



Red Flags Green Lights



MS Connections Conference Edmonton Chapter

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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.



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Adapting

- Getting the Diagnosis
- Sharing the information
- What are the best sources of information?
- Complementary & alternative therapies
- How can I work with my health care professionals?
- Family & career planning
- Special challenges



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The day you heard the news....

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



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Grieving **NORMAL**

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

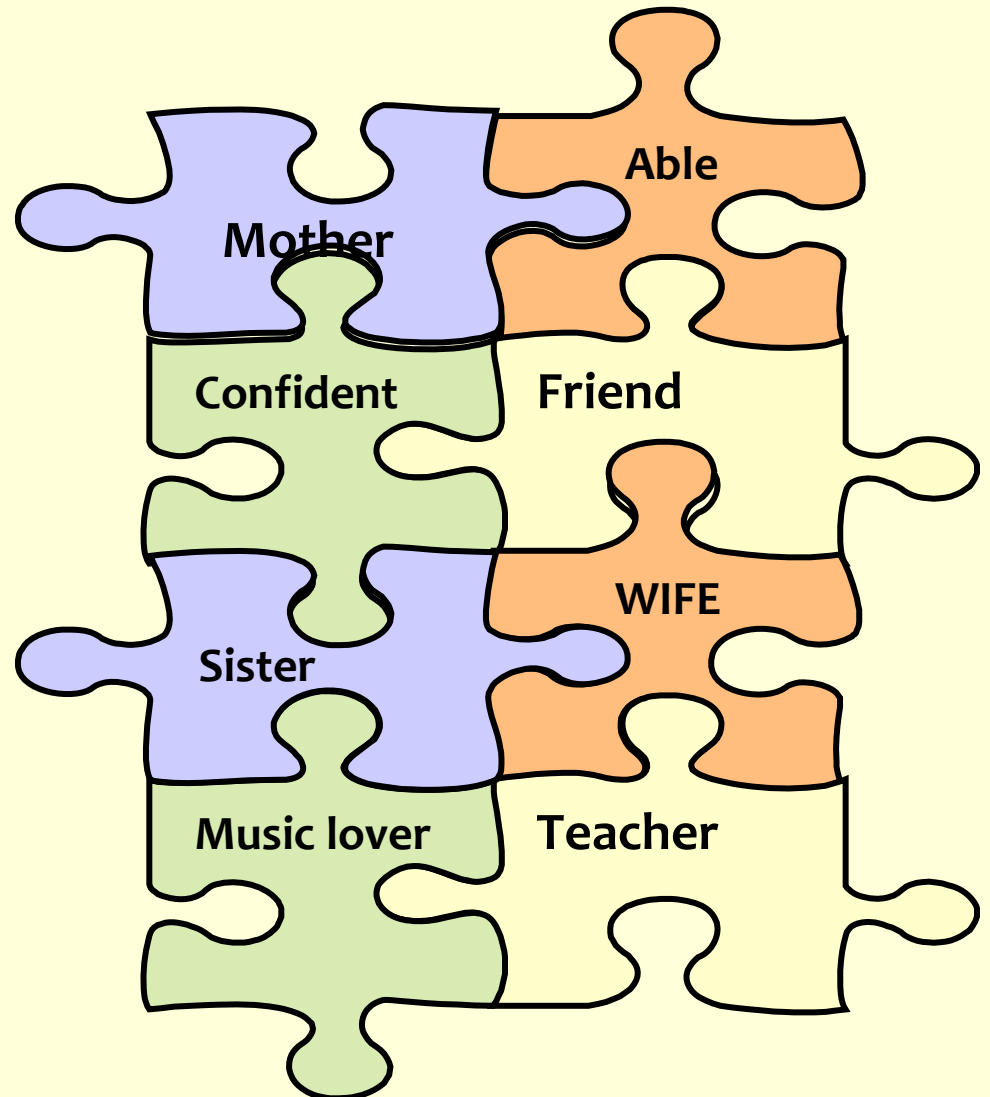
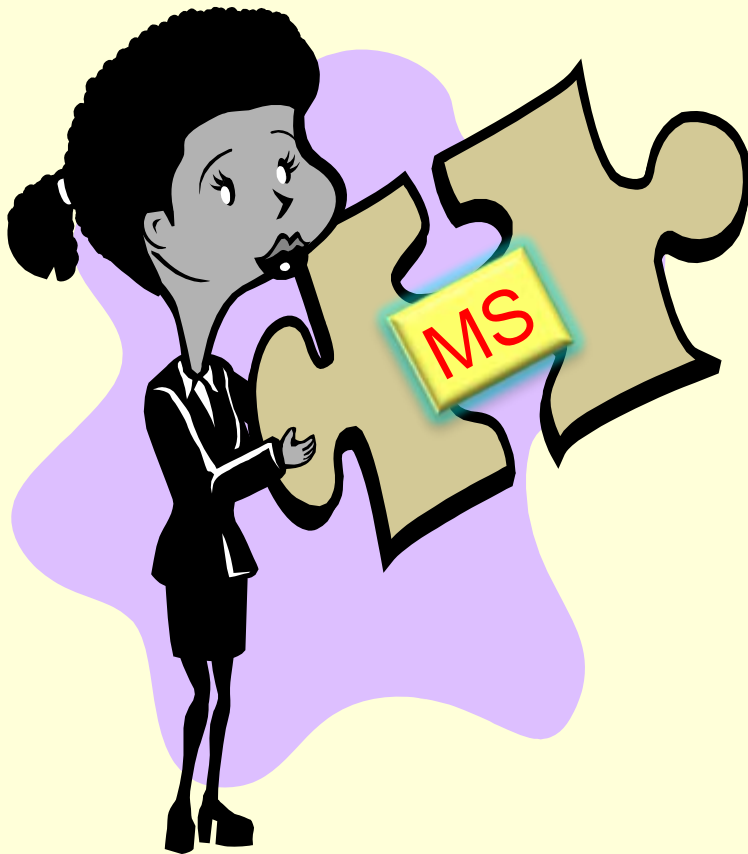


