National Multiple Sclerosis Society

MS Navigator® Symposium
Kay Julian
Executive Vice President, Services

National Multiple Sclerosis Society
2019 Scope of Services Accessible to All

- MS Navigator Program
- Healthcare Access
- Programs and Connections
Services Team

- Total Staff: 200

- Leadership volunteers
  - 800 self-help group leaders

- Advisory Committees:
  - National Medical Advisory Committee
  - Services Advisory Committee
  - Coordination with Activism Advisory Committee & Research Advisory Committee

- Volunteer Councils:
  - Healthcare Provider Councils
  - Multi-cultural Council
  - Impact, Collaboration, Innovation and Marketing
Agenda

• Welcome and introductions
• Overview of MS Navigator
• Spectrum of Support – Case Studies
• Q & A Session
• Closing Remarks
Erin Poznanski
Vice President, MS
Navigator Services Delivery
Basis for MS Navigator®

MS Navigator exists because people with MS face challenges everyday
MS Navigator Team

Our nationwide team works one-on-one with people affected by MS
MS Navigator Team

YEARS OF STAFF EXPERIENCE

* 60% HAVE ADVANCED DEGREES
Serving as Supportive Partners

• Assess current needs and emotional status
• Goal-oriented support, connection to services and resources
• Exploration, support and progress when there are no solutions

Angela, MS Navigator
Case Management

Goal: Increase independent living and quality of life for people affected by MS whose health and safety are compromised
Case Management

Contracted Case Management Professionals

- Contracts with 138 professionals or agencies
- Covering 48 states
Case Management

Common Indicators

- Multiple, urgent issues
- Inability for family to provide care or cope
- Isolation or other health or safety risks
- Lack of home care or adequate housing
- Inability to identify needs
- Imminent potential of admission to a long-term care facility
Crisis Support

MS Navigators are trained and equipped to actively identify and take immediate action on urgent, harmful concerns.
Benefits, Employment & Health Insurance

• Private and public insurance
• Disability benefits
• Disclosure decisions
• Legal protections
• Employment guidance
Learnings

• Need and demand was greater than anticipated, resulting in long wait times and a high abandonment rate among callers

• Complex challenges and barriers often exceed resolution in one call

• The valuable partnership of an MS Navigator is provided at no cost
Response to Challenges

Average call abandonment rate

50% September 2017

6% March 2018
Response to Challenges

Average wait time

45 mins.
September 2017

2 mins.
March 2018
Metrics

- 15,236 People supported in Q2
- 3.5 hours on average spent with each person
Demographics of People Served:

- Median age – 54 years
- 75% are female
- 75% are living with MS
- 85% live in urban or suburban areas, 12% live in rural areas
- Living with MS for an average of 15 years
Impact

• 93% would recommend the program
• 90% are able to utilize new resources
• 77% are better equipped
Impact

MS Navigator is a place for support where I can find solutions:

- 80% Agree / Somewhat agree
- 15% Neutral
- 5% Disagree / Somewhat disagree

Target: 75% agree / somewhat agree
Impact

Did you or do you plan to take action based on the information provided?:

- Yes: 87%
- No: 7%
- Other: 6%

Target: 90% yes
Impact

Top five actions taken/planned:

1. Share information with a family member or friend
2. Make a plan to change a particular situation
3. Share information with someone affected by MS
4. Contact a referral
5. Talk with doctor about information provided
Top 5 Areas of Support

MS Navigators provide connections to resources, expert support and access to funds in the areas of:

- Benefits, insurance and employment
- Social and emotional support
- Housing
- Neurologist referrals
- Home care
Impact

“
My experience with the Society is very positive. They have always been there with fresh ideas to make my dealing with MS more viable."
– MS Navigator service recipient
National Multiple Sclerosis Society Impact
Joy Derwenskus, DO, MS
Neurology Specialist,
Murfreesboro Medical Clinic
Situation

