



Combating Compassion Fatigue for Families and Caregivers of Children with Special Needs

Friday, October 23, 2020

Web Streamed from Vancouver, BC

Presented by

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Certified School Psychologist

Sponsored by:



This workshop is partially funded by the Government of Canada's Emergency Support Fund and the Vancouver Foundation.



Event Schedule

All times are in Pacific Time

9:30 – 10:30	Session 1
10:30 – 10:45	Break
10:45 – 11:45	Session 2
11:45 – 12:30	Lunch
12:30 – 1:30	Session 3
1:30 – 1:45	Break
1:45 – 2:45	Session 4

Tips for Improving the Web Stream Experience:

- Be sure your speakers or headphones are on, and the volume is up.
- Before the presentation and during breaks, the image and audio will be obscured.
- Close open 'tabs' in your browser. This will use your computer's memory and slow the connection.
- Check that your browser is up to date.
- If video is stuttering or jumpy, change the resolution by clicking on the 'gear' icon (bottom right corner of video).
- To go full screen, click on the 'box' icon in the lower right of the image.
- If you are having trouble with Internet Explorer or Safari, try [Google Chrome](#).
- For more troubleshooting information, please visit: <https://xelivebroadcast.com/vimeo/>

Acknowledgements

ACT – Autism Community Training offers our special thanks to Dr. Georgina Robinson, head of the Provincial Outreach Program for Autism and Related Disorders (POPARD), for agreeing to present for our Fall 2020 Free Web Stream Series. As we all struggle to keep our communities healthy, we appreciate that ACT can offer this workshop while maintaining the safety of attendees, staff, and our presenter. Many thanks to the Sheraton Wall Centre and the always practical support of Sean Antonson, Director of Sales, for providing us a base to continue our work. And to Justin Ritchie of XE Live for supporting the web stream!

This event has been made possible thanks to the generous support our sponsor POPARD, as well as of the Government of Canada's Emergency Support Fund and the Vancouver Foundation, and our individual donors. We are very grateful for this collaboration, which has allowed us to web stream this presentation for free to families in British Columbia, across Canada and internationally.

Those who have attended ACT events over the years know that we depend on community collaboration and support to sustain our work. ACT deeply appreciates the many parents and professionals across British Columbia who volunteer their time and support, donate funds, and help spread the word - especially during these challenging times.

Free Resources from ACT

ACT's Coronavirus (COVID-19): Resources for the Autism Community - ACT has gathered resources specific to those who are neurodiverse and useful general resources to provide support to families throughout the pandemic. www.actcommunity.ca/covid-19-resources

Autism Videos @ ACT (AVA) – Over 60 quality online videos available free – without a log-in, thanks to our sponsors. www.actcommunity.ca/videos

ACT's Autism Information Database (the AID) – Like Google for Autism but better! Keyword search nearly 1,500 curated AID records for evidence-informed, practical information resources useful to families and community professionals. www.actcommunity.ca/aid

ACT's BC Community Resources Database – Search by your postal code for professionals and service providers throughout BC. www.actcommunity.ca/aid-search/community

ACT's Autism Manual for B.C - 13 chapters! www.actcommunity.ca/autism-manual-for-bc -

ACT's Monthly News Round-Up & Event Alerts - Sign-up to keep in touch with developments affecting the special needs community. www.actcommunity.ca/updates

ACT's Facebook - ACT carefully sources interesting, insightful stories to inform our 8,000 plus followers. www.facebook.com/autismcommunitytraining

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COMBATTING COMPASSION FATIGUE

FOR PARENTS AND CAREGIVERS
OF CHILDREN WITH SPECIAL
NEEDS

Dr. Georgina Robinson,
October 23, 2020



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Outline

- Associated Concepts and Definitions
- Why parents of children with special needs are at risk
- Compassion Fatigue
- Resilience-Bounding Beyond
- Protective and Combat Factors (systems and personal)
- Self Care
- Mindful Self Compassion
 - Learning Intentions
 - Understand these phenomenon
 - Research Supported Recommendations
 - Application throughout - Leave with some Strategies

2

Setting the Stage

Recognizing that parenting is the hardest, most challenging, most joyful, most important job you do every day

This topic can be tailored parents or helping professionals, but the focus for examples will be from the parent perspective

For this session give yourself a break. Stop. Breathe. Listen

Take care of your needs when you have to

Go to the bathroom. Stand. stretch. Have a cup of tea.

