

Toronto Chapter

April 2, 2008

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Topics for this evening

- What is MS ?
- What causes MS ?
- What can I expect ?
- Treatment Update –what's out there?
- Where are we going with research?
- When should I tell my kids / employer?
- Family planning
- How can I make the most of HCP help?
- What are the best sources of information?

The day you heard the news....

Shock, sadness, fear, anger...for some even relief.

GRIEVING

NORMAL

Many ways to express it
anger, irritability, withdrawal...



Resolving grief takes time
and you may go back
forth. Be patient
yourself.



Some Facts About MS...

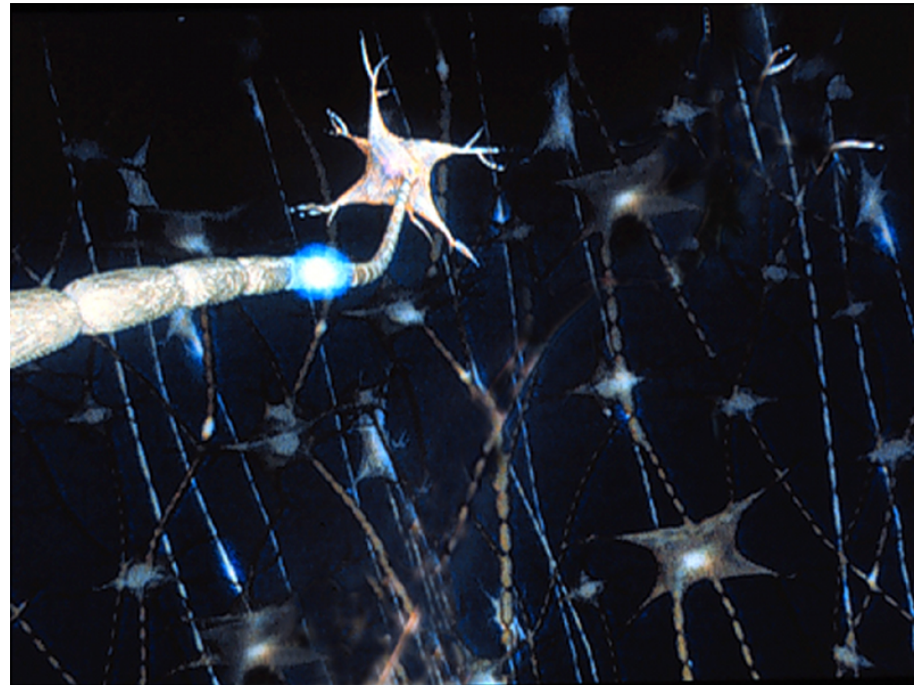
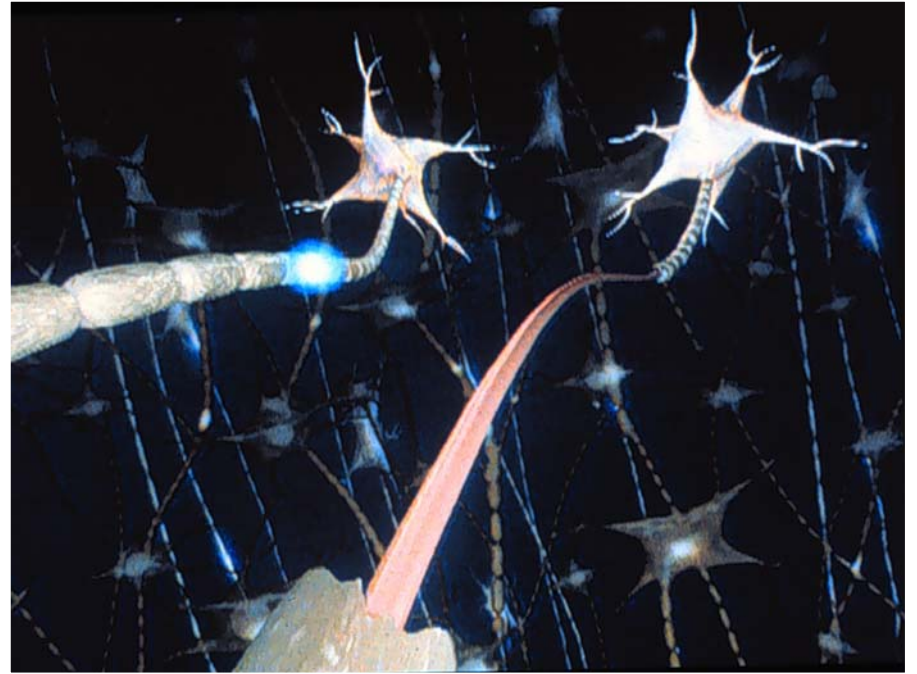
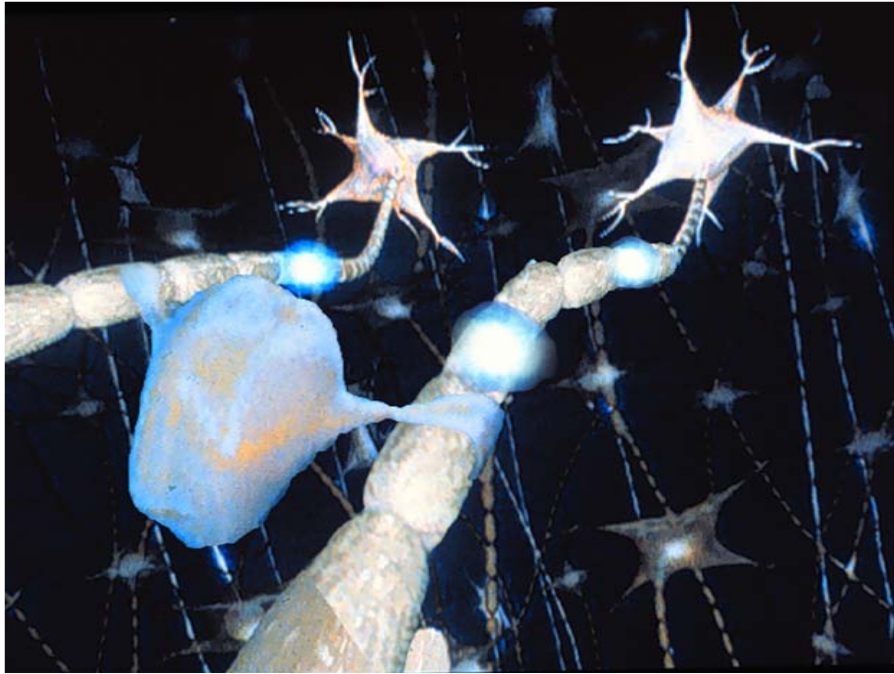
- It is the largest cause of neurological disability in young Canadians.
- 55,000 - 75,000 Canadians are affected with it.
- Typical onset is between the ages of 15 and 40.

