned about anxiety (or anything else), please visit *tumourfoundation.ca/volunteer* to get in contact with our volunteer coordinator.

Maya Kennedy has been volunteering with the Tumour Foundation for over six years and has participated at events far and wide between. Working with the Foundation has fuelled Maya's desire to eventually enter the field of medicine. Maya is a competitive swimmer who loves rock climbing, lazy days with Netflix and her dog.

Photo by Max van den Oetelaar on Unsplash

LIVING WITH THE ANXIETY OF HAVING A CHILD WITH NF

JESSICA JEMENTE

A few hours ago I was fine… Well, okay, not fine but I was suppressing/managing my anxiety to the best of my ability, like I do on a normal basis. BUT last night it all hit me. This is what life is like now. It is fear, sadness, the feeling of being lost, angry, confused and helpless.

This is having a child with an incurable medical condition. Not a medical condition that entails just ONE type of illness or symptom but a terrifying genetic disorder that causes countless symptoms, illnesses, pain and disabilities and there's no way to know when/if they will show up or how severe.

So, when my beautiful daughter complains on and off over a few weeks that her "tummy hurts" pointing to her chest or that her legs hurt or I see new bumps or spots on her skin, my heart sinks. I begin to think of worst-case scenarios and my stomach is in knots. I quickly think about which specialist I need to contact and if this is something that we should see her regular pediatrician for (because she is, after all, a growing toddler) or could it be something more growing inside her, something out of place, a tumor, the list goes on…

My husband and I talk it over and over and over. I reach out to my fellow NF parents and search MANY posts related to what I see my daughter experiencing. Then book an appointment and talk to the doctor about everything that's been leading up to this. I rack my brain trying to remember every diagnosis, struggle, pain, treatment, medication and supplement she's taken at EVERY appointment. It's exhausting and I have to relive the pain this disorder is causing every time but I don't want to miss anything that could be relevant. If I do forget to mention something I am so disappointed in myself for not memorizing every detail of her health by now or not preparing my questions better beforehand. We discuss our plan going forward and what we will do now (X-ray? MRI? Will she need anesthesia again? EEG? Blood work? See another department? Try a med?). Will it be diagnostics today or just monitor this time?

We go home and try to resume our normal day to day life. Then it happens again…Something else pops up. Mya seems to be in pain, she's walking a little strange, she rolls her eyes, and twitches in a funny way. I ask, "Why is she tripping so much all this sudden?" The whole cycle starts

Photo by Derek Thomson on Unsplash


I KNOW A FIGHTER.
I KNOW A FIGHTER.

again- worry, fear, research, questions, which specialist, doctor's appointment, diagnostics, wait and watch, repeat.

All this, not to mention preparing Mya for everything that is going to happen to her. Helping her through doctor appointments, the poking, prodding, needles, wires, "pictures of her bones," checking on her "superhero spots." My little girl has just turned 4 years old. "Why does she have to endure more than most adults?" I ask myself. I feel overwhelmed with sadness but I have to stay strong for her.

And our daughter... Our beautiful, smart, kind, sassy, WARRIOR of a daughter! She gives me so much strength, courage and determination. She lights up everyone she meets and has so much power in that little body of hers! She is so resilient (as are so many little warriors like her) and she handles things that most adults have a hard time with.

This cycle happens over and over. Sometimes we have weeks or even months where little things don't pop up and we don't have to question every movement, pain, groan, strange behavior and tummy ache or eye twitch. In those times, I may go hours, maybe even a whole day without thinking about my daughter's disorder, worrying or thinking about all of the "what ifs" happening inside of her body that I can't see.

I smile, laugh, talk with friends, cry, have bad days and good days, share posts, interact on social media, run my business, we play, our family enjoys time together, we go shopping, cook, clean, do laundry. Everything is NORMAL, as it should be. EXCEPT IT'S NOT... in between all of those normal moments something hits me. It could be a spot on her skin as we get ready, an appointment on the calendar, seeing her freeze up when another kid runs too close to her, watching her struggle a little on a step at the playground or even just a post I see from another NF parent. Sometimes it's for no reason at all...

SHE LIGHTS UP EVERYONE SHE MEETS AND HAS SO MUCH POWER IN THAT LITTLE BODY OF HERS!