Make a u turn

Be kind to yourself

This session hopes to validate your journey and provide seeds of support

Grab a pen and paper

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The joys and challenges of parenthood

- For some, the transition to parenthood is easy.
- For most, some level of anxiety, exhaustion and stress accompany the parenting role.
- For parents who have children with a disability or chronic condition, parenting is monumentally more difficult
- Being a parent to a child with special needs brings unique joys
- A lot of this is due to the human ability of Empathy

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Empathy

- Ability to understand and experience the feelings of another
- Enhanced during parenthood and necessary for successful parenting
- Necessary skill for therapists
 - (Carl Rogers)
- Can result in both positive or negative outcomes for the empathizer
- How we manage empathy is key

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Brene Brown on Empathy versus Sympathy

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STRESS AND COPING

Caregiver stress and coping

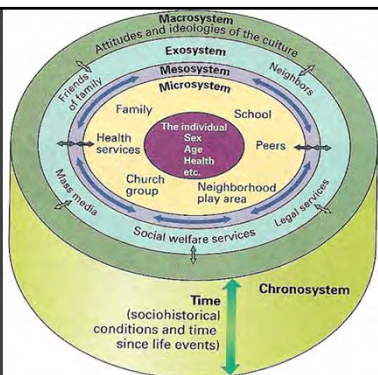
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Stress and Coping (Lazarus and Folkman, 1984)

- *“psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being”*
- An imbalance between demands and resources
 - (internal and external)
- Stress responses are physiological, psychological and behavioural

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BRONFENBRENNER'S ECOLOGICAL SYSTEMS THEORY (STRESS IS INFLUENCED ACROSS SYSTEMS)



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Multidimensional Model of Caregiver Stress and Coping (Raina et al., 2004, 2005)

◦ "The characteristics of the caregiver, the recipient of care, their shared history, and the social, economic and cultural context within which they find themselves combine to create an infinite variety of circumstances from which stress may both originate and be managed. "

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Identify Your Sources Stress

Characteristics of your child

Your own characteristics

Your family

The school

Medical/ treatment centers

Your work

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Compared to Parents of Neurotypical children, Parents of children with disabilities experience

- Greater amounts of stressors
- Greater amounts of compassion fatigue and burnout, and lower amounts of compassion and parenting satisfaction
- Greater incidence of physical health difficulties
 - (including changes in telomere length and DNA, e.g., Berens et al., 2017)
- Greater incidence of mental illness including anxiety & depression

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Some Specific Stressors identified by parents of children with disabilities (e.g., Cousineau, Hobbs, & Arthur, 2019; Neff, 2014)

- High demands of child (severity of disorder & challenging behaviour)
- Frequent interaction with medical, treatment and school systems
- Lack of or inadequate treatment
- Costs and hassles associated with access
- Financial difficulties when parent can not work (needs to care for child)
- Marital stress
- Lack of respite or down time
- Worries about day to day and future of child
- Social and community isolation (social comparison/inability to participate)
- Stigma, self criticism, self blame and shame

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Stigma and Shame

(e.g., Wong, Mak & Liao, 2017)

- Especially if children have invisible disabilities
 - (e.g., ASD, mental health)
- Children display socially inappropriate behavior
 - tantrums, flapping, acting "strange"
- Parents receive frequent criticism and unsolicited judgment from onlookers, family members, professionals
- External blame and embarrassment
- Internalizes into: Self criticism and Shame
- Cultural and societal beliefs and attitudes influence

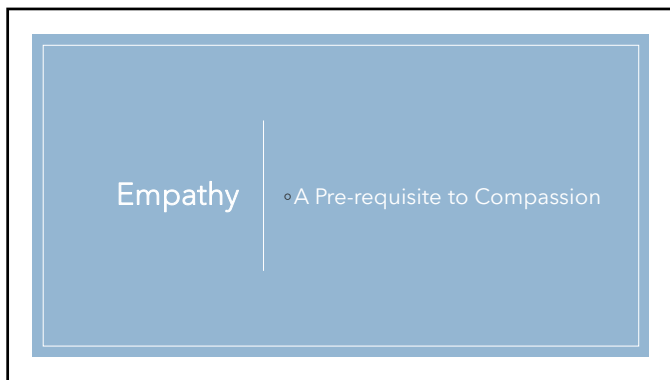
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The Parent Experience

