

# Successfully riding the waves of emotion: Coping with the uncertainty of MS

Hosted by

BC & Yukon Division

**Thursday, April 12, 2018**

11:00 am- 12:30 pm (PST)





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# MS Society of Canada

- **Mission Statement:** To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.



# Presenters

**Dr. Donna Paproski, PhD, Registered Psychologist**

Surfing the waves of emotion: Coping with uncertainty

**Gabrielle Veto**

A Personal Perspective



## Donna Paproski

- Donna Paproski is a Registered Psychologist in British Columbia specializing in therapy with adults, couples, as well as adolescents and children.
- She incorporates a variety of strategies in response to the needs and preferences of her clients.
- These approaches include mindfulness techniques, self assessment and monitoring, ACT and CBT, nonverbal expression, somatic awareness, as well as psychodynamic psychotherapy.
- She has been in private practice for over 20 years.



## Gabrielle Veto

- Gabrielle Veto was diagnosed with MS at the age of 27. Like so many young adults in Canada, Gabrielle was newly married and working hard in a career she loved, as a TV news reporter in Vancouver.
- That diagnosis altered the path of her life significantly. Instead of ambitious plans for travel and career success, Gabrielle's life focus is now on the "smaller" and sometimes more important things in life!
- As a long-time volunteer with the MS Society of Canada, BC and Yukon Division, Gabrielle is a past member of the division board has helped out with communications, public education, major gifts and planned giving, awards, events and most recently the start-up of the MS Ambassador Program. Gabrielle's family and friends join her to raise money and awareness about the disease every year in the MS WALK.
- Now 49, Gabrielle focus' her time and energy on her 2 dogs (great for exercise as she plays agility with one of them), her local choir, light volunteer work, 1 cat and her supportive family (not necessarily in that order!).



# Surfing the waves of emotion: Coping with uncertainty

Donna Paproski,  
PhD, Registered Psychologist



# Uncertainty and MS

- Chronic illness with variable course
- Unpredictable functioning often on a daily basis, as well as over months and years.
- Kinds of functioning that can be effected includes
  - Mobility and strength
  - Balance and coordination
  - Vision
  - Cognition
  - Sexual
  - Bladder
  - Sensory
  - Energy



# Ways MS creates uncertainty

- Work limitations including potential need to reduce or stop employment – effects finances, identity, social contact
- Financial costs of treatments and adaptive assistance
- Relationship stress and possible breakdown
- Having MS may decrease possible future relationships and friendships
- Physical limitations changes many activities – housekeeping, creative outlets, exercise, social, travel. Some things take more time and effort, some things can no longer be done.
- Fatigue limits all activities in terms of intensity and time available
- Cognitive changes effects organization, speed of task completion, future planning.

# Uncertainty and Perspective

- We prefer to be able to plan and have some measure of control over our activities and future.
- MS confronts us with the reality that there is a lot of uncertainty in the future, however we may plan and prepare.
- MS creates uncertainty for the person with MS as well as those who know them.
- The course of MS is individual. Statistics about the course of the illness and the incidence of various changes are not predictive for any one person. These statistics can be guidelines for professionals and patients but unfortunately create tremendous anxiety and negative expectation.
- What matters is how we view and cope with the uncertainty.

