



MANAGING LIFE WITH LUPUS

Hosted by: Brynn Clark



Brynn Clark

- Diagnosed with SLE in September, 2010
- Sole support parent of 5
- 3rd Year Carleton University student (B.Sc. Earth Science)
- Lupus Ontario Board member
- Ottawa Walk for Lupus co-Ordinator
- Ottawa Lupus Support Group co-facilitator

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I didn't like the hand I'd been dealt in life, so I changed the game. My epiphany came when I realized that at the end of the day, it's only my choices that will determine whether this life will be remembered and measured in pain, or in memories.

BRYNN CLARK





HOUSE FLOOF GUINEA PIG RESCUE!

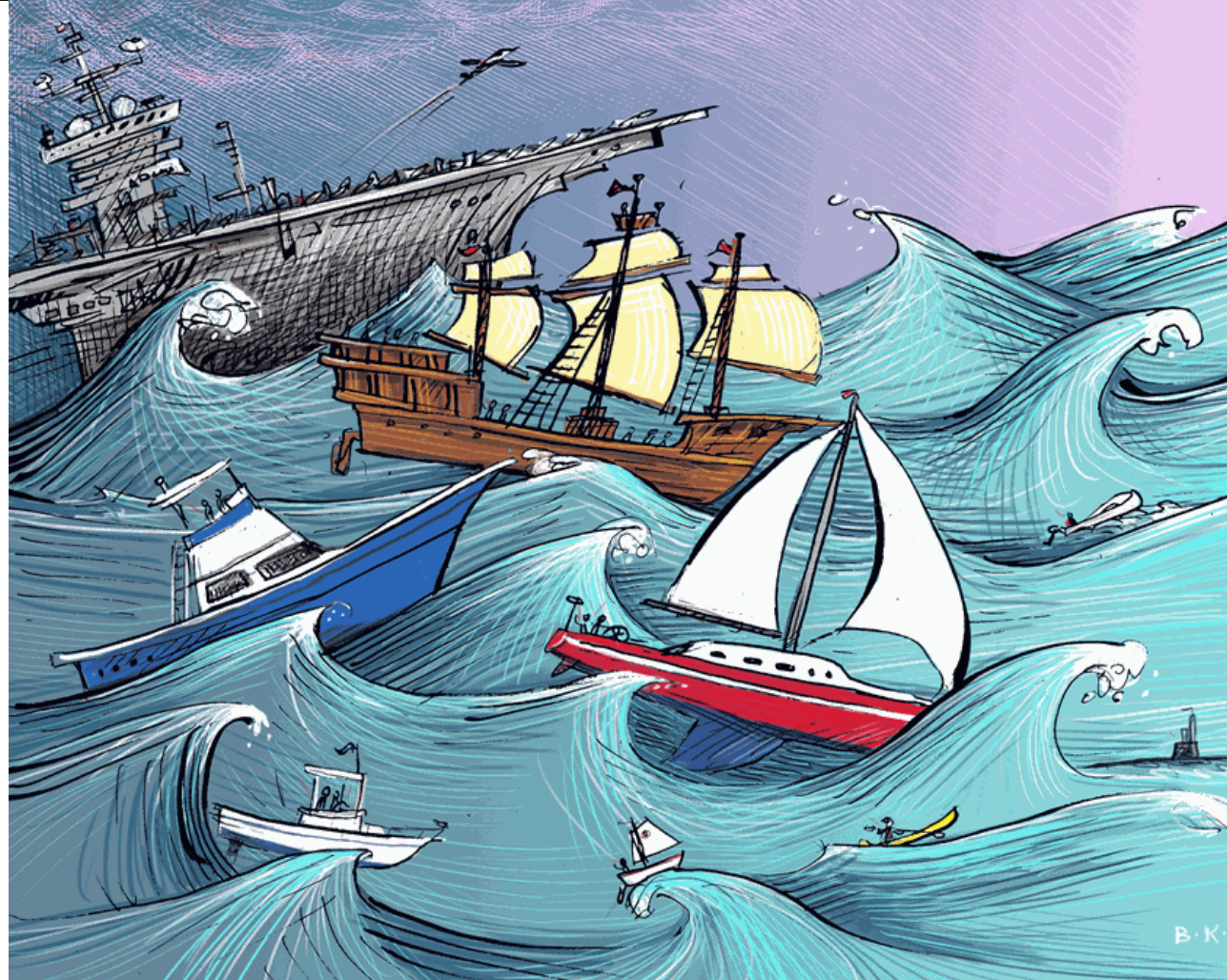
Federally incorporated, not-for-profit guinea pig rescue.

Featuring: Watson, a House Floof OG! ☺

Agenda

- Newly Diagnosed?
 - *Tips for communicating with your healthcare team*
 - *Make that “pain chart” your own*
- Parenting
 - *Age-relevant conversations*
 - *Finding alternatives to activities*
- Managing Common Symptoms
 - *Brain Fog*
 - *Pain*
- Mental Health
 - *Stress Management: Michelle Bruxer, MSW RSW Webinar*
 - *How to say, “No.”*

We're all in the same storm...