For clarity, I wrote about our "normal" day-to-day routine before Covid-19 happened. Now, in the time of "Safer at Home" I find myself home-schooling, doing therapy, working and trying to help Mya adjust to all this without increased anxiety and juggling this strange new way of life just like most every family in the world right now. Mya's yearly and 6 month checkups have all been put on hold and I am left to wonder when she will get her "baseline" appointments with all her specialists again. They are stressful appointments, yes, but also reassuring to have her developmental and baseline health stats, and I am missing those appointments now. I am grateful that Mya just recently had her yearly MRI (which came back clear) and that she has seemed to have no medical issues since this pandemic started, but some parents and children are not so lucky. I've spoken with many other friends in the NF community whose diagnostics have been put on hold. Although this seems like no big deal to some, it's a huge deal for a parent who was just about to find out why their baby girl is having seizures occasionally, why their little boy is having vision issues and headaches so much, a parent that has just been told their child has NF and are left with so many questions because their appts are now delayed. I also know how important safety is not just for patients but the doctors and staff at all hospitals as well. Things are hard for everyone right now and I have to remind myself of that.

Just the thought of having to bring Mya in to a hospital right now for any reason gives my anxiety. I think to myself, "Will a phone appointment be enough? If she has to go to the emergency room, what risk am I putting on her? Is she at greater risk of catching Covid-19 because of her NF?" I know many are currently going through the same thought process.

I am just grateful that our last few months have been good ones and I try to focus on that as much as possible. I also reach out the others around me in the NF community who are in my position as well. Our situations may be different but we can all relate in some way and being there to listen and support other NF parents gives me strength during a time when there is so much uncertainty.

> *WE CAN ALL RELATE IN SOME WAY AND BEING THERE TO LISTEN AND SUPPORT OTHER NF PARENTS GIVES ME STRENGTH DURING A TIME WHEN THERE IS SO MUCH UNCERTAINTY.*

I struggle every day with this anxiety.

I am learning to cope with my daughter's diagnosis and making sure she gets the best possible care. I find myself hypersensitive to the struggles and ailments she endures and some days I am drowning in a pool of tears because I've lost my way. I dream every day that this picture I have just painted for you is no longer our reality. That when something happens to our little girl we will have answers, treatments that work and most of all A CURE. Spreading awareness and funding of NF research is so important to my baby, our family and so many others we've had the honor to build relationships with (most of them amazing young children like Mya). It could bring us closer to treating with medications (like Selumetinib that was just FDA approved!), more support and one day even a world without this awful disorder.

I can't fix everything. I can't know everything. I'm still trying to come to terms with that and one day I will feel like I can handle it all better. One day I will be a little more at peace with the way life happens. Until then I will share, be honest and vulnerable and continue fighting for our daughter, advocating and fundraising for NF research.

This article is reprinted with permission from the Children's Tumor Foundation's website: ctf.org

The facts about NF

1

Neurofibromatosis or NF, as it is commonly known, is a genetic disorder that causes tumours to grow on the nerves throughout the body.

2

NF has been classified into three distinct types: NF1, NF2, and schwannomatosis.

3

NF1 is the most common neurological disorder caused by a single gene, occurring in one in very 3,000 children born.

4

NF is more common than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's disease combined.

5

NF affects both sexes equally and has no particular racial, geographic or ethnic distribution. Therefore, NF can appear in any family.

6

NF is NOT the "Elephant's Man" Disease, although at one time it was believed to be. Scientists now believe John Merrick, the so-called "Elephant Man" had Proteus Syndrome, an entirely different disorder.

7

Although most cases of NF1 are mild to moderate, NF1 can lead to disfigurement; dermal, brain and spinal tumours; skeletal abnormalities; disabling pain, and cancer.

8

NF1 also has a connection to developmental problems, especially learning disabilities, which are five times more common in the NF1 population than the general population.

9

Half of the people who develop NF1 and NF2 inherit it from a parent. The other half, develop it as a result of a spontaneous mutation.

10

Every person with NF1 and NF2 has a 50% chance of passing the condition on to their offspring.

11

NF2 occurs in one in 25,000 people. The hallmark of NF2 is tumours that grow on the eight cranial nerve in both ears, commonly causing deafness and balance issues. NF2 can also cause severe vision problems.

12

Schwannomatosis is the most rare form of NF, affecting one in 40,000 people worldwide.

13

Most individuals with schwannomatosis have severe pain that can be disabling.

14

There are few treatments and there is no cure.

15

In BC, there is no clinic for people living with NF.

Photo by ???

FINDING HEALING IN UNEXPECTED PLACES

DESIRÉE SHER

I was on my way to see a man about a horse.