What is MS?

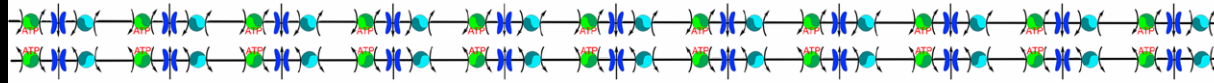
- MS is an immune mediated demyelinating disease of the central nervous system.

What is myelin?

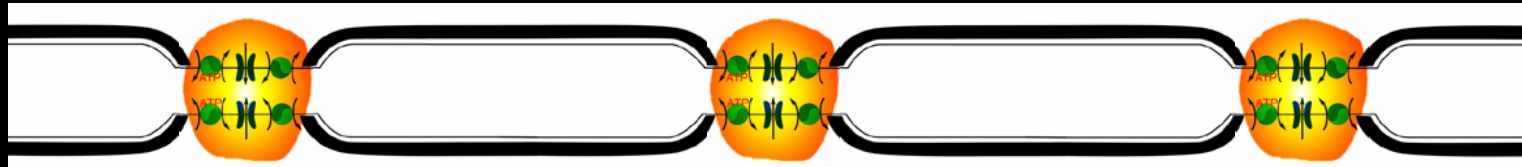
- Myelin is a fatty substance which wraps itself around the nerves in the brain and spinal cord (CNS) and serves to insulate the electrical activity which is nerve impulse conduction.



Nerve Fiber



Myelinated Nerve Fiber



Courtesy of Dr. Bruce Trapp, Cleveland Clinic

Breakdown of the BBB occurs allowing in inflammatory cells that attack the myelin in the brain and spinal cord (CNS), resulting in inflammation and breakdown of the myelin, and often disruption of the electrical activity of the neuron itself.

