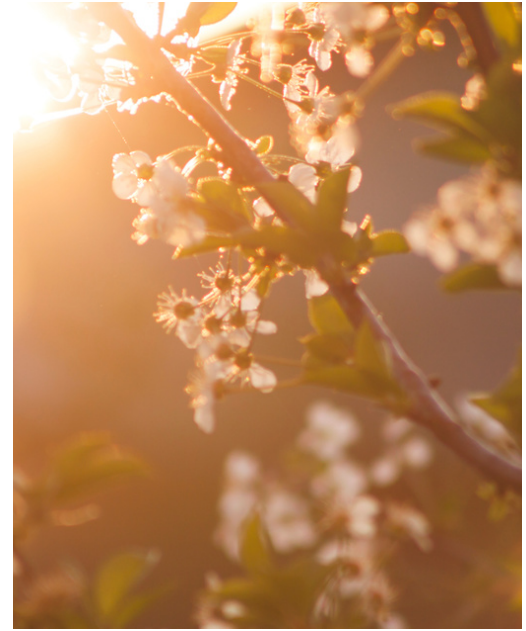


Life After Burns

Spring 2022 Newsletter



Welcome

Spring always brings a smile to many faces as the air gets warmer, the sky gets sunnier, and the world gets more colourful. We welcome you to embrace new growth and love into your life by supporting yourself, your loved ones, and anyone you meet. What you put out into the world is what you will receive back - so lead with kindness and love and you will feel it!

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A Word from Victoria

I am excited to say that the Life After Burns team has been growing! We have a wonderful new social media team, filling our Instagram with awesome content, go check it out if you haven't already. We have some new volunteers helping with HR, and support services. If you are interested in volunteering with us, just fill out a form or email us, we love seeing our team grow.



Looking forward to the upcoming months, get excited for some in person meetups here in the Greater Toronto Area. We have some programs under construction that we want to implement as soon as we have the resources.

If you or someone you know could add their expertise to Life After Burns send them our way. We want to create a large group of resources virtually and in person to continue to build the network of support for burn survivors and loved ones.

We also have a donation page with many ways to donate. Please consider donating so that we can improve and create more resources for the burn community. www.lifeafterburns.ca/donate

“Every human is an artist. The dream of your life is to make beautiful art.”

DON MIGUEL RUIZ



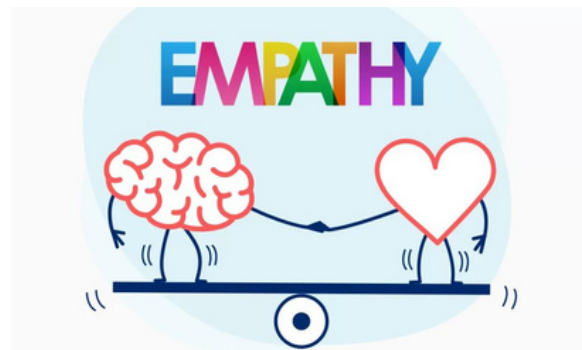
UNWELCOMED EMPATHY

WHEN EMPATHY CONVEYS A NEGATIVE FEELING

BY: MOJTABA (MOE) KHEZRY

Empathy is the capacity to perceive an emotional state similar to another being. Empathy is deemed to be important in building and maintaining social relationships. Empathy can be categorized in two forms: **(1) cognitive** empathy and **(2) emotional** empathy.

Cognitive empathy where one sees the world in other person's view point. This is what we typically call putting ourselves in someone else's shoes.



Emotional empathy is where one shares pain or distress to an extent where they feel similar pain or distress. A good example of emotional empathy is when one gets tearful by watching a sad movie or gets upset by watching upsetting news.

Emotional and cognitive empathy can have both positive and negative effects. The positive impact of being empathetic is that one may experience a more immersive, serene and joyful experience of attending a concert or a movie. The negative impacts of empathy have been well studied in highly empathetic parents; where they tend to have low level chronic inflammation and lower immunity.

Impacts of empathy is well studied in the giving partner, however there is very little known about impacts of empathy on the receiving partner. I have personally never liked it when someone looked at me and said "awww, that must've been painful burn experience" or "awww, it must be tough to deal with social impacts of apparent burn injury like yours". These feelings have been my own personal experiences and affirmed by fellow burn survivors.