# Possible emotional responses to uncertainty

Anxiety

Worry

Fear

Anger

Indifference

Depression

Sadness

Openness

Courage

Acceptance

Stubbornness

Resignation

Denial

Calm

Curiosity

Determination

Hope

Humility

Flexibility

Desperation

Persistence

Avoidance

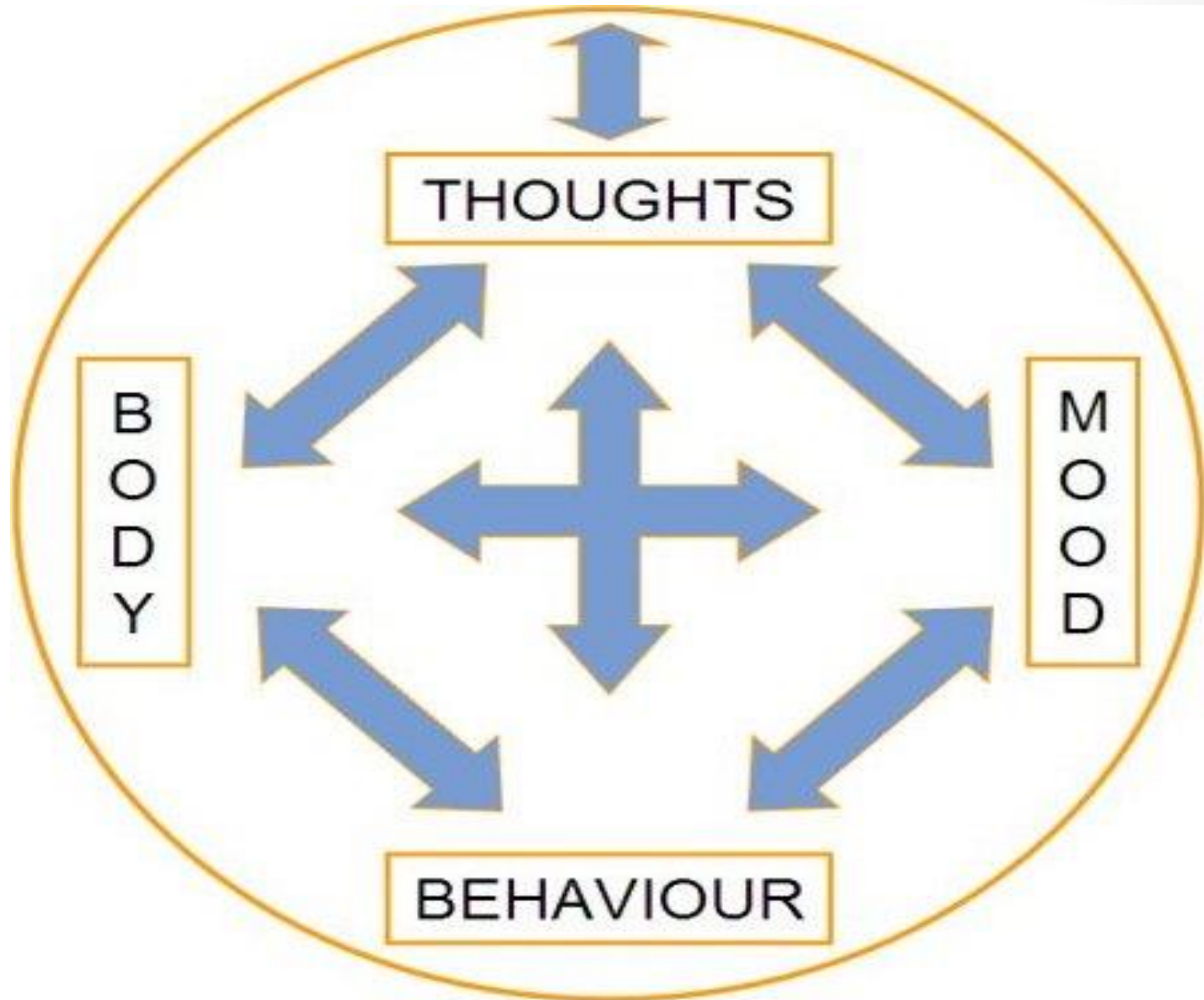
# Possible behavioral responses to uncertainty

