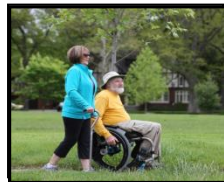




# Developing Client-Focused Care for Younger Persons with Neurological Diseases in Home and Residential Care

A discussion of challenges for both care recipients and care providers from a Multiple Sclerosis perspective.





# Acknowledgement

The MS Society is grateful to Bayshore Health Care for supporting our participation in this Conference and making this workshop possible.





# MULTIPLE SCLEROSIS

- Is a disease of the CNS causing destruction of myelin and nerve damage resulting in changes to the messages sent
- Largest cause of neurological disability of young Canadians
- No known cause or cure
- Course and progression is unpredictable
- MS is a unique experience for each person diagnosed
- Affects people who are working age and at the beginning of their families and careers (Age of diagnosis 15 to 50, average age 28)
- 3 times more common in women



# MS Symptoms

## Invisible:

- fatigue
- visual problems
- sensory dysfunction
  - numbness, tingling, ‘pins & needles’
- cognitive impairment
- bladder and bowel problems
- pain
- dizziness
- depression and mood alterations
- sexual dysfunction

## Visible:

- motor functions
  - walking
  - muscle weakness
  - spasticity
  - tremor
  - drop foot
- speech problems
- lack of balance and coordination



# Common Secondary Symptoms

- Contractures
- Urinary tract infections
- Osteoporosis
- Muscle atrophy
- Skin breakdown
- Respiratory complications due to swallowing problems, Dysphagia



# General Patterns

- There are some general patterns (with many exceptions) that have been observed over time:
  - The first five years
  - The Rule of One-Third
  - Ambulatory aids:  $1/3 \leftrightarrow 2/3$
  - Nature of the symptoms: sensory versus motor
  - Attack frequency: frequent versus occasional
  - Age at diagnosis: late in life versus early



# Some Facts About MS...

Fatigue - most common symptom of MS, 90% of people will experience fatigue

Cognitive Changes - occurs in about 50% of people with MS. Cognitive changes are unrelated to physical disability and can range from mild to severe.

Urinary symptoms affect about 75 to 90% of people with MS



# Some Facts About MS...

- 50% of people with MS will experience a major depressive episode over the course of their disease
- Other mood disorders are also more common in the MS population
- Fatigue and environmental issues such as room temperature and time of day can cause weakness
- 50% of people will experience MS-related pain during the course of their disease





# Non-Medicinal Treatments

- Improve quality of life for people living with MS
  - appropriate exercise
  - physiotherapy
  - rehabilitation
  - massage
  - stress reduction techniques

*These non-medicinal strategies play a key role in managing all types of MS.*



# Physical Activity and MS

- Historically people with MS were advised against physical activity
- Recent research indicates that it is safe and beneficial for people with MS to take part in moderate exercise and stretching.
- Recognized as an important part of the overall care plan





# CHALLENGES OF LIVING WITH MS



# Personal Challenges

- Living with a chronic progressive disease that is unpredictable and episodic
- Impacts people in the prime of their lives
- Lack of awareness & understanding about MS by others



# Impacts on Life

- Financial
- Family/Friends
- Career/Identity
- Autonomy & Independence
- Loss of Hope



# CHALLENGES FOR HEALTH CARE PROVIDERS



# Systemic Challenges

- Designed for geriatric population
- Care policies primarily focus on basic physical needs
- Costs/efficiencies
- Small population of younger residents



# Supporting People with MS

- Lack of knowledge of MS by care staff
- Different needs from general population
- Can be more physically disabled
- Can be more cognitively intact
- Uniqueness of care plans





# Impact of Living in Care for People with MS

- Inappropriate living environment
- Isolation, loss of identity, control
- Increased stress and depression

## Situational responses to living in care

- Intransigence
- Colonization
- Conversation



**HOW CAN WE ADDRESS THESE CHALLENGES....**



# TreeTop Model of Care

## Key to the model

- Understand the persons views
- Unravelling each person's unique experience
- Shared understanding and collaborative care planning.

Taken from: "Multiple Sclerosis: the Treetops model of residential care", 2002, by Sheila Flynn. *British Journal of Nursing*. Retrieved from: <http://dx.doi.org/10.12968/bjon.2002.11.9.10177>.





# TreeTop Model of Care

Noted success of this model:

- Reduction in relapses, infections, pressure sores
- Elimination of need for hospitalization
- Alleviated stress, depression and hopelessness
- Improved nutritional status and maintenance of weight.



