Living well with MS:
The nurse’s role in lifestyle management

Tuesday 10 September 2019
Karolinska Institute, Stockholm Sweden
Executive summary
Living well with MS: the nurse’s role in lifestyle management

Live, educational, full day, international program targeting nurses, focusing on the critical role of the nurse in MS lifestyle management through the viewpoints of three main stakeholders: neurologists, nurses and patients.

The programme was in partnership with and endorsed by the International Organization of MS Nurses (IOMSN) and fully accredited by the Royal College of Nursing (RCN).

The meeting took place at the prestigious Karolinska Institute in Stockholm, Sweden.

The programme was initiated, funded and organised by Merck Global Medical Education & External Relations.

This program was the result of a collaboration between IOMSN and Merck KGaA, Darmstadt, Germany, and therefore was not available to US healthcare professionals. Merck KGaA, Darmstadt, Germany only sponsors medical education programs for US healthcare professionals consistent with ACCME guidelines or similar grantors of accreditation, and consistent with US law and guidance.
MS NursED educational meeting snapshot

10 expert faculty members comprising neurologists, nurses and MS patients

115 attendees onsite and via live webcast from 22 different countries

2 MS in the 21st Century workshops on communicating disease progression

100% of participants strongly agreed or agreed that the meeting fulfilled their overall learning objectives as measured by the feedback form data

89% of delegates felt very confident discussing lifestyle management with their MS patients as a result of attending the meeting

18.5% increase in learning achieved by all delegates

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Meeting report

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Learning objectives

1. Educate MS nurses on current topics of interest in MS, specifically related to lifestyle management

2. Explore topical MS issues through the viewpoints of three main stakeholders: neurologists, nurses and people with MS

3. Provide a forum for MS nurses to engage directly with experts and peers to gain comprehensive advice on multidisciplinary MS care

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Programme was led and expertly delivered by a group of high profile international experts

**co-Chair**

Ms June Halper  
CEO, International Organization of MS Nurses  
New Jersey, USA

**Morning co-Chair**

Prof Gavin Giovanonni  
Chair of Neurology  
Barts and The London School of Medicine and Dentistry, London, UK

**Afternoon co-Chair**

Dr Martin Duddy  
Clinical Director and Consultant Neurologist, Newcastle upon Tyne Hospital Trust, Newcastle, UK

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The international, multi-disciplinary faculty ensured a diverse perspective

**NURSES**

Ms Colleen Harris  
Nurse Practitioner,  
University of Calgary  
MS Clinic,  
Calgary, Canada

Ms Kitty Harrison  
Nurse Practitioner,  
Tergooi Hospital,  
Hilversum, Netherlands

Ms Patricia Pagnotta  
Nurse Practitioner and President of International Organization of MS Nurses,  
Orlando, USA

**HCPs**

Dr Jens Bansi  
Rehabilitation & Exercise Scientist,  
Kliniken Valens, Pfäfers, Switzerland

Asst Prof Sarah Morrow  
Associate Professor of Neurology  
Western University, London, Ontario, Canada

**PATIENT ADVOCATES**

Ms Stanca Potra  
Patient advocate,  
Member of the MS in the 21st Century Steering Group, Bucharest, Romania

Mr Pieter Van Galen  
Patient advocate,  
Member of the MS in the 21st Century Steering Group  
Overijse, Belgium

