



2014 MDF ANNUAL CONFERENCE

Advocating in the Clinic: Educating & Supporting Your Doctors

The DM Patient Perspective

Carolyn Valek

Patient Advocate to Several DM1-Affected Family
Members



Karl's Story

All in the Family

Coping With DM1 Health Issues

- Early Onset Cataracts
- Excessive Daytime Sleepiness
- Gastrointestinal Issues
- Facial Muscle Weakness
- Gall Bladder Removal
- Hypothyroidism
- Central Sleep Apnea
- Obstructive Sleep Apnea
- Type 2 Diabetes
- Ptosis of the Eyelids
- Progressive Weakness in Neck, Face, Hands, Feet, Legs
- Foot Drop
- Dysphagia
- Abnormal EKG
- First Degree AV Block
- Atrial Fibrillation



Karl's Office Visit Challenges

- Too tired to take notes
- Too tired to remember doctor's advice
- Too tired to ask questions
- Too tired to provide feedback on follow-up visits

It became impossible for Karl to navigate his own healthcare management.





DM Patient Survey Results

What Patients Wish Their Doctors Knew

DM Patient Survey Development



- Created as part of a University of Toledo graduate certificate project in Patient Advocacy
- Conducted online survey January-March 2014
- Target audience included MDF Support Group Facilitators and DM support group on Facebook
- 33 survey respondents included:
 - DM-affected individuals, family, caregivers, friends

DM Patient Survey Results

Challenges in Healthcare Mgmt.



81% of respondents:

- Addressing disease management
 - Taking medication
 - Being accompanied to doctor appointments
 - Coordinating care among HCP team
 - Need for information on DM-specific subjects
 - Dealing with excessive daytime sleepiness issues
 - Need for successful strategies for daily living

DM Patient Survey Results

Challenges in Healthcare Mgmt.



81% of respondents:

- Identifying supportive services and HCPs for referrals, i.e. physical therapists, occupational therapists, social workers, dietitians, speech therapists, genetic counselors, and respiratory therapists.

DM Patient Survey Results

Challenges in Healthcare Mgmt.



81% of respondents:

- Addressing disease management
 - Taking medication
 - Being accompanied to doctor appointments
 - Coordinating care among HCP team
 - Need for information on DM-specific subjects
 - Dealing with excessive daytime sleepiness
 - Need for successful strategies for daily living

DM Patient Survey Results

Challenges in Healthcare Mgmt.



61% of respondents:

- Addressing acute care management, such as:
 - Hospital stays
 - Surgeries and the use of anesthetics
 - Accidental falls/injuries
 - Pneumonia

DM Patient Survey Results

Challenges in Healthcare Mgmt.



WRITE-IN RESPONSES:

- ❑ *“Many healthcare professionals have never heard of DM or know very little about it.”*
- ❑ *“Coordination of care with various doctors can be challenging.”*
- ❑ *“Trying to get various medical care professionals to look at each medical challenge from the point of view of the DM.”*
- ❑ *“More education on Myotonic Dystrophy in layman’s terminology for family, caregivers and anyone who has to cope with this disease.”*

DM Patient Survey Results

Patient Advocate Role



MYOTONIC
DYSTROPHY
FOUNDATION

- Handled by family or friends (69%)
- Self-managed (25%)
- Social worker/case manager (6%)

DM Patient Survey Results

Patient Advocacy Duties



MYOTONIC
DYSTROPHY
FOUNDATION

- Helping patient make appointments (77%)
- Keeping track of patient's healthcare services (73%)
- Keeping track of medication (65%)
- Helping patient find doctors and specialists that understand DM (52%)