Let's end this conversation with a Persian poem from Saadi:

*Human beings are body parts of each other, In creation they are indeed of one essence.
If a body part is afflicted with pain, Other body parts uneasy will remain.
If you have no sympathy for human pain, The name of human you shall not retain.*

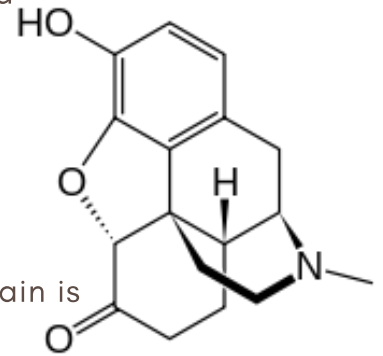


Current Research: literature review

BY: MOJTABA (MOE) KHEZRY

OPIOIDS AND THEIR ROLE IN BURN RECOVERY

Burn survivors require comprehensive care from multidisciplinary healthcare fields. One such area of care critical to patient recovery is pain management. Burn survivors could experience pain and discomfort due to tissue damage and the many medical procedures put in place to ensure long-term safety and speedy recovery of patient. Let us categorize different forms of pain perceptions a patient might be experiencing: (1) **Acute pain**, associated with dressing change and physical therapy, (2) **breakthrough pain**, associated with contractures and tissue healing, (3) **resting pain**, pain that is almost always there (4) **chronic pain**, this will remain with patients for 6 months or longer (5) **neuropathic pain**, this form of pain is associated with damage to nerves, miss-firing nerves.



Molecular image of hydromorphone

While neuropathic pain is often treated with pregabalin, all other forms of painful experiences are treated with opioids, specially during the acute phase of burn care. The journal article cited below poses some important questions relating to pain treatment with opioids as applicable to cancer care, some of which might be interesting to ask of burn care and we beg similar questions of burn care researchers.

Afsharimani et al. discusses the role of opioids as disruptors of extracellular matrix and attachment of new cells to extracellular matrix. Extracellular matrix also has a crucial role in adhesion of grafted skin to the grafted site. We therefore beg the question "Could the use of opioids as pain management effect healing and adhesion of skin graft in burn treatment?"

Afsharimani et al. discusses the immunosuppressive role of opioids in cancer patients. It is also known that during acute phases of burn care, newly grafted skin and other cells affected by the mechanism of injury might be prone to carcinogenesis and metastasis. We hereby beg the question "Are opioids a safe choice, knowing their immunosuppressive role?"

AFSHARIMANI, BANAFSHEH, PETER CABOT, AND MARIE-ODILE PARAT. "MORPHINE AND TUMOR GROWTH AND METASTASIS." *CANCER AND METASTASIS REVIEWS* 30.2 (2011): 225-238.



“WITHOUT SELF-DOUBT, SELF-LOVE CANNOT GROW”

A POEM

BY: LAURA NUCCITELLI



Self-doubt shall forever remain
Even when self-love's seeds are
planted, self-doubt is a
perennial flower
Self love shall flourish
alongside self-doubt
Self-doubt shall forever take
over our minds, even at life's
peaks
For in the absence of
self-doubt, self-love cannot
grow



CAREGIVER STORIES

A MOTHER'S STORY

BY: PEGGY TSUKAMOTO

Hi Everyone - My name is Peggy and I am so grateful to have found LAB as a support group for me. Our son was the victim of arson almost 5 years ago and as a caregiver, I too, was affected by that cruel act. Our son was preparing for his second year of university, two weeks into his first experience of living alone when he encountered the fight of his life. Having received that horrible call from the Ottawa police advising me that he will be arriving by air ambulance to Sunnybrook later that day, still repeats in my head to this day. After two months in hospital, we brought our son home and over the next year, our family healed together. Fast forward, my son returned to Ottawa, completed his studies and re-settled in Vancouver. He is remarkable! We are so very grateful.