Types of MS

- Primary Progressive MS (PPMS) <10%
- Relapsing Remitting MS (RRMS) >75% at onset
- Secondary Progressive MS (SPMS) marked by a marked lessening of attacks while still accumulating disability
- Benign MS <10%

What causes MS ?

Environment

Behaviors

Genetics

What can I expect?

- Variability
- An individual course

Invisible Symptoms

- Heat sensitivity
- Fatigue
- Cognitive changes
- Depression
 - (lifetime prevalence of 50% for MS patients attending MS clinics)

DEPRESSION

- Lifetime prevalence of 50% for patients of the MS clinics
- Same data for general population with MS
- Is ORGANIC, not only reactive
- Affects quality of life and exacerbates other cognitive functions

But MOST OF ALL.....

Depression is treatable !

Treatments

- Management of 'attacks'
 - What is an attack?
 - IV steroids
 - Oral prednisolone
 - REST & patience


Disease modifying agents

What should I expect?

- Avonex Interferon 1a
 - Betaseron Interferon 1b
 - Copaxone Glatiramer Acetate
 - Rebif Interferon 1a
- 
- TYSABRI

- Staying with it is the key. These are long term medications for a long term disease.
- Supports
 - The companies themselves
 - Clinic nurses
 - Peer support

Where are we going ?

- Oral therapies
- Remarkable information about mechanisms of the disease 
 - Progressive disease strategies
- Causation (genetics, environment)
- Nerve repair and regeneration

Why is research so slow?

- Proof of concept
- Safety
- Large numbers to allow for variables and exclude random chance
- placebo response
- Complicated long term disease
- 'placebo controlled' no longer ethical in most cases

World Health Organization Clinical Trials Platform (WHO)



March 26

319 clinical trials worldwide

<http://www.who.int/trialsearch/>

| <i>Disease</i> | <i>Incidence</i> | <i>Clinical Trials (WHO)</i> |
|--|------------------|----------------------------------|
| Diabetes | 1/3 | 2736 (106,330)* |
| Rheumatoid Arthritis | 1/100 | 523 (3190)* |
| MS <small>*WHO stats March 26, 2008</small> | 1/1000 | 319* |

Starting a family...?

Pregnancy seems to provide a protection from relapses.

- There is an increased risk of relapse in the immediate post delivery period
- Having children does not appear to affect your outcome with respect to MS
- The use of DMD's is not suggested during pregnancy or breastfeeding so have a talk with your doctor up front about when after birth to resume treatment.

DISCLOSURE



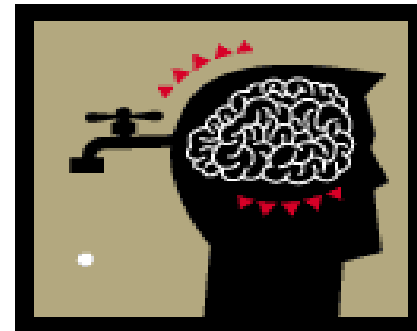
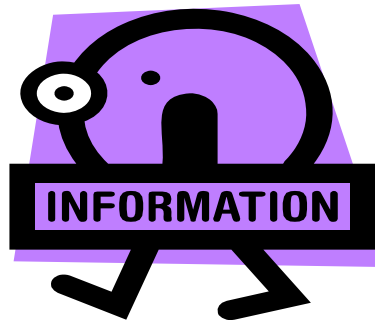
Managing HCP relationships

- GP and general health important
- Community neurologist and MS clinic specialist both good
- Clinic nurses
- A good relationship is a matter of fit and communication. Find the one that is right for you.