Incorporating the patient voice

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Morning agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker(s)</th>
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<tbody>
<tr>
<td>09:30</td>
<td>Arrivals and Registration</td>
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<tr>
<td>10:00</td>
<td>Welcome and Introductions</td>
<td>• Gavin Giovannoni (Chair)</td>
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<td></td>
<td>• June Halper (co-Chair)</td>
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<tr>
<td>10:05</td>
<td>Opening Address</td>
<td>• June Halper (co-Chair)</td>
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<tr>
<td>10:15</td>
<td>Presentation: Treatment advances in MS; the impact on the wider HCP team</td>
<td>• Gavin Giovannoni</td>
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<td></td>
<td>• Colleen Harris</td>
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<tr>
<td>11:15</td>
<td>Nurse-led presentation: Supporting the ageing MS population and managing comorbidities</td>
<td>• Patricia Pagnotta</td>
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<td></td>
<td></td>
<td>• Kitty Harrison</td>
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<tr>
<td>11:45</td>
<td>Break</td>
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<tr>
<td>12:00</td>
<td>[Breakout] MS21 facilitated workshop: Speaking a common language: Communicating a future with MS</td>
<td>Breakout 1: Gavin Giovannoni</td>
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<td></td>
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<td>• Stanca Potra</td>
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<td></td>
<td>Breakout 2: Sarah Morrow</td>
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<td></td>
<td></td>
<td>• Pieter van Galen</td>
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<tr>
<td>13:00</td>
<td>Lunch break and networking</td>
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A lively audience debate with the panel concluded the meeting summarising the role of the nurse in MS lifestyle management.

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<th>Speaker(s)</th>
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</table>
| 14:00 | Afternoon welcome and recap                                            | • Martin Duddy (Chair)  
• June Halper (co-Chair)                                                                       |
| 14:05 | Presentation: Improving patient quality of life through rehabilitation | • Jens Bansi                                                                                 |
| 14:35 | Panel Presentation: Session 1 Case study: Psychosocial aspects of MS - challenges and solutions | • Martin Duddy, Sarah Morrow  
• Patricia Pagnotta, Pieter van Galen                                                             |
| 15:00 | Break                                                                  |                                                                                              |
| 15:30 | Panel Presentation: Session 2 Bringing it all together: The nurse’s role in lifestyle management | • Martin Duddy, June Halper  
• Colleen Harris, Kitty Harrison                                                                  |
| 16:15 | Summary and closing remarks                                            | • Martin Duddy  
• June Halper                                                                                       |
| 16:30 | Meeting concludes                                                      |                                                                                              |
The meeting was attended by 115 delegates

- 22 countries were represented by the 71 delegates present at the Karolinska Institute
- 44 viewers joined the meeting via webinar throughout the day,
  - Including delegates from the webinar, the meeting represented 22 countries
- Attendees were asked to complete pre-meeting and post-meeting surveys
  - 48 completed the pre-meeting survey with 51 completing the post-meeting survey
Gavin Giovannoni and June Halper chaired the informative morning agenda

**Treatment advances in MS; the impact on the wider HCP team**
Prof Gavin Giovannoni and Colleen Harris

Overview of some of the recent advances in MS therapies, particularly those related to lifestyle management, and what implications these advances have for MS nurses.

**Supporting the aging MS population and managing comorbidities**
Patricia Pagnotta and Kitty Harrison

Identifying invisible symptoms, depression, cognition issues and their effects on the patient and carer and to identify best practice for nurses dealing with the psychosocial impact of MS on their patients and carers.

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Communication of disease progression can be challenging

- Two breakout sessions chaired by an HCP and patient member of the MS in the 21st Century steering group
  - Gavin Giovannoni and Stanca Potra
  - Sarah Morrow and Pieter van Galen

- Ensuring patients and HCPs are speaking a common language through
  - “Communication Conundrum” card game explored specific language used in consultations
  - Patient Journey group discussions looked at when the topic of disease progression is typically raised
Communication conundrum

- Many definitions and measures used to describe MS are complicated, easy to misunderstand and negatively perceived
- A redefinition of disease progression or simplified language needs to be agreed
- “Disease progression” is often confused with “progressive MS”
- Language should be adapted depending on patient’s understanding

When to hold disease progression conversations

- Every patient is different – personalise conversations
- Introducing disease progression earlier in patient journey can help with adherence
- Nurses have a unique relationship with patients
- Empathy and sensitivity are vital
Martin Duddy summarised and led the interactive debates in the afternoon sessions

**Improving patient quality of life through rehabilitation**
Jens Bansi

Looking at the importance of rehabilitation, specifically through physical therapy and activity, for people with MS, in order to maintain a good quality of life, highlighting the MS nurses’ role in ensuring rehabilitation is part of the lifestyle management of the patient.