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Dacher Keltner,
UC Berkley psychology
professor and faculty
director of the Greater
Good Science Center,

**Explores the
evolutionary roots of
compassion and
empathy.**

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Yin and yang self-compassion:

Using caring force to change ourselves and our world

Being with
ourselves

Yin:
- Comforting
- Soothing
- Validating

Yang:
- Protecting
- Providing
- Motivating

Acting in
the world

Nair, K. D. & Germer, C. K. (2018). The Mindful Self-Compassion Workbook. New York: Guilford Press.

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Compassion/Caregiver Satisfaction

- Positive cognitive, emotional, behavioural and physical consequences of providing compassion
- Feeling strengthened, accomplished, empowered,
- connected, loved, appreciated
- Positive self image
- Satisfied or proud in the role as a caregiver
- Appreciation and recognition of different values and meaning in life
- Deeper understanding of others and greater ability to be compassionate to self and others



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Compassion Fatigue

(e.g., Figley, 2002)

- Emotional and physical exhaustion, including feelings of irritation, anxiety, hopelessness, and depression leading to a diminished ability to empathize or feel compassion for others.
- "The negative cost of caring"
 - a normal response to challenging and overwhelming situations experienced by those who care for others, including professional helpers, volunteers, and family members.
- It develops over time and in stages


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THE STAGES AND CYCLE OF COMPASSION FATIGUE

Figley institute

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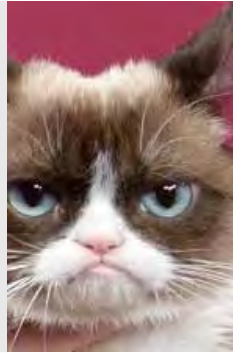
Zealot

- Keen & committed
- Going above and beyond
- New parents promising only to use cloth diapers and home made organic baby food
- Reading up on every aspect of parenting, treatment, disability knowledge
- "I am therapist, nutritionist, coach"

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Irritable

- Unable to meet expectations you've set for yourself
- Avoiding/resisting your emotions
- Frustrated with others and your child
- Use of sarcasm "Sure, I'd love to attend another therapy session where you coach me how to control his tantrums. It's going so well!"
- Don't want to talk about the real issues, distract and redirect



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Withdrawal

- Drained of energy
- Difficulty coping with minor demands
- Feeling sad, isolated, hopeless
- Avoiding your child
- Leaving it to the teacher, babysitter, video game to occupy him
- Don't attend school or treatment meetings
- "That parent never makes it to these sessions."




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Zombie

- On automatic pilot
- Never have fun
- No patience
- No compassion
- Feel burdened
- "I'm the only one who can do this."
- "I'm exhausted but I'm doing it anyway."
- Hopelessness turns to rage



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UNWELL (BURN OUT) VERSUS RENEWAL (RESILIENCE)

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Identify Where You are on the Stages of Compassion Fatigue

Zealot

Irritable

Withdrawal

Zombie

Unwell

Renewed


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Symptoms of Compassion Fatigue
(Figley, 1995, 2002; Hansen et al., 2018)


- **Physical**
 - Lack of energy, exhaustion, sleep disturbance, gastrointestinal issues, headaches
- **Emotional**
 - Overwhelmed, emotionally depleted, sad, irritable, angry, enraged
 - Helpless, hopeless, depressed
- **Cognitive**
 - Inadequate, incompetent
 - Inflexible, rigid, intolerant, blaming of others (and self)
- **Behavioural**
 - Over engagement > Task avoidance, disengagement, detachment

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Do you recognize any symptoms?