In no way did it make sense why I was spending a morning driving to a ranch to volunteer with wild horses. While horses were a childhood passion, living with chronic pain, I had never dreamed I would work with horses again. Thoughts of being too old and too injured were playing on repeat in my mind. Yet, there I was driving up the mountain to the Second Chance Cheekeye Ranch, being pulled forward by some unseen force.

25% of the population living with NF type 1 lives with chronic pain, which has psychological consequences including anxiety, poor sleep habits and a lower quality of life. (Bellampalli, S.S., & Khanna, R. 2019) With no pharmaceuticals specifically for treating NF pain learning to accept the pain and live well in spite of it is the challenge.

My pain is not NF related. Injuries resulting from a car accident have limited by participation in most of the activities I once enjoyed. I experimented with various pain medications but they mostly left my brain mushy, forcing me to find alternate coping strategies to keep my brain sharp enough to work but turning down the volume on the pain enough so I could push through the day.

Meditation, breath awareness, and emotional freedom tapping are the tools I reach for now to manage the pain. But after a summer volunteering at the ranch I learned some new lessons in managing pain and how to expand the happiness in my life.

GET OUTSIDE

Living with daily pain and exhaustion can make your world very small as simple tasks become overwhelming. The horses were a great motivator for me to get out and head to the mountains.

There is an abundance of research highlighting the benefits of getting outdoors. From reducing pain, to increasing happiness and Vitamin D levels, which has great disease-fighting powers, getting outside helps in many ways. Getting outside is good for the body, mind, and soul.

GET ACTIVE

Thinking of getting active when you are a chronic pain sufferer can be daunting. While I have tried to stay active by walking my dog, many days I would get frustrated that I couldn't do the things I use to do to do such as cycling, paddling or running so I wouldn't bother doing anything.

But my love of horses and making a difference again pulled me forward despite the pain. I decided I could start small. I spent time sitting with the horses in a paddock and helping them rebuild trust, I took a horse for a walk on a lead line instead of riding. I limited grooming to just a few minutes. By focusing on what I could do I moved from feeling victimized by the accident to being back in control of my body and life.

CONNECT WITH ANIMALS

Animal-assisted therapy is a growing field that uses dogs and horse, and other animals to help people recover from or better cope with health problems, such as heart disease, cancer and mental health disorders. (Creagan ET, et al. Animal-assisted therapy at Mayo Clinic: The time is now. Complementary Therapies in Clinical Practice. 2015;21:101. *https://pubmed.ncbi.nlm.nih.gov/25900612*)

Research has shown that interaction with animals can decrease the levels of cortisol, the stress hormone, in your body and raise levels of the feel-good brain chemical dopamine.

At the ranch, besides horses there are donkeys, mules, pot-bellied pigs and a plethora of dogs to help soothe and heal. The moment I first arrived and parked my car to see horses roaming freely around the property I could feel the myself relax and joy spread throughout my entire body.

GET OUT OF YOUR HEAD

Thinking about your pain is the way to keep the volume on high. I found that the less I did the more time I had to think about the accident and the residual pain. Going to medical appointments became reminders of what I could no longer do and heighten the frustration and helpless I experienced. Moving my focus beyond my pain to something that made my heart happy helped me stop thinking about all my limitations.

FOLLOW YOUR PASSIONS

What did you love to do before pain was part of your life? What things did you enjoy as a child? Maybe it wasn't being with horses but knitting, dancing, writing or hiking, were your thing. Whatever your thing is that makes you forget about your pain, time, food and even using the bathroom is your soul's deepest passion. Care enough about yourself to make the time to reconnect with what bring your joy. You might not be able to do it at the same intensity or in the

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same way as you did in the past, but finding a way to do the things you enjoy is a guaranteed path to a happier life.

It's easy to say "I can't do ____" (you fill in the blank) because of pain. It's harder to push ourselves out of comfort zone, and break through our limiting beliefs to try something new. But you never how much you can do, until you try.

I wanted to volunteer at the ranch despite my limitations because I wanted to help horses. Turns out the horses did more for me. My time there hasn't made my pain disappear but I am happier and enjoying more life more fully now in spite of pain.

Desirée is the Executive Director of the Tumour Foundation. She is also the author of *Radical Inner Peace: Expanding Inner Peace Without Meditation* and *Refuse to Sink*. Connect with her at ***DesireeSher.com***. Learn more about the horses at the ranch by visiting ***secondchancecheekyeranch.com***

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FINDING MY TRIBE

AN INTERVIEW WITH CHARLOTTE

Charlotte has learned a lot in her mere twenty-two years. She's learned what it means to grow up with NF and how to pick yourself up when the cards just aren't in your favour. Executive Director Desirée had the chance to connect with Charlotte via video call to learn about her experience with NF.