- 49 year-old black female developed right facial pain summer 2017
- Subsequently developed right scalp pain and right hand tingling, urinary leaking and difficulty emptying bladder
- 2\textsuperscript{nd} opinion at Murfreesboro Medical Clinic
- Discussed the diagnosis of demyelinating disease/MS
- Brought several family members in for the next visit to discuss diagnosis, treatment options, and answer questions
Referral

- Referred patient to the MS Society – MS Navigator Services
- Looking for support for newly diagnosed – additional information, local support groups, etc.
- MS Navigator and patient discussion the time it took for diagnosis and her anxiety about the diagnosis
- Patient has great support system at home and is able to work from home - helping with fatigue
Outcome – Follow-Up

- Patient was emailed resources from the MS Navigator:
  - Newly diagnosed including Knowledge is Power
  - Emotional changes and depression
  - Diet
  - Information about cooling programs through the MS Foundation and MSAA
  - Information about support group within 25 miles
**Outcome – Patient Response**

- Patient response:
  - Information provided was very helpful
  - The MS Navigator provided information about different programs and resources available
  - The information was recapped in an email including links which made it very easy to navigate
  - Overall she received good information which helped to ease her anxiety about the new diagnosis and help her on the right path forward
Susan’s Experience

- A young woman at the peak of her career
- 39-year-old female, Caucasian, diagnosed in 2014
- Married, resides in Maryland
- Employed full-time for local school system – worked for school system for over five years (hired prior to diagnosis)
- Worked as librarian in an elementary school
Support from MS Navigator®

• Education on ADA rights
• Interview assistance and guidance
• Guidance on disclosure
• Options to explore employer-sponsored benefits
• Gaining confidence in job search
Timeline of Support

- **January 2011**: Susan employed full-time
- **February 2014**: Susan is diagnosed with MS; connects with Society seeking general info
- **March 2016**: Susan struggles on the job; calls MS Navigator
- **August 2017**: Susan reports she is in a better role at the school
Outcome

“You were so helpful with the resource links and the guidance you gave me over the phone regarding how to re-enter back to work after more than a six-month medical leave due to my multiple sclerosis. I hope you know your work serves a meaningful purpose for others.”

“…your kind words and resources gave me confidence and motivation to help see myself as more than MS.”
Linda Guiod
Associate Vice President,
Case Management
Jackie’s Experience

• Electricity was shut off
• Lost all benefits (Medicaid, food stamps, and home health care)
• Had not left her home in 3 years; needs a ramp to exit
• Neighbor has been bringing her a sandwich each day so she has something to eat
Support from MS Navigator®

- Welfare Check
- Police Respond and provide immediate intervention
- Neighbor agrees to help with grocery shopping
- MS Navigator determines that case management is needed
Case Management: Sustainable Solutions

• Internal CM staff contacts Jackie and implements additional critical support (10/5)
  – Energy Grant / Food Gift Card

• Contracted CM Conducts Home Assessment and identifies Immediate Goals (11/8)
  – Reinstate Benefits / Lifeline Alert / Meal Delivery / Accessibility and safety issues/ Furnace repair

• Additional Goals added (3/21)
  – Access to a computer (3/22)
  – Dental and vision needs (solution 6/22)
  – Medicare paperwork & billing questions
  – Redetermination paperwork
Case Management

Oct. 5, 2016
Internal Case Manager takes action

Nov. 8, 2016
Contracted Case Manager conducts assessment

Nov. 8, 2016 - July, 6, 2017
Contracted Case Manager works with Jackie to achieve sustainable solutions
Outcomes

“When I called the Society it changed my life. I had fallen into a hole and I wasn’t sure I was going to get out of it. I felt powerless and didn’t know what to do. And then the MS Navigator answered my call and my case manager came into the picture, and I felt hope again.”
Questions?
Closing thoughts

MS Navigators help people navigate life with MS
Closing thoughts

We help people navigate life—so you can more effectively partner with patients for positive care and treatment outcomes.
Please help your patients know about the National MS Society and MS Navigator®