PHYSICAL



EMOTIONAL



COGNITIVE



BEHAVIORAL


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Good News

- Not *ALL* parents develop stress disorders and compassion fatigue
- Caregiver resilience and strategies to combat compassion fatigue can lead to adaptive outcomes

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Caregiver Resilience

- The ability to adapt well psychologically, emotionally, physically in the face of adversity and stress.
- The ability to bound back (or beyond)
- Resilient individuals resemble "a *twig with a fresh, green living core. When twisted out of shape, such a twig bends, but it does not break; instead, it springs back and continues growing.*" (Vaillant, 2002)

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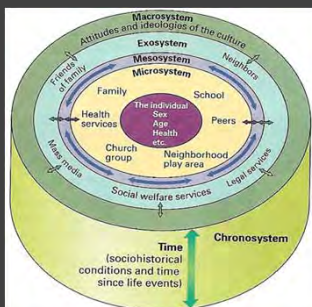
Bounding Back (and beyond) with the Jackalope

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PROTECTIVE FACTORS ACROSS SYSTEMS



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Social Policy

- Policies and ideologies
- Governments and Agencies
- Society influences Policy
- Policy influences Society

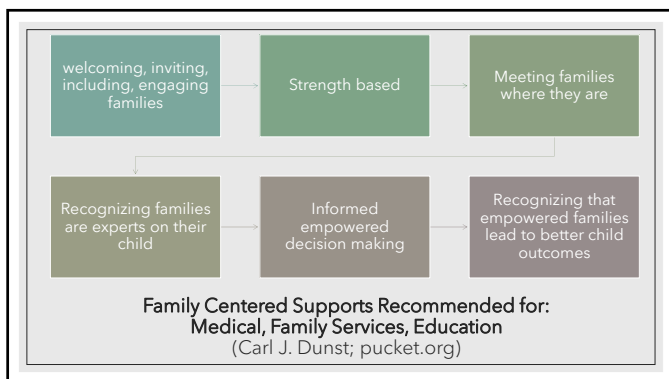
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Your Workplace

- What is necessary?
- What is doable?
- Maternity and parental leave
- Flexible hours
- Results focused versus Presenteeism
- Onsite support
- Note: for caregiving professionals, skilled debriefing rather than venting opportunities are needed

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Parent to Parent Supports

- Specialized focus on parenting children like yours
- Reminds you are not alone, your experience is not unique
- Escape from judgement, criticism, and social comparison
- Can create social support & connections
- Can facilitate individual and group advocacy across systems
- Best when facilitated by someone who has been there, but survived (empowered)
- (with training in group process)

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Parent to Parent Support

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CHARACTERISTICS OF RESILIENT PARENTS

Who successfully combat compassion fatigue


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Access Social Support

- Who's in your context?
- Friends
- Family
- Parent to Parent
- Counselor
- Hobby or interest group
- Fun times?

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Resilient Parents are able to

- Revisit and adapt life goals and priorities
- Pick their battles
- Is this something I can control?
- Do I need to deal with it now?
- Let someone else deal with it
- Take a break
- Stop ruminating

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Mom learning to Let it Go

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PRACTICE SELF CARE

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Are Self-Aware (Mindfulness)

- Self Awareness (Mindfulness) doubles the Impact of Self Care (Lopez, 2019)
- Aware of your patterns, triggers and rabbit holes
- Aware of when you need self-care
- Able to identify and regulate emotions
- Ability to identify and focus on positive aspects of life, child, experiences

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Identify Your Protective Factors

Characteristics of your child	Your own characteristics	Your family
The school	Medical/treatment centers	Your work

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Why Consider Self-Care ?

- Parents who have children with special needs, may spend an inordinate amount of time caring for their children at the expense of caring for themselves
- Myths about self care: Its selfish and lazy
- "Responsible Selfishness" (Welsh, 1999)
- Caring for yourself increases your well-being and makes you better able to care for others

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Components of Self Care

(when practiced increase resilience)

Physical

Social/Interpersonal Relationships

Professional/Work

Personal Development

Psychological/Emotional

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Care for the Body (physical)



- Get enough sleep
- Eat healthy food that nourishes your body
- Exercise by doing something you like
- Monitor use of alcohol and other drugs
- Pay attention to your body and its signals
 - Mindful movement, body scan

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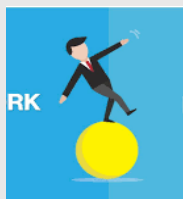
Nurture Relationships (social/interpersonal)