Charlotte was diagnosed with NF1 at just two years old. Visiting two pediatric hospitals for nearly 17 years, NF was just one part of her childhood. "I've known all my life that I've had NF", Charlotte remarks. A struggle felt by many in our local NF community, Charlotte had no single physician to follow her on her journey with NF.

"There wasn't anywhere to get my check-ups regularly (like MRI scans, bloodwork, neurology appointments)." Charlotte still has ongoing challenges with her NF. Most pointedly, tumours. Fortunately, though, Charlotte shared that her main concern is just "a really tiny [tumour] in between the nerves where the eyes and nose connect". Yet in spite of her minimal tumour growth, Charlotte still has fears about her health.

"I notice more tumours on my face. It's just kind of scary because what if one of them gets very big?" But Charlotte's supportive community allows her to stay rooted in the present. She credits her family for teaching her positivity. At the mention of her two older sisters, I had to ask if they ever picked on her. Charlotte said thankfully she was saved from customary sibling teasing, but that she did face bullying in school.

When Charlotte moved to kindergarten, she realized she was different from everyone else. "Young children notice when people are different. Even though I've known all my life that I've had NF, they saw me and thought 'she's different'," Charlotte stated. "I always ask myself why some of them bullied me. Kids will be kids, as crappy as it is. I don't hold it against them." But as she transitioned to middle school and then high school, her friendships became "10 times better".

"It takes time and some effort, but when you find yourself and the group of friends who will stick with you for hopefully a long time, it's worth it." Charlotte doesn't shy away from explaining her diagnosis to the people in her life. "I explain the café au lait spots and that I get benign tumours. I also explain that NF affects everyone differently." And like most individuals with NF, Charlotte has also had to school a doctor or two.

Looking back on one experience with a physician, she notes how sometimes doctors forget how overwhelming NF is to patients.

"The doctor or nurse talking to my parents and I casually mentioned 'Oh, Charlotte has a tumour' and explained what that meant to my parents instead of me. Tumours are usually scary, so I had all these negative ideas come to mind. The person eventually backpedaled and explained that the tumour was very small and likely not harmful. But it was still a crappy interaction."

I THINK IF I DIDN'T HAVE NF I WOULDN'T BE SO UNDERSTANDING AND CARING. I THINK I WOULD BE A MUCH DIFFERENT PERSON. IT'D BE NICE TO GET RID OF THE TUMOURS, BUT THE COMMUNITY THAT COMES WITH NF IS REALLY GREAT.

Yet Charlotte has learned from this experience. When asked what she would to say to someone who isn't getting along with his or her physician, she recommends "looking into other doctors. At the end of the day, there's always going to be someone willing to help you get better."

Charlotte's perseverance and positivity has allowed her to pursue her dream of helping other people. Currently at school in Campbell River to become a support worker, her learning disabilities have never held her back. While it was a challenging transition to online learning, Charlotte was once again able to reframe her situation by choosing a "glass half-full" perspective.

"It's harder to do homework by myself now that our classes are on Zoom. It's also harder without any social interaction, but it has been a good challenge. So far so good!"

After completing her education program in March, Charlotte hopes to work with Campbell River Care in Counseling to support at risk youth and youth with disabilities. After that, Charlotte dreams of an adventure. "I'd really love to move to Victoria," she admits. "Or maybe go travelling across Canada or Australia on my time off – I would love that." When asked about the future of NF, she hopes that young adults become aware of the support available to them. "I feel that not many people outside of the NF community know about NF. The Tumour Foundation needs to keep reminding people that they aren't alone and that it's okay to have NF."

Since attending school and living with a genetic disorder (all amidst a pandemic), Charlotte knows the importance of self-care. When she faces tough days, Charlotte likes to talk to loved ones, eat some ice cream, or get outside to enjoy her new favourite hobby – roller skating. “I just got some really nice skates recently,” she says with glee. “I’ve been trying to go out every day it doesn’t rain.”

Charlotte’s optimism shines brightly as we discuss a variety of topics. Unsurprisingly, when asked if she would ever get rid of her NF, Charlotte says she wouldn’t jump at the offer. “I think if I didn’t have NF I wouldn’t be so understanding and caring. I think I would be a much different person. It’d be nice to get rid of the tumours, but the community that comes with NF is really great.”