I am part of the caregiver support group with really fabulous people and am fairly new to the group but feel like I am already part of another family. I am able to express feelings I have that I was not quite sure how to process, only to be reassured that they are normal and other caregivers experience similar feelings and share their journey. It is very clear that there will be struggles with what happened, but I am comforted by the fact that I am not alone and can reach out whenever I need to. Future plan, how do we expand this program? Support for survivors and caregivers in Ontario seem to be sparse. Hopefully for a future newsletter, there will be an update to that!



CAREGIVER STORIES

A MOTHER'S STORY

BY: ASHLEY CORREIA

In April 2019, I had the honour to be a guest speaker at the Joey Conte Gala. The Joey Conte Foundation (JCF) is committed to raising funds for the Burns and Plastics Unit at SickKids in memory of Joey. Never would I have imagined standing in front of 900 guests (I was so nervous!) and sharing our families experience with the burns & plastics unit. This experience gave me the opportunity to thank the burn team – a phenomenal group of people that helped my daughter Brooklyn and our entire family during one of the most vulnerable points in our lives – while also helping to raise money for a wonderful cause.

On February 13, 2013, at two months old, Brooklyn sustained a very serious scald burn injury to 15% of her body. She had second- and third-degree full thickness burns that would require a skin graft surgery. We spent five weeks at SickKids Hospital in Toronto, where she received incredible care in the PICU and the Burns and Plastics unit.

A year and a half into her recovery, we learned about a new laser therapy treatment that was meant to help with scar management. There are two types of lasers – the carbon dioxide laser which helps to soften and flatten a raised scar, and the pulsed-dye laser which helps to reduce redness and itch. SickKids became the first hospital in Canada to offer laser therapy treatment. We felt (and still feel) extremely grateful to Dr. Joel Fish, Nurse Practitioner Charis Kelly and to all the private donations that helped to bring this technology to SickKids. Though the laser therapy would never completely make a scar go away (or take away any of the painful memories of the initial accident), we are very thankful that Brooklyn has been given the opportunity to receive this treatment.

Each time we return to 8C (Burns & Plastics Unit) it brings a mixture of emotions and a flood of memories back for me as her caregiver. It has taken a long time for me to stop thinking about the “what ifs”, and I will always carry guilt for not being able to protect Brooklyn on the day of her injury.



CAREGIVER STORIES

A MOTHER'S STORY

BY: ASHLEY CORREIA

By now, Brooklyn knows what to expect when she goes in for a procedure – to date she has benefited from over a dozen laser therapy sessions. She knows she must try and get lots of rest the night before, and eat a good meal because she can't have any food past midnight. She always brings her favourite stuffy 'Fluffy' for comfort. When we arrive at the hospital, it is always nice to find a familiar face among the staff. Many of them have gotten to see Brooklyn grow over the last 9 years. Though the laser procedure itself usually does not take long, it takes time for the anesthetics to wear off and for Brooklyn to start to feel like herself again. She spends the remainder of day doing low key activities – reading a book, playing games or watching tv and is usually counting down the minutes to when she can remove the dressing. Within a few days she is back to her regular activities. Her bravery and courage inspires me every single time.

We do not know what the future will hold, but my husband Chris and I do our best to remind Brooklyn that she is brave, strong and beautiful and that she can do anything she puts her mind to. Because she was so little when she had her injury, her scars are all she has ever known. I hope that as she grows up, she will remain confident and comfortable in her skin. This summer Brooklyn will get to attend Camp Bucko (Camp for Burn Survivors in Ontario) for the first time. I hope she will have the opportunity to make lifelong memories and friendships with other burn survivors.

One of the most important lessons that I take away from this journey is the importance of gratitude. I will never take anything for granted and will always be incredibly grateful for the burn team, for the family that was with us day in and day out, and for the friends we have made along the way.

Don't be afraid to share your story and always know that you are never alone.



Books You Should Know

CAN YOU SEE MY SCARS? BY: SAMUEL MOORE SOBEL

www.samuelmoore-sobel.com

Relatable and authentic, Samuel writes his story, candidly detailing the challenges he faced after being severely burned from sulphuric acid. I had the pleasure of meeting Samuel virtually and he will be presenting at our May 19th Session. He has amazing energy and is a talented columnist and author. Check out his book and make sure not to miss his Session in May.