- Schedule dedicated time with adult friends, you can have fun with
- Spend time just having fun with your child
- Get help when needed
- Identify people you can call upon for support
- Resist the urge to withdraw

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Manage and Appreciate your Work



- Balance work and home – leave work at work
- Where are you able to spend less time if needed?
- Take vacation and sick days
- Set boundaries – learn to say no or to delegate
- Let go of perfectionism
- Recognize that you are not the ONLY person who can do this
- Seek supervision (when dealing with professional compassion fatigue)
- Notice joys and accomplishments


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Make Time for What's Important to *you* (Personal)

- Identify what's most important for you in life
- What are your values and goals?
- Do you spend time focusing in those areas?
- Remember the *you* before you had children, do you make time for her?
- Dedicate at least some time to things you value (even if no one else in the family likes it)

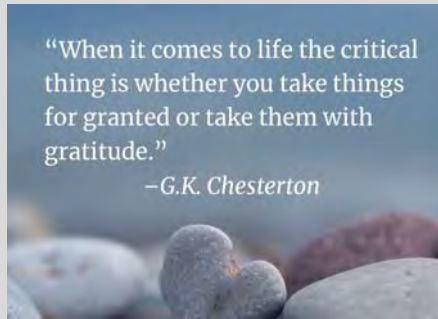
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Mind Your Mind (Psychological/Emotional)

- Find ways to escape when needed (time away)
- Say "yes" to down time and fun
- Spend time in nature
- Create a safe space just for you
- Find ways to relax (yoga, progressive muscle relaxation, bubble bath, meditation)
- Do something physical (run, walk, silly dance)
- Find expression outlets (art, music, crafts)
- Pay attention to what is going well
- Practice gratitude
- Become aware of and manage your emotions

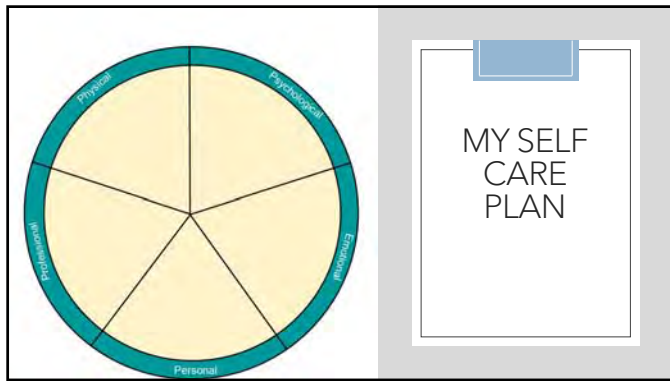
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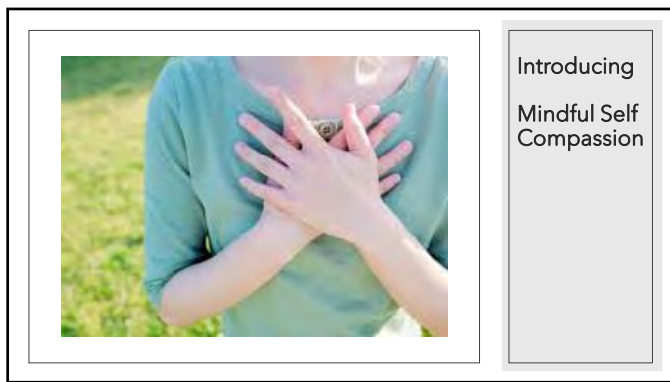
What are you Grateful for?

◦ <https://thnx4.org/>

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Research Demonstrates that MSC

(centerformsc.org)

- Increases positive emotions (happiness, optimism)
- Increases social connectivity
- Improves emotional awareness and regulation
- Health and physical wellness
- Agency and goal re-engagement
- Decreases emotional and behavioral reactivity
- Decreases feelings of stress, anxiety, self criticism, and shame

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In MSC You learn

- How to evoke good will and kindness towards yourself (especially when you are suffering)
- How to stop being so hard on yourself
- How to handle difficult situations and emotions with greater ease
- How to respond with awareness rather than reacting impulsively
- How to motivate yourself with encouragement rather than criticism

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Components of MSC

Mindfulness

Kindness

Common Humanity

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Mindfulness

Mindfulness is....