KNOWLEDGE

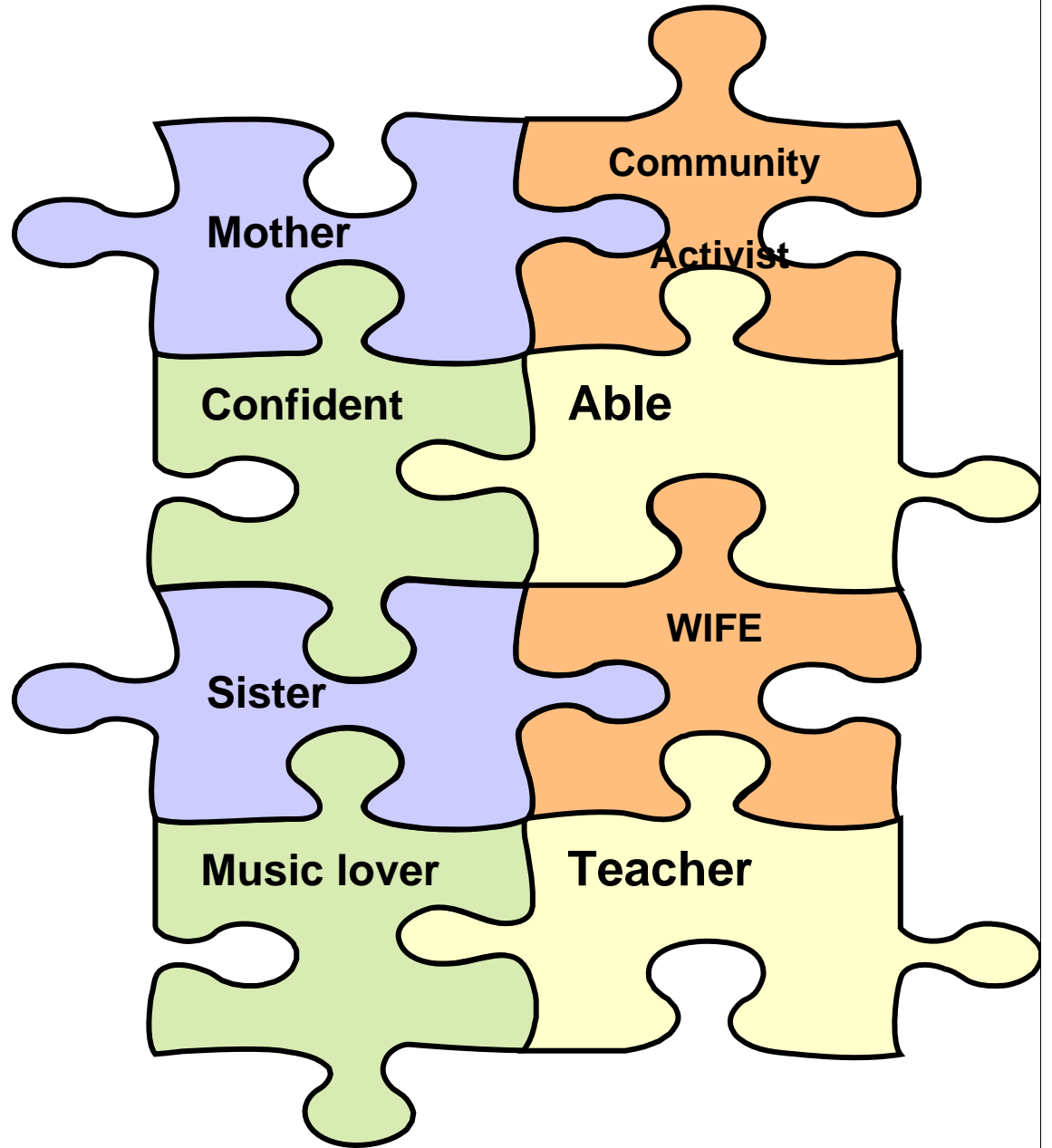
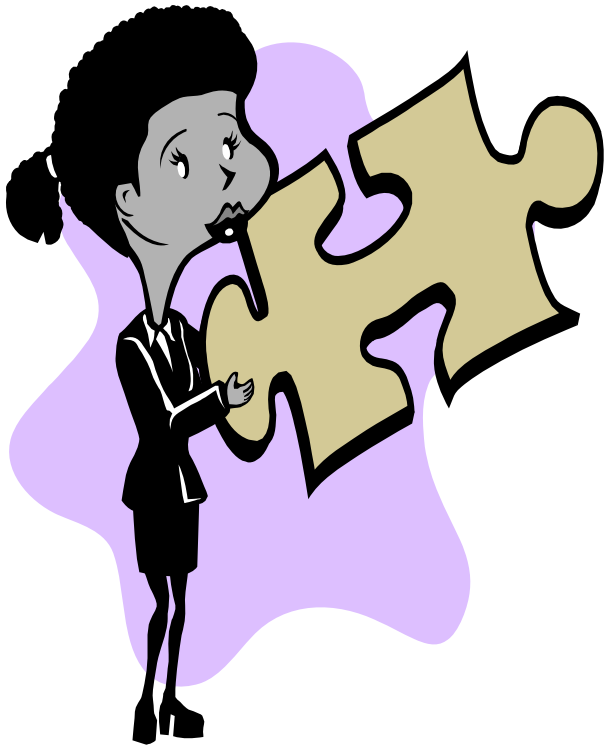
Get Reliable Information

Consider the source...