# Treetop Model of Care

Bonding and development of relationships is key, with 3 distinct phases:

1. Baggage people carry with them
2. Barriers to bonding
3. Bonding in Residential Care

3 Distinct areas of assessment:

Clinical, psychological and social



# 7 Conditions for Dignity Enabling Environments

1. Self-Expression
2. Safety and Security
3. Meaningful relationships
4. Community and civic life
5. Participation in work, school or leisure
6. Respectful care relationships
7. Control, flexibility and spontaneity

Taken from: "Disability and dignity-enabling home environment.", 2012, by Gibson, Secker, Rolfe, Wagner, Park and Mistry. *Science and Medicine*, Vol 74 (2).





# Take Aways

- Individuals with MS have unique and individual care needs that differ from each other and the general population
- Care providers need education on MS to provide dignity enabling care
- This population has significant social and emotional needs that should be an important part of their care plan.



# Take Aways

- The current care system is not designed to meet these needs.
- Much of this can be applied to individuals with other neurological conditions, or other working age people needing care.





# Case Scenarios



# Long Term Care Setting

56 year old mother of 2 (8 & 12 year old) who was diagnosed with MS when she was 20 years old. Her condition has progressed and on admission to LTC home she presents as:

- difficulty with mobility (inconsistent with transfers)
- having difficulties with swallowing/communication
- needs assistance with self care tasks
- no longer able to go to work her job as an editor for the local paper

Questions:

How do we assess this individual?

What are the priorities to consider?

How do you manage her in your setting?

WHAT WOULD BE YOUR APPROACH?





# Home Care Setting

- 32 year old woman who lives with her boyfriend in a one bedroom apartment ; employed as an educational assistant at an elementary school; plays ultimate frisbee on a local team

Recently has been having issues with pain , fatigue (particularly in the AM) and dizziness. She is also reporting a new “tremor” that she is experiencing while doing fine motor activities.

Her extended health insurance provides coverage for some personal support hours.

Questions:

How do we assess this individual?

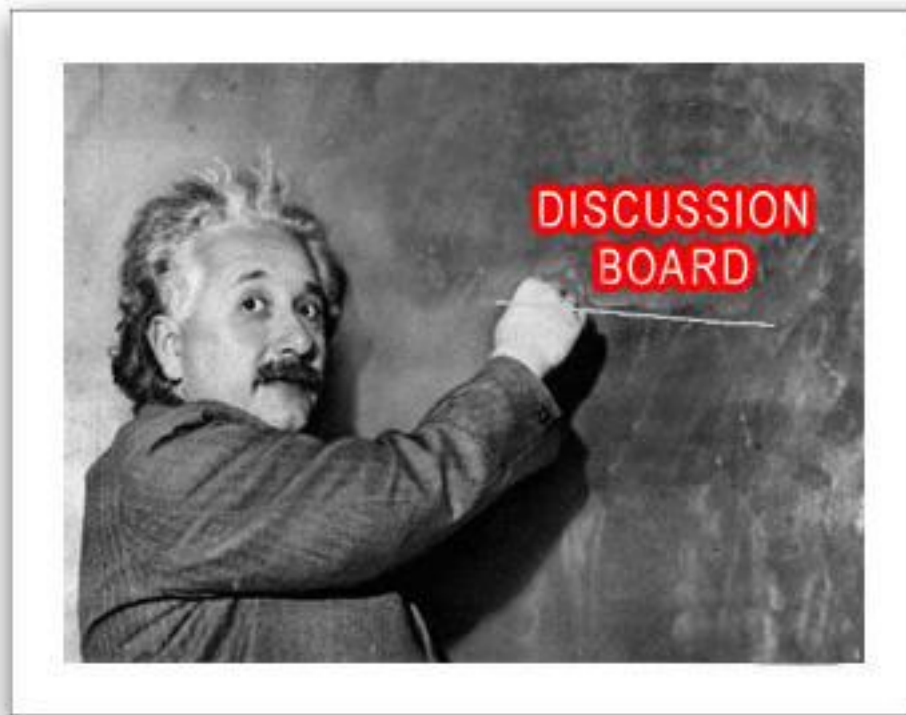
What are the priorities to consider?

How do you manage her in her home ?

WHAT WOULD BE YOUR APPROACH?



