Coping with multiple sclerosis

...Defining a New Normal for patient and family

Tamara Lott, LCPC
“As it is not proper to cure the eyes without the head, nor the head without the body; so neither is it to cure the body without the soul.”

- Socrates
Focus Today

Coping, mood and stress management for both MS patients and families
Counseling

• An option for navigating MS

• Do Not Be Afraid

• It may not be what you think it is…
It is not this...
Here’s Where it gets Tricky….

• Many symptoms of MS and Depression & / or Anxiety can overlap
  • Sleep
  • Appetite
  • Concentration
  • Memory
  • Interests
  • Psychomotor skills
- Helpful to find a therapist familiar with MS

- Often focusing on one problem that has initiated an avalanche of change

- Stages
  
  • **Acute**: get you through rehab
  
  • **Post-acute**: Now What?
  
  • **Long-term**: less frequent, but follow-through and tune ups
Wrapping your head around MS

Why?

• Larry – “…wow….don’t know what I ever did to deserve this”

• Jackie – “I brought this on myself”

• Terri - “They don’t get it…they’re frustrated with me…”

(You can walk and you can talk)

• Coping issues for severe vs. “mild”
Coping Issues

- How to cope with THIS
- Daily adjustments
- Cognitive compensatory strategies- planner example
- Vocational exploration
- Monitoring mood and stress
- Teaching stress management
- Talking about your feelings good and bad
- Some discussion of past or unresolved issues in your past that might still affect you today
“Happy” on hold?

• Don’t wait for “that day” to be happy
• Don’t want my patients waiting to participate in life
  - Walk
  - Cure
  - The Station
  
  - Robert J. Hastings
MS Stress

- Change in every day life
- The unpredictability of the disease
- Unrealistic expectations from self and others
MS Stress (Continued)

- Financial changes and stress
- Transportation
And then there’s the rest of your life…

- While your dealing with MS…all the other parts of your life and the world continues. This impacts your mental and physical well-being
- Focus on managing your stress, not stopping it
Now What?

- I had plans
- Grieve
- Redefine
- New Game Plan
- Who am I?
- Your body and MS
  - Nutrition and hydration
  - Sleep / fatigue / rest
  - System sensitive – fever, infection, etc.
Just because it’s different, doesn’t mean it can’t be good

“...I had to learn to measure myself by a different yardstick...”
Who are you now?
For Patients - Summary

• Don’t be afraid to ask for help with coping
• Prioritize basic human needs as a base
• Be a good patient and listen to your doctor
• Make a new game plan
• MS does not define you
• Balance acceptance, “owning it”, and Fight
Supporting MS Patients

You are not alone.
Listen. Sometimes an ear is all someone needs. Many patients express feelings of guilt about this. Do your best to just be there.
Struggle and adversity can enrich relationships

Worst Case Scenario is not usually the path
Important relationships take effort and energy — even without the challenges of MS. While MS does pose some additional adversities, it can also enrich relationships and bring people closer together.

The first step in figuring out how to deal with MS in your personal interactions is to recognize that the disease affects all of you — whether you have the disease or care about someone who does.

The next step is to decide whom you want to tell about the MS and what you want them to understand about it.

And the third step is to look for ways to make room for MS in your personal and professional relationships without giving it more time, attention, and energy than it really needs.
Family and Friends
MS happens to the whole family

Part of “Now What” includes family and friends
Signs that you may need to take better care of yourself:

- Missing or delaying your own doctor appointments
- Ignoring your own health problems or symptoms
- Not eating a healthy diet for lack of time
- Overusing tobacco and alcohol when you feel stressed
- Giving up exercise habits for lack of time
- Losing sleep
- Losing connections with friends for lack of time to socialize
- Bottling up feelings of anger and frustration
“Put the Fear Aside. Fear is the opposite of Faith. Waking up every day wondering if this will be the day that your spouse loses all ability to walk is not the way to live your life. Instead, be greatful that every day – you get to live your life with them.”

“Fight participate in the MS walk. Raise money for the cause. Rally your friends and family to join you…”

“It’s not their fault. It’s not your fault. It’s no one’s fault. It’s just life. We ar humand. And we are here on this earth to stretch and grow.”

- Words from blog of Carrie Stroud, wife of MS patient
Depression

Sleep
Interests
Guilt
Energy
Concentration
Appetite
Psychomotor Skills
Suicidal ideation
Anxiety

Looks different in different people

Generalized anxiety

Excessive worrying

Panic Attacks
Stress is caused by an existing stress-causing factor or "stressor".

Anxiety is stress that continues after the stressor is gone.
Stress is like chocolate

* A little bit won't kill you. In fact, small blocks here and there can be good for you.

* But chronic and severe stress can damage your body and mind, including exacerbating medical problems.
How can I possibly relax!?
Go ahead and make that to-do list

* But use pencil, not pen

* Be flexible

* Once you feel that first heart palpitation, cut the list in half!
Stress management strategies

• Stress dots
• Gratitude journal
• Worry time
• Sleep
• Caution Tape
• Apps for imagery – Head space
When walking, walk.
When eating, eat.
-Zen proverb
Simplify

Declutter
Give yourself permission to rest and relax
Don’t overschedule
Take off your cape

Ask for help

Accept it when it’s offered
LAUGH

- Just as chronic and severe stress can damage systems in our body, humor can heal. When people laugh, the autonomic nervous system mellows out and the heart is allowed to relax. Laughter can also boost the immune system, and increase a person’s ability to fight viruses, and reduce the levels of stress hormones. Plus it’s just fun to laugh.
So many tangles in life are ultimately hopeless that we have no appropriate sword other than laughter.

Gordon W. Allport
Exercise

- No, you don't have to tackle a lineman, or run a marathon

- Just 30 min 5 x / week of cardio- enough to get your heart rate up, and keep it up
Exercise relieves stress in several ways. First, cardiovascular workouts stimulate brain chemicals that foster growth of nerve cells. Second, exercise increases the activity of serotonin and norepinephrine. Third, a raised heart rate releases endorphins and hormones which reduce pain, induce euphoria, and help control the brain’s response to stress and anxiety.
Breathe...breathe...breathe

• 10-15 minutes, 3 x per day.....clear your head....re-set
Cardiac meditation study

- A nine year study of 201 African American men and women with coronary artery disease, average age 59, participated in either Transcendental Meditation® or health education classes. In addition to a 47 percent reduction in stroke, heart attack and death, the participants who meditated also experienced a “significant” reduction in blood pressure.
Nature and Mood


Great for finding focus, peace and perspective
Rest is not idleness. And to lie sometimes on the grass on a summer day listening to the murmur of water, or watching the clouds float across the sky...is hardly a waste of time.

- John Lubbock
* Simplify

* Ask for help

* Take time for yourself

* Laugh

* Breathe, move, meditate

* Reconnect with nature / time outdoors
We’re in this together