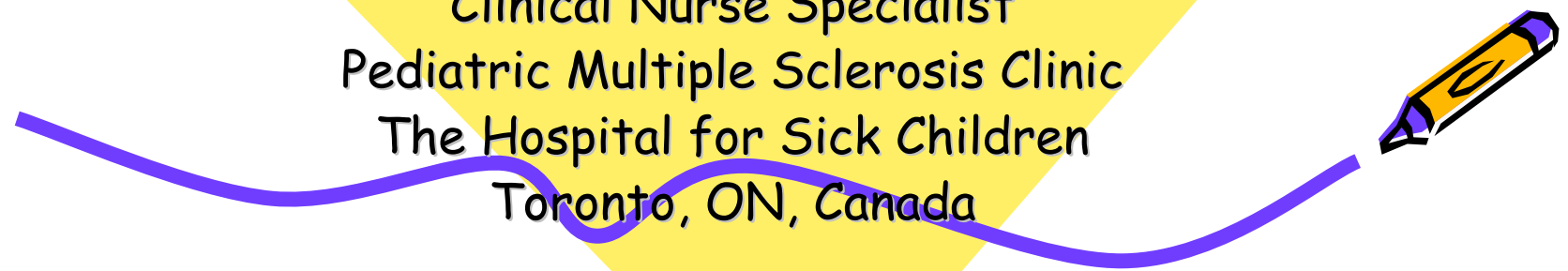




# Perceptions of MS in Children and Teens

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Pediatric Multiple Sclerosis Clinic  
The Hospital for Sick Children  
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# Developmental Tasks



- School-age children (6-12 years)
  - Developing a sense of industry
  - Learning responsibility, social and work skills, cooperation and fair play
- Adolescents (13-18 years)
  - Developing a sense of identity
  - Learning who they are and their purpose in society by participating in social experiences and increasing their independence

(Erikson, 1963)



# Developmental Considerations of School-Age Children

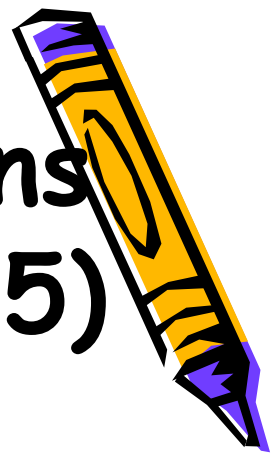


- Beginning abstract thinking but continue to think concretely
- Strongly influenced by peers, want to conform and avoid being different
- Desire parent and family for comfort and support
- Increased independence but want more than capable
- School expectations for performance increase



# Developmental Considerations of Early Adolescence (12-15)

- Continuing to develop abstract thinking
- Spend more time away with peers
- Ambivalent about freedoms/independence
- Starting to work on self-identity and relationships with the opposite sex
- Body image important, self-conscious about their bodies, overly sensitive and critical of their appearance
- Focused on the present and the world around them and constantly revising their views of the world
- Beginning to think about the future but goals are idealistic and change frequently



# Developmental Considerations of Middle Adolescence (15-17)



- Moving towards more psychological independence from family
- Future oriented and able to understand future consequences
- Peers/peer group and young adult respected models important
- Preoccupied with personal appearance
- Do best when parents remain available for encouragement and support around problem solving
- Believe they are omnipotent, invulnerable and immortal





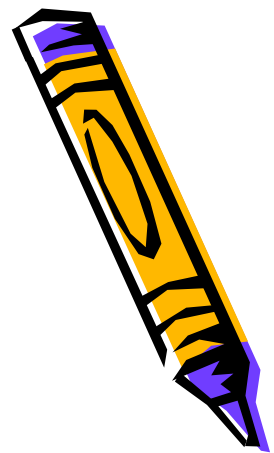
Boyd, J.R. & MacMillan, L.J. (2005).  
Experiences of Children and  
Adolescents Living with Multiple  
Sclerosis. *Journal of Neuroscience  
Nursing* 37(6), 334-342.