"paying attention on purpose,
in the present moment,
non-judgmentally...."

Jon Kabat Zinn


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Mindfulness is

Awareness and acceptance of our thoughts, feelings, body sensations

Contrasted with behaving automatically, without awareness, preoccupied with plans and worries

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CONTRAST WITH MINDLESSNESS

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Mindfulness is a Super Power

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SENSE
AND
SAVOUR



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Mindfulness of Daily Life Practice

When you shift your focus to your senses or your body, you shift away from your thoughts and intense emotions



LOOK



LISTEN



TOUCH



SMELL



TASTE

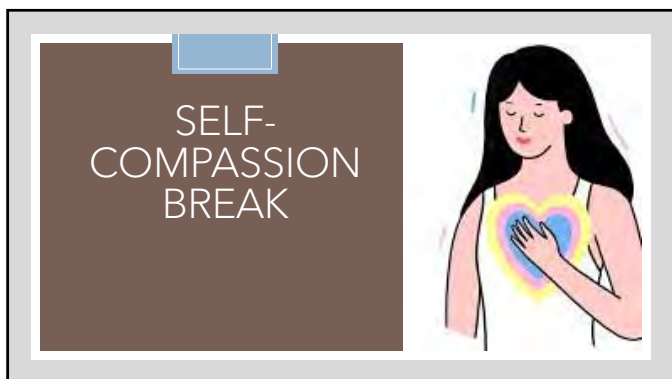
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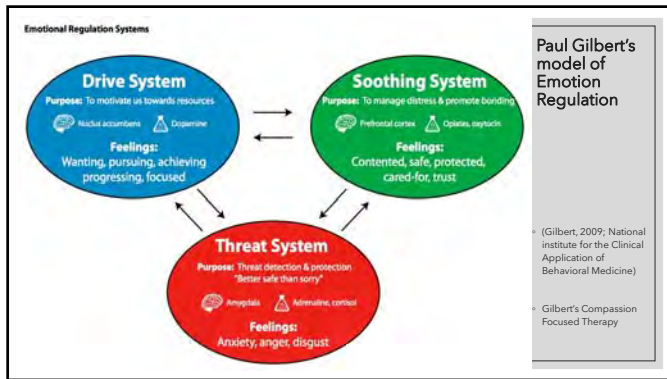
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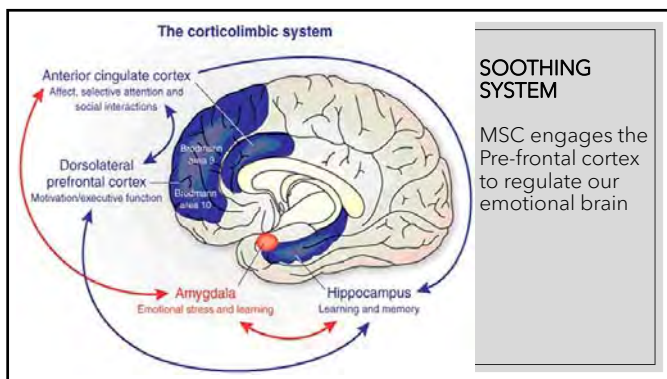


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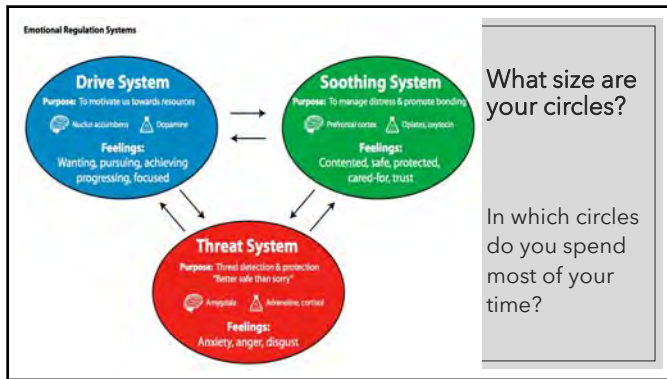
MSC Activates the Soothing System

- Opiate system ..pain killer
- Regulates both the threat and drive systems
- Regulates emotions
- Puts you in the "driver seat"
- Reduces sensitivity to pain in the short term and overall threat sensitivity in the long run

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Mindfulness is Awareness

- Noticing when we are suffering without trying to avoid or resist
- "You've got to *feel it to heal it!*"
- "You've got to *name it to tame it!*"

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RESPONDING TO YOURSELF WITH KINDNESS

- Treating yourself like you would a dear friend when they are suffering

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Can you see how great you are?