THE FOUR AGREEMENTS BY: DON MIGUEL RUIZ

www.thefouragreements.com

Review by Pat Dixon

Victoria highly recommended the incredible book THE FOUR AGREEMENTS: A Practical Guide to Personal Freedom, by Don Miguel Ruiz. It is a fantastic book for stress management and personal growth. If you are looking to go on a healing journey this book sets the ground rules perfectly. I found the teachings to be so profound that I apply the teaching daily. I've listened to the audio book several times. It is only 2 ½ hours long, it is concise, insightful, and has the power to change your life by changing the way you think. Here is a brief synopsis of the four agreements.

The first agreement is to BE IMPECCABLE WITH YOUR WORD: This agreement stresses the importance of avoiding gossip, or talking about people behind their back. Our words can hurt others more than we realize, and in hurting them, we hurt ourselves

The Second agreement is DON'T TAKE ANYTHING PERSONAL. This agreement stresses not to take things personally and other people's behaviors are a reflection of them not you. Taking things personal creates inner turmoil.

The third agreement is DON'T MAKE ASSUMPTIONS. A lot of stress is created when you assume you know what other people are thinking without checking with them. We set ourselves up for failure if when we make assumptions. If you don't know something, ask, don't make assumptions.

The fourth agreement is ALWAYS DO YOUR BEST. Do the best on any given moment so you'll have no regrets. Some days your best isn't as good as other days as long as you put an honest effort in and do your best that particular day.

Focusing on the four agreements has been transformative for me by helping me avoid thought and behavior patterns that create stress and other negative emotions. Learning and applying the four agreements in my daily practice has improved my life and it has the power improve yours as well.



PEER SUPPORT GROUPS

BURN SURVIVORS & LOVED ONES

Our monthly support group for burn survivors and loved ones focuses on peer-to-peer support. It is an open chat, with a topic or speaker at each session. Hosted over Zoom every 4 weeks on Wednesday's at 7pm EST.

www.lifeafterburns.ca/peer-support-groups

CAREGIVERS

A monthly support group for caregivers and family members of burn survivors. This group allows the chance to connect and discuss various topics unique to the experience of providing care for a burn survivor at different stages of their healing journey. Be a part of the community by asking questions, sharing your story, and reflecting.

This group is run by Barb Hodge, a retired Occupational Therapist, and Sandy Cook, a caregiver and wife of a burn survivor.

This is a closed group, for caregivers only.

www.lifeafterburns.ca/peer-support-groups

SHARE YOUR STORY

Would you like to share your story with others?

Sharing your story is a great way to inspire others. By finding similarities in each others stories, it helps us live more fulfilling lives.

In sharing your story, you can:

- Make others feel less alone
- Give others a voice, find your voice
- Spread hope and awareness

Share at www.lifeafterburns.ca/share-your-story.



Programs

SESSIONS

Experts join us once a month to talk to us about an important topic relating to burns, self care, and healthy and happy living. Hosted over Zoom. Every 3rd Thursday, a speaker discussing a burn-related topic will join us for 40-60 minutes. There will be a chance to ask questions after the speakers presentation.

April 21 2022, 7pm EST

John Westhaver, How do I pick up the pieces and keep going after a major trauma?

May 19 2022, 7pm EST

Samuel Moore Sobel, The Secret Power of our Scars

Register at www.lifeafterburns.ca/sessions

(You only need to register once to receive monthly links)

DONATE

Consider donating to Life After Burns to help us create more programs for our community! All proceeds go towards our programs and operations supporting those benefiting from our resources.

www.lifeafterburns.ca/donate

VOLUNTEER

Come volunteer with Life After Burns. There are many different ways you can bring your skills to our organization.

www.lifeafterburns.ca/volunteer

CALENDAR

Stay up to date with the burn community events, groups, and programs.

www.lifeafterburns.ca/calendar



Resources

LIFE AFTER BURNS

www.lifeafterburns.ca

ourlifeafterburns@gmail.com

CANADIAN BURN SURVIVORS COMMUNITY

www.canadianburnsurvivors.ca

ADVANCEMENT OF CARE AT SUNNYBROOK HEALTH SCIENCES

<https://www.youtube.com/SunnybrookHospital>

PHOENIX SOCIETY FOR BURN SURVIVORS

<https://phoenix-society.org/>

MSKTC

<https://msktc.org/burn>