COMPLIMENTARY MEDICINE / ALTERNATIVE THERAPY

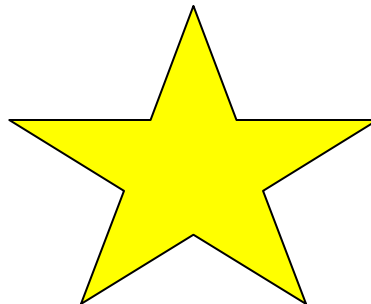




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Commit to ...

HEALTH



4

Don't sweat the small stuff

RULE OF 5'S

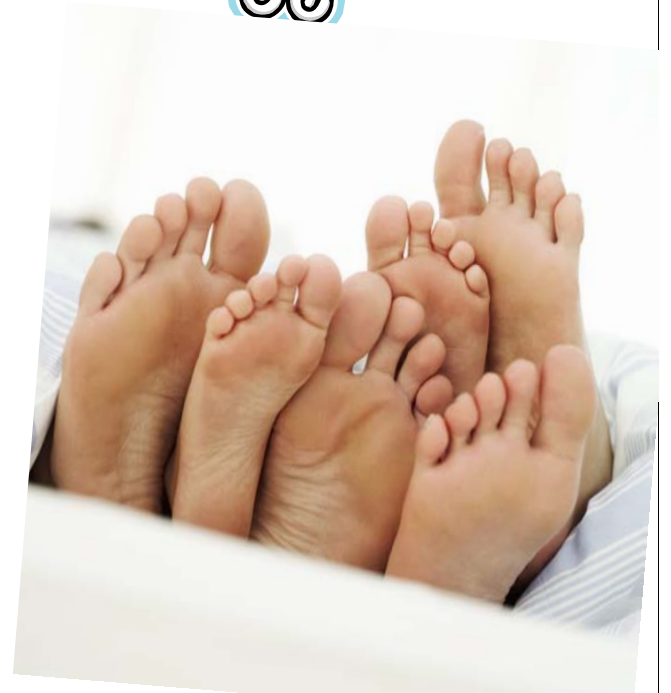


3

Find your MS
free zone



**DO NOT
ENTER**



2

Be Your Own Best Friend

Listen to your inner voice

Respond to what you hear

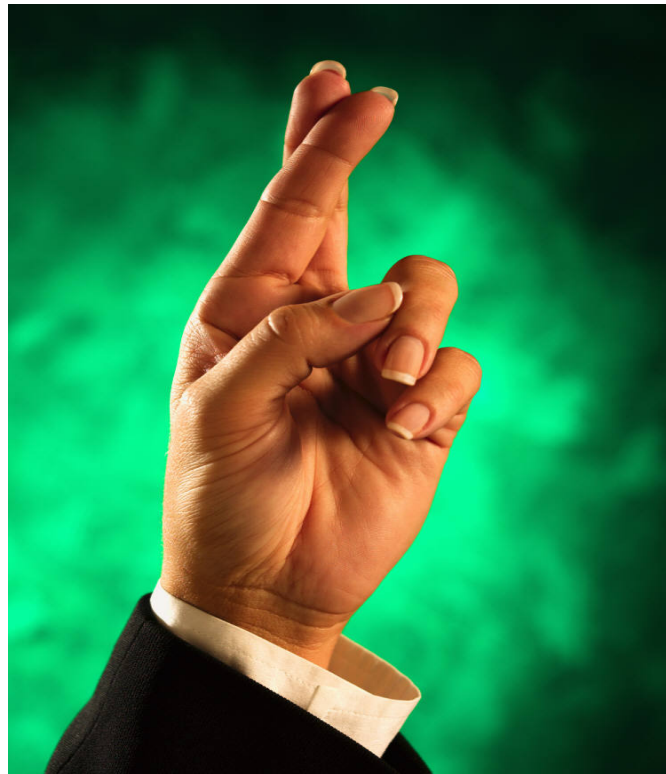
Be reliable and consistent

Be kind and gentle

Be patient

1

Keep Hope Alive



REMEMBER....



Knowledge is POWER so....
here's to you for coming out tonight!



And thanks for being a great audience!