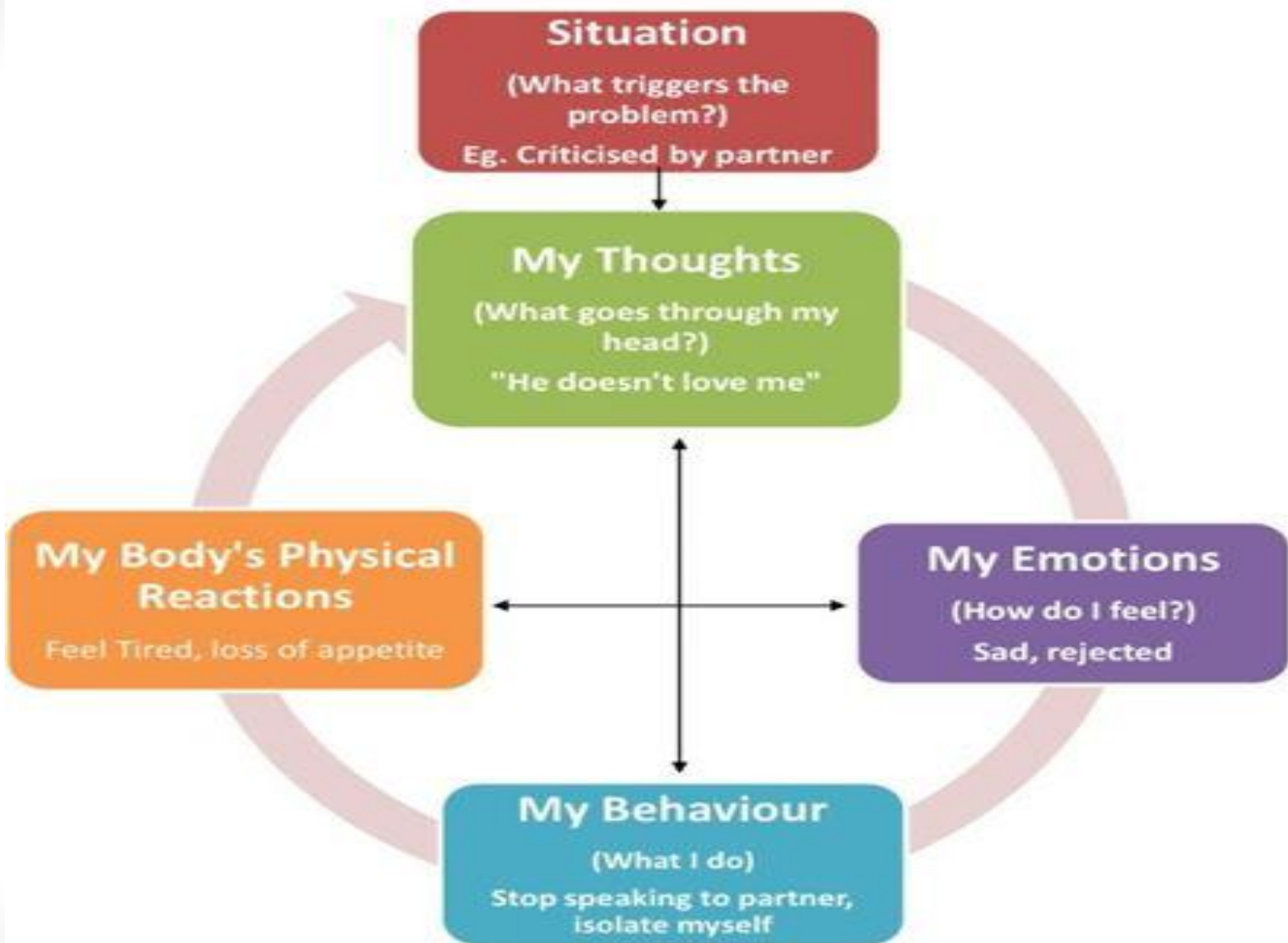
- Isolating/withdrawing vs connecting to others
- Abandoning vs revising plans
- Seeking alternative activities
- Sidestepping or ignoring feelings vs being with and acknowledging feelings
- Seeking professional support for ideas and symptom management
- Ruminating about negative outcomes, spiralling into extreme emotional states such as anxiety, depression and hopelessness vs recognizing signs of being overwhelmed and using ways to cope with uncertainty

# Assessing your coping

A framework for assessing yourself and working with changes that occur in the course of MS

- Feelings
  - Thoughts
  - Behaviors
  - Beliefs, values, and perspective
- 
- This model is based on Acceptance and Commitment Therapy which builds on CBT (cognitive behavior therapy). There is research supporting the effectiveness of using ACT for MS.