DM Patient Survey Results

Patient Advocacy Duties



MYOTONIC
DYSTROPHY
FOUNDATION

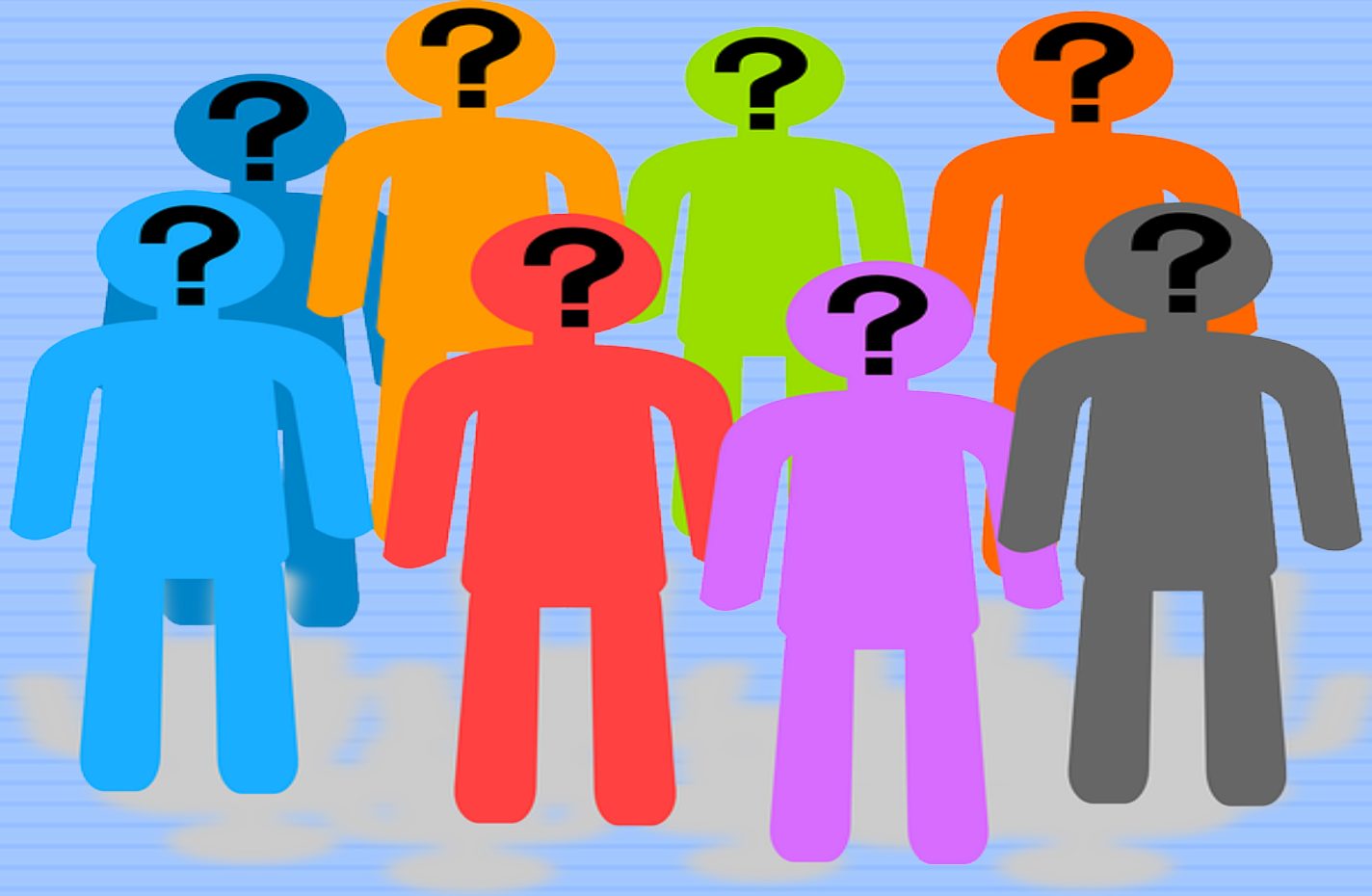
- Helping patient understand their diagnosis and treatment options (61%)
- Making certain doctors and other members of the healthcare team are communicating to each other about the patient's ongoing care (56%)
- Helping with the referral process to ancillary services like home health care, medical supplies, orthotics, medical devices, and outpatient therapy (52%)

DM Patient Survey Results

Patient Advocacy Duties



- WRITE-IN RESPONSES:
 - Providing emotional support
 - Encouraging social interaction and activities
 - Providing transportation
 - Dealing with the insurance company
 - *“Not allowing doctors to push symptoms under the rug because they have never seen them before”*



DM Patient Tips for Advocating in the Clinic

Learn as much as you can about DM and share your knowledge.



DM Patient Tips for Advocating in the Clinic

Ask Someone to Help You Piece Together an Effective Way to Manage Your Health (or Empower Yourself!)



DM Patient Tips for Advocating in the Clinic

Build and Support a Team of Health Care Professionals Willing to Go the Extra Mile.