

Maintaining Independence in Light of Disability

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"The moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadow of life, the sick the needy and the disabled."

- **Hubert H. Humphrey**

Disability

- In Multiple Sclerosis:
 - For the clinician the focus:
 - Prevention of disability
 - For the patient the focus:
 - Potential loss
- Natural History Data:
 - Many patients will progress to a progressive course
 - DMAs may prevent that from happening

ICS

- Independence Care System (ICS) operates a nonprofit **Medicaid** managed long-term care plan in New York City whose motto is: “Adults with Physical Disabilities Welcome Here”.
 - Services are similar to what is provided on a regular basis in a nursing home although the majority of members receive them in their home
 - Members are required to receive home care (aide)
- Majority of members have an underlying neuromuscular diagnosis.
 - 20% have Multiple Sclerosis
- Average age is 52 years old.
- Most members are self directing

When Disability Lingers

- Preventative: Minimizing the risk
- Transitional: Symptom management
- Cumulative: Adapting to change

An Approach to Care

“One day I will find the right words, and they will be simple.”

— Jack Kerouac, *The Dharma Bums*

Approaching the Assessment

- ROS:
 - Changing how we ask questions
 - What are you doing well?
 - What do you want to be able to do?
 - What is the goal?
 - » Some times it may need to be adapted
- Clinical Examination:
 - Can you show me what you are able to do?

Approaching Care Options

- Having a Discussion:
 - Based on your ROS and Exam
 - Allow the patient to lead the discussion
 - Try to find areas that they have had the ability to overcome
 - Discuss your findings
 - Collaborate with the patient when setting goals
 - Try to determine if past successes can be applied

Creating a Care Plan

- Minimizing health risks
 - Secondary conditions
 - Linking to primary care
- Maximizing Independence
 - Adaptive equipment
 - Mobility devices
- Keeping patients in the Community
 - Using home based service
 - Maximizing the role of the home care aide

Questions?

Thank you!

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