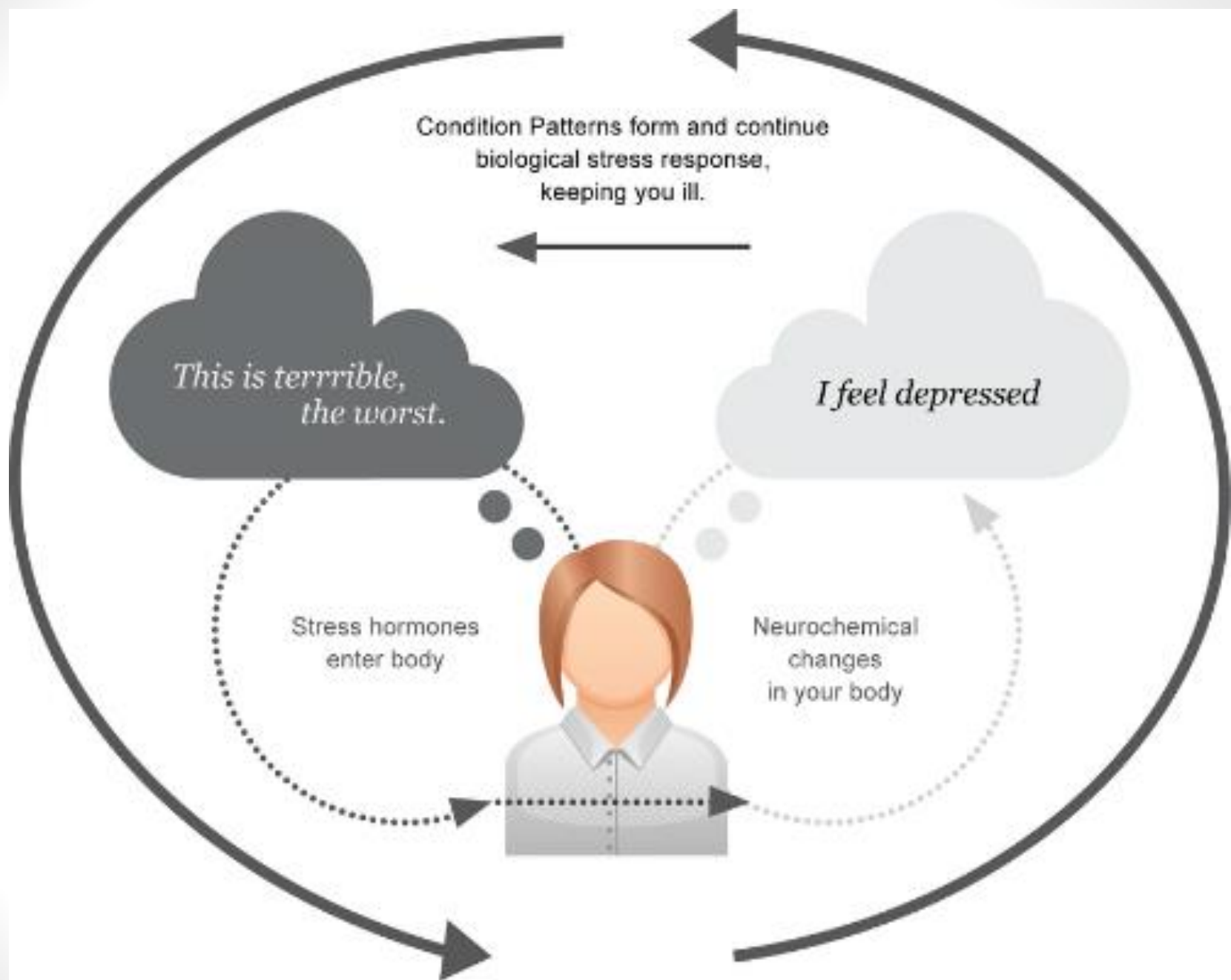




**Trigger - real or imagined danger**







# Feelings/Emotions

- Start with noticing what you feel. As much as possible just acknowledge without judgement. This can be challenging as we want to avoid discomfort
- Feelings are information. Not static but changeable. Linked to thinking and behavior and values.
- Cultivating the ability to stay present with your feelings is a powerful way of managing change. It takes courage. This is a skill that can be developed.
- As you sit with your feelings, you will notice where you feel sensations in your body, the thoughts you have, and the beliefs behind your thinking.
- Mindful awareness and meditation are ways of staying present

