

# ADDRESSING THE UNIQUE NEEDS OF PERSONS WITH MULTIPLE SCLEROSIS DURING NATURAL DISASTERS

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# OBJECTIVES

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# OBJECTIVES

1. Elucidate the specific challenges that individuals with Multiple Sclerosis (MS) face with extreme weather conditions, such as hurricanes and storms
2. Review current guidelines on emergency preparedness for people with disabilities
3. Propose recommendations for preparedness for patients
4. Provide resources for healthcare professionals to share with their patients to improve their readiness

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# EPIDEMIOLOGY AND PATHOLOGY OF MS

- A total of 2.8 million people is estimated to be affected by MS worldwide
- There is a steady increase in the prevalence of MS, especially in the North America region.
- As of 2019, nearly one million individuals are living with MS in the U.S.
- People with MS often suffer from chronic fatigue, vision disturbance, impaired mobility, and self-care, cognitive and/or communication deficits, bladder dysfunction, spasticity, and complications such as constipation and depression

# CLIMATE CHANGE AND MS

- The proportion of Category 4 and 5 hurricanes have increased at a rate of 25- 30% per degree Celsius of anthropogenic global warming. The storms linger for a longer time and result in greater risks for flooding.
- Climate change increases the vulnerability of those living with MS.
- Individuals with MS are susceptible to heat sensitivity
- Under these climate changes, persons with MS are more prone to be subjects of neglect from the society, injuries from clutter, and communication difficulties in addressing their own needs.

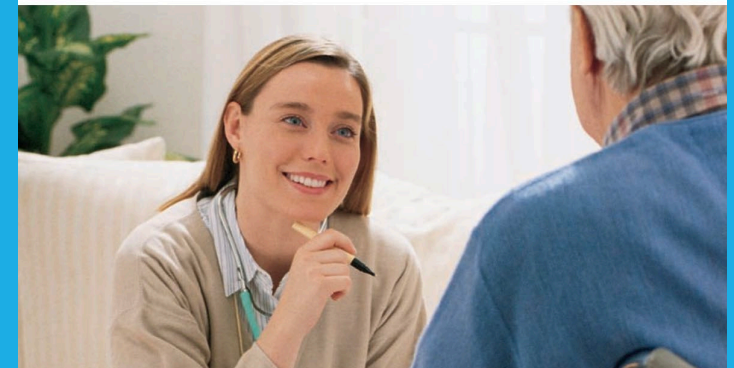
# PROBLEM

- The Federal Emergency Management Agency and the American Red Cross Community have published a booklet, “Preparing for Disaster for People with Disabilities and other Special Needs”
- Yet, there is a paucity of established guidelines on how individuals with MS can prepare for hurricanes/ storms
- There is also a lack of guidelines on how healthcare professionals can establish continuum of care with individuals with MS to ensure storm readiness.