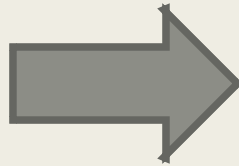
Kelly, B. (2019). Not in the same boat [Photograph]. *Directory of Illustration*.
https://www.directoryofillustration.com/illustration_image_details.aspx?AID=6123&IID=277899

...but not in the same boat.

Newly Diagnosed?

Multi-decade Veteran of Lupus?

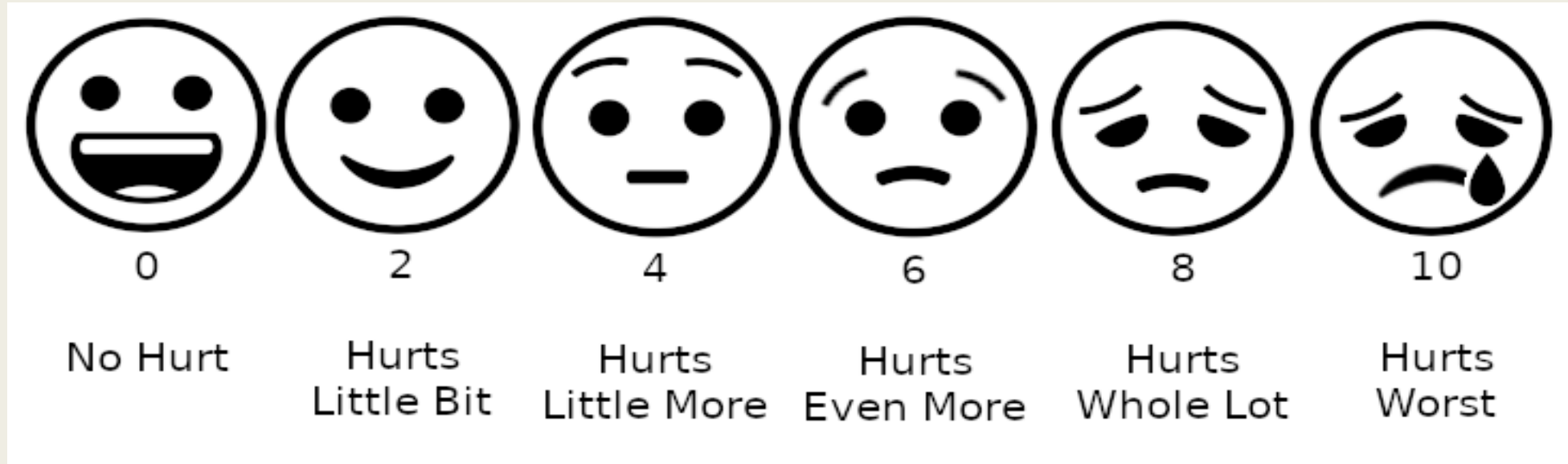
- Don't know where to find accurate, **credible resources**
- Fear
- **Feelings of loss of control, invisibility**
- Anger – how to make family & friends aware? (*anger is a reaction/symptom of a deeper, root emotion*)



- Have found new coping skills
- Communication with healthcare professionals
may have solidified
- The power of setting one's boundaries
- LOSING THE GUILT (still trying to!)

Wong-Baker Pain Scale

(aka, Nope...No, thank you)



Is this what normal
Feels like?

Weird, but okay

Not happy
Migraine

Not functioning
Childbirth

Gallstones
Kidney Stones

“I’ve had FIVE children, I have a high tolerance for pain. Solid 8 on my scale.
The fact that I’m bringing up where my pain levels are, should indicate to you that I
need your help.”

Parenting

- Books: allows you to see examples of other patient experiences
- Do these examples work for you? Why or why not? How would you modify the suggestion?
- Finding age-appropriate language
- Have a list of activities to choose from – i.e. To be dependent upon which symptom is most aggravated
- Most challenging: Having Covid (*October, 2020*), and trying to manage home, kids, health, etc.



2010, just prior to receiving Lupus diagnosis
Kids were 15 (not shown), 11, 5, 3 year old twins

“Brain Fog”