Resolving grief takes time
and you may go back and forth. Be
patient with yourself.



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Disclosure





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Kids....

- You know your kids best, but remember that they are SMART, and sense something is wrong.
- We are all frightened by what we don't know.
- This can be an opportunity to show how we work together as a family to support each other in tough times.



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EMPLOYERS....

Suggest 'need to know' basis...

Seeking support

vs

Work interests



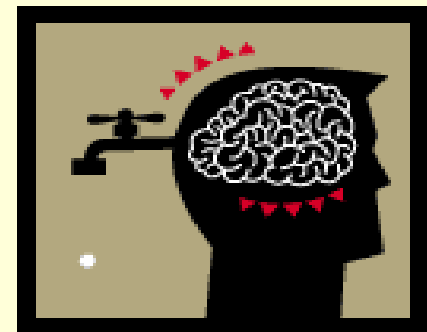
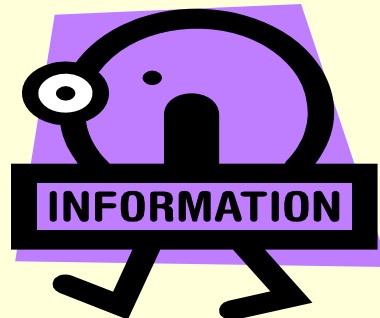


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Getting reliable information... consider the source





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Complementary medicine / alternative therapy





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The popularity of these remedies is no surprise when there is no cure to be offered for this disease. Beware of :

- Extreme remedies
- Prescriber's selling remedy
- Practitioners who ignore 'traditional' medicine
- Financial ruin



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DO...

- Share the information with your health care team
- Evaluate your own response to the treatment
- Check compatibility with your pharmacist
 - These remedies should be treated as any pharmaceutical preparation



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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.



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Before an appointment...

- Make a list of what you want to talk about with your doctor.
- Bring a list of all the medications you are taking, including how much and how often.
- Write down your top 2 or 3 questions.
- Bring someone with you.



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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.



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Things to consider...

- Family income
- Fatigue issues
- Age spacing



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Clinical Programs offers genetic and reproductive information available at:

<http://www.mssociety.ca/en/hcp/rc/default.htm>



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Career

Plan for the worst, expect the best

- Disclosure & advancement
- Changing employers
- Benefits & long term security



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Invisible Symptoms can be especially challenging...