# Thoughts

- Our thinking is a powerful. It is how we shape our experience by creating expectations of ourselves, others, and the world.
- Notice the phrases and words used especially during intense experiences of feelings.
- Begin to change words and phrases to be less absolute, more curious, open to possibility.
- For example, Janice woke with new feelings of tingling and numbness in one foot. She noticed feeling anxious and worried. Spending time being with her feelings, she noticed herself saying, “This is terrible. It’s going to get worse and soon I won’t be able to walk at all.” After sitting mindfully with her thoughts and feelings, she was able to notice her thinking and revise it to, “I am concerned about this new numbness but I’m not sure what it is. Maybe it’s just temporary. I’m going to consult with my neurologist and see what she says. We’ll figure it out.”

# Behaviour

- Once you are more centered and accepting of the feelings and thoughts that you are experiencing, you can consider what behaviours are helping or hindering how you cope.
- Support system – professional, social, family
- Ways to relax or shift focus (altered states, creative acts, exercise/movement, music)
- Activity that gives you meaning/purpose
- This is the opportunity to mindfully choose how you respond to change, uncertainty and feelings that arise.

# Values - Commitment

- As a final step consider how your values are key to your choices.
- Some domains of values include
  - Relationships – family, friends, significant other, companion animals
  - Creative expression
  - Intellectual exploration/learning/sharing
  - Community involvement – political, environmental, social
  - Financial stability and simplicity
- Values are best described in active terms so that it is easier to know if you are living your values. For example, I want to be a friend who is involved and has weekly contact

# Mental Health Issues in MS

- This presentation is intended to support everyone with MS knowing that many will face uncertainty and find ways to cope with the emotions.
- A significant proportion of people with MS will also cope with diagnosable mental health challenges at some point, usually some form of anxiety and/or depression.
- It is vital to have professional assessment and support if the degree of emotional intensity has a significant effect on daily functioning beyond a few hours or days.
- The following slides will explore depression and anxiety but it is important to have a professional consultation if you or those who care about you find your struggle to cope is unmanageable on your own.

# Depression in MS

- Depression is not the same as having a bad day or feeling off for a short time.
- Nearly 10% of the population will experience depression in their lives, i.e. 1 in 10 people.
- With MS, the lifetime incidence is reported as 21-25% (Marrie, 2015, Chwastiak & Edhe, 2007)
- Reasons for higher incidence may be coping with a chronic disease or a part of neurological changes, including changes in immune function, but the cause of higher incidence is not fully understood.

# Symptoms

- Sadness throughout the day, nearly every day for 2 weeks
- Loss of interest in or enjoyment in activities
- Feelings of worthlessness
- Excessive or inappropriate feelings of guilt
- Thoughts of death or suicide
- Trouble making decisions
- Trouble concentrating
- Feelings of irritability
- Fatigue or lack of energy
- Aches and pains ( headaches, stomach pain, joint pains or other)
- Sleeping too much or too little
- Change in appetite or weight
- Feelings of restlessness or being slowed down



# Anxiety in MS

- The incidence of clinical anxiety disorders is reported to range from 21-36% among people with MS (Marrie, 2015; Chwastiak & Ehde, 2007).
- Clinically disabling anxiety can take many forms – and anxiety is also experienced for short periods of time by all people in response to change, uncertainty, and stress.
- When anxiety persists over time and becomes unmanageable it is important to consult with a professional
- Anxiety can manifest as panic, phobias, waves of fear and shaking, obsessive-compulsive behaviors and rumination.

# Alcohol and Substance Misuse

- Misuse of alcohol and other substances can be a way of coping although not very effective and potentially quite harmful.
- The incidence of alcohol abuse among people with MS is reported to be 15% and substance abuse, not cannabis use for medical reasons, at 2-3% (Marrie et al, 2015).
- It is vital to find other more effective ways of coping with the effects of stress and uncertainty.
- There are many healthy ways to alter one's state of mind for distraction or a different perspective, including listening to and making music, creating art, dance or other movement, movies, intense exercise, changing environments, i.e. being in nature.