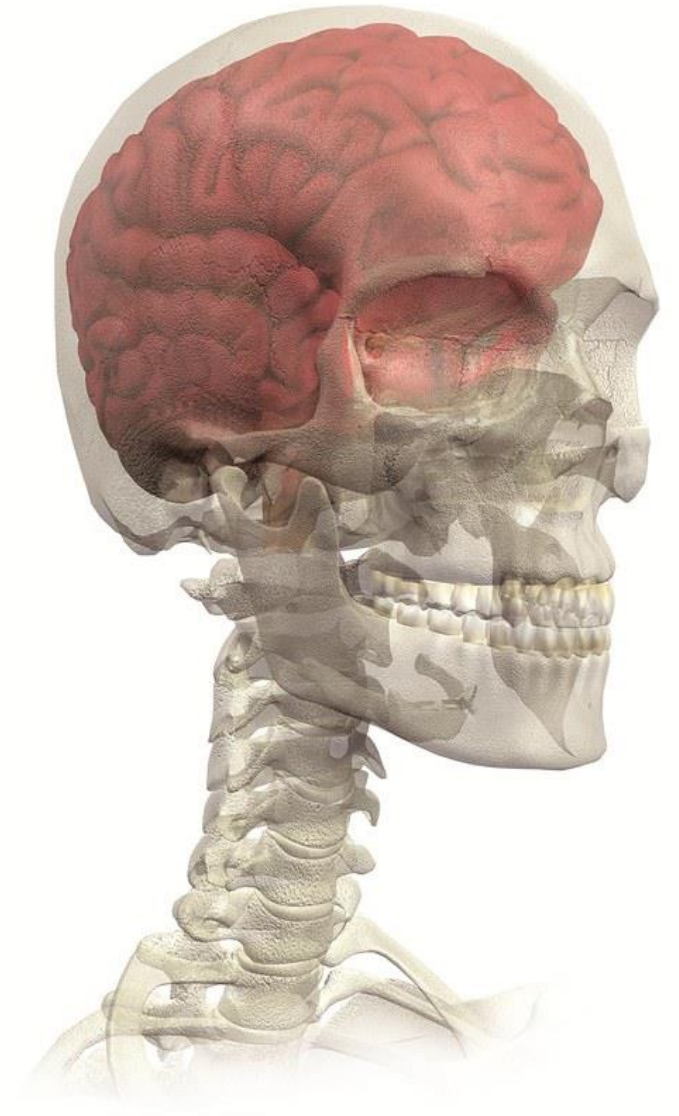
(in air quotes, but it's REAL)

- Out of 19 different types of neuropsychiatric lupus, **cognitive dysfunction**, (what Lupus patients call brain fog), is represented as having any difficulty with normal thought functions or processes.
- Some possible causes of cognitive dysfunction are:
 - Stress
 - Anxiety
 - Depression
 - Lack of sleep
 - Illness
 - Pain
 - **Medication**
 - Diet

(can all be made worse during periods of flares)

Coping...

- Calendars...yes...plural
- **Notebooks**
 - *Everywhere! Yes. Absolutely **everywhere**.*
- Lists
- Schedule nap/powernap (10-15 mins)
- **PRIORITIZE!**
- Meditation (*okay, so NOT for me...the hamster won't allow it*) = *adapting to find alternative self-care*
- Brain games!
 - *Word search; crosswords*



Pain & Fatigue

(that dastardly duo...)

- *Critical point: **reducing inflammation**
- Keeping A1C in check & daily blood glucose levels
- Moving HURTS: BUT!! small movements are better than no movements = lower blood glucose levels = lower inflammation
- Emma's "Dance & Movement: The Intersection Between Movement, Art & Chronic Illness", Lupus Ontario
- Set a timer for 2 minutes (5, 10, etc)
- Walk up & down a flight of stairs
- Use resistance bands for seated movement
- Significant mental health effects, positive OR negative!

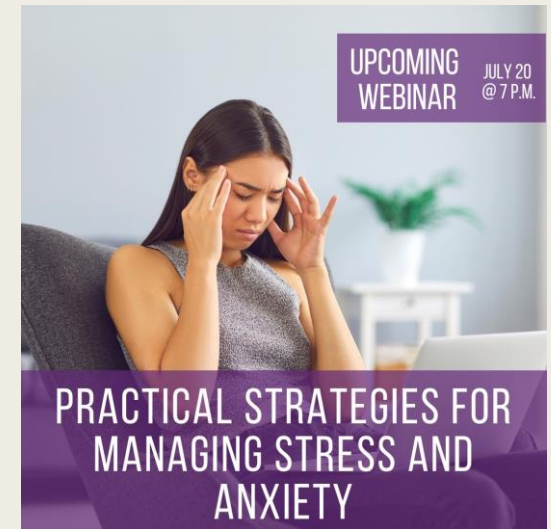


Mental Health

(here's where it gets “real”)

- Brain Trolls are Boggarts
 - Not All Rainbows, All of The Time, nor “Whine-1-1”
- BOY, have I ever had to own my proverbial s....
 - I have to ask for help
 - I have to look for resources (ex, Lupus Ontario website)
 - I have to decide how long to feel my less-than-stellar emotions
 - I have to find adaptations to information to educate in a way my family & friends will better relate
- It was during having Covid that were my darkest hours
- Found an online counsellor through my university
- Asked my doctor to renew my depression medication pre-emptively prior to courses restarting this fall

!!!HOW TO SAY “NO” AND LOSE THAT GUILT!!!



- Lupus Ontario Website
- Under “Living with Lupus”
- Under “Education”
- Recording of July 20th presentation by Michelle Bruxer!



MY KEY TO LIFE:

I make so many **choices** each and every day to craft a life with Lupus that is worth living.

I don't want to be remembered for having Lupus, at my end of days.

I want to be remembered for *living a life despite* having Lupus.

SO DO YOU...because YOU MATTER.