Supported by an unrestricted research grant from  
Biogen Idec Canada



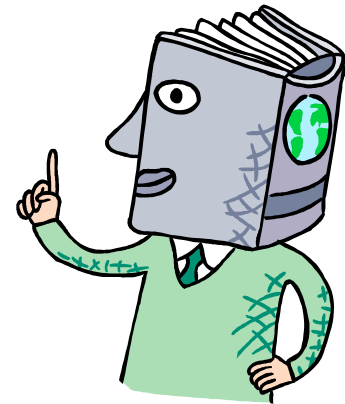
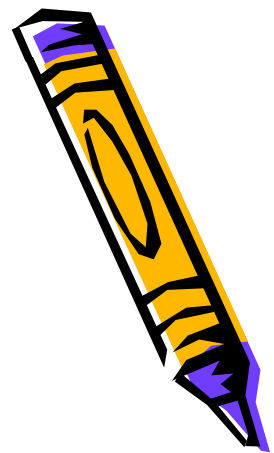
# Learning the Diagnosis

- Not knowing what MS is
- Feeling scared, sad, worried, confused and/or relieved
- Thinking the worst - "I'm going to die"
- Thinking it will go away



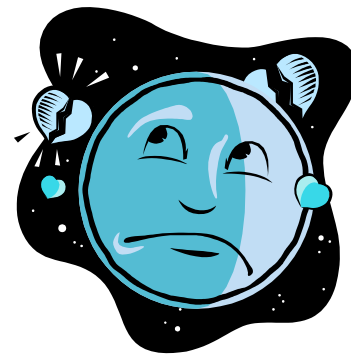
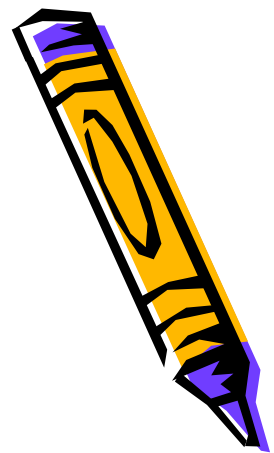
# Knowledge of MS

- Basic knowledge
  - Related to the nervous system and antibodies
  - Messages not getting through cause symptoms
  - Potentially leads to disability (few)
- Relate to own experiences
- Don't remember details

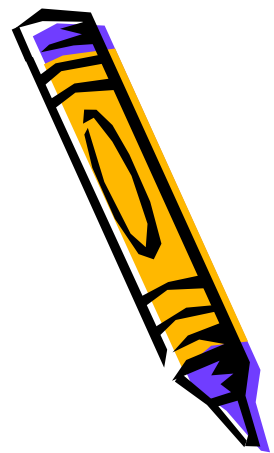


# Feelings and Views About Having MS

- Scared about unpredictability of relapses, uncertain future and impact on life
- Frustrated with symptoms
- Feel sorry for self and depressed
- Want to be cured
- Part of who they are
- Don't take life for granted



# Staying the Same

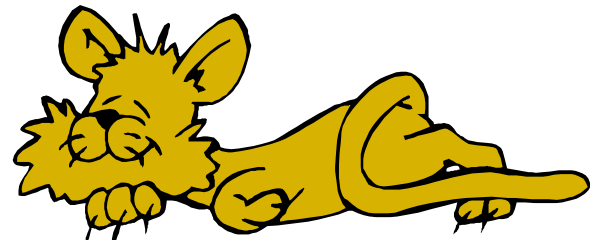
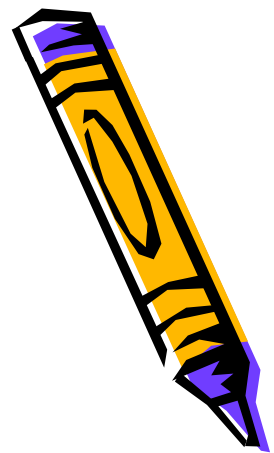