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



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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





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Warning signs that depression may be present include:

- Disturbed thinking
- Feelings of sadness or irritability
- Loss of interest or pleasure in activities once enjoyed
- Changes in weight or appetite
- Changes in sleeping patterns



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- Feelings of guilt, hopelessness or worthlessness
- Inability to concentrate, remember things or make decisions
- Fatigue or loss of energy - withdrawal
- Restlessness or decreased activity noticed by others
- Complaints or physical aches and pains for which no medical causes can be found
- Thoughts of suicide or death
- Feeling overwhelmed
- Depression, if not treated, can last many months or years.



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Depression is treatable !





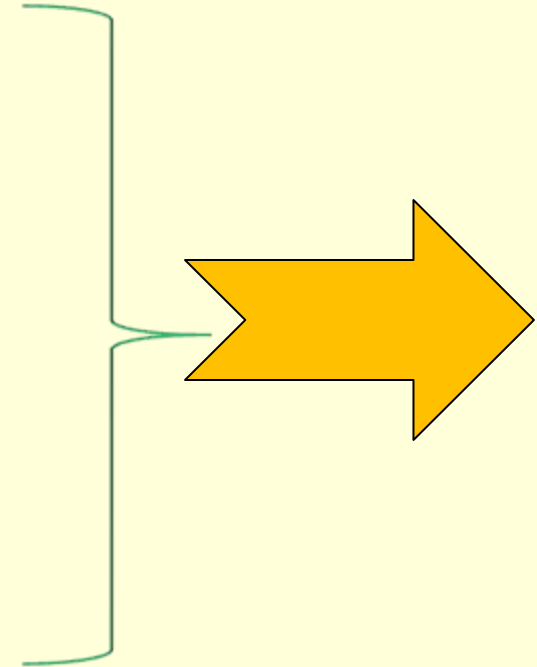
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Speaking of treatment...

- | | |
|-------------|--------------------|
| • Avonex | Interferon 1a |
| • Betaseron | Interferon 1b |
| • Copaxone | Glatiramer Acetate |
| • Rebif | Interferon 1a |
| • Tysabri | Natalizumab |





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



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Where are we going?

Oral therapies FTY 720 & Cladribine

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



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World Health Organization Clinical Trials Platform (WHO)



July 16, 2009

627 clinical trials worldwide (564 in Feb 09 same time last year)

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



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Disease

Clinical Trials

Diabetes

4544

Rheumatoid Arthritis

2031

MS

627



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<u>Disease</u>	<u>Incidence</u>	<u>Clinical Trials</u>
Diabetes	300/1000	4533 188,100
Rheumatoid Arthritis	10/1000	2031 6270
MS	1/1000	627
WHO stats July 2009		



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MS Society of Canada

- Over \$110,000,000 in the first 60 years
- Now, over \$10,000,000 per year
- Basic and clinical research, master, doctoral and post doctoral studentships
- MS Foundation \$12,000,000 over the next 3 years



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5 TOP TIPS





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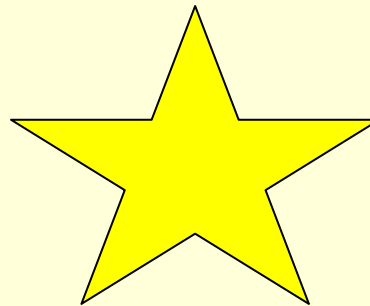
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Commit to

HEALTH





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4

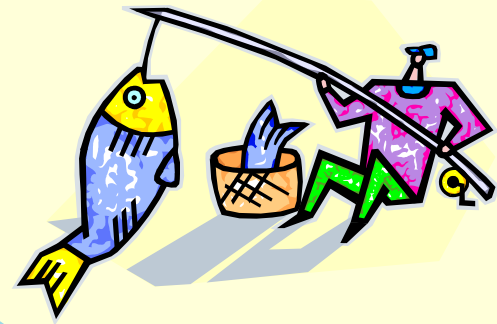
Don't Sweat the Small Stuff

Rule of 5's



3

Find your MS
free zone



**DO NOT
ENTER**





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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





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Keep Hope Alive





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REMEMBER

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



And thanks for being a great audience!