# Diagnosis

- Diagnosis should be made by physician, psychologist, social worker, or nurse practitioner.
- Several online screening tools can alert you to the likelihood of having a diagnosable problem with mood, anxiety, alcohol or other substances but diagnosis must be made by a professional.
- A diagnosis validates your experience and will provide you with treatment options.

# Treatment - Professional

- Research evidence supports the effectiveness of both medication and psychotherapy for depression and anxiety.
- Medications most frequently prescribed are antidepressants.
- Medication can moderate the intensity of symptoms and help to moderate mood to support more you in developing effective coping.
- Must be prescribed by a family physician or psychiatrist.
- Psychotherapy can validate your experience and give you strategies for managing thoughts and feelings and choose behaviors that are supportive and consistent with your values.

# Treatment - Professional

- Psychotherapy can validate your experience and give you strategies for managing thoughts and feelings and choose behaviors that are supportive and consistent with your values.
- Family doctors can refer to psychiatrists but there are usually waitlists
- Private psychologists, social workers, and counsellors.
- Coverage may be available through employee assistance programs, or through extended medical benefits plans and have an annual limit.
- Free or lowcost therapy is sometimes available.

# Coping with Hopelessness

- Feeling hopeless can increase the risk of giving up on life and lead to thoughts of self harm and suicide. It may indicate significant depression.
- It is vital to get help if you are feeling overwhelmed and considering hurting yourself.
- See GP, visit hospital emergency, call 911, call the crisis line, call a friend or family member.
- Talking to someone can help in the short-term but frequent suicidal thoughts requires ongoing professional intervention.
- Important to consider who and what gives you meaning, purpose, and hope.

# Planning

- Include your family and friends in a support network.
- Identify who in your network can be available for support during crises.
- Develop many strategies for coping with dips in mood and energy, i.e. exercise, music, movement, social time, meditation, spiritual practices, creative expression.
- Maintain ongoing professional support for psychological tune-ups and/or medication monitoring.
- Recognize that some days are harder than others, and that those times are temporary.
- Cultivate compassion for yourself.
- Find what is meaningful and live your life with purpose.

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# A Personal Perspective

Gabrielle Veto





# Gabrielle Veto

-person with MS, wife, sister, friend, daughter, aunt, neighbour, niece, student, chorister, agility partner, volunteer, citizen