- Do the same activities
  - Go to school
  - Play/hang out with friends
  - Participate in sports
  - Go to dances, movies, sleep-overs
  - Read, listen to music, play on computer
- Have the same emotions
- Same person (personality)
- Have fun



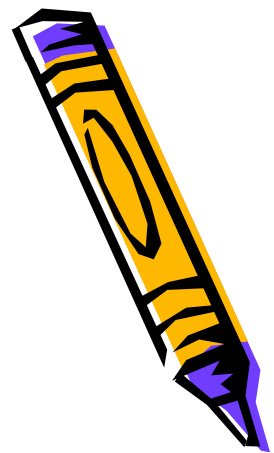
# Dealing with MS

- Stressors
  - Intermittent and ongoing symptoms
  - Unpredictability of relapses
  - Uncertain future
  - Restrictions on lifestyle
  - Impact on family
  - Treatment regimen
  - Being treated differently
  - Missing school



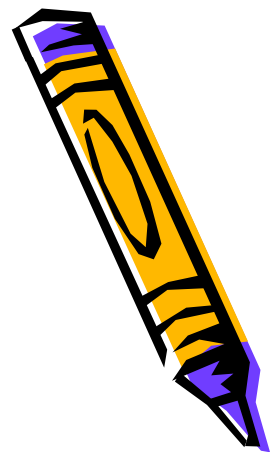
# Dealing with MS

- Coping strategies
  - Maintaining a positive outlook
  - Striving for goals and dreams
  - Downward comparisons
  - Identifying positive role models
  - Normalizing, adapting lifestyle
  - Seeking support
  - Distraction
  - Accepting treatment



# Dealing with MS

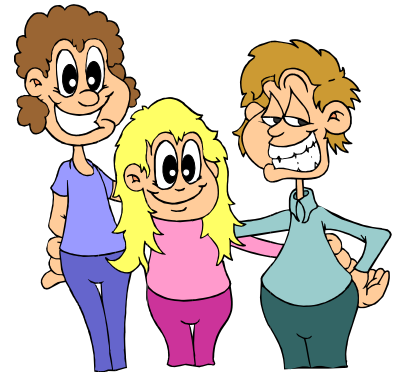
- Less adaptive coping strategies
  - Denial
  - Manipulation
  - Distractions (eating sweets, smoking marijuana)
  - Putting stressors on others
  - Avoidance
  - Hiding differences (symptoms, treatment)



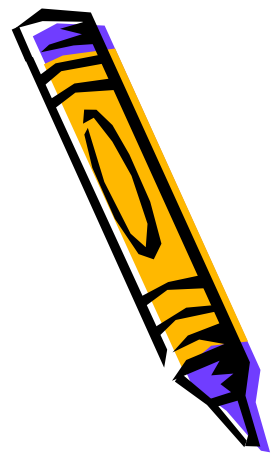
# Impact on Relationships



- Feel closer to family
- Parents worried/overprotective so hide problems
- Treated as "special"
- Distance created in some relationships (ignore problems or are insensitive to needs)
- Feel not understood by others (e.g., teachers)
- Need to test new relationships
- Relationships stay the same for many



# Impact on Lifestyle

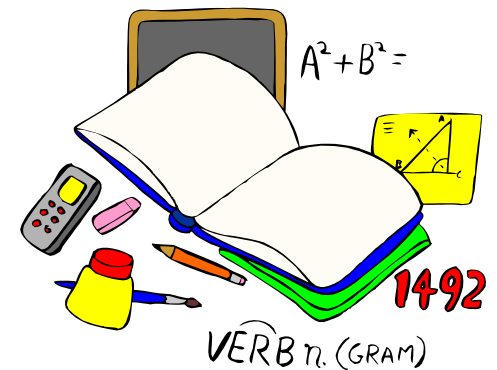


- Do same activities as peers
- Made some modifications to lifestyle (recreational vs. competitive sports)
- Limit activities
- More careful, take fewer risks, don't push self