## Preparing for Disaster for People with Disabilities and other Special Needs



FEMA





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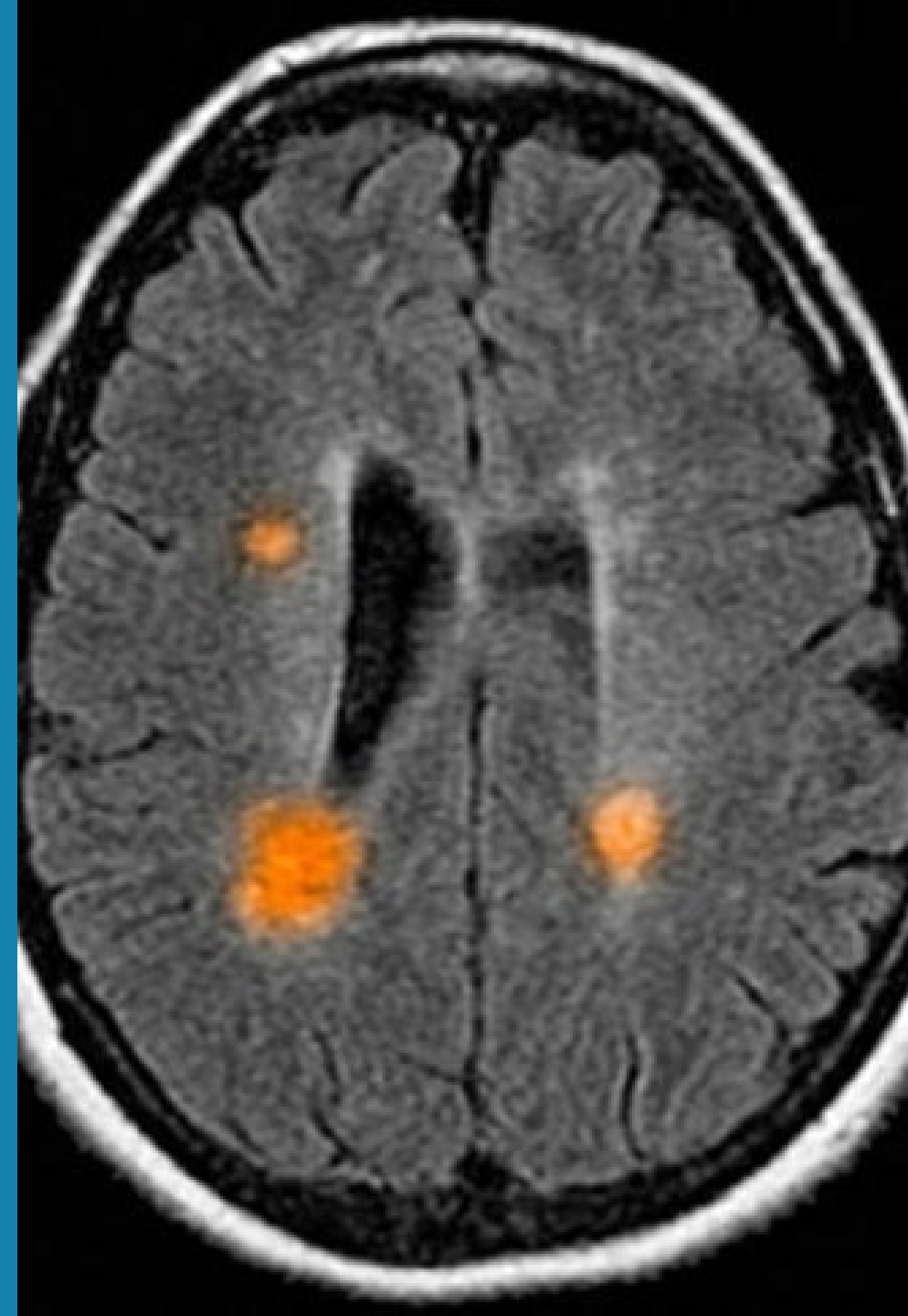
# CHALLENGES: MOBILITY

- Muscle spasticity as well as impairments in strength, balance, vision, and/ or coordination may contribute to mobility challenges
- Physically demanding to navigate the wheelchairs around storm debris
- Wheelchairs, gait aids, and/ or ramps can become damaged during or after hurricanes
- Patients can be dependent on a caregiver, who may be unavailable



# CHALLENGES: COGNITIVE IMPAIRMENT

- Decreased capabilities in planning for an evacuation route, restocking essential supplies, or communicating with caregivers and family members
- Impaired ability to access information and encode memory
- Those with impaired judgement may fail to heed warnings of authorities to evacuate from homes
- The absence of light from electrical outages can deprive individuals' cues to time and place



## CHALLENGES: SENSORY IMPAIRMENT

- Approximately 50% of persons with MS report pain and altered sensations such as tingling and numbness
- Painful paresthesia can lead to individuals' avoidance of maneuvering around floodwaters
- Optic neuritis can impair individuals' sense of balance
- Disorders of smell can make individuals unable to detect harmful molds or a gas leak.



## CHALLENGES: SPEECH AND SWALLOWING DISORDERS

- Disorders of articulation, intonation, and voice quality
- Patients may be neglected or misunderstood by emergency personnel during disasters
- Dysphagia is a common complication of MS
- Diet alterations may be difficult to prepare for in the event of a disaster



# CHALLENGES: NEUROPSYCHIATRIC ISSUES

- Hurricanes pose tremendous psychological distress among affected persons
- Storm- related stressors can worsen symptoms of pre-existing anxiety and depression
- Suicidal ideation and risk of self harm in individuals with MS is significantly higher than in the general population
- Direct exposure to natural hazards may aggravate patients' perceived loss of control