Charlotte has learned some invaluable lessons through her journey with her genetic disorder, including “that it can be challenging at times but that’s why your family and friends are there for you – to help you grow as a person”.

Charlottes wants the NF community to know that just like everything else in life, managing NF just takes trial and error. “Just know that it gets better. Even when you feel alone, know that you aren’t. Reach out to your loved ones or the Tumour Foundation online. It takes effort but it’s totally worth it in the end.”

Interviewed by Desirée Sher

WHY OUR VOLUNTEERS CHOSE THE TUMOUR FOUNDATION

JILL, PRESIDENT

"I volunteer with the Tumour Foundation because I believe that focus, passion and persistence can result in meaningful change. I never want to look back and wonder if we could have done more to improve the lives of those with living with NF."

ALISON, BOARD MEMBER

"I volunteer for the Tumour Foundation because as a young adult living with NF1, the cause is very important to me. Living with NF is hard, but I want to find ways to make it easier for others."

JASSIE, ADMINISTRATIVE VOLUNTEER

"I volunteer with the Tumour Foundation because I feel a need to take meaningful action. It is incredibly satisfying to be able to support this foundation in making a positive difference in the lives of those with NF. Not only have I been able to develop my knowledge about NF, I am glad I have been able to give back by using my skills in a productive way."

MAYA, SYMPOSIUM AND MAGAZINE VOLUNTEER

"I volunteer with the Tumour Foundation because I love being able to foster and witness the amazing connections that take place at our events."

STEVE, PAST PRESIDENT

"I volunteer with the Tumour Foundation because my son has NF and I want to help a community that supports and cares for him."

SIMRAN, ADMINISTRATIVE VOLUNTEER

"I volunteer with the Tumour Foundation to make a positive impact in the NF community. It gives me pride knowing the skills I acquired from school helps to make a difference in the lives of others through the volunteering I do at this foundation."

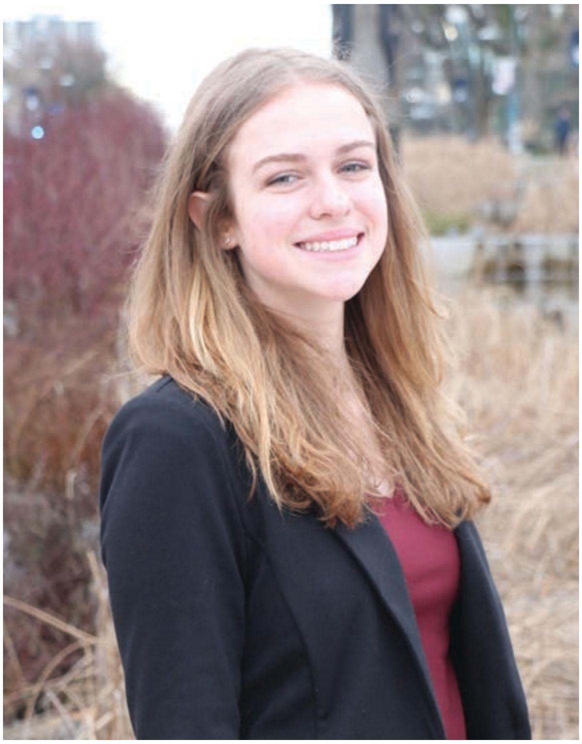
WANT TO GET INVOLVED?

Help us empower families. Find out more at *tumourfoundation.ca/volunteer*

Jassie

Steve

Jill



Maya

Make an impact

Making a difference doesn't need to involve a big time commitment or a large monetary gift. A small donation or volunteering a few hours can make a significant impact to the children and families living with neurofibromatosis (NF).

As the only charitable organization in BC serving the NF community, the demands of our programs continue to grow.

Learn how you can help us empower families at:
tumourfoundation.ca

TOGETHER WE CAN MAKE A DIFFERENCE!

Share your story

MAKE OUR VOICES HEARD

In each issue of ***Inspire***, we bring you stories of people just like you – stories of courage, of struggle, triumph and hope. Living with NF is hard, but we aren't alone and there is strength in facing the challenges together.

We need your story, too.

Readers just like you are eager to hear about your experiences and your journey. Please be a part of our next issue.

Visit **tumourfoundation.ca** to find out how you can take part.

WE'RE IN THIS TOGETHER

Tumour Foundation
of BC