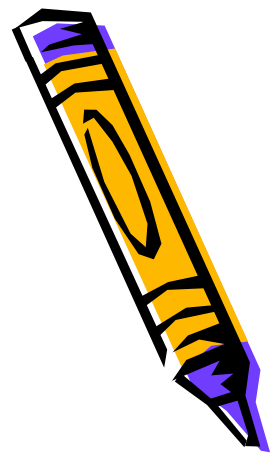
# Impact on Schooling

- Absenteeism
- Difficulty with learning
- Memory and concentration problems
- Work harder for the same marks
- Mood affects motivation
- Need to decrease course load



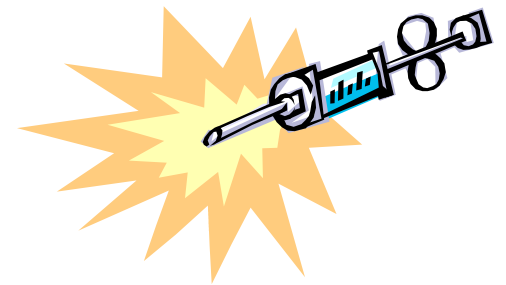
# Impact on Future

- Moving forward and hopeful
- Uncertain about future effects of MS
- Only looking at near future such as impact on attendance at school/college
- Others trying to influence career choices



# Views on Treatment

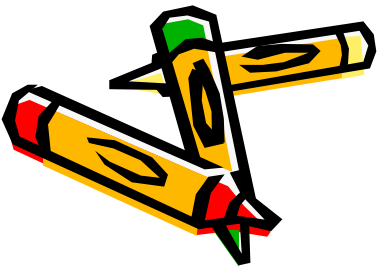
- Cause discomfort and cosmetic changes
- Worst part about having MS for some
- Recognize benefits/understand rationale
- Expectations of parents
- Part of life and routine
- Regular reminder of diagnosis
- Would prefer another treatment



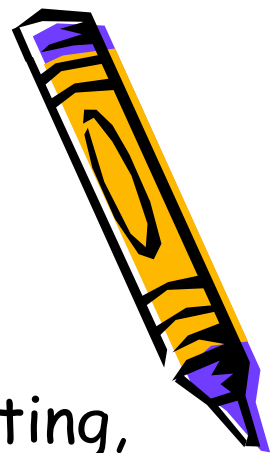
# Disclosing the Diagnosis to Others



- Tell those who need to know
- Selective about who they tell
- Sometimes more know than they want
- Feel it is important for others to know because they can be understanding of needs and can help
- Relationships are tested



# Advice to Others



- Remain positive about life, carry on, keep fighting, believe in yourself
- It's not that bad, there are worse things you can have, you barely know you have it
- You can't die from MS
- Modify your lifestyle to decrease stressors and fatigue
- Life will change but not necessarily in a bad way
- You need to be more cautious
- MS involves needles, tests and uncertainty
- Involve others who can help





"You definitely have to rearrange your lifestyle to suit you better and it's not a bad thing. Like, people look at it in a bad way, like you have to change your whole life. It's not that...it's because the things you used to do you'll see automatically that you just don't want to do them anymore. Like it's not that you can't do it, and it's not that you're like 'Oh I have to change it', because no one can ever change what you like to do. But you'll realize that the things that you like to do will change because of your fatigue level, because of everything. So I think my advice would be to definitely just like look at, or reexamine kind-of your life and make sure you have everything, like, stress-free. Like deal with it daily, like slowly, one step at a time not kind-of looking at the future. Always make sure that you change your lifestyle so you're in a relaxed environment all the time and make sure you're stress-free because if you're stressed then it's not going to go away. It's just going to only be more intense. Don't really get your hopes up on the 'I'm going to live a normal life', because then you'll just be let down. Because it's not true. You're not going to go back to how you used to live and it's not a bad thing. It doesn't have to be a bad thing. It can be a very good thing."