**Case study: Psychosocial aspects of MS - challenges and solutions**
Martin Duddy, Sarah Morrow, Patricia Pagnotta and Pieter van Galen

Identifying invisible symptoms, depression, cognition issues and their effects on the patient and carer and to identify best practice for nurses dealing with the psychosocial impact of MS on their patients and carers.

**Bringing it all together: The Nurse’s role in lifestyle management**
Martin Duddy, June Halper, Colleen Harris and Kitty Harrison

Summarising the key learnings and actions from the day and discussing specific, actionable ‘next steps’ for delegates.

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A significant gap in knowledge was shown from the meeting survey

- 48 nurses completed the pre-meeting questionnaire
- Before the meeting, the nurses did not consistently give correct answers (<60%) demonstrating a gap in knowledge in the programme topics

Correct answers given for each pre-meeting content specific question

<table>
<thead>
<tr>
<th>Question</th>
<th>% of nurses</th>
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</thead>
<tbody>
<tr>
<td>Q1: HRQoL</td>
<td>60%</td>
</tr>
<tr>
<td>Q2: Treatment advances</td>
<td>20%</td>
</tr>
<tr>
<td>Q3: Ageing and sleep</td>
<td>30%</td>
</tr>
<tr>
<td>Q4: Communication</td>
<td>10%</td>
</tr>
<tr>
<td>Q5: rehabilitation</td>
<td>20%</td>
</tr>
<tr>
<td>Q6: Psychosocial</td>
<td>40%</td>
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The majority of delegates did not feel very knowledgeable about supporting patients with lifestyle issues

Psychosocial support was the area where nurses felt most knowledgeable (14.58%)

Exercises specific to diagnosis and health status was the area where the highest percentage of nurses (10.42%) reported to requiring more knowledge.

Only 33% of nurses reported having completed additional courses relating to improving patient lifestyle management in MS.

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Engaging speakers delivered highly relevant and quality sessions

Participants strongly agreeing or agreeing that the sessions contained relevant and high quality content

- Treatment advances in MS; the impact on the wider HCP team
- Supporting the aging MS population and managing comorbidities
- MS in the 21st century workshop speaking a common language; Communicating a future with MS
- Improving patient quality of life through rehabilitation
- Case study: Psychosocial aspects of MS - challenges and solutions
- Bringing it all together: The Nurse's role in lifestyle management

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Delegates demonstrated a 22% increase in confidence discussing lifestyle issues with their patients.

How comfortable are nurses discussing lifestyle management with MS patients before and after the meeting?

- **Pre-Meeting**
- **Post-Meeting**

After the meeting, 41 out of the 46 (89%) responded saying they were very confident and comfortable discussing lifestyle management with their MS patients.
Delegates offered ways in which they would apply learnings to change behaviour*

Focus on individual patient rehabilitation

Encourage a nutrient rich diet for patients

Support patients with exercise plans

Be aware of communicating clearly

Offer greater attention to managing comorbidities

Adapt clinical language when speaking to patients

Provide informative resources for patients to help understanding of lifestyle management

Educate patients on the importance of staying active

Consider referral of relevant patients to psychologist

Consider patient perspective

Empathise

*Topics proportionally represented according to number of times suggested

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Faculty-led content fulfilled all delegates’ overall learning objectives

**All 51 (100%)**
participants who completed the feedback form strongly agreed or agreed that the meeting fulfilled their overall learning objectives

**Over 60%**
strongly agreed that the content was relevant to their practice, had varied sessions that added value to the meeting and that having CME accreditation also added value to the meeting

**50 out of the 51 (98%)**
found their personal learning objectives were met

**Over 70%**
strongly agreed that the meeting interactivity offered good value to the meeting

**Over 70%**
more than 70% of delegates strongly agreed or agreed that the meeting was well organised, well facilitated and held at a good venue

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All elements of the meeting received positive feedback

Delegate quotes

“Case studies were really effective to show us how to apply what we have learnt”

“Hearing experiences of nurses from other countries was great”

“Great faculty and a great meeting”

“Hearing from an MS patient really helps to understand their MS journey”

“I feel empowered to make a difference to patients’ wellbeing”

“Inspiring speakers”