# Group Discussion

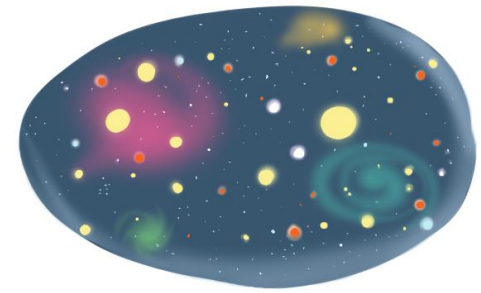


# QUICK FACTS

- Approximately 30,000 British Columbians will live in a residential care facility each year. For most it will become their last home.
- Approximately 59% of the residential care population is 85+ years in age.
- Approximately 15% of the residential care population is 65- years in age.
- Residents in care facilities are often treated as if they are all the same. They are not.



# ENVIRONMENT



An LTC facility is a persons home, as well as where others work. It is a collective setting in which the rights of the individual must be balanced against the rights of other residents living there, as well as the rights and responsibilities of the staff and administration.



# Challenging Myths



- Staffing levels is the single most important issue in LTC in BC
- Long term care in BC fails to treat either residents or care providers with dignity and respect



# Long Term Care





# Long Term Care





# Quality of Life Issues

- Patient Boredom
- Isolation
- Resident Engagement





# Table Questions



1. How does your facility/program currently accommodate individual needs to ensure high quality of life for all residents given the diversity in the population?
2. What strategies have you employed in your own facility or program that have been particularly successful in working with younger individuals?
3. How can patient advocacy groups like the MS Society support LTC providers and staff in their work?



Focus on what  
you can do, not  
what you can't.

Small steps turn  
into miles.....



[WWW.LIVELIFEHAPPY.COM](http://WWW.LIVELIFEHAPPY.COM)





**The MS Society of Canada is  
a resource to help support  
and educate care staff and  
advocate for change.**

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

**1-800-268-7582**





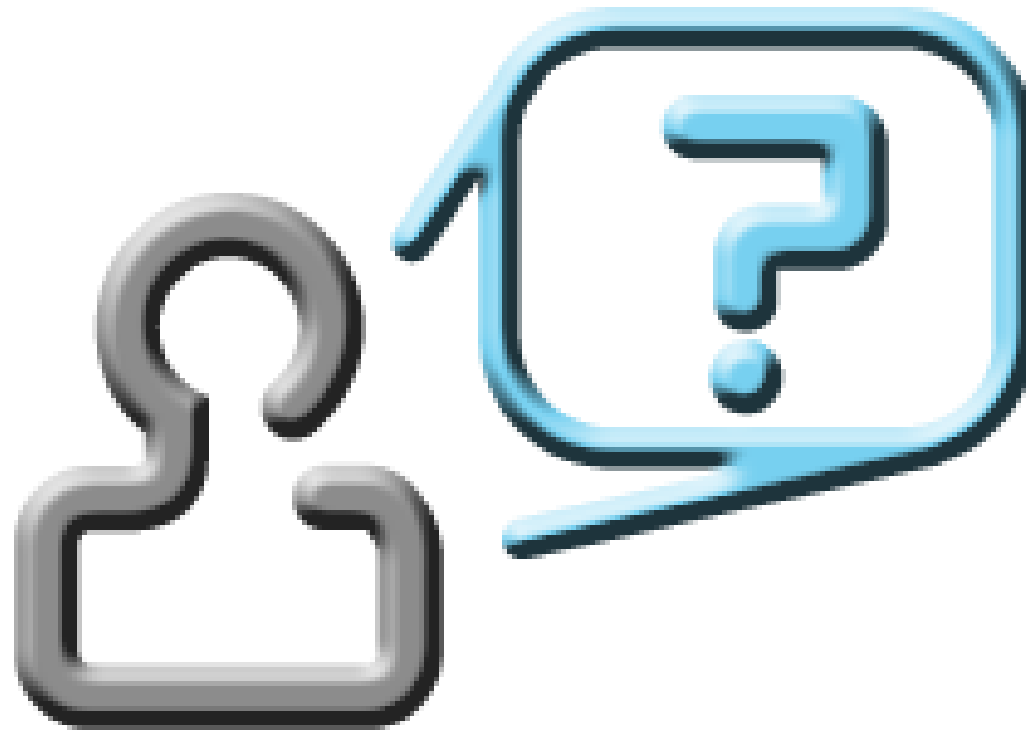
# Resource

National MS Society. (2015). Managing Progressive MS. Retrieved from:

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Thank you!





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