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Common Humanity

- Everyone Suffers, You are not alone
- Chances are you are sharing the same experience with millions of people at any time

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EVEN MAMA BEAR BENEFITS FROM SELF COMPASSION

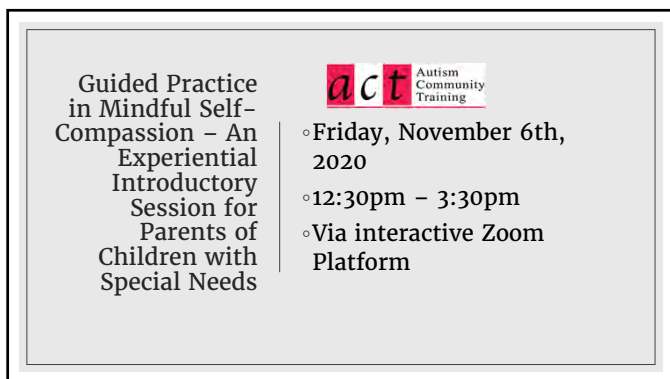
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To Learn more about Mindful Self Compassion
(qualified teachers, upcoming training and courses)

- Georgina Robinson's MSC Site
- <https://mindfulselfcompassionforlife.com/>
- Center for Mindful Self Compassion
- <https://centerformsc.org>
- Kristen Neff's Self Compassion Site
- <https://self-compassion.org/>

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To Learn more about Mindful Self Compassion
(qualified teachers, upcoming training and courses)

- Christopher Germer's Site
- <https://chrisgermer.com/>
- Center for Mindfulness Studies
- <https://www.mindfulnessstudies.com>
- University of California Center for Mindfulness
- <https://medschool.ucsd.edu/som/fmph/research/mindfulness/Pages/default.aspx>

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Selected Sources of Research on MBIs

- Centre for Mindfulness Research and Practice, Bangor University
- <https://www.bangor.ac.uk/mindfulness/>
- Kristen Neff Research site
- <https://self-compassion.org/the-research/>
- University of Oxford Mindfulness Research Centre
- <https://www.psych.ox.ac.uk/research/mindfulness>
- Mindfulness Research UMASS Medical School
- <https://www.umassmed.edu/psychiatry/education/mindfulphysicianleadershipprogram/mindfulness-research/>

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Selected Sources of Research on MBIs

- Developmental Disabilities and Mental Health lab York University
- <https://ddmh.lab.yorku.ca/>
- Journal of Autism and Developmental Disorders
- <https://www.springer.com/journal/10803>
- Greater Good Science Center, U. Berkley
- https://greatergood.berkeley.edu/?_ga=2.170015010.30315911.1603222797-662927979.1602990393
- Online Gratitude Journal
- <https://www.thnx4.org/>

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MBI Research benefits in parents who have children with special needs, Increases in:

- Mindfulness, self compassion
- Positive emotions (happiness, optimism)
- Nonjudgmental acceptance of child and self
- Global adaptive functioning & life satisfaction
- Health and physical wellness
- Agency and goal re-engagement

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MBI Research benefits in parents who have children with special needs, Increases in:

- Self efficacy and alignment with personal growth
- Emotion awareness and regulation
- Adaptive responses/resilience to stress
- Forgiveness and gratitude
- More sensitive to needs of others and self
- parenting competence
- Improved child behaviour

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MBI Research, Decreases in:

- Negative emotions
- Anxiety
- Worry and rumination
- Depression
- Emotional reactivity
- Impulsivity
- Negative self beliefs, criticism and blame
- Feelings of shame
- Interpersonal reactivity
- Isolation and withdrawal
- Over-identification (empathy to the point of personal detriment)