-diagnosed in 1996

-relapsing remitting with fatigue

-stopped working in 2003

-newly married, working





# Surprise! You have MS.







# Finding help





# Emotional rollercoaster

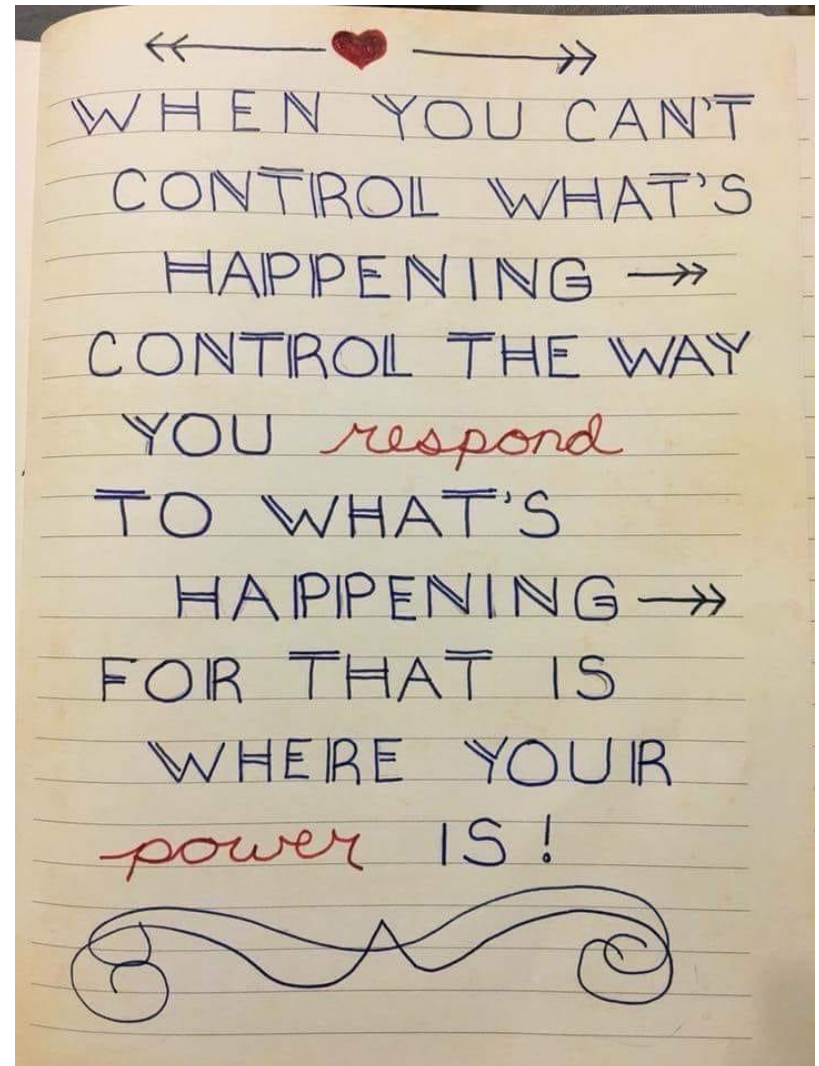
- Options
  - You are unique (peer support, self-help groups, counseling)
  - Not everything works for everybody
- Choices
  - Making more than you realize
- Time
  - No rulebook





# Expectations

- changed job positions
- devastating second relapse
- approx. 25 relapses over 4 years
- remissions
- power of choice





# Forgiveness

- 2000 serious relapse
- went “on drug”
- 2003 fatigue begins, stop working
- who am I?

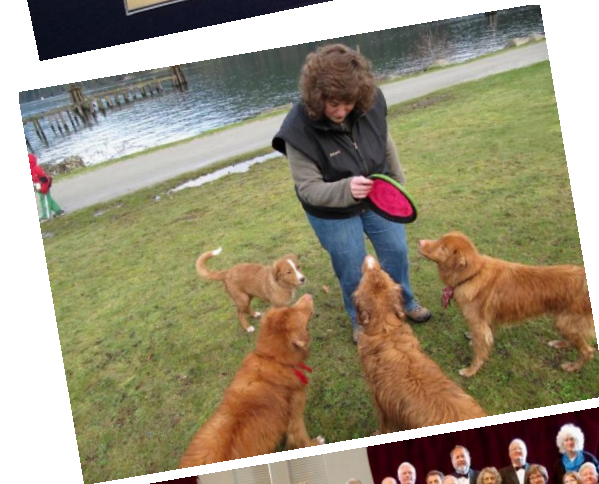
Forgive yourself for not knowing  
what you didn't know  
until you lived through it.  
Honor your path. Trust your journey.  
Learn, grow, evolve, become.

- creig crippen -



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# Finding a new “normal”





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# Finding a new “normal”





# Living WITH hope not IN hope

- Hope is crucial
- Balance
- Stop waiting for something better

Beware of destination addiction—a preoccupation with the idea that happiness is in the next place, the next job and with the next partner. Until you give up the idea that happiness is somewhere else, it will never be where you are.

ROBERT HOLDEN, PH.D

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There will be very painful moments in your life that will change your entire world in a matter of minutes.

These moments will change you. Let them make you stronger, smarter, and kinder. But don't you go and become someone that you're not.

Cry. Scream if you have to. Then you straighten out that crown and keep moving.





# QUESTIONS?



**Donna Paproski**



**Gabrielle Veto**



## For Further Information Please Contact

MS Navigators

1-844-859-6789

BC and Yukon Division Office

604-689-3144/1-800-268-7582

[www.mssociety.ca](http://www.mssociety.ca)

Email: [info.bc@mssociety.ca](mailto:info.bc@mssociety.ca)



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