## CHALLENGES: DISRUPTION OF HEALTHCARE DELIVERY

- Delayed access of care due to decreased staffing of healthcare providers and closure of medical offices
- Sudden dislocation of the medical supply chain can put patients at risk for withdrawal
- Power outages and the inability to access life-sustaining equipment which require electricity
- Interruption of telehealth services due to power outages



# CHALLENGES: FINANCIAL ISSUES

- Those living with MS face higher rates of unemployment and risk for health-related financial toxicity
- Need for additional expenses such as transportation and lodging in the event of an evacuation
- Damage to one's home, vehicle, and medical equipment may also necessitate pricy repairs



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# EQUIPMENT AND SUPPLIES

- Patients should be reminded to have at least a **7-day supply** of everything, including food and water
- Patients are encouraged to create supply checklists
- Ample supply of medications and personal equipment, including bladder catheters and/ or wound care supplies
- Danger of medication withdrawal symptoms
- Medication coolers can be used for temperature-sensitive medications, such as interferon



# EVACUATION

- Patients are encouraged to develop a personal support network of at least **three trusted people** in proximity
- Patients should write out key information for potential caregivers or rescuers to ensure needs are met
- Back-up standard or transport wheelchair for those who rely on power wheelchairs for mobility
- Evacuation chairs for those who live in high-rise buildings



# CHRONIC MEDICAL CONDITIONS

- Healthcare professionals should assist patients by evaluating any storm-related injuries
- Help obtain replacements of any lost or damaged equipment and supplies
- Resume provision of health care services, including infusion therapy and rehab services
- Screen patients for symptoms of depression and/ or anxiety and refer for mental health services
- Help identify available social support programs

Medical Conditions: .....

Allergies: .....

Medications/Dosage/Frequency: .....

Special/Other Information: .....

Blood Group: ..... Organ Donor: Y N

Signature: ..... Date: .....

MO Signature: ..... Date: .....

Action In Case Of Emergency: [Redacted]

I.C.E. Enter MedibandPlus Code: [Redacted] [www.medibp.com](http://www.medibp.com)

# HOW HEALTHCARE PROFESSIONALS CAN HELP



Assist patients in recognizing what their needs might be in the event of a disaster



Remind patients to maintain appropriate stockpiles of meds, foods, and supplies



Educate patients to register with local government for evacuation assistance



Encourage patients to develop a personal support network of at least three people



Plan for continuity of care



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# LEARNING POINTS

- When major hurricanes strike, individuals living with disabilities, including MS, face unique vulnerabilities
- Health care professionals caring for persons with MS living in hurricane-prone communities should assist patients in the development of comprehensive storm preparedness plans before the approach of hurricane season
- Improving patients' emergency preparedness requires consideration of the impact of their mobility, sensory, cognitive, communication impairments, financial needs, and healthcare delivery during a disaster
- It is important to promptly restore access to health care services among persons with MS in the aftermath of a hurricane.

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## REFERENCES

- [1] Hall, T.M., Kossin, J.P. Hurricane stalling along the North American coast and implications for rainfall. *npj Clim Atmos Sci* 2, 17 (2019).
- [2] Christogianni, Aikaterini et al. "Temperature sensitivity in multiple sclerosis: An overview of its impact on sensory and cognitive symptoms." *Temperature (Austin, Tex.)* vol. 5,3 208-223. 5 Sep. 2018, doi:10.1080/23328940.2018.1475831
- [3] HabibiSaravi R, Abedini M, Ghasemi Hamedani F, Seyedin H. Multiple Sclerosis and Disaster. *Multiple Sclerosis Journal*. 2016;22(S1):2-84.
- [4] Merson RM, Rolnick MI. Speech-language pathology and dysphagia in multiple sclerosis. *Phys Med Rehabil Clin N Am*. 1998 Aug;9(3):631-41. PMID: 9894114.
- [5] Espinel Z, Galea S, Kossin JP, Caban-Aleman C, Shultz JM. Climate-driven Atlantic hurricanes pose rising threats for psychopathology. *Lancet Psychiatry*. 2019 Sep;6(9):721-723. doi: 10.1016/S2215-0366(19)30277-9. Epub 2019 Jul 18. PMID: 31327708.
- [6] Strober LB, Callanan RM. Unemployment in multiple sclerosis across the ages: How factors of unemployment differ among the decades of life. *J Health Psychol*. 2021 Aug;26(9):1353-1363. doi: 10.1177/1359105319876340. Epub 2019 Sep 14. PMID: 31522567.